



Health Care

For People Who Need Extra Support:

A health literacy guide to support the health of people with a cognitive impairment or intellectual disability

ACKNOWLEDGEMENTS

This guide was developed
by Dr Rachel Skoss.

Institute for Health Research, The University
of Notre Dame Australia.

School of Population and Global Health;
University of Western Australia
Telethon Kids Institute.

The guide was funded by a Western
Australian Department of Health Research
Translation Project grant; developed from the
associated research entitled “Health service
use for people with disability living in
supported accommodation – an intervention
to improve health literacy in disability service
organisations”. The author acknowledges
this guide also incorporates resources
developed by others and is grateful for the
wisdom of participants who shared their
stories of both challenging and successful
access to health care.

The author acknowledges the following
people who shared their wisdom and gifted
their time to provide feedback on the
resource: Debra Letica, Tricia Dewar,
Meredith Blake, Donna Cross, Sarah Falconer,
Mary Butterworth.

Acknowledgement of Country

We acknowledge the traditional
custodians throughout Western Australia and
their continuing connection to the land,
waters, and community. We pay our respects
to all members of the Aboriginal communities
and their cultures, and to Elders past, present,
and emerging.

The first step in living alongside, and
working with, the Aboriginal community is to
establish respectful relationships. Crucial to
these respectful relationships is
acknowledging the history of Aboriginal
people and recognising the importance of
connection to family, culture, and Country.

Please email any suggestions for resources
or improvements to:

idhealthguide@gmail.com

Suggestion citation: Skoss R (2022) Health
Care For People Who Need Extra Support:
A health literacy guide to support the health
of people with a cognitive impairment or
intellectual disability. Fremantle: Institute
for Health Research, The University of
Notre Dame Australia.

TABLE OF CONTENTS

Introduction	8	Section 5 - Understanding Change in Someone's Health Status	64
<hr/> Part A <hr/> Promoting Good Health <hr/>		Soft signs to look for	65
Section 1 - Healthy Lifestyle	12	When soft signs are a signal of an emergency	66
Healthy diet	12	Taking observations – measuring vital signs	67
Exercise and activity levels	18	Recognising pain	74
Healthy weight	20	Recognising change in health	76
Sleep	22	Identifying deteriorating health status	77
Alcohol and other drugs	25	Section 6 - End-of-Life Care	80
Mental wellbeing	28	The process of dying	80
Healthy skin	34	Palliative care	81
Section 2 - Proactive and Preventative Care	36	Talking about death and dying	83
Annual health assessments	36	Advanced planning	84
Common health screening assessments	38	Making a person comfortable	85
Dental care	44	Supporting people after bereavement	85
Immunisation	47	<hr/> Part C <hr/> Using Health Services <hr/>	
<hr/> Part B <hr/> Managing Health Conditions <hr/>		Section 7 - Primary Care in the Community	86
Section 3 - Managing Chronic Health Conditions	48	The role of the General Practitioner	86
The role of the General Practitioner	48	Choosing a doctor	87
Your role in supporting chronic illness	49	Continuity of care	88
NDIS disability-related health supports	50	Initiating a visit to the doctor	89
Common chronic conditions	51	Preparing for the appointment with the doctor	90
Section 4 - Managing Mental Health Conditions	58	Supporting communication between doctor and patient	91
Different types of mental health conditions	58	During the appointment	92
Identifying symptoms of a mental health condition	59	After the appointment	93
Supporting a person experiencing a mental health condition	60	Section 8 - Hospital-Based Care	94
Mental health treatment	60	Communication with the hospital	94
Learning more about mental health	61	Urgent health issues	96
		Outpatients and day surgery	98
		Hospital admission	99
		Easy Read resources for hospital visits	103

— **Part D**

Building Health-Related Skills and Knowledge

Section 9 - Communicating About Health	104
Supporting a person with communication difficulties to understand and be heard	104
My Health Record	114
Health Passports	116
Care plans	118
Section 10 - Decision-Making in Health	120
The decision-making process	121
Dignity of risk	123
Informed consent	124
Responsibility for clinicians to support informed decision-making	125
Your role in supporting decision-making	126
Tools to support decision-making	127
Section 11 - Setting Health-Related Goals	130
Identifying what could be changed	131
Setting a goal	132
Making a health action plan	133
Section 12 - Building coping skills to manage health (and health appointments)	134
Tips to improve waiting for an appointment	135
Social stories	135
Easy Read resources	136
Have a safety plan	137
Managing traumatic experiences	138
Desensitisation	142
Section 13 - Finding Good Information	144
Internet information	144
Other information sources	147

— **Part E**

Understanding the Health System

Section 14 - The Australian Health System	148
The Australian Charter of Healthcare Rights	148
Health sector governance	149
Disability sector governance	150
A brief overview of the structure of the Australian health system	150
How health care is paid for	152
Section 15 - The Health Care Team	154
Roles in the health care team	155
Person-centred care	158
Section 16 - Making Complaints in the Health and Disability Systems	160
References	162
Appendix A - Healthy Living Checklist	166
Appendix B - Medication Pathway (information for caregivers and family of people who are prescribed or may be prescribed psychotropic medication)	176
Appendix C - The NEWS2 scoring system and thresholds	180
Appendix D - Legal Framework for Decision-Making	182
The United Nations Convention on the Rights of Persons with Disabilities	182
Guardianship	183
Advance Health Directives	184
Appendix E - Health Passports	186

INTRODUCTION

WHY THIS GUIDE HAS BEEN DEVELOPED

People with intellectual disability (ID) often experience poorer health than people without disability.¹ They are more likely to have common health conditions undermanaged,² and have more than one physical and/or mental health condition simultaneously.³ At the same time, health promotion messages (to support people to improve their health or maintain good health) are not targeted at people with ID.

In the research underpinning this guide, people said there was a need to think about health holistically – which means thinking about health in terms of keeping people healthy, as well as what happens when they are ill or injured and need to use health services. People said that while there was a lot of useful information available on the internet, it was often difficult to find and that it would be helpful to bring relevant information and resources together in one place. People also said they wanted the focus to be on practical information that would help build the skills of both people with ID and those who support them. This guide aims to provide information in an easy-to-understand way and link the reader to more information where appropriate.

WHO THIS GUIDE IS FOR

While the guide is also aimed at supporting the health of people with cognitive impairment, for ease of reading it makes reference to people with ID throughout. Whether the person with ID lives independently, with family, or in supported accommodation, they may need additional help to access health services, and engage with clinicians. This type of support for someone with disability may come from:

- a carer who provides support or care to a relative or a friend
- a family member or friend who is not in a caring role
- a support worker or other paid employee in an organisation providing support
- a volunteer providing unpaid work to an organisation
- a person providing support through work experience or internship.

In this guide, anyone providing help to a person with ID is considered a 'supporter'. This guide is intended as a resource for anyone who is helping to support the health of someone with ID, whether they are in a paid or unpaid role. The guide may also be used by health professionals who are supporting the health of a person with ID.

HOW THE GUIDE HAS BEEN DEVELOPED

The guide has been developed using a health literacy approach. 'Health literacy' describes the skills and abilities someone needs to find, understand, and use health information. The way health information and services are provided also affects what you know and what you can do about your health. When people have good health literacy, they find it easier to understand the available options and make the best decisions about their health. As a supporter of someone with ID, you may need to help them develop their own health literacy skills and knowledge, and advocate for them to be at the centre of the decisions being made about their health.

The guide was developed from interviews with people with ID and cognitive impairment, family members, people working in disability service organisations, and clinicians. Many of the people with ID highlighted what they found helpful to manage their health, and what they expected from people helping them with their health. Family members and caregivers drew attention to resources that were useful in building skills and understanding in the person with disability that they support, as well as resources they know health professionals have found useful. Clinicians provided information about what they found helpful in providing care, what people with disability can do to optimise their health and prevent illness, and resources that would be helpful in managing chronic health conditions.

The guide also used trusted online sources of information about supporting health (e.g. **Health Guide**), and where needed, modified the content to suit the needs of supporters of people with ID.



STRUCTURE OF THE GUIDE

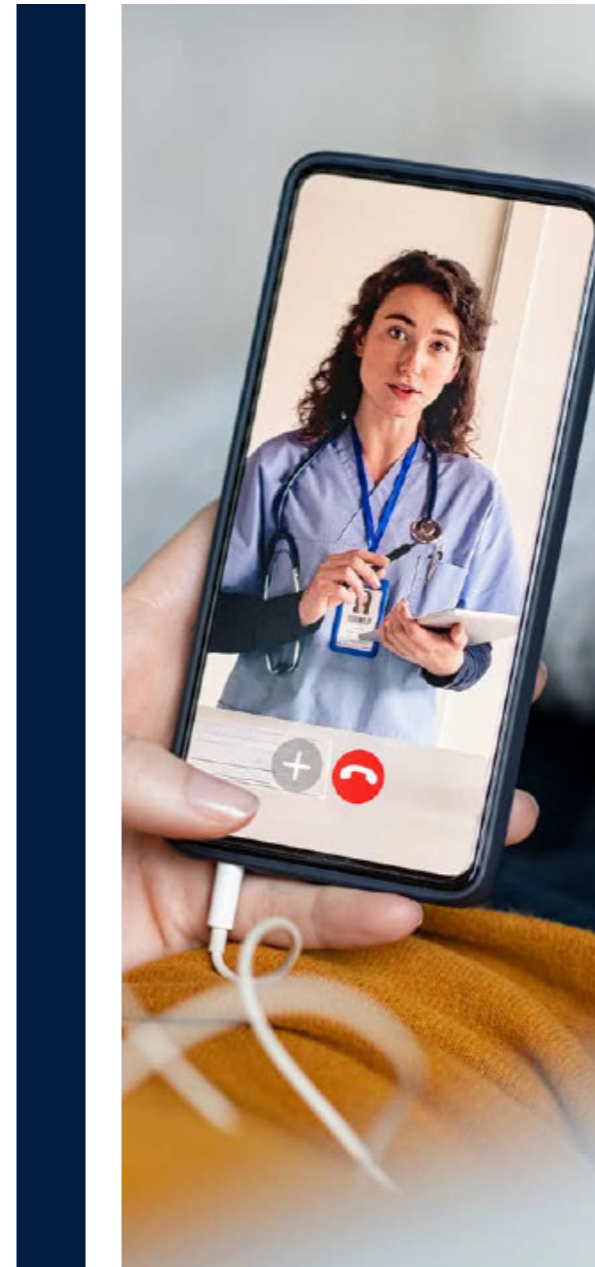
This guide is not intended to be read from beginning to end. Every situation is different – so it is likely that people may need different types of information to best help the person they are supporting. What you take from this guide will be influenced by your health literacy strengths and opportunities to learn more, as well as the health literacy strengths and health needs of the person you are supporting.

A DEFINITION OF HEALTH

The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease”.⁴ This guide takes a broader view of health and functioning, as a person’s health and wellbeing depends on determinants (things that influence health), interventions (e.g. prevention, health promotion, treatment and care), and resources (e.g. financial or technological resources, data, equipment, and health care staff).⁵ The guide will take a health promotion approach, focusing on factors that have potential for change (e.g. improving health behaviours, more effective engagement with health services, accessing preventative medicine) – in order to provide the tools for people to increase control over their health with the aim of improving their health.

A DEFINITION OF HEALTH LITERACY

In health, building health literacy skills is an important way to empower people to have greater control over the decisions and actions that affect their health. Health literacy is not just whether people can read health information, but also how people access, understand, appraise, and apply information about health and health care, and take appropriate action. Health literacy includes how people are understood and supported by health care providers, and how they engage with those providers. Health literacy influences how people work together to achieve good health outcomes for people with disability they support.



This guide is based on the understanding that health literacy incorporates different skills and beliefs, including⁶:

- Feeling understood and supported by health care providers
- Having sufficient information to manage your health (or that of the person you support)
- Having social support for health
- Ability to:
 - » actively manage your health (or that of the person you support)
 - » assess whether health information is true or important
 - » actively engage with health care providers
 - » navigate the health system
 - » find good health information
 - » understand health information well enough to know what to do.

PART A

PROMOTING GOOD HEALTH

Health care is not just about getting treatment when people are unwell or have injured ourselves.

Unfortunately, people with ID or cognitive impairment are not always included in health promotion campaigns designed to improve health. Similarly, while everyone has the right to access preventative health care, they may not know what is available, or how to obtain it. This section focuses on topics of health promotion, and opportunities for preventative health care.

SECTION 1 - Healthy Lifestyle

Lifestyle choices can influence a person's health. Good health is supported by good health habits, which help prevent lifestyle-related chronic health conditions like heart disease, stroke, obesity, type 2 diabetes, and some cancers. In your role supporting a person with ID, you may need to consider how to assist the person to make healthy lifestyle choices. It is also important to consider what health-related goals could be incorporated into a person's National Disability Insurance Scheme (NDIS) plan.



HEALTHY DIET

The food people eat (i.e. their diet) impacts on how healthy they feel, their energy levels, mood, and how well they sleep. Dietary choices influence digestion (and bowel habits), a person's weight (and associated chronic conditions), and their immune system. Sometimes people with ID have poor diets. In some cases, this may be because they have a poor understanding of what a healthy

diet is. They may be dependent on a caregiver to help them buy, prepare, and/or eat food, so it is important that caregivers know what a healthy diet is. Research has shown that many people with ID can learn about food and make healthier choices if given the support to do so.

SOME IMPORTANT NUTRITION TERMS

A good diet includes a combination of protein, carbohydrates, and dietary fats, which are sometimes called macronutrients. The body also needs important vitamins and minerals, called micronutrients. It is important to know which nutrients our body needs to be healthy.

Proteins

are made up of amino acids, which are used in different ways in the body. Protein is very important for cells to grow and repair, and for transporting molecules throughout the body. Different amino acids are used in antibodies (which fight infections), enzymes (which help chemical reactions occur in the cells), and messenger proteins (which transmit signals throughout the body). Protein can also be used for energy if there is not enough carbohydrate in the diet. Protein can come from a variety of foods, including plant-based foods such as legumes, tofu, nuts and seeds, and animal-based foods like lean meat, poultry, eggs, fish and dairy products.

Carbohydrates

are in all fruit and vegetables, grains and cereals, and sugary foods. The body digests the different types of carbohydrates in the small intestine, breaking it down into a sugar called glucose. Glucose is used for energy by the brain and the muscles. Some excess glucose is stored in the liver as glycogen, and the rest is stored as fat.

Glycaemic Index (GI)

is the speed at which the carbohydrate in food is digested – low GI foods take longer to digest, so a person feels full for longer. High GI foods are digested quickly, so people can have a sugar spike, but then have blood sugar lows. If a person has diabetes, low GI foods (e.g. unprocessed foods, most vegetables, legumes) help keep blood glucose levels stable.

Fats

are needed for energy and to help absorb some vitamins. Some fats are better than others. Unsaturated fats help reduce the risk of heart disease and lower cholesterol. Omega-3 and omega-6 polyunsaturated fats are found in fish and nuts, while monounsaturated fats are found in olive oil, canola oil, avocado, and some nuts. Saturated fats are often in dairy food, meat, in many bakery goods (e.g. cake, pastries), and in deep-fried or processed foods. Too much saturated fat is linked to heart disease and high cholesterol.

Dietary fibre

is linked to a lower risk of many diseases and is important for good bowel function. Fibre is found in plant foods like vegetables, fruit, nuts and seeds, legumes, and whole grains. High-fibre foods are good sources of vitamins and minerals. Many people do not eat enough fibre in their diet – adults should eat 25-30g per day. The nutrition label on food gives information about dietary fibre (e.g. 2 slices of wholegrain bread have 6g, 1 cup of baked beans has 10g).

Vitamins and minerals

are important in a person's diet, as they support all the body's processes. Vitamins are made by plants or animals, and can be broken down by heat, air, or acid. Minerals come from soil and water and are absorbed by plants or eaten by animals. Most people get all the vitamins and minerals they need from a balanced diet, and don't need supplements. However, some people may have a particular medical condition and their doctor may recommend a supplement. Vegans (who do not eat any animal-related products) may need vitamin B12, vitamin D, iron, and omega-3 fatty acids. Women who are pregnant should take folic acid (a B-group vitamin), and may also need iron and vitamin D.

Kilojoules

(or calories) are a measurement of energy. Kilojoules are often used to describe how much energy is in food and drink, to give people an idea of how much they should be eating and drinking as part of their diet. Kilojoules are also used as a measure of how much energy a person needs in order to do their daily activities. In general, if a person consumes more energy than they use, the extra energy is stored in the body as fat. A typical adult needs 8,700 kilojoules a day, however the amount of energy that a person needs varies depending on their age, gender, height, weight, whether they are growing, how much muscle they have, and how active they are.

A BALANCED DIET

A healthy diet should be balanced, which means eating a variety of foods from each of the five food groups⁷:

- **Vegetables and legumes** – these have a lot of vitamins, minerals, and dietary fibre. Where possible, eat vegetables/legumes when they are in season, and aim to eat different colours (e.g. green, red/orange/yellow, purple, and white vegetables). Adults should eat 5-6 serves a day, which is ½ a cup of cooked or 1 cup of raw vegetable per serve.
- **Fruit** – a good source of vitamins and dietary fibre. Fruit juice should only be occasional, as juice doesn't have the fibre, and often has extra sugar. Adults should eat 2 pieces of fruit a day.
- **Grains and cereals** – wholegrains have protein, dietary fibre, vitamins, and minerals. Adults should eat 3-6 serves a day, depending on age, gender, and activity levels. A serve is a slice of bread, or ½ cup of cooked rice/pasta, or 30g of breakfast cereal. The more processed grains can lose some of their nutrients.
- **Lean meat, poultry, fish, eggs, tofu, nuts, and seeds** – these foods provide protein, minerals, and vitamins. It is good to eat a variety of foods from this group. Adults should have 2-3 serves a day. A serving size depends on the product (65g of cooked red meat, 80g poultry, 100g fish, 2 eggs, 170g tofu, 30g nuts/seeds).
- **Dairy products (milk, cheese, yoghurt or alternatives)** – these foods contain protein, vitamins, and calcium. Adults should have 2-4 serves a day (1 cup of milk, 2 slices of cheese, 200g yoghurt). If plant-based alternatives are being used instead of milk, use products that have at least 100mg of calcium per 100ml.

Some foods do not have much nutritional value, and have a lot of saturated fat, sugar, or salt. These foods should only be eaten in small amounts, and not be part of a regular diet. These foods can contribute to serious diseases that can affect a person's quality of life and lifespan. In Australia, packaged food has a food label, which can help you identify its nutritional value. You can find a useful guide to reading and understanding food labels here:

Nutrition Information Panel.

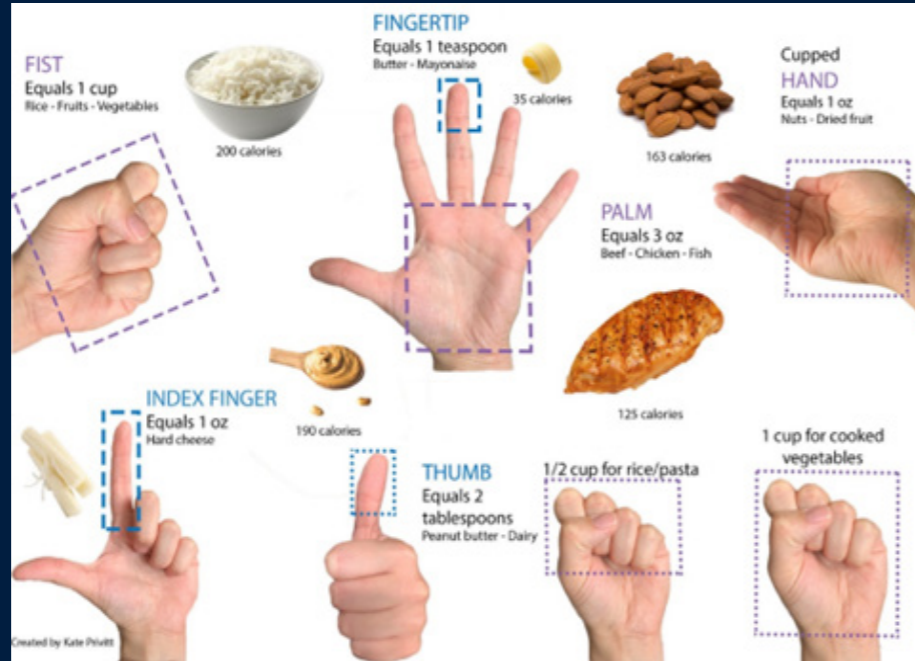
If you are supporting someone with ID, it is important to talk about healthy food choices. Junk food is high in kilojoules, fat, salt, and sugars. While a person may want junk food regularly because it can be tasty, there should be a discussion about how it is not healthy to eat it too often. Also discuss that other foods are tasty or can be modified to improve taste (e.g. increase use of fresh herbs and spices). Everyone has the right to make unwise choices (see dignity of risk), but they need the right information and support to understand the risks and the consequences of their choices properly. There are some good Easy Read and picture resources about healthy eating that can be found here: ***Good Food.***



AN IMPORTANT NOTE ON PORTION SIZES

It is important to remember that people can be eating a balanced diet, and yet still over-eat. It is easy to have more food than you need if the portion sizes are too big. Sometimes it can be helpful to explain a portion size in different ways. Not all foods are packaged in single-serves. The food label includes how many 'servings' are in the package. This is the same as a 'portion'.

Figure 1 on the right is a useful guide to portion sizes⁸ – the 1oz weight is approximately 30 grams.



FLUID AND HYDRATION

It is important to stay hydrated. There are lots of processes in the body that require water – for example, people need water to regulate body temperature, digest food, and get rid of waste products. Generally, people get about 20% of the water they need from food, and the rest they need to drink. It is best to drink 6-8 cups of water a day. Water is the best fluid to drink for hydration. Tap water in Australia is safe to drink. Although coffee, tea, juice, and soft drinks count towards a person's total fluid amount, those drinks can have a negative health effect as they have extra kilojoules, can damage your teeth, and may contain caffeine (for caffeine impacts, see p.22 'Sleep Hygiene'). Coffee and tea also have mild diuretic properties, which make the kidneys remove more water from the blood. Carrying a water bottle is a good way to remember to drink lots of water. It is important to drink enough water in warmer weather, and during exercise. If a person is feeling dizzy and faint, is more confused than usual, or has very dark urine, then it can be a sign that they need to drink more water. It is important to know that some people may have medications or specific health conditions which mean that what they drink needs to be monitored. A doctor will let you know if this is necessary for the person you support.

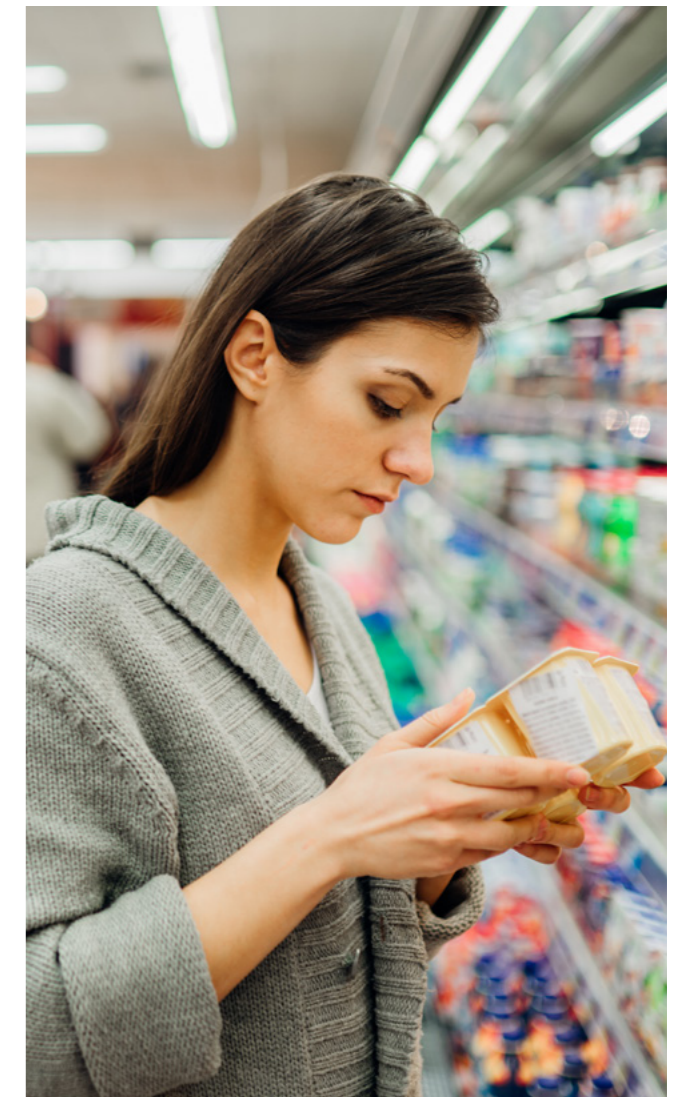
WHAT TO DO IF A PERSON HAS FOOD ISSUES

It may be difficult for a person to eat a balanced diet for a range of reasons. Some people may have specific dietary requirements – some allergies and medications mean they shouldn't eat a particular food. If you are supporting a person who has severe food allergies, it is important to know what symptoms they might experience if they have a bad reaction, and what you need to do about it. Talk to the person's doctor for more information.

Other people may have swallowing difficulties, where it is difficult to take their food by mouth. Home enteral nutrition (HEN) is a way to provide nutrition if a person can't eat and drink normally or get enough nutrition to keep them well and healthy. Some people need nutritional supplement drinks to increase their kilojoule intake for good health. For some people, modification of food such as thickening fluids is needed to enable safe eating and drinking. You may need to know what texture and consistency the food needs to be to be safely eaten. For other people, enteral feeding may be needed to deliver the food and fluids directly into the stomach, bypassing the swallowing difficulty. A percutaneous endoscopic gastrostomy (PEG) procedure is where a flexible feeding tube is placed through the abdominal wall into the stomach. If a person is PEG fed, you will need to learn how to care for the feeding tube and PEG site, to be aware of possible complications, and to know how the person with the PEG can continue participating in their everyday activities.

More information can be found here: [nourish course](#).

Some people have sensory issues which may mean they want to avoid types of foods or food textures. If you are supporting a person who may have food avoidance issues, then a dietitian may be able to suggest different ways to improve the diet the person is able to tolerate. In some cases, goals related to increasing exposure tolerance to different foods may be useful to consider. It is important that a person is not forced to eat (or that food is withdrawn if they do not want to eat it), as this is called restrictive practice.



EXERCISE AND ACTIVITY LEVELS

Being active is important for health, helping a person's fitness, including balance, flexibility, strength, and aerobic endurance. Exercise also improves mobility, joint functioning, and bone strength. Being physically active can reduce the risk of some lifestyle diseases, prevent weight gain, and improve blood pressure and cholesterol. Activity is also important for mental wellbeing, improving mood, and reducing pain.

Most people with ID are more sedentary than they should be (i.e. not moving their bodies), spending most of their day sitting or lying down.⁹ Sometimes, it may be difficult for a person to be active or exercise, because of physical constraints, lack of access to equipment or venues, or because they don't feel welcome or comfortable in the environment. It is important to look for opportunities to increase activity levels. Being active doesn't only mean scheduled exercise, but can include tasks in daily life like cleaning, hanging out the washing, or gardening. Any activity is better than none, and it is important the person is doing activities appropriate to their ability.

EXERCISE GUIDELINES

The Australian Government's physical activity and exercise guidelines recommend being active every day.¹⁰ Each week, people should do a minimum of 150 minutes of moderately intense physical activity (e.g. briskly walking or swimming), or 75 minutes of vigorous physical activity (e.g. jogging, fast cycling, or soccer), or a combination.

Moderate exercise takes some effort, but a person can still have a conversation while they are doing the activity. Vigorous exercise requires more effort, and a person is breathing harder and faster – they are huffing and puffing, and might be able to say two or three words at a time.

People should also do muscle-strengthening activities on at least two days each week (e.g. body-weight movements like push-ups and squats; gym exercises; or household tasks involving lifting, carrying, or digging – like gardening). Strength exercises help to improve balance, posture, and mobility. Strength exercises also help to reduce the risk of falls and injury and are important in helping people maintain their ability to do daily tasks. Even if a person is doing the recommended amount of activity, it is also important they do try to sit less. People often do activities that require a lot

of sitting (e.g. watching TV, using a computer), and it is important to regularly move from the seated or lying posture if possible.

Guidelines suggest people should stand up and move around for 10 minutes every hour. This is important for posture.

PLANNING FOR EXERCISE

If a person has not been active, it is important they get checked by a doctor before starting anything new. If a person also has a physical disability, it is good to get advice from an exercise physiologist, or a physiotherapist. Starting slow and gradually building up over a month to the recommended amount of activity is the best approach. If the person experiences any pain, discomfort, nausea, chest pain or shortness of breath, they should see the doctor.

Exercise should be done safely, so consider any potential risks (e.g. when outside, be sun-safe and wear a hat, sunscreen, and protective clothing; when at the beach, swim between the flags; when riding a bike, use a helmet and make sure the bike has recently been serviced). However, it is

important not to use 'risk' as an excuse for not allowing a person try different activities. You may need to consider how the activity or environment can be modified, or what type of support the person needs to participate safely.

There are many ways activity can be incorporated into a daily routine. If you are supporting a person to move more, then consider creating opportunities to walk more (e.g. park a little further way; climb stairs instead of taking a lift/escalator; go for a walk around the park; consider getting a dog for regular walking). Exercise can be fun (e.g. community fun run; flying a kite; playing a fitness game) and often more enjoyable when participating as part of a group or with friends, so consider how the person can also benefit socially (e.g. meeting a friend

for a walk instead of a coffee; joining a sports team). You can find interesting workouts on YouTube that are good for beginners, including seated exercises, yoga, and low-impact aerobics.

It is important to remember that consistency is key to see fitness gains. As a supporter for someone who needs to exercise, there may be days they don't want to exercise. While they have the choice not to exercise, sometimes they may feel better about it after they have started. Your role may be to motivate them to give it a go, even if just for 5 or 10 minutes. You may also need to think about what is preventing the person from wanting to do the activity – whether it is the right activity for them, they've had a bad experience in the past, or if there is another barrier preventing them from participating and enjoying the activity.



EXERCISE PROGRAMS

There are many types of exercise – and it is important to help a person explore what is right for them. Some forms of exercise don't require much skill but focus on different aspects of fitness (e.g. strength, aerobic endurance, flexibility, balance). There are different exercise programs available in the community that might be beneficial (e.g. at the gym), or a personal trainer can provide one-on-one guidance. A person may also choose to follow a universal exercise program targeted to their level of fitness – such as: **Activity Guides**.

Other forms of exercise may be more difficult to learn but provide fitness benefits. For example, individual or team sports and activities such as swimming and dancing involve learning new skills. Some people enjoy being able to play a team sport or participate in competitions. There are many disability-specific and mainstream community-based programs that a person can access. These activities often have the added benefit of providing opportunity for social interaction.

HEALTHY WEIGHT

Being within the healthy weight range is important, as it reduces the risk of some diseases. People who are overweight are at risk of developing health problems like cardiovascular disease, type 2 diabetes, high blood pressure, sleep apnoea, and some cancers. They are also putting additional load on their joints, which can potentially result in problems in the knees, ankles, and foot joints. People who are underweight can also have health problems, like anaemia, osteoporosis, and some heart problems. Being underweight can reduce the ability of the person's immune system to fight off infections and viruses. It can also cause problems with women's reproductive cycles. What is a healthy weight? It varies depending on a person's height, and how much muscle they have.

ASSESSMENT OF HEALTHY WEIGHT

Waist circumference is one way to quickly assess whether a person is at risk of obesity-related chronic diseases, as it gives an indication of the amount of internal fat deposits coating the internal organs like the heart, liver, and kidneys. The measurement is taken midway between the top of the hip bone and the bottom of the ribs. For men, 94cm or more means a person is at increased risk, and 102cm or more means they are at greatly increased risk. For women, the measures are 80cm and 88cm respectively.

Body mass index is another way to quickly assess whether weight is in the healthy range, although it is not a perfect measure. It is calculated by dividing a person's weight (in kilograms) by the person's height (in metres squared.) A healthy range is 18.5-24.9 BMI, but it tends to be lower for people of Asian background, higher for people of Polynesian background, higher for older people, and higher for people with lots of muscle.

SUPPORTING A PERSON TO ACHIEVE A HEALTHY WEIGHT

Losing weight is a common goal. People with ID are more likely to be obese (severely overweight) than the general population.⁹ This is because they are less likely to eat a balanced diet and do regular exercise. Some people may also be on medication which makes them put on weight. To lose weight, a person needs to be physically active and follow a healthy eating plan. It is important to make sure the person is not trying to lose weight too quickly (i.e. faster than 0.5-1kg per week). While some fad diets promise rapid weight loss, they often do it by cutting



out food groups which can mean the person is not getting all the nutrients their body needs. Fad diets can be harmful to a person's health and difficult to sustain in the long term. A doctor or dietitian can provide good advice on weight loss.

Once the goal is achieved, then the person can always set another goal. This tip is also useful for people who need to gain weight.

If you are supporting a person who is overweight, you can help them understand the choices they can make. Although people have the right to make unwise choices, it is important to provide the right information and support, so they understand the risks and consequences of their choices.

An example of an Easy Read that provides clear information about the balance between diet and exercise can be found here: [***Lets Talk About Keeping Healthy Web.pdf***](#).

There are some practical ways you can help a person to lose weight – and it is important that everyone providing support to the person is consistent in their approach. Consider whether you can do any of the following:

- Support the person to see their doctor for an annual health check and discuss their optimal weight.
- Share information about buying and cooking healthy food and help the person plan and cook healthier meals and eat appropriate portions of foods.
- Encourage the person to be more active. Find out what activities they enjoy and provide opportunities to do those activities. Exercise doesn't have to be formal – it can be as simple as dancing in the lounge room to enjoyable music.
- Try to be a good role model for healthy choices. For example, model healthy decisions about food options when choosing take-away food.
- Try to avoid using food and drinks as a reward. Instead, consider other ways a person can be rewarded.
- Remember that you can be the motivator and cheerleader or coach. Celebrate progress when it occurs and help them try again if they've had a set-back.

SLEEP

Sleep is very important for a good quality of life, and for a person's health. Sleep helps the body physically restore, and the brain to organise itself. We need sleep so the body and mind can function properly. Adults need 8 hours sleep (on average) a day. Our sleep is linked to the hormones produced in our biological clock – when the sun rises, the body produces cortisol which is a hormone that makes us feel awake and alert. As it gets darker, the body releases the hormone melatonin which makes us feel sleepy.

SLEEP PROBLEMS

Poor sleep has been linked to an increased risk of health conditions like heart disease and high blood pressure. Not getting enough sleep can affect the immune system, and a person's concentration and mood.

Insomnia is a condition where it becomes hard to fall and stay asleep or causes a person to wake up too early and not be able to get back to sleep. Sometimes, people may have insomnia for a short time – for example, if they are worried about something. If a person has insomnia for three months or more, it is considered chronic.

Sometimes, people may have a sleep disorder (e.g. sleep apnoea where breathing stops and starts; restless legs syndrome where a person has a strong urge to move their legs), affecting the quality of their sleep.

Sometimes sleep problems may be due to medical issues (e.g. hormone changes during menopause, digestive problems, being overweight), or life stage. Insomnia can also be made worse by stress and be a symptom of anxiety and depression. Sleep habits can also influence the quality and quantity of sleep.

SLEEP HYGIENE

Personal habits also influence sleep – this is called sleep hygiene. Some habits influence sleep in a negative way:

- Caffeine and nicotine are stimulants, which can interfere with the ability to fall asleep. This means that cigarettes, coffee, tea, and energy drinks should be avoided for at least four hours before going to bed
- Alcohol interrupts the quality of sleep, so should be avoided for at least four hours before going to bed
- Using electronic devices can suppress the production of melatonin. It is best to not use them two hours prior to going to bed. However, should electronic devices be used close to bedtime, put them in night-mode to reduce blue light emissions and brightness
- Bedroom lights should be dim, as normal indoor light levels can suppress the production of melatonin
- Naps during the day can impact the quality of sleep at night. If a person needs a nap, they should have it before 3pm, and make it less than an hour
- Not getting enough exercise can lead to sleep issues. However, strenuous exercise too close to bed can also interfere with sleep.

There are many habits that help promote good sleep:

- A regular routine every day (i.e. going to bed and getting up at the same time) helps your body adjust. Some people like to have a ritual just before going to bed, such as 15 minutes of breathing exercises or stretching, or a cup of herbal tea. A glass of warm milk before bed can also help a person to feel sleepier
- Sleep when sleepy – a person should go to bed when they feel tired or sleepy, rather than spending too much time awake in bed. If a person is unable to fall sleep after 20 minutes, they should get up and do something calming and boring in dim light until they feel sleepy, and then go back to bed and try again
- Having a hot shower or bath an hour or so before bed can be helpful. It raises the body temperature, but then a person gets sleepier as their body temperature drops again.
- Check what is being eaten before bed as hunger can distract from sleep. If a person has eaten a heavy meal, that can also interfere with sleep.
- Check the bedroom environment is helpful to sleep – a quiet space (or have earplugs if there is too much noise) that is cooler with enough blankets to stay warm, and curtains or an eye mask to block out early morning light. Ideally, the bedroom should be screen free (e.g. no phone, computer, tablet, or TV)
- Outdoor exercise first thing in the morning can help reset the body clock, as sunlight stimulates cortisol production.



TREATMENT FOR SLEEP ISSUES

It is good to talk to a doctor if a person is having trouble sleeping or feels tired and sleepy for no reason. The doctor will ask about sleep habits, the amount of caffeine and alcohol a person is using and check for medications which can influence sleep. They may also ask if the person is experiencing pain, has any mental health concerns, or other symptoms indicating an underlying health condition. Keeping a diary for up to two weeks before going to the doctor is a good way to identify what is happening.

There are different treatment options for insomnia. The first approach is to check the person's sleep habits to assess if there are any changes that could be made.

There are also different relaxation exercises that can be helpful to address insomnia symptoms:

- **Deep breathing** – inhale deeply through the nose for seven seconds, hold for four seconds, exhale slowly through the mouth for eight seconds. Repeat. There are apps that may be useful (e.g. **Reachout** 'Breathe', available from the app store)
- **Progressive muscle relaxation exercises** – tensing up different muscles, then relaxing them. A guide can be found here: **Progressive Muscle Relaxation.pdf**. There are also YouTube guides (e.g. **Reduce Stress through Progressive Muscle Relaxation**)
- **Meditation** – concentrating the mind on one thing (breathing, sound, body movement, or feeling). Smiling Mind has a free app which can help with meditation exercises: **Smiling Mind app**. There are many meditation videos on YouTube (e.g. **Daily Calm | 10 Minute Mindfulness Meditation | Be Present**)

If sleep habits and relaxation exercises have not been effective, cognitive behaviour therapy (CBT) can be used. Usually provided by a psychologist, CBT is a structured program helping people identify and replace thoughts and behaviours that cause or worsen sleep problems with habits that promote good sleep. The therapy can address many underlying causes of insomnia.

When other methods have not worked, a doctor may prescribe sleep medication for short-term use. Regular long-term medication use may make insomnia worse, become addictive and cause other side effects (including night wandering, agitation, balance problems, impaired thinking, or excessive drowsiness).

The doctor may also prescribe melatonin which is the hormone the body naturally produces as it gets darker. Melatonin can be used to reset the body clock, or as a mild sedative. It is generally taken one hour before bed.

There are over-the-counter sleep remedies available from pharmacies or supermarkets. Prior to purchasing these, it is important to seek a doctor's advice, as they may interact with other medications and should not be used for long periods of time.



ALCOHOL AND OTHER DRUGS

ALCOHOL

In Australia, many people drink alcohol to socialise, and to relax. If a person is drinking alcohol in moderation, it can be part of a healthy lifestyle (if they are eating a balanced diet and exercising). Moderation means drinking no more than 10 standard drinks in a week, and no more than two standard drinks in a day. It is important to know an alcoholic beverage must be labelled with the number of standard drinks it contains – this information helps understand how much alcohol is being consumed. For example, one can of mid-strength beer is one standard drink, but a can of full-strength beer can be more than two standard drinks.

Drinking too much can cause harm to both physical and mental health. Some people with ID may have trouble with alcohol, particularly those with little social support. Too much alcohol reduces self-control, which increases the risk of being exploited, or having an accident. Long-term effects of alcohol abuse include increased risk of liver damage, heart disease, stroke, dementia, and some cancers.

SMOKING

Smoking cigarettes increases the risk of cancer, heart disease, and stroke. Passive smoking means breathing in smoke from other people's cigarettes. It can put people at risk of the same diseases as smoking the cigarettes. People who smoke every day are more likely to experience anxiety and depression. Tobacco smoke contains many chemicals harmful to health, 70 of which have been found to cause cancer. It is also a very expensive habit, costing about \$15,000 a year if a person smokes 25 cigarettes a day.

Some people use e-cigarettes (called vaping). While most e-cigarettes do not contain tobacco, there are still toxic chemicals that could cause harm. There is emerging evidence of a link between vaping and serious lung disease.

There are different ways to quit smoking:

1. **Going 'cold turkey' or stopping suddenly.** This method needs strong willpower, and support to avoid triggers that remind the person of smoking.
2. **Gradually cutting down.** This works for some people, but people may need motivational support.
3. **Nicotine replacement therapy.** This method uses skin patches, chewing gum, inhalers, or nicotine lozenges purchased from a pharmacy. It is a way to gradually reduce the nicotine in the body, so that the person doesn't get the physical craving symptoms.
4. **Medication.** The doctor may be able to prescribe medication.
5. **Alternative approaches.** Some people find hypnotherapy or acupuncture helpful.



OTHER DRUGS

A drug is any substance that has a physiological effect on the body when taken. A psychoactive or psychotropic drug affects a person's mental processes, and can influence mood, behaviour, cognition, and perception.



HELPING SOMEONE TO SEEK HELP FOR DRUG AND/OR ALCOHOL USE

People may not recognise they have a problem with alcohol or other drugs, so will not know they need to seek help. If you are trying to help a person to recognise they need help, there are some strategies you can try:

- Find out the latest information about the drug(s), and how it affects people. It is good to have all the facts at hand. You can find more information here: **Drug Facts**
- Find a good moment to talk when the person is sober (not on the drugs), and you are both calm. Getting angry about it is not helpful in the long run.
- Try to talk about it in an ordinary conversation, so the person tells you what they like. Be open and do a lot of listening. It is okay to show your concern, but don't be judgemental as they may get defensive and not want to talk about it. It is important to have open, calm, and respectful discussions.
- You can discuss the pros and cons of the drugs.
- You can find more information about helping someone seek help here: **Seeking Help**

Some drugs are illegal (e.g. cocaine, methamphetamine, some cannabis, ecstasy). There are laws to stop people from possessing, using, producing, or selling illegal drugs.

Some drugs are legal (e.g. over-the-counter or via a prescription). It is important these drugs are taken as prescribed or directed on the packet. This means not taking more or for longer than recommended. It shouldn't be taken in ways other than recommended (e.g. not crushed up and injected), combined with other drugs, or shared with other people.

People may use drugs for many reasons – to fit in with a group, because they are curious, to cope with pain or trauma, or for relaxation and enjoyment. Sometimes, a person may become addicted to a medication they were prescribed – this is more likely if they were prescribed a strong painkiller, or some types of relaxant-type medications.

The effects of any drugs vary from person to person, depending on their size, weight, and health, whether they are used to taking the drug, or are taking any other drugs. For legal drugs, the active ingredient is regulated and controlled – but they can still be abused if the person takes more than the recommended amount. If the drug is illegal, the strength of the drug is often uncontrolled, and may contain other unknown ingredients.



MENTAL WELLBEING

Mental health is very important to a person's quality of life. People with ID have higher rates of mental health conditions; however, they sometimes don't get the help they need as symptoms may be different (making diagnosis difficult), or an assumption is made that symptoms are due to their disability. A person with ID may have difficulties communicating, learning new information, coping, and solving problems on their own. This may put the person under stress and increase their vulnerability for poor mental health outcomes.

PROMOTING MENTAL WELLBEING

The World Health Organization defines good mental health as 'a state of wellbeing in which every individual realises their own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to contribute to their community'. Mental wellbeing isn't just about being happy. It is also about being able to have meaningful and positive relationships, being able to contribute, use our strengths, and be able to do activities that are enjoyable and challenging. More information about wellbeing can be found here: [WellBeing](#).

Lifestyle plays an important role in wellbeing. In your role supporting a person with ID, by helping them to maintain a balanced diet, get enough sleep and exercise, and have daily routines, you are supporting factors that contribute to mental wellbeing. Social connectedness and participation in enjoyable activities are also important for good mental health, so connecting with friends in the community and online, joining clubs, participating in hobbies, and learning new tasks all help mental health.

As you are supporting a person, it is important to think how you are helping them build skills in decision-making to improve their autonomy. It may also be valuable to consider whether the person can develop their skills for emotional regulation (e.g. via zones of regulation [learn more about the zones](#)). By supporting people to learn and grow, you are helping to build their self-esteem, resilience, and coping skills. These are all very important protective factors against developing mental health conditions.

It is important to understand the underlying causes of mental illness, and lifestyle alone is not the only factor. However, promoting and supporting a healthy lifestyle is important for a holistic approach to health. An Easy Read fact sheet for tips to help mental health can be found here: [Tips to help mental health.pdf](#).

SUPPORTING SPIRITUAL BELIEFS AND CULTURAL PRACTICE

Spiritual and religious beliefs and cultural practice can enhance quality of life for a person with ID, as it often provides an opportunity to be part of a community that provides a social outlet. There may also be routines and rituals which provide comfort and meaning to the person.

In your role supporting a person with ID, you may need to help them explore what is meaningful for them in terms of their spirituality, religion, and/or connection to culture. This does not mean that you are imposing your belief system on the person you support, but instead helping them consider what is important to them. It can be difficult to know where to start or what words to use. A helpful resource to guide exploration can be found here: [Spirituality Cards](#)

People with ID have the right to choose whether they want to participate in a faith community of their choice or express their spirituality in another way. They also have the right to determine which cultural practices they want to adhere to. They have the right to choose not to participate. In your role supporting a person with ID, you can facilitate their involvement in activities that are individual, or in a group. This may be as simple as supporting the person to perform certain routines, eat according to dietary requirements, or travel to a meeting or event. However, you may also need to advocate for inclusion and support the person's full participation if necessary, identifying and overcoming any barriers that are preventing the person's involvement.



SUPPORTING HEALTHY RELATIONSHIPS

Relationships include friendships and partnerships. People are different, and sometimes relationships require communication and compromise. In your role supporting a person with ID, you may need to assist them identify their values, and discuss the following components of healthy relationships:

- **Respect** – this means having self-respect to be true to their own values and beliefs, but also respecting that others may have different values, beliefs, opinions, and ideas.
- **Communication** – this requires being able to express feelings and ideas without getting angry or upset. It is okay to agree to disagree.
- **Compassion** – having concern for other people is important, especially if they made a mistake or there has been a misunderstanding.
- **Equality** – friends are equal, not one more important than the other.
- **Trust** – this allows belief in the friend or partner, as they are reliable. One person is not trying to control the other and doesn't doubt what they say.
- **Honesty** – being truthful in what is being said, and in actions.
- **Boundaries** – understanding the other person in the relationship may want personal space and alone time and being able to set boundaries for oneself.
- **Consent** – for people in a sexual relationship, there is an understanding that they can choose to say no, and it will be respected. They are not pressured into doing anything. It also means the person understands the need to ask for consent, and respect it if someone else says no.

PROMOTING EDUCATION ABOUT HEALTHY RELATIONSHIPS

Healthy relationships are just as important for people with ID as they are for anyone else. People with ID can have rewarding personal relationships; however, some people may need support to develop the relationships, explore their sexuality, explore their gender identity, and find suitable information that meets their needs. It is

important to recognise while some people may have received health education at school, others may have missed out. Accurate information about sexual and reproductive health is necessary to empower the person with ID. It supports protective behaviours and improved decision-making, which will reduce the person's vulnerability.



Promoting appropriate education for the person with ID is very important. If you think the person you are supporting may benefit from developing protective behaviour skills, then it may be useful to suggest they consider including a relevant goal in their NDIS plan to develop the knowledge and skills to increase their safety. In Western Australia, the following organisations have specialty knowledge regarding educating people with ID about relationships and sexuality:

- SECCA supports people with disability to learn about relationships, sexuality, and sexual health: **SECCA Workshops**
- People 1st Programme is part of the Family Planning Association of WA, providing education to people with disability, carers, and families: **SHQ Education**



There are other resources available for supporters to help a person with ID learn about sexual and reproductive health. The following resources may be useful:

- SECCA have developed a free book about sexuality and the law for people of all abilities, which can be found here: **Sexuality Relationships And Your Rights Resource**.
- Family Planning NSW developed a series of fact sheets to help supporters have conversations and provide information about sexuality and relationships, which can be found here: **All About Sex**. One of the fact sheets provides advice for how supporters should use the resources.
- The healthy relationships workbook is a resource written for people with ID, used to help learn about friendships, healthy relationships, consent, and different types of abuse. The workbook can be found here: **Healthy Relationship Workbook.pdf**.
- A guide specifically for women with ID may be found here: **Being A Healthy Woman.aspx**.
- The person's General Practitioner (GP) is also a good person to provide appropriate information about sexual health issues. A resource to guide GPs can be found here: **Sex and intellectual disability.aspx**.
- You can support the person's learning about 'Relationships, dating and intimacy' and 'Finding and building friendships' through side-by-side learning modules by Open Future Learning. The modules can be found **here**.

PREVENTING SEXUAL ABUSE OR EXPLOITATION

Unfortunately, people with ID experience abuse at higher rates than the general population. There are many reasons for this, including inadequate education about their rights regarding bodily autonomy, being used to being told what to do, or being unable to resist (because of power relationship, communication difficulties). Any sexual assault should be reported to police and sexual assault support agencies.

There are several protective factors a person can develop to reduce the risk of being abused or exploited. These protective factors include knowing their rights, recognising safety, understanding the warning signs (e.g. their own physical and emotional responses), and having a network (e.g. knowing both how to ask for help, and who to ask for help).¹¹ The side-by-side learning module 'About abuse' may be helpful, and can be found here: [**SideBySideModules**](#).

It is important that people with ID are encouraged to think and act independently, set boundaries, and have decision-making skills. These skills are developed over time – so consider how you are supporting the person to practise these skills. For example, providing opportunities to experience a variety of social situations and build a peer support system, demonstrating helpful social skills, and being inquisitive are all ways you can provide support to a person to learn and practise useful skills.

The important principles of safety for the person with ID require they:

- Can decide who touches them, and know that they have a right to say no to unwanted touch.
- Understand privacy, and know what private parts of their body are.
- Know the difference between safe and unsafe secrets.
- Know which people they can talk to if they are confused or upset, or if they have concerns or questions.
- Feel safe talking about their feelings and problems with a trusted person.
- Know how to ask for help within their network of friends, family, and other caregivers.



CYBER SAFETY

Digital technology including phones, tablets and computers are important in today's world. For people with ID, they are an important tool to meet friends, participate in activities (like games and learning), watch videos, and conduct life activities such as communicating with people, managing money, and accessing online services. However, it is important to recognise people with ID may be at increased risk of experiencing negative aspects of the digital world, such as being exposed to cyber abuse (i.e. threatening, intimidating, harassing, or humiliating online behaviour). According to a report on internet use of young people with ID,¹² other negative online experiences include accidental purchases, online scams, and fraud, sharing private information, and seeing or sharing inappropriate content (e.g. pornography, violence).

There are many considerations to ensure a safe online environment. Depending on the person's capability, the person may need one-on-one support to develop online skills (and whether you are comfortable providing that support). They may need support to access and connect their device to the internet. The person you support may need special software to help, for example, speech-to-text, or text-to-speech, depending on their needs. A toolkit for supporters on how to support people with ID to use technology can be found here: [**Technology Supporters**](#).

Some individuals with ID find it valuable to enlist people they trust as online communication partners to practise skills safely. You may also need to help the person you support understand how their device can be used within their daily routine – and help them avoid excessive screen time which can impact other areas of their life.

It is also important to provide information about the warning signs, to reduce the risk of inappropriate online interactions. For example, while people may want to expand their online social circle, it is important to know how to do this safely. Visual cues can support safe use. The person should also learn how to take screenshots of anything they are unsure about to then share with a trusted person. This practice also saves evidence, useful if the person is experiencing any form of cyber abuse. They should also understand the types of information or images to not share online, such as full name, address, phone number, bank details, or inappropriate photos (i.e. sexually suggestive nude or partially nude photos).

It is important to help the person you support access the online environment safely. The following resources may be helpful for the person you support to access the internet safely:

- Staying safe on social media and online Easy Read – [**staying safe online.pdf**](#)
- Cyber safety visual cue from SECCA Easy Read – [**Cyber Safety Resource.pdf**](#)
- Sexting brochure from SECCA Easy Read – [**SECCA Sexting DL Brochure.pdf**](#)
- Various resources for carers developed by the Australian Federal Police – [**Parents and Carers**](#)



HEALTHY SKIN

Skin is an important organ and is like a protective wrapping for the body. It is waterproof and airtight, protecting the internal organs from the environment. The skin helps protect the body from bacteria, so there is less likelihood of infections. The body uses blood flow to the skin to help control temperature, increasing blood flow when the body needs to release heat from the body, and decreasing blood flow to keep warmth in. There are also sensory receptors in the skin which help people to feel touch, pain, vibration, and temperature.

Skin integrity relates to whether the person has an injury to the skin. A tear can occur from a sharp object which can go through the skin to the fat tissue underneath (e.g. cut from a knife or a scratch from a fingernail). A person may also have a surface wound which doesn't go through all the skin tissue (e.g. an abrasion from falling over, or a scratch from a fingernail). Bruising is bleeding into the skin from blood vessels that were damaged by an impact. A pressure wound is an injury to the skin because of prolonged pressure, often forming over bony parts of the body (e.g. hips, base of the spine, sitting bones). The ongoing pressure reduces blood flow to the area, causing injury.

RISK FACTORS FOR POOR SKIN INTEGRITY

People with ID may be more at risk of skin tears or pressure wounds for many reasons. It is important to consider whether the person has any of the following risk factors:

- They are unable to reposition themselves regularly.
- They are not able to communicate that they are experiencing pain from skin injury.
- They are using medications which put them at greater risk of skin injuries (e.g. anti-psychotic drugs, anti-depressants, diuretics).
- They have urinary or faecal incontinence.
- They have poor nutrition (missing the vitamins and nutrients required to maintain healthy skin and assist with wound healing).
- They are either underweight or overweight.
- They are dehydrated.
- They are restricted to a bed or a chair.
- They are at risk of falling.
- They are unable to feel pain or pressure (e.g. have a spinal cord injury).

PREVENTION OF PRESSURE WOUNDS AND SKIN TEARS

Pressure wounds often result from a person being in the same position for too long, so it is important to help the person to change their position regularly. If the person is bed bound, they should change position every two hours. If they are in a wheelchair, they should change position for two to five minutes every hour. If the person wears a brace or has other equipment, then seeking regular fit assessments from orthotists or occupational therapists will assist in ensuring the equipment fits correctly. This is particularly important if the person has grown or changed weight. Consider whether the person can use a pressure relieving cushion or mattress (e.g. made from gel, foam, or sheep skin).

Transferring from wheelchair to bed is also a time where the skin is at risk from a tear if it is dragged across surfaces. If you are assisting in helping the person transfer, then it is important to use correct lifting techniques and appropriate equipment (e.g. slide sheets).

If a person has continence issues, then a regular toileting schedule is required. Disposable continence aids and barrier cream may be useful to prevent sores. Avoid hot water during hygiene practices and dry the skin well.

ASSESSMENT AND MANAGEMENT OF PRESSURE WOUNDS AND SKIN TEARS

While cuts and abrasions can be obvious, signs of pressure wounds developing can be harder to observe. Generally, there is a red or pink appearance (on lighter skin), or ashen or blue appearance (on darker skin). The area might be painful. The temperature or texture may feel different from other parts of the body, and the area doesn't change colour when you press the skin.

A visual inspection of the skin can be used to identify any damage or changes to the skin. If you are assisting in daily hygiene care, then you may observe whether the person has any broken skin or pressure sores, rashes, bruises, or reddened areas. The location of the wound can help identify the cause.

It is important to manage any skin damage through tears or pressure injury with appropriate dressings. If wounds are not healing, then it is important to seek medical advice.





SECTION 2 - Proactive and Preventative Care

Health care can be reactive or proactive. Reactive health care is going to the doctor when you are sick. Proactive health care is what you can do to help prevent poor health or promote better health. Many people with ID miss out on proactive health care, so this section outlines different ways you can support a person to access these opportunities to improve or maintain health.

Supporting a person with an ID to see their doctor for proactive health care also helps them form a relationship with the doctor and nurse and helps the doctor know what is 'normal' for the person. This means the doctor will be more able to notice when the person is unwell at a later point. The person you support may find the following information about different types of health checks helpful: **Types of Health Checks Easy Read Fact Sheet.**

ANNUAL HEALTH ASSESSMENTS

A person with ID is eligible for an annual health assessment, which should be done by the person's usual doctor (usually a GP). The practice nurse may also be part of the assessment process. The health assessment is comprehensive and structured so the doctor can assess the physical, psychological,

and social function of patients with ID, to identify if any medical intervention and preventive health care is required.¹³

The health assessment includes all the following items relevant to the person with ID (or their representative):

- a. Check dental health (including dentition)
- b. Conduct aural (hearing) examination (arrange formal audiometry if audiometry has not been conducted within five years)
- c. Assess ocular (eye) health (arrange review by an ophthalmologist or optometrist if a comprehensive eye examination has not been conducted within five years)
- d. Assess nutritional status (including weight and height measurements) and a review of growth and development
- e. Assess bowel and bladder function (particularly for incontinence or chronic constipation)
- f. Assess medications (including non-prescription medicines taken by the patient, prescriptions from other doctors, medications prescribed but not taken, interactions, side effects and review of indications). Advise caregivers of the common side effects and interactions. Consider the need for a formal medication review
- g. Check immunisation status, including COVID-19, influenza, tetanus, hepatitis A and B, measles, mumps and rubella (MMR) and pneumococcal vaccinations
- h. Check exercise opportunities (with the aim of moderate exercise for at least 30 minutes per day)
- i. Check whether the support provided for activities of daily living adequately and appropriately meets the patient's needs, and consider formal review if required
- j. Consider the need for breast examination, mammography, cervical screening, testicular examination, lipid (cholesterol) measurement and prostate assessment as for the general population
- k. Check for dysphagia and gastro-oesophageal disease (especially for patients with cerebral palsy), and arrange for investigation or treatment as required
- l. Assess risk factors for osteoporosis (including diet, exercise, vitamin D deficiency, hormonal status, family history, medication fracture history) and arrange for investigation or treatment as required
- m. For patients diagnosed with epilepsy, review of seizure control (including anticonvulsant drugs) and consider referral to a neurologist at appropriate intervals
- n. Check for thyroid disease at least every two years (or yearly for people with Down syndrome)
- o. For patients without a definitive aetiological diagnosis, consider referral to a genetic clinic every five years
- p. Assess or review treatment for comorbid mental health issues
- q. Consider timing of puberty and management of sexual development, sexual activity, and reproductive health
- r. Consider whether there are any signs of physical, psychological, or sexual abuse.

There are different Medicare items for the health assessment, which relate to the time that it will take a doctor to complete the assessment. Brief assessments will take up to 30 minutes, while a standard assessment takes 30–45 minutes. If a person has more health issues to consider, or there is a need to develop a range of longer-term strategies to manage health, then the long health assessment might take 45–60 minutes. If a person has more complex health needs which need to be managed through a comprehensive preventative health care plan, then a doctor may do a prolonged health assessment taking more than 60 minutes.

The Comprehensive Health Assessment Program (CHAP) is a two-part questionnaire designed to prompt health care and screening for people with ID. The first part of the questionnaire creates a comprehensive health history, completed by the person with ID and their supporters (families, carers). The second part of the questionnaire prompts a doctor to consider health conditions commonly missed or poorly managed, or that are specific to a syndrome (if relevant) and perform a review of the person's health. Currently, the tool costs \$10, and may be purchased from here: [CHAP](#). An alternative preparation document from the UK can be found here: [Health Check](#)

Similar free tools are available to help the doctor conduct an annual health check:

- From the UK, in the resources section – [Health Check Toolkit](#)
- From Canada – [My Health Care Visit](#)

It is important to encourage the person you support to have an annual health check with their doctor. An Easy Read explanation of why to have one and what will happen can be found here: [Yearly Health Check Easy Read Fact Sheet.pdf](#)



COMMON HEALTH SCREENING ASSESSMENTS

A person's family health history helps a doctor understand the need for different screening tests, as it influences the 'risk' of a particular disease, such as some cancers, coronary heart disease, diabetes, amongst others. Knowing a person's family health history is also important as it assists them to make lifestyle decisions that can help to minimise the risk of disease.

For some people living with ID, family health history may not be known, however it is important that efforts be made to collect information where possible. A family health history is developed by talking to relatives of the person, beginning with those closest to the person (parents, siblings), and then asking about more distant relatives (grandparents, aunts, and uncles). For each person, it is important to know their name, sex, year of birth and age (or age when they died), and ethnicity. It is important to know what major medical conditions they had, and when each one developed – especially if before the age of 60. It is also useful to find out whether they had any lifestyle issues that could be related to the illness, like smoking, drinking, or type of employment (e.g. working outdoors, or with chemicals). You can find a form to create a family health tree here: [Family Health Tree.pdf](#)

SCREENING FOR CANCERS

Cancer is a disease where some of the cells in the body start to grow uncontrollably and can spread to other parts of the body. There are a lot of different types of cancers. Some people have a genetic mutation which may put them at increased risk of certain cancers (e.g. breast cancer, bowel cancer). In Australia, there are three population-based screening programs to check whether people have the following cancers:

- Breast cancer – the state-based service will invite women aged between 50 and 74 for a free mammogram every two years. A mammogram is an x-ray of the breast. The doctor should be told if there is a family history of breast or ovarian cancer, if the person has had breast cancer in the past five years, or has any breast cancer symptoms such as:
 - » Changes in breast size, shape, or colour
 - » Changes in the nipples, like redness, discharge or it has turned inside out
 - » Skin changes, such as dimpling, swelling, and bulging
 - » Irritation or rashes
 - » Pain that doesn't go away
- Bowel cancer – men and women will be invited to do a screen when they turn 50, and every two years after that until age 74. A sample of poo is taken to check for blood, which can be a sign of bowel cancer. The doctor should be told if there is blood in the urine, poo, or in the toilet bowl. The cancer can grow without the person noticing any symptoms.
- Cervical cancer – for people aged between 25 and 74 who have a cervix, and who have been sexually active. This screening detects the human papillomavirus (HPV), which is a virus that can cause cervical cancer. It has replaced the previous screening (the 'pap test'), which looked for cell changes in the cervix.



Other cancers can be screened for but must be requested. It is important to talk to the doctor to see if it is appropriate for a person to have the following screenings:

- **Prostate cancer** – men considering being tested for prostate cancer should understand the benefits and harms of testing and treatment. It is common for men over 50 to experience symptoms related to urinary flow, urgency, or control. Common tests for investigating whether someone has prostate cancer include the prostate specific antigen (PSA) blood test, digital rectal examination, and ultrasound. A prostate biopsy is the only method to definitively diagnose prostate cancer.
- **Skin cancer** – people at risk of skin cancer should see their doctor for regular skin checks. People at higher risk of skin cancer have a personal or family history of skin cancer, many moles, fair skin type and colour, a history of bad sunburns, have spent lots of time outdoors unprotected, have suntanned or used solariums, or have a compromised immune system.
- **Lung cancer** – people can be screened annually if they have a high risk of lung cancer (i.e. aged between 55 and 80), a heavy smoking history (e.g. one pack/day for 30 years) and currently smoke, or quit smoking recently. Symptoms can be non-specific, meaning they could be due to a range of different diseases. Potential symptoms include a new or changed cough, coughing up blood, persistent chest infection, chest or shoulder pain, shortness of breath, hoarse voice, and weight loss or loss of appetite.



COMMON BLOOD TESTS

A visit to the doctor may require some blood being taken. It is important to ask the doctor if the test needs to be done when the person is in a fasted state. Depending on the symptoms or situation, the doctor may request different blood tests. The following is a brief description of some common tests that may be requested¹⁴:

- **Blood glucose tests** – usually used to check for or monitor diabetes. Glucose is a sugar in the blood, providing energy for the body. Sometimes a blood glucose test is done when the person has not eaten anything (fasting), or when they have been given a sugar drink to see how blood glucose reacts over time. A person needs this test if they are at risk of developing diabetes or have symptoms related to diabetes. A person who has diabetes often needs to regularly monitor their blood glucose levels at home, using a finger-prick test and a special machine.
- **Calcium tests** – used to check how much calcium a person has in the blood. Sometimes if a person has too much in their blood, they may feel tired, weak, thirsty, need to urinate frequently, have lost their appetite, or are constipated and have stomach pain. Sometimes a person can have too little calcium in their blood if they have numbness around the mouth and in hands or feet, or if they get muscle spasms. If a person is taking some medicines like diuretics or vitamin D supplements, the doctor will ask them to stop taking them before the test.

- **Cholesterol and lipid tests** – measure the amount of cholesterol and other fats in a person's blood. The test is used by a doctor to assess the risk of a person developing heart disease. For most people, the test is recommended every five years once a person turns 45. Some people may need the test more frequently if they have high blood pressure or diabetes, or a family history of high cholesterol.
- **Full blood count** – a general health check which can provide information about several different conditions like anaemia, infection, bleeding or clotting problems, and symptoms like tiredness/weakness. The test looks at the number, types and sizes of red blood cells, white blood cells, and platelets that are in the blood. The test also measures haemoglobin which is the protein that carries oxygen around the blood.
- **Iron studies** – look at how much iron is in the blood. There are different tests to measure each aspect of the iron. A serum iron test measures the amount of iron floating freely in the blood. A serum ferritin test measures the quantity of a protein that helps store iron in the body. A transferrin test measures how well the body transports iron in the blood. These tests are usually done after a full blood count has shown that a person is anaemic or has another problem with the red blood cells, or if a doctor thinks they may have too much iron in their blood.
- **Kidney function tests** – look at how much creatinine and urea are in the blood. Some tests may also look at the level of electrolytes (sodium, potassium, chloride, or bicarbonate) in the blood. These tests help to see whether the kidneys are filtering the waste from the body and regulating the electrolytes in the blood.
- **Liver function tests** – look for the level of proteins and enzymes in the blood, showing how well the liver is working.

The liver is an important organ responsible for many different things, including processing alcohol and other drugs, storing vitamins and minerals, and making bile, proteins, and enzymes.

- **Prostate specific antigen (PSA) test** – used to help detect or monitor prostate cancer by looking at the amount of the protein PSA in the blood. The test is only recommended for men who have symptoms or are at risk of prostate cancer.
- **Thyroid function tests** – measure the level of different hormones. Usually, the amount of thyroid stimulating hormone (TSH) is measured first, and if abnormal, thyroxine (T4) and triiodothyronine (T3) are measured. These hormones help control the body's metabolic processes, including heart rate, blood pressure, body temperature and weight.
- **Vitamin B12 test** – measures the amount of vitamin B12 in the blood. The vitamin is important for making red blood cells, for cell and tissue repair, and for nerve health. Sometimes a doctor might request this test if there has been an abnormal blood test, or the person has anaemia. The test is sometimes used to check a person's nutritional status, especially if they have a limited diet, or to help understand the cause of changes in a person's mental state or behaviour. The test is often done after the person has fasted for six to eight hours.
- **Vitamin D test** – looks to see whether a person has enough vitamin D. Most people get their vitamin D when they expose bare skin to ultraviolet light from the sun, so people who don't get much sunlight from staying indoors, or who always cover their skin with clothes, or who have naturally dark skin, may be at risk of low vitamin D. This vitamin is important for strong bones and may help prevent some diseases. The test is usually given only to people who may be at risk of low vitamin D.



HEARING TESTS

A person with ID may not know how to communicate they are experiencing hearing loss. People with ID are at greater risk of having undetected hearing loss – for example, hearing screening of Special Olympics athletes showed 20-50% of the athletes experienced hearing loss, 10 times more than the general population.¹⁵

Some people may experience hearing loss after an ear infection or acquired injury. However, for many people hearing loss occurs gradually over time. Signs may include a person starting to talk louder, needing to be looking at the person talking, having difficulty hearing in noisy environments, or wanting the TV/radio volume turned up.

Hearing tests, done by an audiologist, check a person’s ability to hear sounds of different pitch and loudness. Types of hearing tests performed by an audiologist include:

- Pure tone audiometry - how loud different sounds need to be for a person to hear them
- Air conduction - measures whether a person can hear different tones played through headphones
- Bone conduction - how well a person’s cochlea picks up vibrations
- Tympanometry - checks the eardrum.



LIFESTYLE SCREENING

Sometimes, a doctor may ask some general health assessment questions related to a range of different risk factors for non-communicable diseases. These diseases are not infections, nor are they able to be transmitted from one person to another. They are diseases caused by genetics or lifestyle and behavioural factors, and include cardiovascular diseases, cancer, chronic respiratory diseases, type 2 diabetes, and obesity. They usually develop over time but can often be prevented if lifestyle factors are changed.

Lifestyle screening is not a diagnostic tool – instead, the screening will help a doctor understand which lifestyle factors might influence a person’s health. The assessment helps the development of goals supporting long-term health, by making positive changes to lifestyle. For example, the doctor may ask about diet and exercise, alcohol intake or other substance use, sleep issues, and anxiety or depression. The doctor may also ask about a person’s social support, sexual activity, personal safety, and quality of life. These are called screening questions, and help the doctor consider what other assessments would be useful, what type of supports should be recommended, and what type of health-related goals the person could consider. *The Healthy Living Checklists* (Appendix A) are a good way to prepare before visiting the doctor for a health assessment, as they include lifestyle questions a doctor is interested in.

How frequently a person with ID should have a hearing test depends on their age, if they wear a hearing device, and whether they have Down syndrome. In general, a person with ID should have their hearing tested every five years from ages 18-50, and then every three years after that. If a person has Down syndrome, they should have their hearing checked every three years from ages 18-35, then annually after that. Anyone using a hearing device should have their hearing assessed annually.

A doctor may also check for build-up of ear wax - a reversible cause of hearing loss, However, many people with ID do not have it checked regularly (at least once a year).

VISION TESTS

Vision may change over time, and a person with an ID may not be able to identify changes that have occurred. The doctor can perform a quick vision test using the Snellen chart (or the Tumbling E display if a person does not know their letters but can still match shapes). This test measures visual acuity, one eye at a time, with the person reading the letters in each row aloud (or manipulating a shape), from a distance of six metres. The doctor may refer the person to an optometrist for a more comprehensive vision assessment.

Many people go directly to an optometrist as a referral is not needed for a general eye test. Vision should be checked regularly, with Medicare allowing for an annual assessment.

There are different types of tests, and not everyone will need each kind. The tests check the ability of a person to see details up close and at a distance. Some people may need glasses to correct the vision problems. Other tests check a person’s peripheral vision, and whether the muscles around the eyes are working together properly. The optometrist may assess different parts of the eyes for any problems, as there are some conditions like

glaucoma or cataracts that develop as people age. An Easy Read explanation of an eye test can be found here: [How to be eye care aware Easy Read](#)



SCREENING FOR SEXUALLY TRANSMITTED DISEASES

It is important to consider carefully whether there is a possibility that a person with ID is sexually active, rather than assume they are not. Sexually transmitted infections (STIs) are passed on during unprotected oral, vaginal, and/or anal sexual activity. Some STIs cause noticeable symptoms, while others may not be noticed – but they may cause health problems if they are not treated. People should consider an STI test if they have frequent changes in partners, they have a new partner, or their partner has recently had an STI.

Tests can be done by visiting a GP or a sexual health clinic. The doctor will ask questions about risk to decide which STI tests are required, depending on the person's individual situation. The test will require a urine sample, a blood sample, or a swab of the throat, vagina, or anus, depending on the type of test and situation. Most STIs can be treated and cured (or in the case of herpes or HIV, controlled).



DENTAL CARE

Good oral health means a person has healthy teeth and gums. This is important for overall health, as well as for eating and drinking, breathing, and speaking.

Many people with ID experience poor oral health. This can be due to their need for assistance with activities required for oral hygiene, communication and/or behavioural challenges, the use of enteral feeding, and barriers to accessing quality dental care. For some people, it may be difficult to diagnose if they are in pain or losing the ability to eat certain foods. Gum disease can be painful and lead to tooth loss and is also linked to an increased risk of some diseases. Cavities in the teeth can also be painful and lead to tooth loss. It is recommended that people visit the dentist every six months, so that the health of the mouth, gums, and teeth can be monitored. Regular visits help the dentist put preventive strategies in place, depending on the risks.

CAUSES OF POOR ORAL HEALTH

Oral hygiene is the way a person looks after their teeth and means brushing and flossing daily. For a person with ID, factors limiting their oral hygiene include needing support from a caregiver, specialised equipment, being resistant to mouth care routines, not being motivated for oral care activities, having competing priorities, or not having the time.

Plaque is a sticky coating on teeth, which contains bacteria. Some bacteria use sugar for energy and produce acids that can dissolve our teeth over time. This is how tooth decay happens. When there is a build-up of plaque on teeth and along the gum line, the immune system tries to get rid of the plaque, and the redness and swelling of the gum around the tooth is a sign of the inflammation response.

PREVENTING POOR ORAL HEALTH

The Australian Dental Association recommends the following tips to help prevent tooth decay and gum disease¹⁶:

- Eat a healthy diet.
 - Tooth friendly foods and drinks include fresh fruits and vegetables, especially crunchy vegetables which get the saliva flowing. Saliva is helpful as it washes away some of the sugars and acids on the teeth.
 - Unsweetened dairy products (cheese and milk) that have calcium help strengthen the hard outer shell of the tooth (called the enamel), which helps protect against tooth decay.
 - Drinking water or milk helps rinse out the mouth, washing the bacteria and sugars away.
 - Avoid sugary drinks (e.g. energy drinks, sports drinks, fruit juices, and sugary sodas). If they are consumed, it is best to have them at mealtimes when there is more saliva.
 - Avoid candies and lollies that stay in the mouth for a long time (e.g. toffees, lollipops, sticky lollies).
- Brush teeth regularly with a fluoride toothpaste, reaching all surfaces of the teeth. Brushing should take at least two minutes each time. You can find a handy Easy Read checklist of the steps to brush teeth, plus videos showing how to support people to brush their teeth (depending on the level of support needed and the type of toothbrush used) here: **Brushmyteeth**
 - Brushing stops the bacteria from getting out of control and removes plaque.
 - Fluoride helps to strengthen and repair teeth.
 - Consider if you are using the correct toothbrush, and/or the correct technique (especially if you are helping someone to brush their teeth).
 - Note 1 – if you are brushing someone else's teeth, then it is important to think about safety for everyone. Hands should be washed before and after the teeth brushing, and gloves should be worn. You may need to use protective glasses, so you don't get any splashes into your eyes. Keep your fingers safe. Make sure you are not injuring the person you are helping by brushing too hard or with the wrong technique.
 - Note 2 – dental experts usually say teeth should be brushed twice a day. In some situations, a person may need a lot of help to brush their teeth well, or it may be a difficult routine. If this is the case, then it might be better to emphasise the right length of time, the right brush, and the right technique, and brush less frequently.
- Floss between the teeth.
 - Dental floss is used to remove food and bacteria from between the teeth. The floss is pushed gently between the teeth, and then a gentle up-and-down motion rubs the floss along the side of each tooth. The floss should go a little under the gum to remove the plaque from that area.
 - There are alternatives to dental floss. Floss picks have a handle which holds a piece of dental floss and are used in the same way as dental floss. These can be helpful for a person learning to floss their own teeth. Interdental brushes are like a very small bottlebrush, which have a handle on a thin flexible wire that is covered in bristles. The brush head is put in the triangular-shaped space between the teeth, close to the gums.

- Visit the dentist regularly. While tooth decay is preventable, it can also be repaired or healed if it is noticed early. Having regular check-ups will mean decay is found early, which can reduce the amount of treatment needed.
 - The dentist is a partner in long-term dental care. They can provide advice on prevention, as well as treatment options.
 - Consider whether the practice is disability friendly. There are specialist dentists who may have additional experience and understanding of how to provide dental care to a person with ID. Some dentists will also provide training to support workers and other caregivers if requested. The WA Health Department also has a special needs dental service (see here for more detail: [Special Services](#))

MAKING AN ORAL HEALTH PLAN

People may need extra support to look after their teeth and gums, which means having good oral hygiene. It may be a good idea to develop an oral care plan with the person to be included in their overall care plan, with the assistance of other people in the family or support team. The oral care plan depends on the specific needs of the person with disability, and may relate to brushing the teeth, becoming more independent with oral hygiene, visiting the dentist, modifying the diet, modifying habits (e.g. like smoking or drinking alcohol). Oral care planning has the following steps:

1. Assess the problems that should be considered in the plan. There may be more than one issue, so talk with the person, care team, and (potentially) the dentist to understand the priorities. The assessment is individual, and should consider the person's abilities, preferences, and needs. You may want to think about:
 - a. What does the person want addressed?
 - b. What level of support does the person need, and are they able to increase their independence with self-care?
 - c. Is brushing effective?
 - d. Is the mouth healthy?
 - e. Is the mouth dry?
 - f. Are there any other relevant issues?
2. Set goals in the oral care plan, so everyone understands what will be achieved. Goals are individual to each person but should address the prioritised problem(s). Goals should be realistic, achievable and measurable. Examples of goals include the person wanting to:
 - a. Arrange a dental check-up
 - b. Reduce sugar in their diet
 - c. Increase independence in tooth brushing
3. Set out how to meet the goals by action planning. This means identifying who needs to do what, where, when, and how. Sometimes the steps may be simple, but it is helpful to think about each step, so they get done. Some tasks may be time-sensitive or needing to be done before another task. Using the examples above:
 - a. Arrange a dental check-up. This might include needing to find a dentist, looking to see whether they would be suitable, arranging an appointment (and transport) and putting details into the client management system, finding an appropriate social story, gathering relevant health information, etc.
 - b. Reduce sugar in their diet. This may include making and keeping a food diary, learning to look at food labels, talking to a dietitian, creating menus, shopping for different foods, etc.

- c. Increase independence in tooth brushing. This may require an assessment by an occupational therapist, consideration of different toothbrushes or floss, creation of visual chart for the tooth brushing steps, demonstrations (or video watching) of tooth brushing, and continued observation and support.
4. Document progress towards the goals. Consider whether the goals need to be changed, depending on how progress is going – sometimes we underestimate how long things will take, while other times we overestimate how long things will take.

IMMUNISATION

Immunisation is important in preventative care, as it is a way to protect people against harmful diseases before they are exposed to them. Immunisation includes the process of vaccination (receiving the vaccine by injection or as drops in the mouth) and developing the immunity to the disease. For specific vaccines to be approved for use in Australia, they have gone through very thorough testing to make sure they are safe and effective for people.

The immune system is important – it stops people getting sick from germs like bacteria and viruses. The immune system recognises harmful bacteria and viruses. When a foreign virus or bacteria first enters the body, the immune response produces mucus to try and flush out the harmful 'invader' germs and stop any more from entering the body. Then the immune response sends white blood cells to surround the germs to prevent more harm. Finally, the immune response produces special proteins called antibodies which can lock onto the germ and destroy it.

The vaccine tricks the immune system into thinking it has already had the disease, producing an immune response without causing illness. The immune system creates

antibodies to protect from future infection. It has memory cells which will recognise specific germs or viruses in the future, so if a person gets infected, then the immune system can respond more quickly to destroy the invaders. Sometimes a person may still get the illness, but they will get a less serious case.

People with ID or cognitive impairment should be vaccinated like other Australians, as many are at greater risk of complications from respiratory viruses such as COVID-19 or the flu. There is a National Immunisation Program which funds free vaccines for Australians. The doctor is a good person to talk to about what vaccinations a person needs, and when. Easy Read resources about the COVID-19 vaccination can be found here: [COVID-19 vaccination – Easy Read resources | Australian Government Department of Health](#).



PART B

MANAGING HEALTH CONDITIONS

Some people with ID or cognitive impairment may also have a coexisting health condition unrelated to their disability, or their disability may include a specific health condition. This section has a focus on how to support a person to manage chronic health and mental health conditions, and how you can identify whether their health status is changing (so you can support the person to seek help if needed).

SECTION 3 - Managing Chronic Health Conditions

A chronic condition is an illness or condition that lasts a long time (more than six months) or doesn't go away – it may lead to a person's health gradually getting worse or requiring regular treatment. Most chronic conditions are not usually immediately life-threatening but can shorten life expectancy, particularly if they are not well managed. Sometimes, the person's disability can cause a chronic condition that needs to be managed.



THE ROLE OF THE GENERAL PRACTITIONER

General Practitioners (GPs) are doctors who are qualified in general medical practice. They may also have specific interest and expertise in men's or women's health, mental health, or other health areas. GPs are usually the first point of contact with the health system, and usually care for their patients over an extended period rather than for just one specific episode of illness or injury. GPs also have a role in prevention of illness and injury and can provide advice and education on health.

GPs are essential to good management of chronic conditions. They can develop a management plan, which provides an organised approach to the care of the condition based on treatment goals. The plan identifies both the health and care a person requires, highlighting who will provide each component of service or care, and the actions required for effective care.



If the person has specific complex care needs requiring multidisciplinary care, the GP can also develop Team Care Arrangements. This means the GP can be more involved in care coordination, collaborating with other health or care providers delivering treatment or services. The GP may also recommend a case conference, which is a meeting between two or more members of the multidisciplinary care team (e.g. allied health professionals, home and community service providers, personal care workers, or another medical practitioner). GPs can use Medicare items to organise, coordinate and participate in a case conference.

The GP also has an important role in ongoing review of the care plans. It is important that treatments and care are reviewed to ensure they are working as anticipated and having a positive effect on the person's health. The recommended period of review is three to six months, depending on the complexity of the person's health needs. Review of medications is recommended annually.

YOUR ROLE IN SUPPORTING CHRONIC ILLNESS

For anyone with a chronic condition, it is empowering for them to understand their condition. This helps them take control of their health, know what questions to ask the doctor, and select treatments best suited to them. In your role supporting a person with ID, you can help provide access to information they can understand, and support to them to help manage the condition (e.g. by keeping a healthy lifestyle). It is helpful that you understand their condition, understand treatment and/or therapy, and learn how the person can control the symptoms (if possible).

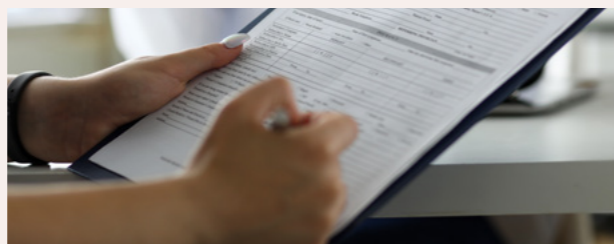
Try to support the person to maintain their social relationships during the onset of symptoms, to avoid social isolation and by providing emotional connections. The person you are supporting may benefit from a facilitated support group from a disease-specific organisation (e.g. Diabetes Australia, the Asthma Foundation), or a generic group. These groups may be peer-to-peer or facilitated by trained educators who can help people develop self-management skills.

Specific activities related to treatment (e.g. taking prescribed medication) or therapy should be included in the person's care plan so that everyone supporting the person understands what is required. The care plan should also include how the person will be supported to attend regular GP or specialist appointments (including who has the responsibility in making appointments and supporting the person while they attend the appointment).

Depending on the health circumstances of the person you support, you may have a role in medication management.¹⁷ It is important to know if you have authority to administer the medication – some medications require a person to undergo training and have met certain competencies. If you have authority to administer medication, it is important to know which medicines need to be given on a strict schedule, and how they need to be administered. The amount of medicine and when it needs to be given will be detailed on the prescription, and the packet of the medicine. Other medicines may need to be given ‘as-needed’ (also written as ‘PRN’ (pro re nata) meaning unscheduled administration), common for some pain medications. A pharmacist can make up a dose administration aid (e.g. Webster packs, which puts the week’s medications in different segments of the pack), which is helpful if a person is taking more than one medicine, or if they need to be taken at specific times of the day. If a person is unable to take a medicine in its usual state, the pharmacist may be able to identify other ways the person can take the medicine, for example by making smaller tablets, suspending the drug in fluid, or putting the drug in an ointment which can be absorbed through the skin. The pharmacist can also provide more information about how to manage medications.

Where possible, provide an environment for the person you support to be as independent as possible in managing their chronic health condition(s). Continue to look for opportunities to provide relevant information in accessible formats, for example:

- **Chronic Health Plans Easy Read Fact Sheet**
- **Easy Read Health Leaflets and Films**
- **Information for Patients**
- **Patient Information**



NDIS DISABILITY-RELATED HEALTH SUPPORTS

The person you are supporting may have funding for disability-related health supports in their NDIS plan for continence, diabetic management, dysphagia, epilepsy, nutrition (for percutaneous endoscopic gastrostomy (PEG) feeding and home enteral nutrition (HEN)), podiatry supports, respiratory supports, and wound and pressure care supports. This type of funding generally pays for a range of different things, such as¹⁸:

- Equipment (e.g. if they have equipment like a ventilator, for respiratory support)
- Consumables (e.g. continence consumables, like catheters, pads; wound care consumables like dressings, bandages)
- Training for a suitably qualified and competent worker to provide monitoring (e.g. epilepsy seizures), implementation (e.g. diabetic management plan), and daily maintenance and care (e.g. diabetes blood glucose testing and provision of subcutaneous insulin injections)
- Plan development by suitably qualified and competent clinician (e.g. dysphasia supports, diabetic management).

COMMON CHRONIC CONDITIONS

There are many different chronic conditions. The following chronic conditions are not a definitive list but are some of the most common conditions.

ARTHRITIS

Arthritis refers to more than 150 different conditions affecting the muscles, bones, and joints. It affects people in different ways (depending on which condition they have), but common symptoms are joint swelling, muscle aches and pain, stiffness or reduced movement of the joint, joint pain, and general fatigue.

Osteoarthritis is the most common form, occurring when the bones' protective cartilage wears down over time. It occurs most often in weight-bearing joints like knees, hips, and the spine. Inflammatory arthritis is when a person's immune system is overactive, causing inflammation in the joints – and can affect many joints at the same time.

You may need to help the person you support manage their pain. Depending on the situation there are different management strategies, for example, cold packs may reduce inflammation, and heat packs can reduce muscle pain. The person may also be able to take medication like analgesics (e.g. Panadol), or non-steroidal anti-inflammatory medication (e.g. ibuprofen) for pain relief. Other types of medication may target the immune system, or control inflammation. A healthy lifestyle is important for managing arthritis. Physical activity helps a person maintain strength and flexibility and manage pain. Keeping to a healthy weight reduces strain on the ankles, knees, and hip joints.

You can find more information here: [**Arthritis**](#)





ASTHMA

Asthma is a respiratory condition that causes difficulty breathing. A person with asthma has sensitive airways in their lungs, which react to triggers (e.g. pollen, activity, cold). People may have different triggers, so it is important to understand what they are sensitive to. When asthma is triggered, the muscles around the airways squeeze tight, restricting airflow to the lungs. Asthma can also produce mucus, making it harder to get oxygen into the lungs.

If a person has asthma, it is important an asthma action plan be included as part of their care plan, so everyone knows how to help should they see symptoms. An asthma action plan outlines what medication to take, how to tell if the asthma is getting worse, what to do if symptoms get worse, and what to do if the person has an asthma attack.

There are two types of asthma medications: preventer and reliever. Preventer medications need to be used daily. They make the airways less sensitive. Even if a person feels well, they should take their preventer medication daily or as prescribed. Reliever medications act fast to give quick symptomatic relief. They relax the muscle around the outside of the airway allowing it to open, therefore need to be near a person with asthma should they experience symptoms.

Each person's asthma symptoms can be different. Most commonly, they will feel shortness of breath, tightness in the chest, and cough and/or wheeze. A sudden onset of symptoms is called an asthma attack, and for some people it can become an emergency unless appropriate first aid is applied.¹⁹ The range of asthma signs or symptoms include:

- Mild to moderate asthma – the person may have a cough or wheeze and some difficulty breathing but are still able to talk in full sentences and walk around.
 - Actions: help the person keep calm and sit up straight. Then help them use their reliever inhaler. Wait four minutes, and then if symptoms don't improve, help them to use their reliever inhaler again. Note, people use different types of inhalers, so it is important to know the correct dosage.

- Severe asthma – the person has obvious difficulty breathing and can't speak a full sentence. They may have a cough or wheeze.
 - Actions: call for an ambulance and start first aid.
- Life-threatening asthma – the person is gasping for air, and unable to speak one or two words per breath. Their lips may be turning blue. Their symptoms are getting worse very quickly. They may be confused or exhausted or may have collapsed. They are not getting any relief from their inhaler.
 - Actions: Call for an ambulance and start first aid.

Asthma is considered well managed if a person doesn't have symptoms more than two days a week, and doesn't need their reliever medication more than two days a week. Their activities aren't limited by their asthma, and they don't get any symptoms at night or first thing in the morning.

You can find more information here: [**Asthma**](#)

COELIAC DISEASE

When a person has coeliac disease, the lining of their small intestine is damaged by gluten – a protein found in grains. The damage reduces the amount of surface area in the bowel that absorbs nutrients from food. This can lead to a person not getting the nutrients they need from the diet, causing deficiencies (e.g. low iron).

There are many symptoms for coeliac disease, including gastrointestinal symptoms (diarrhoea or constipation, discomfort in the tummy), weight loss, tiredness, irritability or depression, and easy bruising. You can help the person you support tell the doctor about what symptoms they have. A doctor may ask for a test to screen for coeliac disease – the test looks at the antibodies in the blood that have been produced in response to gluten. Coeliac disease can only be diagnosed from a procedure that collects biopsies from the small bowel, examining for signs of damage. Managing coeliac disease is done by having a gluten-free diet. This means the person cannot have ANY gluten. You may need to help the person you support change their diet and learn about what foods and drinks they can safely consume.

You can find more information here: [**Coeliac**](#)



DIABETES

The amount of glucose in the blood is controlled by insulin, which is a hormone that converts glucose into energy. Diabetes is a health condition where there isn't enough insulin. There are two types of diabetes:

- **Type 1 diabetes** occurs when the immune system destroys healthy cells in the pancreas and stops it from producing insulin. People with this type of diabetes need to have insulin every day by injection or an insulin pump.
- **Type 2 diabetes** occurs when the body doesn't produce enough insulin, or the cells don't respond effectively to insulin. This type of diabetes is progressive – at first, it can be managed by lifestyle changes (i.e. regular activity, healthy eating, losing weight). However, this type of diabetes can progress until people need medication, and eventually insulin.



Diabetes management requires balancing the type and amount of food a person eats, their activity level (using energy), and medication taken. It is important that blood glucose levels are kept within a healthy range. When blood glucose levels are too high (hyperglycaemia), the person may be very thirsty, have a dry mouth, headache, nausea, blurry vision, be confused, need to frequently urinate, and have shortness of breath. When blood glucose levels are too low (hypoglycaemia), the person may have a headache, be hungry, feel shaky and dizzy, may be sweating, have a fast heart rate, and be confused, irritable and not able to concentrate.

If you are supporting a person with diabetes, you may need to help them to check their blood glucose levels using a blood glucose monitor. The doctor or diabetes educator will provide information about how and when to check blood glucose levels. More information can be found here: **Blood Glucose Monitoring**. You may also need to help the person monitor their diet, to make sure they eat the right types of foods (e.g. low GI, high fibre). If a person is on medication, then it is important they take it regularly and at the right time of day.

When blood sugar levels are too low or too high, you may need to provide first aid. If a person has mild hypoglycaemia, you can give them a fruit juice or a lolly to quickly raise their blood sugar. If they are confused, have blurry vision or are having a seizure, it is an emergency so call an ambulance. If a person has mild hyperglycaemia, they need to take their diabetes medication or insulin to stabilise blood sugar levels. If they have nausea and vomiting, are confused, have shortness of breath or are in a coma, it is an emergency so call an ambulance.

You can find more information here: **Diabetes**.

EPILEPSY

Epilepsy is a term for a number of different brain conditions which cause a person to have seizures, from disrupted electrical activity in the brain. The cause of epilepsy isn't always known.

The type of seizure depends on what part of the brain is involved. For some people, the seizure might affect the whole body which is a generalised seizure. For other people, the seizure might only involve body parts controlled by part of the brain. Seizures fall into the following categories:

- **Generalised tonic-clonic seizures.** A person with this type of seizure will have a sudden loss of consciousness. The body becomes stiff, and then the muscles may be jerky. It is common for the person to lose control over their bladder, bite their tongue, and turn either red or blue. After the person has regained consciousness, they may be confused, drowsy, or agitated. They may have a headache, and not be able to remember the seizure. This type of seizure was previously known as a 'grand mal' seizure.
- **Generalised absence seizures** are brief. The person will lose their expression, stop activity, and be unresponsive. Sometimes the person may stare, blink their eyes, or the eyes may roll upwards. The person usually has no memory of the seizure and recovers quickly and can resume the activity they were doing at the time of the seizure. This type of seizure was previously known as a 'petit mal' seizure.
- **Focal seizures** start in one part of the brain, and only affect the parts of the body controlled by that part of the brain. The seizure may take the form of unusual feelings or sensations, or unusual movements. The person can have different levels of consciousness during the seizure.

If the person you support has epilepsy, you can assist by helping them manage the epilepsy. This means it is important to ensure the person takes any anti-epileptic medicine that their doctor has prescribed. The person's doctor may request regular blood tests to check that the medicine is keeping certain measures within the right levels, and not causing some other medical problem. The person may also need to avoid certain triggers, e.g. too much stress, caffeine, not enough sleep, or food, flashing lights, etc.

You may also have a role in keeping the person safe. If the person has the generalised type of seizures, they may be at greater risk of injury. For example, they may fall and hurt themselves. Some people may need to wear protective head gear if they are having frequent seizures. If the person is eating or drinking when they have a seizure, they may breathe in the food or liquid so you may need to be nearby during mealtimes so can assist if required. The person may also need assistance around water, to prevent drowning.

You can also assist the person by helping them keep a seizure diary. A seizure diary includes information like date and time of the seizure; a description of the seizure; what happened before, during and after the seizure; what medication was taken and what medication was missed that day; any triggers that were observed; and the person's general health and wellbeing. This helps the doctor understand how well the epilepsy is being managed. It may also help to identify if there are any triggers causing the seizures. If the seizures are becoming more frequent, then it is very important that the person sees the doctor.

You can find more information here: **Living with Epilepsy**



HIGH BLOOD PRESSURE

High blood pressure is often called hypertension. Many people have high blood pressure with no symptoms – however, it puts them at greater risk of developing heart disease, kidney disease or having a stroke.

If you are supporting a person who has high blood pressure, it is important to encourage them to make lifestyle changes. If they smoke, they should stop. If they drink alcohol, they should reduce their intake to one drink per day or none. If they are overweight, losing weight will help reduce their blood pressure. They should also reduce the amount of salt they have in their diet – reducing processed and takeaway foods and using herbs and spices for cooking instead of salt.

Sometimes, a person may need medication to help reduce their blood pressure levels. It is important they see a doctor regularly who can monitor their blood pressure and prescribe the type of medication that will work best for the person if it is required.

HIGH CHOLESTEROL

Cholesterol is a type of fat that is produced by the body and found in foods that come from animals. There are two types of cholesterol. The high-density lipoprotein cholesterol helps clear fat from the arteries. The low-density lipoprotein cholesterol is the bad cholesterol as it leaves fat to build up in the arteries, making it harder for blood to flow through.

If you are supporting a person who has high cholesterol, it is important to encourage them to eat a healthy diet, including lots of fibre and limited saturated fat. If the person is not active, then they should be encouraged to increase their physical activity which can also help to reduce cholesterol level.

If people are at high risk of a heart attack or stroke, the doctor may prescribe a cholesterol-lowering medication. These are called statins and help to lower the bad cholesterol. They should be used in combination with a healthy diet and regular exercise.

OSTEOPOROSIS

Osteoporosis is a bone density disease that makes bones more fragile. While everyone's bones get weaker as they get older, lifestyle (e.g. not being active, smoking), medications, or other conditions can reduce bone density more quickly. For example, anti-seizure medication can decrease bone mineral density, putting a person at greater risk of having osteoporosis. A person with osteoporosis is at greater risk of breaking a bone if they fall.

If you are providing support to a person with osteoporosis, they may have prescription medication and calcium and vitamin D, to help strengthen their bones. Exercise also helps strengthen bones (e.g. by doing weight-bearing exercises) and reducing the risk of falling (e.g. by doing strength-training and balance exercises). Other lifestyle factors are important – for example, the person you support should be encouraged to stop smoking and limit alcohol intake. It is also important to consider how their environment may need to change to reduce the risk of falls (e.g. by wearing sensible shoes, clearing clutter to keep the floor clear, or providing a walking frame).

You can find more information here: [About Bones](#)



SECTION 4 - Managing Mental Health Conditions

It is often a person's behaviour that suggests they may be experiencing a mental health condition. They may refuse to do activities they've previously enjoyed, become irritable and aggressive, or have more problems sleeping. If a person's behaviour has changed, it is important to support them see their doctor, to find out what treatments may be helpful. You may need to help the person you support attend ongoing appointments with health professionals such as their GP, psychologist, counsellor, or psychiatrist.

It is important you support the person to have a healthy lifestyle as healthy diet, enough exercise, and adequate sleep are necessary to manage mental health. If treatment is prescribed, it is also important to support them to comply (e.g. medication, counselling, cognitive behaviour therapy). It is also helpful to support the person to reduce stressful situations in their daily routine and to help them identify triggers that worsen their mental health. This section contains more in-depth information on how to support a person experiencing a mental health condition.

DIFFERENT TYPES OF MENTAL HEALTH CONDITIONS

Depending on the cause of disability, a person with ID may be more likely to have a specific type of co-occurring mental health condition. There are several different types of mental health conditions found in people with ID:

- Anxiety disorder – a person may experience fears that affect their quality of life and ability to do the things they want to do. Anxiety disorders include anxiety, obsessive compulsive disorder, phobias, panic disorder, and post-traumatic stress disorder.
- Mood disorder – a person may experience sadness or happiness more intensely and for a longer period than would be expected for their life circumstances. Mood disorders include depression and bipolar disorder.
- Psychotic disorder – a person may think, hear, see, or experience things in a way that is different from other people. Schizophrenia is an example of a psychotic disorder.
- Eating disorder – a person may have thoughts about eating, food, and their weight resulting in choices that affect their physical health. Bulimia and anorexia nervosa are the most common eating disorders.



IDENTIFYING SYMPTOMS OF A MENTAL HEALTH CONDITION

It can be complex to support a person who experiences poor mental health and has ID. They may not be able to describe their feelings or communicate what they need. At times, they may use behaviour to communicate their distress. They may describe their emotional symptoms using physical descriptions (e.g. their heart hurts, they are sad in their stomach).

If there is any change to a person's thoughts, feelings, or behaviour, that impacts on how they function and their quality of life and persists or worsens over time, it may indicate a mental health condition. There are several signs and symptoms indicating specialist mental health support is required²⁰:

- Physical complaints (headaches, weight loss or gain, pain)
- Decreased or increased body movement
- Doing things instead of going to bed, waking a lot, resisting going to bed
- Apparent decrease in skills
- Changes to speech (more talkative or louder than usual, asking repeated questions, speaking quickly)
- Changing quickly between activities
- Increased difficulty completing tasks
- Onset or increased self-injury (hitting/biting oneself, pulling out hair)
- Appearing fearful or uncharacteristically suspicious of family members or familiar caregivers
- Anger or agitation (disruptive behaviours like shouting/screaming, swearing, lashing out at others)
- Being unwilling to take part in normal activities they've previously enjoyed – or participating but not appearing to enjoy them
- Being unwilling to eat meals, spitting out the food, throwing it away
- Seeking excessive reassurance that they are a good person or are doing well
- Obsessive behaviours (handwashing, organising/arranging)
- Withdrawing from others
- Seeking more attention
- Acting much more confidently than usual

You may be able to talk to the person you are supporting about the different symptoms they are feeling. Examples of resources relating to mental health symptoms can be found here:

- ***Mental Health***
- ***HFS ER Mental Health***

SUPPORTING A PERSON EXPERIENCING A MENTAL HEALTH CONDITION

To support a person with ID who may be developing mental health issues requires early identification of warning signs, and encouragement to seek help from appropriate health professionals. It is best to get help as soon as possible, as people can feel better if they get the right help.

You can also support healthy lifestyle habits, social contact, and encourage activities you know they enjoy. You may need to listen without judgement and support their decision-making. If a person has previously experienced poor mental health and received help from a health professional, it should be documented in the person's care plan so that all caregivers are aware of the appropriate responses. Check to see what support is required and let other care team members know what to look for and how to respond.

In a crisis, you may need to call an ambulance or the police. It is important you let responders know the person has ID, they are experiencing a mental health crisis that requires medical help and describe the person's symptoms and behaviour. If the person has a legal guardian, you need to let them know as soon as possible. It is important to reassure the person you are supporting and let them know what is happening or likely to happen. You may need to advocate for the person.



There are several places to seek further information on how to support a person with mental health issues:

- Beyond Blue mental health information: ***The Facts***
- Mental health first aid (specific for ID): ***ID Guidelines***
- Mental Health Commission resources: ***Resources***
- 'Head to Health' online mental health resources: ***Head to Health***

Resources to help the person with ID understand about their mental health (in plain English) can be found here: ***Feelings***

MENTAL HEALTH TREATMENT

Sometimes, a person may require specific treatment for their mental health condition. If the person is in crisis with their life in immediate danger, then call 000 or take them to the hospital emergency department. If the person is not in a crisis, then it is good to support them to go to their GP. The GP will then decide what help the person needs by making a mental health assessment. They may refer the person to a psychiatrist, or another mental health professional like a psychologist, counsellor, social worker, or occupational therapist. They may prescribe medicine to treat depression or anxiety.

The GP may develop a mental health plan, with Medicare covering some of the costs associated with seeing a mental health professional (up to 20 sessions per year). The mental health plan includes goals for treatment, treatment options, and support services available.

Psychological therapies for mental health conditions provide a safe environment for people to talk about their thoughts and feelings with a specially trained professional to understand and cope with their symptoms. Cognitive behaviour therapy (CBT), acceptance and commitment therapy (ACT), family therapy, and general counselling are all types of psychological therapies. These therapies can be helpful for people with ID; however, the clinician may need to adapt their techniques by using simplified language and concepts, explicit rather than abstract examples, visual communication methods, and going at a slower pace. These types of treatments can be effective, but don't work for everyone.

Prescription medications are also used to treat mental health issues. There are different types of drugs that may be prescribed, depending on the person's diagnosis. Antidepressant medications treat depression, anxiety, phobias, and some eating disorders. Mood-stabilising medications are used for people who have bipolar disorder. Antipsychotic medication is mostly used to treat psychotic illnesses but may also be used for major depression or severe anxiety. It is important that medication is carefully monitored. People with ID may be more sensitive to some medications and require a lower dose. Their side effects may be more severe, or they may have unusual reactions to the drug. They may also be on other medication, which interacts with the prescribed drug for the mental health issue (which is called polypharmacy). Appendix B provides more information about a medication care pathway, and how you can support the person with ID to receive appropriate medication safely.

LEARNING MORE ABOUT MENTAL HEALTH

The 3DN team at the University of New South Wales have developed the following free online training programs for carers found ***here***:

- ***Intellectual Disability Mental Health e-Learning for Carers*** will allow you to learn about mental health and ID. It includes information about what to do if you think the person you support needs help, and how to talk to health professionals. The course takes 2 ½ hours.
- ***Specific Mental Illnesses – A Course for Carers*** will help you learn about different types of mental illnesses. It will help you identify when something might be wrong, and how to seek support from a health professional. The course takes 3 ½ hours.
- ***Adapting Healthy Lifestyle Interventions for People with Intellectual Disability*** is about important principles to consider when designing or running lifestyle interventions. The course takes 1 ½ hours.

There are also several online modules for people working in the disability and health sectors, costing \$30-\$60. Courses can be accessed from [here](#). A 'Mental Health' learning module can also be found here: ***Mental Health***

There are also modules that can be done with the person you support, 'Looking after my mental health', which can be found here: ***My Mental Health***

The core capabilities framework outlines important knowledge and skills you can develop in supporting a person who has co-occurring ID and mental health problems. The framework can be found here: ***Core Capability Framework Intellectual Disability and Co-Occurring Mental Health***
Further information about specific skills required for mental health professionals to work with people with co-occurring ID and mental health problems can be found here: ***Core Competency Framework***

SECTION 5 -

Understanding Change in Someone's Health Status



When you are supporting a person over time, you get to know them well. It is important to know what is normal or typical for the person you are supporting – what their usual sleeping, eating, drinking, and toileting patterns are like, their typical behaviour, what they are generally able to do, and what mood they are in. ‘Soft signs’ are when there is a change to any of these behaviours, signalling that someone’s health is deteriorating. The changes can be subtle, but because you know a person well, you are more likely to notice it. Sometimes, you may not know what is wrong, but you may sense that someone ‘isn’t themselves’. You may pick up on these signs days before any biological changes can be measured. Looking out for soft signs is useful when caring for someone who may have difficulty communicating.

What biological changes can be measured? Physical observations like temperature, blood pressure, blood sugars, oxygen saturation, respiratory rate and heart rate are called ‘hard signs’ or ‘vital signs’, as they can be directly measured. It is still important to know what is normal for the person you are providing support for – for example, a resting heart rate can be considered ‘normal’ anywhere between 60 and 100, but a slower or faster heart rate than normal can be a sign of health problems.

SOFT SIGNS TO LOOK FOR

There are a lot of different signs related to someone’s behaviour, their mental or physical state. Some signs may be the same for everyone – for example, vomiting is generally a sign someone is unwell. Some signs may be specific to the person – for example, not wanting to participate in an activity they usually enjoy. The table below is from the Wessex Patient Safety Collaborative and West Hampshire Clinical Commissioning Group and details several ‘soft sign’ observations to be mindful of when thinking about the person you are supporting.

Some examples of observable ‘soft signs’

Behaviour	Mental state	Physical state
<ul style="list-style-type: none">• Tiredness/not wanting to get out of bed• Changed sleep patterns• Outbursts of anger or frustration• Louder and more animated than usual• More restless• Less interest in personal care• Less interest in favourite activities	<ul style="list-style-type: none">• More anxious or agitated than usual• Withdrawn• More argumentative or tearful• Worse than normal lethargy• More confused than usual• Less alert than normal• Reduced levels of concentration	<ul style="list-style-type: none">• Cold hands/feet• Worsening shortness of breath• Shivery, feels cold or clammy• Fever, feels very hot• Off food, reduced appetite• Reduced fluid intake• Can’t pee/reduced pee• Diarrhoea, vomiting• Less mobile or less coordinated

WHEN SOFT SIGNS ARE A SIGNAL OF AN EMERGENCY

Some soft signs may be a sign of a medical emergency. According to Healthdirect, it is important to call for help immediately when the person you support experiences any of the following:

- Central or crushing chest pain lasting more than 10 minutes
- Unconsciousness or seizure (fit)
- Severe difficulty breathing or turning blue
- Severe bleeding, or bleeding cannot be controlled with pressure
- Sudden inability to move or speak, or sudden facial drooping
- The effects of a severe accident.



CALLING FOR HELP:
call triple zero (000).
If you have a mobile and 000 is not working, try calling 112.

There are some symptoms common in heart attacks. However, not all people will have all symptoms, and women may experience symptoms different to men. If someone experiences any combination of symptoms listed below for more than a few minutes, call 000 for an ambulance. Symptoms to look for include²¹:



- Discomfort or pain in chest, arms, or shoulder; can be dull or severe; can spread to the jaw, neck or back
- Sudden fatigue, weakness, or fainting
- Nausea or vomiting
- Sweating and clammy, grey in colour
- Shortness of breath or difficulty breathing.

Stroke is another important condition to watch out for, with the soft signs often very important in recognising someone needs help and getting them to treatment. You can remember the main symptoms of stroke using the acronym F.A.S.T.

- **FACE** – has their face or mouth drooped?
- **ARMS** – can they lift both arms?
- **SPEECH** – is their speech slurred? Do they understand you?
- **TIME IS CRITICAL** – if you see any of these signs, call triple zero (000) immediately and ask for an ambulance.

You may need to use your knowledge of the person you are supporting to decide on whether you can observe those symptoms, as their disability may impact the face, arms, and speech. Other possible signs to look for are²²:

- Weakness or paralysis in the body, on one or both sides
- Loss of sensation, usually on one side
- Loss of vision or blurred vision in one or both eyes
- A sudden and severe headache
- Dizziness, loss of balance or an unexplained fall
- Difficulty swallowing



TAKING OBSERVATIONS – MEASURING VITAL SIGNS

At times, you may need to record observations throughout the day. These observations provide a doctor with information about someone's health, or how someone is responding after treatment. Other times, it may be important to keep track of signs because they are linked to a health goal. For people with ID who may also have chronic health issues, it is important to understand what is 'normal' for their vital sign measurements.

TEMPERATURE

Our body temperature ranges between 36.1°C-37.2°C. Measuring temperature is easy with a digital thermometer. The panel shows the temperature



- If measuring in the mouth, place the probe under the person's tongue and ask them to close the mouth. They should use the lips to hold the thermometer tightly in place and breathe through the nose. The thermometer is left in the mouth for 3 minutes, or until it beeps.
- If measuring in the armpit, the thermometer is placed in the armpit. Press the arm against the body. Wait until the thermometer beeps.
- If measuring in the ear (with a special ear probe), gently place the thermometer in the ear. Leave it until the thermometer beeps.
- Some thermometers will measure temperature on the forehead. Place the thermometer against the forehead until it beeps.

A person has hypothermia when their temperature is below 35°C, causing the heart, nervous system, and other organs to not work properly. They may have soft signs like shivering, slurred speech, confusion, shallow breathing, weak pulse, and drowsiness. Someone is not usually aware they have hypothermia, as the symptoms can be gradual. If you suspect someone has hypothermia, seek medical help. If they have wet clothes, provide warm, dry clothes and blankets while you are waiting for help to come.

When a person's temperature is above 38°C, they have a fever. It is often a symptom of an illness. The person may also be sweating, shivering, be irritable, have a headache or muscle aches, and feel weak. It is important you help the person drink water, rest, and keep the room at a comfortable temperature. If the fever doesn't go away or you are concerned, seek medical advice.

WEIGHT



WEIGHT

Weight is generally measured using electronic scales. The person remains still on the scale, until the weight can be read. If you are providing support to someone who cannot stand independently, you will need to weigh them in a seated position with the chair on the scale. You can then subtract the weight of the chair from the total weight recorded.

There are many reasons why someone may have unexplained weight loss or weight gain. If there is sudden weight change (either losing or gaining 5% in six months without trying), it is best they are checked by a doctor to make sure there isn't an underlying medical reason for the change.

HEART RATE

Measuring heart rate is easy with a wearable device, like a fitness tracker. If the person doesn't have a device, you can measure the heart rate (or pulse) at their wrist, by placing two fingers between the bone and tendon on the thumb side of their wrist. You need to measure their resting heart rate – when they are relaxed and sitting or lying down. Measure the heart rate after five minutes of the person being in that relaxed position. Count how many beats you feel in 60 seconds to get the number of beats per minute. If you know someone has an irregular heartbeat, measure the heart rate two or three times so you can get an accurate average. If you notice that the pulse is irregular and you haven't noticed that before, it is important to tell the doctor.

A normal resting heart rate can be between 50 to 90 beats per minute. Usually, a lower heart rate means the heart is working more efficiently, and the person is fit. However, many factors can influence heart rate, including age, fitness, whether they smoke, medications, body size, emotions, and the weather. If the person has a slow pulse, it can be a sign of problems. Talk to the doctor about it if they have been feeling faint, dizzy, or short of breath.

Heart rate may also be measured when exercising for fitness. The fitness program may have a target heart rate for the person to achieve to see how intense the exercise is. In general, the maximum heart rate is calculated as 220 – (minus) the person's age. Moderate exercise is between 50% and 70% of the maximum heart rate. Vigorous exercise is between 70% and 85% of the maximum heart rate. This is a guide. Before anyone starts an exercise program, they should talk to their doctor as it may be important to check out what risk factors they might have (for example, for diabetes or heart disease).

BLOOD PRESSURE

Blood pressure is the measurement of the force on the walls of the blood vessels as the heart pumps blood. It can be measured at home with a device called a sphygmomanometer, but now we can use a digital blood pressure monitor. The digital device usually comes with a cuff that goes around a person's upper arm, with the lower edge 2-3cm above the elbow. The cuff inflates quickly, then slowly deflates, providing two blood pressure measurements: systolic and diastolic. Systolic blood pressure is the pressure when the heart beats, while diastolic blood pressure is the pressure on the blood vessels when the heart muscle relaxes. Normal blood pressure is when systolic is under 140 (mmHG), and diastolic is under 90 (mmHG). If a person has hypertension (either systolic or diastolic blood pressure above those numbers), then they should let their doctor know so it can be followed up. If a person has hypotension (low blood pressure with systolic lower than 90 and diastolic lower than 60), it is important to talk to the doctor.

RESPIRATORY RATE

The respiratory rate is the number of breaths you take per minute. Normal respiration rate for an adult at rest is 12-20 breaths per minute. To measure, you count the number of breaths a person takes during one minute. If a person has been exercising, their respiration rate can be much higher. However, anxiety, asthma, pneumonia, congestive heart failure and some medications can also increase the respiratory rate. A low respiratory rate may be a sign of a heart problem, or too much of a medication like a strong painkiller.





BLOOD SUGAR LEVELS (OR BLOOD GLUCOSE LEVELS)

Blood glucose levels are measured when a person has diabetes. One of the main aims of diabetes treatment is to keep blood glucose levels within a target range, as it can help reduce the risk of developing complications. If you are helping a person who is diabetic, the doctor or diabetes educator will have a schedule of when the levels need to be checked, as it depends on the type of diabetes, and whether tablets or insulin are being used. Testing may need to be done at different times across the day, such as before breakfast (fasting), before another meal, two hours after a meal, and/or before bed, or at other times requested by the doctor.

Blood glucose is tested with a special device called a blood glucose meter. There are different types of these devices. Usually, they work by pricking a finger to get a drop of blood on a blood glucose strip, which is then put in the meter for measurement. Blood glucose levels are measured in millimoles per litre of blood (mmol/L), and the doctor or diabetes educator will provide the individual target range for the person you are supporting. The target range before meals will likely be different from the target range 2 hours after a meal. It is very important to record the blood glucose levels at the required times, as changes in the pattern of blood glucose levels can be a sign the diabetes management need to change.



BLOOD OXYGEN SATURATION

If a person has been experiencing breathing or lung problems, there may be a need to measure how much oxygen is in the blood. Pulse oximetry is a test used to measure how well oxygen is being sent to the parts of the body away from the heart. A pulse oximeter is a device placed onto a finger or an ear lobe, which uses light to measure levels of oxygen in the blood. It is important to not place the pulse oximeter on a person's finger while also measuring blood pressure on the same arm as it will result in incorrect readings.

Blood oxygen levels are not routinely collected – a doctor would usually request the measure be taken, to decide whether a person needs extra oxygen. However, if a person has COVID-19 and is being cared for in their home, their oxygen saturation levels are a good indicator of when medical help needs to be sought. A normal oxygen saturation is above 96% (when measured by a pulse oximeter). If levels fall below 90% it is important to seek medical advice quickly. However, some people live with lower oxygen saturation levels so if this is the case for the person you are supporting, a drop of 5 in their score requires prompt medical advice. If a person is on supplemental air or oxygen, then ask the doctor what levels you need to watch for. Note that some people have smart watches which also measure blood oxygen saturation, but the levels tend to be lower than would be measured by a pulse oximeter on the ear or finger.

URINE OUTPUT

Sometimes there is a need to measure how much urine a person is producing, or the frequency or colour of the urine. This may give a doctor important information about how well a person's kidneys are working. To measure the volume of urine, a large plastic container is placed in the toilet bowl to catch the urine, then the volume can be measured.

The urine colour (see chart to the right) gives an indication of how hydrated a person is. The aim is to have urine the colour of pale straw, which is odourless and plentiful. Medium-dark yellow urine indicates a person is dehydrated, and they should drink 2-3 glasses of water. Darker strong-smelling urine in small amounts can be a sign of dehydration, and it is important that the person drink water immediately.

Frequency of urination is the number of times a person needs to urinate. The number of times a person needs to urinate depends on lots of different factors but is usually around 6-7 times a day. Some medical conditions may cause someone to need to urinate more often, so it may be important to note down how often they go.

It is important to help a person tell the doctor if they have blood in their urine, if their urine is discoloured, or if their urine is white and cloudy. If there is a strong or abnormal smell to their urine (that is not caused by eating asparagus), then it is also good to tell the doctor.



Am I drinking enough water?

Use this urine colour chart to assess how hydrated you are. It is important to drink plenty of water every day to stay healthy.



?
What can change the colour of my urine?
Certain foods, medications and vitamin supplements may change your urine colour even if you are hydrated.

!
Important
The colours on this chart should only be used as a guide and should not replace the advice of a health professional. Speak to your doctor if you are worried about the colour of your urine, the amount of water you drink or dehydration.

www.healthdirect.gov.au

BOWEL MOVEMENT

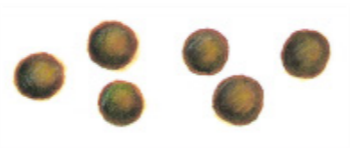




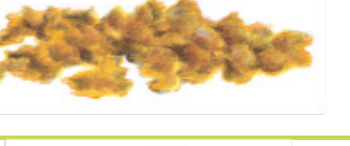

It can be normal to poo three times a day, and it can be normal to poo three times a week.

Most people have a regular pattern of doing a poo – they may do it at similar times each day.

Sometimes it may be important to take notice of what the poo looks like. Doctors use the Bristol stool chart (see the scale to the right) to classify poo into seven groups:

1. Type 1 are separate hard lumps that look like nuts and can be hard to pass. They have spent a long time in the bowel. If the stool looks like this, the person is probably constipated. If it lasts longer than a couple of weeks, tell the doctor.
2. Type 2 is sausage-shaped, but lumpy. This can be a sign of constipation, and more fibre is needed in the diet. The person should also drink more water.
3. Type 3 is sausage-shaped with cracks on the surface. This is soft and easy to pass and is considered normal.
4. Type 4 is sausage-like, or snake-like, and is smooth and soft. This is the ideal type, as it is easy to pass without straining.
5. Type 5 is soft blobs with clear-cut edges. It is easy to pass, but the person may feel a sense of urgency about getting to the bathroom. It can be a sign of mild diarrhoea but will mostly go away on its own in a couple of days.
6. Type 6 has fluffy pieces with ragged edges and is mushy. If a person has this more than three times a day, they have diarrhoea. It is important to drink plenty of fluids. While water is good, there may also be a need to replace the electrolytes that are being lost.
7. Type 7 is watery with no solid pieces, as it has moved through the bowel so quickly that the solid pieces can't form. A person should see a doctor if they have had more than three of these a day for longer than two days. The doctor should also be told if there are other signs of dehydration, severe pain in the tummy or bottom, or a high fever.

The Bristol Stool Form Scale

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces ENTIRELY LIQUID

Distributed with the kind permission of Dr K. W. Heaton; formerly reader in Medicine at the University of Bristol. Reproduced as a service to the medical profession by Norgine Ltd. ©2017 Norgine group of companies.

UK/COR/0118/0853. Date of preparation: January 2018

The colour of poo may also be important to notice. Generally, the colour depends on diet, plus how much bile it contains. A healthy poo will reflect a mixture of all the colours of the food that has been eaten, plus yellow-green from the bile. Almost any shade of brown is considered okay. If it is closer to green, then it might mean the food is moving through the digestive system too quickly for the bile to break down the fats in the diet. If the poo is red and the person hasn't been eating red food (e.g. beetroot) or having a red medicine, then it may mean there is bleeding in the intestine or rectum. If the poo is black and the person hasn't been taking an iron supplement or eating liquorice, then it may be a sign of bleeding in the stomach. Yellow poo may indicate too much dietary fat, and the person is having trouble absorbing nutrients. White or chalky looking poo may be a side effect of medication, or the bile duct is blocked. If poo remains any of these for more than a few days, check with the doctor.

DIETARY INTAKE

At times, people may need to have their diet watched carefully as they either need to lose or gain weight. A food diary is a great way to keep a record of what a person consumes over the day. There are different apps that work on phones or tablets that can also be helpful (e.g. *My Fitness Pal*). It is important to record everything, no matter how small the portion size is. It is ideal to measure the amount in volume (e.g. $\frac{1}{2}$ cup), weight (e.g. 50g), or amount (e.g. 6 almonds). It may also be important to record how the food has been prepared and include extra things like sauces, toppings, or dressings.

LEVEL OF ALERTNESS

A person's level of alertness can change for many reasons. For example, a person may have a reaction to a new medication or may have had a fall and knocked their head. It is important to consider whether anything has changed from their usual state.

The level of alertness can be measured using the ACVPU scale:

- **Alert** – someone who is behaving and responding normally and opens their eyes without prompting. They move their arms and legs and communicate as they normally do.
- **Confused** – someone who is newly confused, or more confused than usual. If someone is normally confused or has dementia, you would only record a C if the confusion has worsened.
- **Voice** – someone will only respond to your voice and is sleepier than normal. Try clearly saying their name and asking them to open their eyes or squeeze your fingers.
- **Pain** – someone who will not open their eyes or respond to your voice but will move or groan when you cause them pain. You must only check this by pressing on their fingernail if you are concerned about their level of alertness.
- **Unresponsive** – someone who will not move, make any sounds, or open their eyes.

Seek medical advice if you have measured a person's alertness as C, V, P or U.

RECOGNISING PAIN

It can be difficult to identify when a person with ID is in pain. They may not be able to communicate their pain in a way we understand. Sometimes, people disregard observable pain signs and symptoms of a person with ID, believing they have a high pain threshold, or assuming the physical signs or symptoms are attributed to their disability. At other times, the person with disability may have common facial and behavioural expressions of pain (e.g. moaning, facial changes) even when they are not in pain, so it can be difficult for a caregiver to identify that the person they support is in pain.

Sometimes, a person may have a common health problem causing pain (e.g. tooth decay, reflux or heartburn, middle ear infection, constipation, urinary tract infection, or scoliosis.)²³ Their condition may also put them at greater risk of having a health condition that causes pain. It is important to identify when someone is in pain so you can take action to help manage it and seek medical advice. Sometimes people with ID have treatable conditions which go undiagnosed because their pain goes unnoticed. Sometimes, a person may also develop challenging self-injurious behaviours because they are in pain.

Some people who experience communication difficulties may be able to express their pain if provided with visual supports. It is important not to assume a person will know how to use the visual supports, so you may need to help the person to learn how to use the pain rating scale before they need it. A communication board was developed in Queensland to help communication between paramedics and patients. The communication board can help a person communicate how they are feeling and includes a 10-point scale for pain. The tool can be found here:

Medical Signing Board

One example of a simple pain tool is the Wong-Baker FACES Pain Rating Scale (see below), found here: [wongbakerfaces](http://wongbakerfaces.com). This pain scale is to help the person with ID to communicate their level of pain by choosing the face that best represents their current level of physical pain. This pain scale is not used by caregivers or health professionals to assess pain.



©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission.

Instructions for Usage

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

Some tools have been developed to help caregivers identify whether someone who is unable to communicate verbally is in pain. They rely on a caregiver observing the person over time. It is helpful when the caregiver knows the person well, and understands what is normal for them, and what is different. The following tools may be helpful to understand what to observe, and how to record it:

- **Paediatric Pain Profile** – although developed for children, it has been used successfully with adults. The tool is individualised for the person and allows measurement of behaviours related to pain on good days and bad days. Having a record of these behaviours over time is helpful to understand what causes pain, and how it can be managed. The tool can be found here: [Pain Profile](#)
- **Non-Communicating Adult Pain Checklist** – requires observation over an hour or two, before the checklist is filled out. The tool can be found here: [Pain Checklist](#). There is an equivalent tool for children which has also been successfully used with adults, found here: [Children's Pain Checklist](#).

- Disability Distress Assessment Tool – requires observation of appearance and behaviours. The tool is designed to promote better understanding of the signs that show a person with communication difficulties is distressed. The tool can be found here: **Disability Distress Assessment Tool**
- Abbey Pain Scale – this is a measure of pain for a person who is non-verbal. The measure is designed to be used when the person is being moved (e.g. for care activities like washing, going to the toilet). The tool can be found here: **Abbey Pain Scale**

If you are supporting a person with ID who may be in pain frequently, recording signs and symptoms through regular observations is helpful for the doctor. These observations may show a pattern, which may be linked to a particular event with hindsight. For example, a person who has reflux may show more pain signs after eating, or after lying down.



RECOGNISING CHANGE IN HEALTH

At times it can be difficult to recognise that someone is becoming unwell, and the person may not be able to communicate how they are feeling. The ‘STOP AND WATCH’ early warning tool was developed by Florida Atlantic University. The tool is a structured way to assess someone’s condition when you notice that they are ‘not themselves’:

- **S** – Seems different to usual. Often early signs of a problem show when a person is not quite right or is acting out of character. You may have an instinct or gut feeling that something is wrong.
- **T** – Talks or communicates less. Whatever a person’s communication style is, are they doing it less often or less well?
- **O** – Overall the person needs more help. The person is more dependent, asking for help more than normal for usual activities.
- **P** – Pain, new or worsening. Pain is often a symptom of something not being right. The pain is new to the person or is worse than normal.
- **A** – Ate less. The person’s normal eating pattern has altered. They may be eating less or avoiding certain foods.

- **N** – No bowel movement in three days, or diarrhoea. There is a change in the person’s bowel habits, which can be an important indicator of someone being unwell.
- **D** – Drank less. The person may have signs of dehydration, including dry skin, dry mouth or tongue, and new or worsening confusion.
- **W** – Weight change. The person lost or gained weight (without trying). They may have swollen limbs, a drawn face, or their clothes or jewellery do not fit properly.
- **A** – Agitated or more nervous than usual. The person may fidget or look scared or worried.
- **T** – Tired, weak, confused, drowsy. The person may appear to have less energy than normal. They may be more confused.
- **C** – Change in skin colour or condition. Apart from dry skin being a sign of dehydration, there are other changes to look for. The person may have bronzing of the skin or yellowing of the skin and whites of the eyes. They may have a rash that doesn’t respond to treatment and is accompanied by other symptoms like fever, joint pain, and muscle aches. They may have broken skin or emerging pressure sores.
- **H** – Help with walking, transferring, or toileting is needed more than usual. Needing more help than usual may be a sign of acute illness.

You can then use the information from STOP AND WATCH to decide whether there is a need to ask for medical help. The information is also useful to pass on to health professionals if required. The next section will help you decide how urgently you need to seek medical help.

IDENTIFYING DETERIORATING HEALTH STATUS

Sometimes it may be important to communicate that a person is becoming increasingly unwell, or is very sick, particularly when there are a lot of different observations to consider. It is difficult to know how they all fit together. It is also difficult to know when to seek help.

In the UK, the ‘National Early Warning Scores’ (or NEWS2) was developed to help people assess how unwell someone is, and quickly recognise any deterioration so treatment can be started. The NEWS2 score summarises a person’s health status clearly and concisely. (See Appendix C for the scoring system outlined below). The score gives an indication of clinical risk so health professionals can prioritise care effectively and escalate care if required. The NEWS2 score supports clinical judgement; it does not take the place of the health professional’s experience and expertise.

Depending on each measurement, NEWS2 assigns a score for each measurement ranging from 0 (normal), to three (very abnormal). Another 2 points are given if someone is on oxygen therapy (i.e. has supplemental oxygen that has been prescribed). The total score is the NEWS2 score between zero and twenty. The higher the score, the more unwell a person is likely to be.

The NEWS2 score is calculated from six observations. The score is then aggregated and increased by two points for people who require supplemental oxygen to maintain their recommended oxygen saturation. The NEWS2 score is calculated as follows:

- Breathing or respiratory rate – if the breathing rate is:
 - » 12-20, the score is 0
 - » 9-11, the score is 1
 - » 21-24, the score is 2
 - » 8 or less/25 or more, the score is 3
- The level of oxygen in their blood (oxygen saturation) – for most people, if the oxygen saturation is:
 - » 96% or more, the score is 0
 - » 94-95%, the score is 1
 - » 92-93%, the score is 2
 - » 91% or less, the score is 3
 - » Note 1 – there are some people who live with a lower level of oxygen in their blood. These people would have a usual oxygen saturation range of 88-92%. There is a different scale that is used for these people.
 - » Note 2 – if someone is on oxygen therapy, then an additional score of 2 is added.
- Blood pressure – if the systolic blood pressure (the top reading) is:
 - » Between 111-219, the score is 0
 - » Between 101-110, the score is 1
 - » Between 91-100, the score is 2
 - » 90 or less/220 or more, the score is 3
- Heart rate – if the resting heart rate is:
 - » Between 51-90, the score is 0
 - » Between 41-50, or 91-110, the score is 1
 - » Between 111-130, the score is 2
 - » 40 or less/131 or more, the score is 3
- Level of alertness – if the person is:
 - » Alert, the score is 0.
 - » Newly Confused (C), the score is 3
 - » Responsive to Voice (V), the score is 3
 - » Responsive to Pain (P), the score is 3
 - » Unresponsive (U), the score is 3
- Temperature – if a person's temperature is:
 - » Between 36.1°C-38.0°C, the score is 0
 - » Between 35.1°C -36.0°C, or 38.1°C -39.0°C, the score is 1
 - » 39.1°C or more, the score is 2
 - » 35°C or less, the score is 3

As a support worker or carer, the NEWS2 score can help you understand how urgently you need to seek medical advice. First, you need to know what is considered normal for the person you are supporting. Generally, if someone's score is 3, their health can probably be managed in the community at a GP clinic. If someone's score is 5, they require an urgent review – so an immediate appointment at a GP clinic, an appointment at an urgent care clinic, or the emergency department is needed. If someone's score is a 7 or above, they are likely very unwell and probably require hospital care. An ambulance should be called or take the person immediately to the emergency department.

Remember, if in doubt, it is always best to seek the advice of a health professional.

You may need to continue taking regular observations, depending on what is happening to the person and whether you have specific protocols (if working for an organisation). In general, if the person's NEWS2 score is 0, record the observations every 12 hours until there are no more concerns. If they score 1, take observations at least every 6 hours. If they score 2, take observations every 2 hours. If they score 3-4, or have a single observation score of 3, then take observations every 30 minutes. If they score 5-6, take observations every 15 minutes. If they score 7 or above, there is a need to continuously observe and monitor them until they can be transferred to hospital.





SECTION 6 - End-of-Life Care

Dying is part of the life cycle. However, often caregivers are supporting people at the end of their lives with limited experience in dying. A learning module 'End of Life Care' will tell you what to expect, and what your role is, and can be found here: [Single Modules](#)

THE PROCESS OF DYING

Dying is part of the life cycle. Dying is a process, where different parts of the body start to slow down in a progressive way.²⁴ The speed of dying can vary from person to person, and may take days, with progressively more physical signs. As you are providing care, you may notice the signs below and can respond to them as follows:

- **Sleep and alertness** – the person may be drowsier, more difficult to wake up, and may spend more time asleep. The sleep may gradually become periods of unconsciousness. Allow the person to sleep when they want to. You can talk with them when they seem most alert, in a natural and calm way.
- **Appetite and thirst** – the person may lose their desire to eat or drink. It is important not to force people to eat or drink. Sips of water or a moist swab in the mouth can be helpful.

- **Incontinence** – while the body produces less urine as the person is drinking less fluid, some people may lose control of their bladder and bowels. If this happens, there are incontinence products (e.g. pads, sheets) that can improve the person's comfort and hygiene.
- **Mucus and saliva** – as the swallowing and coughing reflexes slow down, the person may have a gurgling noise coming from the back of the throat. It doesn't usually cause distress to the person. You may help the person change their head position (e.g. support them with pillows so the head is lifted slightly and turned to the side). There are medications that can slow down production of mucus and saliva if the person is uncomfortable.
- **Temperature** – some people may have slower circulation, which results in legs, arms, feet, and hands becoming cooler. If the person feels cold, then use light bedding to keep them warm rather than heavy blankets as becoming too hot can make people restless. Make sure the room is ventilated, with the air circulating. If a person feels hot and clammy, then use cool damp towels.
- **Skin colour** – the skin may become blotchy and darker as the circulation is slowing down. You may want to provide gentle touch to the person, as it lets the person know you are caring for them. Touch provides comfort and can be very important if the person no longer has sight, hearing or speech available.
- **Breathing** – the sound and pattern of breathing can change as the blood circulation slows down and waste products build up. The breathing may become shallow or may become noisy. The breathing may speed up or have long gaps between breaths. The person is generally not distressed by the changed breathing.
- **Restlessness** – with the change in circulation and other bodily processes, the person may become agitated or distressed. Light touch, calm speaking, and familiar music can all help to reduce the restlessness. There are medications available which can also be helpful.

Death has occurred once breathing has stopped and there is no heartbeat. The person's eyelids may be half open, and their pupils are fixed. The person's mouth may be open.

PALLIATIVE CARE

Unfortunately, people with ID often miss out on good end-of-life care. Palliative care is a specialised form of health care which focuses on improving the quality of life of people when they have a life-limiting illness. Palliative care can be defined as²⁵:

“Person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure, and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life”.

If a person with ID is at a point where palliative care is required, then it is important that they are included in planning care, and the decision-making process. An Easy Read explanation of palliative care can be found here: [Pall Care for You](#)

The National Palliative and End of Life Care Partnership from the UK have six important ambitions when considering end of life care²⁶:

1. Each person is seen as an individual. People are given opportunities to have honest, informed, and timely conversations and to know that they may die soon. They are asked what matters most to them. The people who are providing care know the person's wishes, and work with them to do what is possible.
2. Each person gets fair access to care. End-of-life care is provided regardless of the circumstances of their lives, or who they are.
3. Maximise comfort and wellbeing. Care is regularly reviewed, and every effort is made for the person to have support, care and treatment that might be needed to help them be as comfortable and as free from distress as possible.
4. Care is coordinated. The person gets the right help from the right people at the right time. The team working with a person knows the person's needs and plans. They work together to help the person achieve them. There is someone available who can listen and always respond.
5. All staff are prepared to care. Wherever the person is, health and care staff bring empathy, skills and expertise and provide competent, confident, and compassionate care.
6. Each community is prepared to help. Everyone recognises that we all have a role in supporting each other in times of crisis and loss. People are willing, ready, and confident to have conversations about living and dying well. People are ready to support each other in emotional and practical ways.



TALKING ABOUT DEATH AND DYING

It is important to support a person with ID to build their awareness and understanding of death and dying. This is generally done by talking about it when a natural opportunity comes up, rather than having a planned conversation. You don't need to wait until the person you support or someone close to them has a terminal condition. However, you will need to consider the background knowledge that the person already has, and their knowledge of what is happening now and what will happen in the future. Information about the future is more difficult to understand than information about the present, and is influenced by the person's intellectual capacity, their capacity for abstract thinking, and their concept of time. A learning module 'Breaking Bad News' can help guide you in the process of helping someone understand bad news, and can be found here: ***Breaking Bad News***

When a person or someone close to them has received a diagnosis that they have a life-limiting condition, then it is important that they get the opportunity to talk about it and learn about what it will mean. A discussion might include their understanding about the illness and prognosis, and what preferences they have for types of care or treatment. The discussion may also include the person's concerns about what will happen, and the values that are important to them. If everyone assumes that someone else will talk about the person's condition or avoid it because they think the person won't understand or will become distressed, they are reducing the person's opportunity to make decisions about what they want to do in their final days, or about the type of care they want to receive.

As a supporter of a person with ID, you might be an appropriate person to talk about death and dying and the life-limiting condition, as you know the person well and have a good understanding of their state of knowledge and personal preferences. While some palliative care staff may be able to talk about death and dying, many don't have training in providing care to people with ID,²⁷ so do not feel comfortable talking about death and dying to a person with ID. Whether the health professional has a conversation can be influenced by how they perceive the person's capacity to understand, whether they have a relationship with the person, their experience, and the values of the palliative care staff and other caregivers.

If the person you support has a team of caregivers, then it is important to make sure that everyone is responding to the person's questions and concerns in a consistent way. Caregivers may need to prepare for having these conversations, with a plan in place to ensure the conversation is able to be continued whenever the person with ID needs it. While it can be difficult to be open to the conversation, it is important to allow feelings to surface, and to let the person know that it is okay to be sad – they are not alone.²⁸ 'Protecting' people from the conversation may result in them not being able to process what is happening and make them think they need to hide their feelings.

Guidance for how to break the news can be found here: ***Ten Guiding Questions***. It can also be helpful to use an Easy Read resource which gives the person a starting point for conversations and allows them to ask the questions they want to (e.g. see the Council for Intellectual Disability Easy Read here: ***Talking About Death***).



ADVANCED PLANNING

Many people with ID will be considered to lack the capacity for the formal legal document of an advance health directive (see Appendix D). However, they should be encouraged to think about what their choices are with respect to the types of treatment they want to receive or do not want to receive as their illness progresses. This means that everyone who supports them advocates on behalf of the person's wishes. There may also be a need to advocate regarding reasonable adjustments that may be needed for the person to access end-of-life care (e.g. a need for Easy Read information; requirements if the preferred place for care and treatment is at home, etc.)

It is also important to encourage planning about other aspects of the person's life during the end-of-life phase. By providing information about what is going to happen at each stage, there is opportunity for person-centred planning and supporting the person with ID to be central to the decision-making. Many people with ID have a group of people who help them make decisions about their life, so it gives time for them to be included. It also provides time to do 'bucket-list' activities and say goodbye to people.

Planning might also include how the person you support needs to be emotionally supported over time. Some people may need specialised counselling to help manage the feelings that they will experience as their illness progresses.

As disease progresses, there may be additional visits to hospital or hospice required. If the person you support is likely to become distressed with new medical interventions or medical visits, then you may need to prepare the person beforehand. This can help to reduce anxiety about an admission or treatment.

It is important to remember that planning can be revisited. Things may change as the illness progresses, so conversations about what the person wants should be ongoing, rather than once only. It is also important to remember that people with ID may express their views in non-verbal ways. Care should be taken to accommodate their communication requirements.

The plans need to be documented and updated as required. An online planning tool can be useful to help step through all the different choices that can be made, for example, see the Hospice UK tool here: [Planning Ahead](#). An end-of-life plan example can be found here: [End-of-Life Support Plan](#). Once plans are made, they need to be shared with all the health and care team so there is a common understanding regarding the person's wishes.

MAKING A PERSON COMFORTABLE

The aim of a 'good death' is that people are in a supported and dignified setting and are comfortable and relatively free from pain. People with ID may have difficulty communicating about the type and amount of pain they are in, so may not get the appropriate level of pain relief medication prescribed. As you know the person well, you are well placed to assess the person's pain levels from their posture, facial expressions, and other behaviours and vocalisations. See Section 5 ('Recognising Pain' on p.74) for more detail. You may need to track pain over time so that you can advocate on the person's behalf.

Everyone providing care should work together in a way that is responsive to the needs of the person with ID. It may need caregivers to work in a more flexible manner so that care is provided in a way that suits the person best (rather than suiting the caregiver). A consistency of caregivers, coordinating appointments so a person is not overwhelmed, and a clear understanding of roles and responsibilities of all involved caregivers, all contribute to more effective care.

Wellbeing is also important to consider during end-of-life care. Psychological distress impacts on the person's experience, so the following ideas can help improve wellbeing:

1. Maintain normality – as much as possible, support the person to continue to enjoy their favourite foods, and activities.
2. Maintain connections with people and places – arrange for friends to visit and spend time with the person. If the person has a favourite place, then helping them visit for an hour or two can reduce distress.
3. Be responsive to changes in behaviour – the person is probably trying to tell you something. Consider whether they are frightened or in pain, or whether they need something.

People can show their distress in different ways – some people may express it physically, some vocally, while others may become very quiet and withdrawn. It is also important to know what a baseline level of distress is for the person you support, and how they react. DisDAT is a helpful tool to identify distress cues in people who have limited communication and can be found here: [Disability Distress Assessment Tool](#)

SUPPORTING PEOPLE AFTER BEREAVEMENT

They may need time to process what has happened and how things will be different, needing more than one conversation over time to understand. They may feel sad, which is a common reaction to loss – those feelings may take time to emerge, and grief may be expressed in different ways. A helpful guide to supporting a person through a time of grief and loss can be found here: [Grief Packet](#)

The person you support may want you to sit and talk to them. It can be helpful to encourage them to remember the person who has died, and the experiences they shared. Some people find comfort in looking at photos or objects that are important. Other people may want to know more about the detail of what has happened. Expressing your own feelings can help the person with ID express their feelings. It is also important to recognise that bereavement can be a difficult time for caregivers, so they may also need to access support and counselling.

PART C

USING HEALTH SERVICES

People may access health services in the community, or in hospitals. While the following section focuses on going to the GP, much of the information is relevant to working with other health professionals in the community.

SECTION 7 - Primary Care in the Community

Primary care is usually based in the community, such as going to see a General Practitioner (GP). There are many reasons a person will go to see a GP. Sections 1 and 2 included a lot of information about proactive and preventative health care which a GP can help with. Many people will also go to the GP when they are not feeling well or have injured themselves – but it isn't an emergency. This section will talk about different things to consider when the person you support needs to go to the doctor. An Easy Read fact sheet explaining different things to think about when going to the doctor can be found here: [*Me and My Dr*](#)



THE ROLE OF THE GENERAL PRACTITIONER

A GP is a doctor that has completed extra training in general practice – this means they have the knowledge and skills to treat a wide range of health issues. They are very good at treating injuries and illnesses not immediately life-threatening and providing ongoing care if a person has a chronic condition. The GP can prescribe most medicines, give vaccinations, and do many of the health screening tests. The GP can also initiate a medication review to maximise the benefit of a person's medication regime and prevent medication-related problems.

The GP is often the first person to see for serious conditions that don't require emergency treatment. GP's refer patients on to the appropriate specialist if that is required. They can also coordinate care when there are many different specialists involved in a person's care.



CHOOSING A DOCTOR

It is important for everyone to find a good general practice doctor that they feel comfortable with. For people with ID, it is even more important that the doctor develops an understanding of who the person is, how they communicate, and their preferences. When a person sees a different doctor each visit, the doctor doesn't develop this understanding, and can't build a relationship with the person. From the person's perspective, they may have a more difficult time trusting the doctor.

It is better if people can choose a doctor that they like. Some people have different reasons for liking a particular doctor – for example, women with ID often prefer to see a female doctor. Others may want to see a doctor who is older or younger, or who speaks their language. They may also like to see a doctor who has been recommended by a friend, or because the doctor has a particular knowledge and interest that is important to the person.

Sometimes, people choose doctors because of the way they are treated. Many people with ID prefer a doctor who talks to them (rather than their support worker), listens, and helps them make decisions. They also like being able to ask questions when they feel the doctor hasn't explained information well enough and don't like being rushed and not listened to. People like to be respected and seen as an individual first – not their disability diagnosis first. They like a doctor who is proactive about a person's health, and responsive to their needs.

Other people choose a doctor because their practice is in a convenient place, with suitable opening hours, accessible by public transport (so they can get there independently), or because the clinic will do home visits or telehealth. They may also choose a doctor because the practice will bulk-bill Medicare, so they don't have to pay the gap fee.

It is important to talk to the person you support and find out whether they like their current doctor. If not, you can support them to find a new one. It is okay to change doctors if they are not meeting the person's needs. Some people ask others they know for recommendations for a doctor. You can also find doctors here: [*Australian Health Services*](#)

A helpful Easy Read resource on finding a new doctor can be found here: [*Finding New Dr.*](#)

CONTINUITY OF CARE

Continuity of care is considered a very important component of the health system and is associated with improved health outcomes. For a person with ID, there are three factors of continuity to consider:

1. **Continuity of relationships.** In a practical sense, this means the person can develop a relationship with the doctor (and vice versa). This gives the person with ID time to develop trust. It gives the doctor time to understand the complexity of the person's health issues, and how they communicate. While people are allowed to see a range of different doctors, it is beneficial to find one that they are happy to see regularly. If their doctor is unavailable for a particular reason, then it is best to see a different doctor in the same practice if possible as they will have access to the person's health information and will also be able to provide an update to the person's regular doctor if required.
2. **Continuity of information.** For people who may have communication difficulties, there may be difficulties in providing the relevant health information so the doctor can make their best clinical judgement. There also may be challenges in ensuring information from the doctor is passed on to caregivers (when appropriate). For example, when a person is living in supported accommodation, there is a need to ensure health is monitored and documented appropriately, and information is made available to the doctor when required. In Australia, there is no universal system for health information – hospital information systems are different from primary care information systems, and both are different from disability organisation client management systems. As a result, it is important that think about how information will be provided if a person is unable to provide it (or needs support to do so). Similarly, it is important to think how the person with disability will be supported to access the information they require to make decisions about their health.
3. **Consistency of care delivery.** For people supported by a variety of caregivers, it is important they all know details of the person's care plan, and how to support them (e.g. what needs to be followed up, what medication needs to be taken, what lifestyle changes need to be encouraged and supported).



INITIATING A VISIT TO THE DOCTOR

In your role supporting someone with ID, you may need to initiate a conversation about the need to see the doctor. This could be due to a range of reasons, including noticeable changes in the person's health (see Section 5), requiring a medical test, or an annual health check.

The person you support may want to talk about their health symptoms with you. Having these conversations helps them to judge how bad their symptoms are and to clarify what they should do about them. For people with a legal guardian, their guardian may need to be contacted if they need to be present at an appointment or made aware of the potential need for decision-making.

If possible, help the person you support to book their appointment with the doctor. This can often be done on the clinic's online booking system (if available) – this helps the person understand their options and choose a time that suits them best. Otherwise, the clinic can be called, and the medical receptionist can identify doctor availability and appointment times. Book a long appointment if one is required. Some clinics also have doctors who will make home visits, so ask if that is possible if the person you support would prefer it. If the health issue is urgent or an emergency, consider whether an urgent care clinic or emergency department is a more appropriate place to seek care.

PREPARING FOR THE APPOINTMENT WITH THE DOCTOR

Before going to the doctor, it is important to prepare for the appointment. If the visit to the doctor is for an annual health check, a pre-health check questionnaire for people with ID can be found in the resources section here: **Health Check Toolkit**, or here: **Annual Health Check**. The healthy living checklist (Appendix A) may also be a useful reference. Other actions you can take to help prepare the person you support to go to the doctor include:

- Be clear about the reason for the visit. It may help to write down the person's symptoms or identify why the person needs to see the doctor (e.g. for a new script, for a check-up). It can be useful to fill out the Surrey Place 'My Health Care Visit' form with details about the health care visit. An online form can be found here: **My Health Care Visit**. Think about any issues that have been bothering the person recently, such as:
 - » Pain
 - » Eating
 - » Level of energy, or the amount of sleep
 - » Feelings and emotions
 - » Relationships
 - » Bathroom habits
 - » Sexual health
 - » Injuries or falls
 - » Hearing or vision
 - » Medication
- Talk with the person you support about what questions they would like to ask the doctor – they may get some good ideas from the Easy Read resource found here: **Questions to ask visiting the doctor or hospital**. You can also help the person to use the 'Question Builder' website found here: **Question Builder**. You may also have additional questions related to how you can best support the person's health. It is best to write these questions down so the doctor can work through the list.
- Help the person you support to prepare for the visit to the doctor.
 - » Some medical tests may require the person to be 'fasted', which means having tests done before eating anything that day. This happens for some blood tests.
 - » Sometimes the person may need to prepare a urine sample before going to the doctor.
 - » The person may need to see a different health care provider for an assessment or test before going to the doctor.
- » If the person you support is anxious about going to the doctor, provide a social story or Easy Read resource to help them understand what is going to happen, and why. If they have a safety plan, consider what activities may be useful to bring along to the appointment. (See Section 12 for more details about safety plans).

- Gather any information that needs to be given to the doctor. This may include:
 - » A list of all the medication the person is currently taking (including over-the-counter and prescription medicines)
 - » Relevant medical records
 - » Copies of relevant assessments from other health or disability professionals
 - » Details of all health professionals in the person's care team
 - » Communication profile (if relevant)
- Take a notebook and pen so you can write down what the doctor says.

SUPPORTING COMMUNICATION BETWEEN DOCTOR AND PATIENT

Communication is often more effective if the person you support has seen the doctor over time, so the doctor understands the person's communication needs. Therefore, it is important the person you support visits a doctor they are comfortable with – and to see that doctor every time they need one.

When you are in the doctor's rooms, you can facilitate the person's involvement in the conversation, and encourage the doctor to have effective communication.²⁹ If the doctor is new, before you introduce yourself, it is important to introduce the person you support. You may need to explain how the person communicates and highlight their communication abilities or provide the person's communication profile or passport if required.

You may need to model effective communication skills. For example, maintain eye contact with the person you support, and use age-appropriate language. If the doctor starts asking you questions, you can ask the person you support if it is okay for you to talk about their health problem, or you can repeat the questions to the person for them to answer. Sometimes you may need to repeat what the doctor has said in simpler language. If this is the case, you may also need to ask the doctor to explain difficult ideas using simple words, and to speak slowly and clearly.

It is important to check the person you support understands what the doctor has said, as many people will say 'yes' because they think that is what the doctor wants to hear. One way you can do this is by asking the person you support what the doctor has said. If they don't understand, there may be some pictures or an Easy Read resource that can help them. You can demonstrate a variety of communication techniques that are required for the person to understand their choices, or what is happening. For example, the use of pictures can be helpful to support the communication, as they reduce the need to remember the words which can be helpful for people who may have processing or memory difficulties.



Before the doctor does anything to the person you support, the doctor will make sure the person is as comfortable as possible with what needs to happen. It is important for the doctor to use simple language to explain what will happen, and show the equipment they want to use, or diagrams of what will happen. The person you support may want to ask questions about it, and you may need to help them get the information they require to be comfortable with what is going on.

If the appointment was too short, or the health problem is complicated, you may need to ask whether you can come back for another appointment when the doctor has more time. You may also ask whether there is a practice nurse who can help explain what the person you support needs to understand.



DURING THE APPOINTMENT

If the person is seeing the doctor because of a health issue, the doctor will need to follow different protocols, depending on the situation. At all times, they should be talking directly to the person you support. It is good to keep checking whether the person you support has any questions.

If treatment is recommended, it is important to make sure the person you support gets all the information they need to decide about treatment options. In most cases, you can help them decide what to do (see Section 10). In most cases, the person will have time to think about their options unless it is a very urgent problem. It is important to remember to ask for a second opinion if they are unsure. Sometimes, the doctor may need consent from the person's guardian if they do not have decision-making capacity. If that happens you will need to know who that person is and how they can be contacted.

For any follow-up, it is good to ask the doctor to write down an action plan, for example by filling in the relevant part of the 'my health visit form'.³⁰ It is okay for you or the person you support to ask questions about anything that is not clear. Sometimes, the doctor may need to explain difficult words. If the doctor prescribes a new medication, it is important to ask about what the side effects may be so you can watch out for them.

The doctor may refer a person on to a specialist if needed. The doctor may know of a particular specialist that can help, but it is okay to see a different person with the same speciality.

Get copies of letters if the doctor is making a referral to a specialist. This gives a written summary of the doctor's thoughts and may also include information about test results. If the person is being referred to a specialist for ongoing treatment, then you may like to ask whether it is possible to get an indefinite referral which can last longer than 12 months.

When the person is visiting for a reason that is not because of illness or injury, the doctor can have more time to think about preventative care. At this time, it is good to ask questions about how to prevent health problems, or about suggestions for healthy lifestyle goals the person may like to consider.

If the doctor is doing an annual health check, it is also important they consider some of the common health problems that get missed (e.g. hearing, vision). The doctor may find the following resources helpful:

- Comprehensive health assessment tool (Canada) **Health Check**
- Syndrome specific medical health checks (UK) **Health Check Toolkit**
- Positive cardiometabolic health for adults with ID (Australian GP resource) **Positive Cardiometabolic Health For Adults With An Intellectual Disability**



AFTER THE APPOINTMENT

Check in with the person you support to see how they feel about the appointment. If they have any questions about what happened, you can help them find more information. If they are not clear on what the doctor recommended, you can ring the clinic and ask for more detail. You can also find some useful information from trusted websites or find some Easy Read explanations (see Section 12). The person you support may find the following fact sheet helpful: **After Visiting Dr.**

It is important to follow up after the doctor's visit. If you are supporting a person who has accommodation support through a disability service provider, there will likely be a process you need to follow, such as making sure the person's care plan has been updated with actions. There may be other health professionals in the person's care team who need to be informed about the appointment outcome.

If there are other appointments that need to be scheduled (e.g. a review with the doctor, or a referral appointment), it is important to action those right away so they can be put in the calendar. If there have been any medication changes, there may need to be additional training so all caregivers can give the medication.

SECTION 8 - Hospital-Based Care

When a person with ID goes to hospital, it can be confusing about what role the hospital staff have in meeting the person's support needs with respect to personal care and communication. The Western Australian (WA) Department of Health has a set of guidelines, detailing the responsibilities of the health service and the disability service organisation (if involved in care of the person).³¹ This section focuses on your role providing support to a person with ID, but if you work for a disability service organisation you are encouraged to consider the organisational responsibilities throughout the person's health care journey in hospital, found here: ***Hospital Stay Guideline for Hospitals and Disability Service Organisations***

COMMUNICATION WITH THE HOSPITAL

Sometimes, people with ID may not be able to tell health care staff what their support needs are or provide detail on how they are feeling. In your role supporting the person, you may need to support the communication as it will improve the quality of care (see Section 14, Health Sector Governance). The following communication tools may help the person you support to communicate with health staff:

- The medical signing board, developed in Queensland for paramedics: ***Medical Signing Board***
- The hospital communication book developed in the UK: ***Hospital Communication Book***



While the information contained in the health passport may meet the needs of the health care staff (see Appendix E), things often happen very quickly, and the information may not be passed on. This may mean you need to advocate for the person you support if there is a shift change, the person is moved to a different ward, they go for a test or procedure, or when the discharge plans are being developed. It is very important there is effective communication with the hospital regarding the additional needs of the person you support, particularly when there are transitions of care such as the following³²:

- Change in staff due to shift change or ward transfer
 - » Let staff know what types of support the person may need – for communication, for feeding, and for personal care. Be clear about the level and amount of support you can provide.
 - » Let staff know about medicines the person is taking. You also need to detail whether the person has any allergies or reactions to medicines they've taken in the past.
 - » Ask if there is a person you should contact if there are any questions about the care the person you support is receiving. It may also be helpful to ask whether a social worker is available in case the person you support needs additional help, as they can advocate for that from within the health care team.
 - » Tell the staff about any changes in health that you have observed in the person you support.
 - » Advocate for the person you support with respect to their preferences, expectations, and goals of care.
- Change due to tests or procedures
 - » Talk to staff about any of the above points that are relevant.
 - » You may also need to ask for more information on behalf of the person you support if they are uncertain about the tests or procedures. This may include asking questions about how the test will be done, what it will feel like, and where you can find good information about it if more is needed. You may need to know how to help the person get ready for the test, and what happens during and after the test. It may be helpful to understand how long before results will be back, and if/how they will be shared with other people on the care team.
- Discharge planning
 - » It is important to find out what needs to happen after the person you support leaves hospital, such as whether there will be follow-up appointments, or changes to medications or treatment regimes.
 - » Talk to the discharge team about their expectations of the person's support needs following discharge. Be clear on the level and amount of support you will be able to provide.
 - » Ask for contact details for someone on the ward team in case there are immediate concerns when the person gets discharged.
 - » If you or the person you support have additional questions, ask if there is information you can take with you, or where you can find trusted information.
 - » Make sure you have a copy of the discharge summary, which summarises the reason the person was in hospital, the care they received, the action plan for what happens after hospital, and any follow-up appointments.



Urgent Health Issues

URGENT CARE CLINICS

There are two options when a person needs urgent medical care – but not all urgent health problems are emergencies. In the metropolitan area, people can go to urgent care clinics. These clinics have GPs who can treat people who need to see a doctor on the day, but who don't have a life-threatening injury or illness. The clinics have access to pathology and radiology services and have treatment rooms to conduct minor procedures. GP urgent care clinics are the best place to go if the person has minor musculoskeletal injuries, gastrointestinal illness, illnesses of the eye/ear/nose/throat, skin conditions (e.g. cuts, burns and rashes, bites, and insect stings), and infections (e.g. urinary tract infection, wound infection).

EMERGENCY DEPARTMENTS

Emergency departments (EDs) provide health services for people needing urgent medical care after a serious accident or sudden life-threatening illness or serious condition. A person may go to the emergency department by ambulance, or because someone has taken them there.

When a person gets to the emergency department, a triage nurse will assess their condition. This means they look at the illness or injury and decide how urgent it is so they can prioritise care. A triage score of 1 needs emergency care – for example, if someone needs resuscitation immediately. A triage score of 5 is less critical, and the person is likely to be asked to stay in the waiting room – although some pain relief medication may be given. This means that triage 1 patients will always be treated ahead of other patients, even if they have just come in. Less critical patients will need to wait. However, it is important to let the triage nurse know if the person's condition gets worse while they are waiting.

Emergency departments always try to see the person within four hours, but sometimes it is very busy, and people may need to wait longer. When it is time to be seen by the doctor, patients are taken to a private area where they can be assessed, and the doctor decides what treatment or medication is needed, or what tests need to be done.

From the emergency department, some people will have their health issue treated (e.g., by being prescribed medicine, or having a procedure done like stitches). They may require follow-up by their GP or be referred to a specialist or outpatient clinic. Some people may need to remain for observation (for example, if they have had a fall and hit their head). People may also be admitted to hospital from the emergency department or transferred to another hospital for treatment.

An emergency department in a public hospital is free to the patient, but a fee is likely to be charged if the person goes to an emergency department in a private hospital.

GOING IN AN AMBULANCE

In an emergency, you may need to call for an ambulance. In Australia, you call 000 in an emergency.³³ The call will be answered by an operator who will ask whether you need police, fire, or ambulance. If someone is seriously injured or in need of urgent medical help, you will need to say 'ambulance' to be transferred to the ambulance service. There is no translation service, so people who can't speak English will be transferred to the police. If you have a mobile phone, calling 112 will also connect you to emergency services.

If you are on a fixed landline, the address details will automatically appear on the operator's screen. If you called from a mobile phone, you need to give an exact address – try to provide the street number and street name. You will need to tell the operator what the problem is, how old the patient is, and whether they are breathing or conscious.



Generally, if a person goes in an ambulance, they will be taken to an emergency department. Not all hospitals have emergency departments, so it is important to ask which hospital the ambulance is being sent to. It may not always be the closest hospital.

If possible, before the ambulance arrives, pack a small bag with anything the person you support may need. Include all their current medications. You will need to let the paramedic know if the person has any special requirements or allergies.



YOUR ROLE SUPPORTING SOMEONE WHILE THEY ARE HAVING A HEALTH EMERGENCY

Emergency departments can be confusing and distressing. They can be a chaotic environment, with busy people, unwell people, and a lot of noise and bright lights which may cause a problem for people with sensory issues. It is critical you provide information to the person you support so they know what is going on and keep them as comfortable as possible. If they are anxious, then use strategies from the person's safety plan to keep them as calm as possible (see Section 12).

In your support role, you may have to provide information about a person's health status (e.g. see Section 5) and relevant health information (e.g. see Section 9), and advocate on behalf of the person you support. It is important that you are letting the staff know about the person's support needs – for example, whether they can be left alone (e.g. if you need to go to the toilet), or if they always need someone with them. Other support needs may relate to the person's communication, feeding, self-care (including toileting), and mobility. Let the staff know about strategies that will support understanding of a person's behaviour and the best ways to respond to their unmet needs (if appropriate), as that will reduce risk to both the person you support and the staff.

You will likely need to facilitate communication so the person you support is at the centre of the health care and support their part in the shared decision-making process. You may also need to liaise with health staff about treatment plans, and other relevant discussions about admission or discharge.

If a person is discharged from emergency, transport needs to be arranged in advance. Make sure you have all their possessions, including medication and equipment. You may also need to monitor their health after they have been discharged – although their health may have been stable on discharge, it can deteriorate afterwards (see Section 5).

OUTPATIENTS AND DAY SURGERY

Many hospitals have outpatient clinics, where people come for treatment or follow-up appointments following their stay in hospital, or for public health service specialist care. Often, people will not be given an exact time for their appointment, but a block of time in which the appointment will occur. This is because the doctors are often on call to attend emergencies in ED or on the ward, which takes them away from the outpatient clinic. Other health professionals will also be working in outpatient clinics (e.g. allied health therapists), so a person may not necessarily see a doctor during the appointment.

Day surgery is when a person attends hospital for a small procedure and gets to go home later that day. In many cases, the person may be given instructions about what to do before attending hospital. This may include not eating or drinking for a specific time (fasting), taking a special drink a certain time before they get there, washing themselves using a particular soap, or preparing in some other way (e.g. for a colonoscopy or endoscopy).



HOSPITAL ADMISSION

People are admitted to hospital because they are unwell or injured and need to have ongoing medical support, or because they are going to have a procedure or treatment that needs to happen in hospital. At times, hospital admissions can be planned. However, hospital admissions can also be unplanned in an emergency if the person has a serious injury or illness.

PRE-ADMISSION APPOINTMENTS

When a hospital admission is planned, there may be a pre-admission appointment a day or two prior to the admission. This appointment makes sure the hospital has the correct information about the person, obtains consent for tests or procedures, and the admission clerk outlines what will happen (i.e. when the person must arrive at hospital, how long they will stay for, whether they can eat or drink), fees associated with their stay, and other relevant information. In this meeting, your role is to support the person to participate in the meeting, including assisting them to provide informed consent if appropriate. Know who the person's guardian is for the consent process if required.

If the person you support has a health passport or communication profile, it may be useful to provide copies, or identify what information the admission clerk is able to put in the hospital notes about the person's support needs. You may also need to flag specific needs for consideration in the discharge planning process.



WHAT TO TAKE TO HOSPITAL

It can be very tempting to over pack when a person is going to hospital. Remember they may need to share a room, providing limited storage space. Consider packing the following for the person you support:

- Clothing items – comfortable clothing, sleepwear, underwear
- Toiletries – toothbrush, hairbrush, sanitary products, continence aids, etc.
- Medicines/equipment – anything the person needs, labelled with their name, including:
 - » Medications – clearly marked, in their correct bottles. Include regular medications and those used occasionally (e.g. asthma inhalers). Include an up-to-date medication list, detailing the dosage and frequency of each medication
 - » Mobility aids – e.g. wheelchair, walking stick, splints, orthotics (if required)
 - » Feeding aids – e.g. special plates/cutlery/drinking container (if required)
 - » Communication aids – e.g. phone, AAC device, picture boards (if required)
 - » Charging cables or extra batteries for relevant devices
- Comfort items – anything that will help wellbeing, including:
 - » Sensory items – fiddle toys, weighted blanket, night light, pillow
 - » Activities to entertain – tablet, book, drawing items
 - » Items required for the safety plan (see Section 12).

Consider what you will need if you are staying with the person you support. You may also need many of the above items.

WHEN THE PERSON IS IN HOSPITAL

Depending on the situation, the person you support may be in hospital for a short or long time. They may stay in one ward or move to a different ward, depending on their health and the demand for hospital beds. It is important you explain what is going on (as required) and support them to cope with any changes.

While the person is in hospital, hospital staff are responsible for medical care and treatment. However, if the person you support requires additional supports, hospital staff may not have the time or appropriate

training to provide this. It is important to have calm discussions with the health care team to best understand how you can provide support and what will be done as standard medical care while the person is in hospital. If the person you support has specific feeding requirements, confirm each meal is suitable.

DISCHARGE FROM HOSPITAL

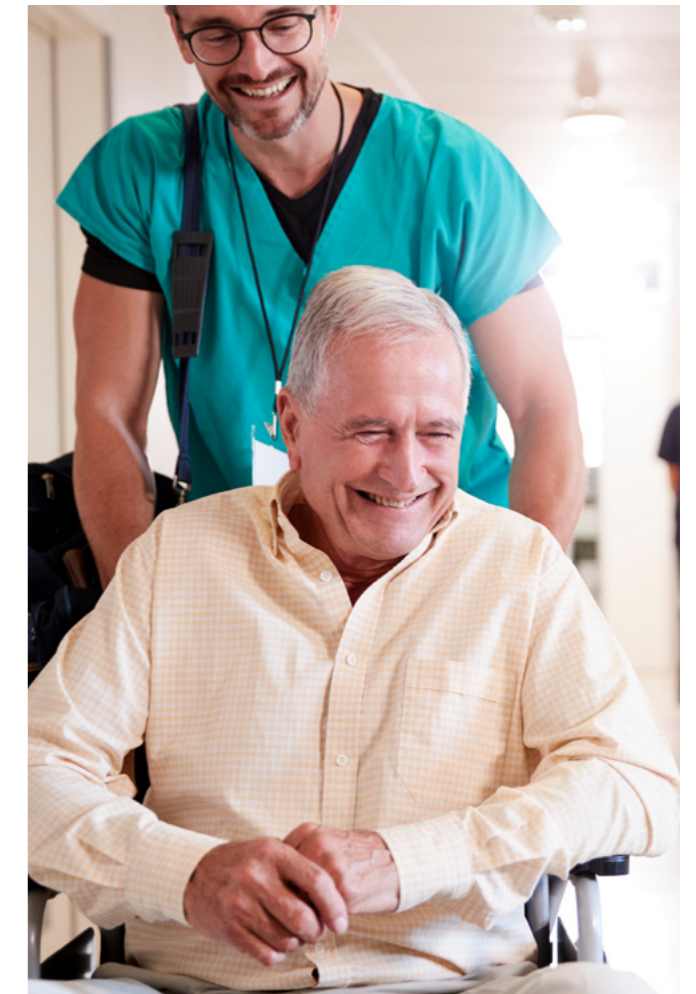
The discharge planning process should begin as soon as a person is admitted to hospital, as some things can take time to put in place. Planning should include health staff, the patient, and relevant caregivers or family (as required). The aim of discharge planning is for a smooth transition from hospital to the person's home, with relevant people knowing what they need to do. When a person has additional support needs, discharge planning is very important to make sure the person's health is not compromised due to inadequate supports. In your role supporting a person with ID, you may need to advocate for those supports to be provided, as health staff may be unaware of what is required.

It is important to consider whether the person you support has additional needs while they recover from their hospital stay. If they do, then the discharge planning process needs to include a specific focus on supports allowing for those needs to be met. For example, if the person's functional capacity or mobility has changed, they may need to make a change of circumstances request on their NDIS plan, so obtaining the report from the medical team before leaving hospital is easier than chasing it up afterwards. You may also need to consider whether any equipment needs to be hired in the short-term (e.g. wheelchair, walking frame).

The person may have follow-up appointments or treatment (e.g. needing an appointment with a specialist, their GP, or at an outpatient clinic), or a changed medication regime. It is important to make sure you have all the

relevant documentation, including medication scripts, referral letters, and any relevant reports or test results.

The discharge summary is a document that is usually prepared by one of the hospital doctors who was treating the person. One copy of the discharge summary goes to the person's GP, and another should be given to the person. The summary includes why the person was admitted to hospital, what care happened (e.g. tests, treatments, or procedures performed; medications prescribed), adverse events - if any (e.g. allergies or bad reactions to medications), and what follow-up is required.



In your role supporting the patient through the discharge process, it is important to consider the following:

- Do you understand what the person must do (e.g. future appointments or follow-up rehabilitation)?
- What do you need to look out for (e.g. deterioration of health, progress signs)?
- What is your role in ongoing treatment/rehabilitation (e.g. learning and understanding a new medication and regime, making follow-up appointments)?
- Are there any services the person is eligible for to support their transition home (e.g. Silver Chain, Hospital in the Home, Complex Needs Coordination Team, Rehabilitation in the Home, other community-based services such as transitional accommodation or drop-in services funded by WA Health)?
- Does the person have enough medication to last until their next GP appointment?
- Is transport arranged to get the person to their home?
- Have all the person's (or your) questions and concerns been answered before they leave hospital?
- Who do you call (name and number) if there are any concerns or questions after the person leaves hospital?

Before the person leaves hospital, check they have all their possessions. When they get home, you may need to monitor them for a period to make sure they are recovering as expected.



EASY READ RESOURCES FOR HOSPITAL VISITS

Going to the hospital can be a scary experience for people with ID. Hospitals are often crowded and noisy. If a person is unwell or injured, there will potentially be a series of different health workers helping them. You can help the person you support understand what is going to happen by using a social story or Easy Read fact sheet. The Health Consumers Council (WA) have the following resource describing different aspects of the hospital visit: ***Going to hospital***

The following Easy Read guides focus on different aspects of the hospital visit. The guides are from the United Kingdom (UK) but reflect what to expect in an Australian hospital – although staff titles and laws are a little different. The resources can be found here:

- What will happen in an emergency department – ***A journey through the Emergency Department***
- What happens when you go to hospital – ***What happens when you go into hospital***
- Getting ready for a visit to hospital (e.g. for outpatients or day surgery) – ***Getting Ready for My Visit to Hospital***
- Coming into hospital for an operation (day surgery) – ***Coming Into Hospital For An Operation***
- Going to stay in hospital – ***Getting Ready for My Stay in Hospital***
- Getting ready to go home from hospital – ***Going Home***
- Having anaesthesia – ***Having An Operation With Anaesthesia***
- Questions to ask at the hospital – ***Questions to ask when you go to the doctor or to a hospital***

PART D

BUILDING HEALTH-RELATED SKILLS AND KNOWLEDGE

Empowerment of the person with ID is important. With appropriate support, opportunities exist for most people with ID to build skills to increase active participation in their health care journey.

The Health Consumers Council (WA) developed an Easy Read resource highlighting the person's health care rights, their responsibilities, and other important topics related to getting quality health care. The resource can be found here: [**Better Care for People with Disabilities**](#)

The following sections outline important concepts to consider so the person you support can more effectively:

- communicate about their health
- engage with clinicians
- make decisions
- cope with appointments, and
- find quality information.

It is important to remember that learning skills takes time for everyone. By providing accessible information, opportunities to practise, and expectations the person you support will be involved in their health care - you will contribute to their development of health-related skills and knowledge.



SECTION 9 - Communicating about health

When people access health care, there is often the need to tell health professionals the same story about the person's health again and again. This may be information about the person's likes and dislikes, symptoms, how they are feeling, and medical history. It can be difficult to remember all the important information, particularly in stressful times (which is often the case when someone needs health care). Many people in Australia now have an electronic health record called the 'My Health Record', which can contain medical history.

At times, the person you are supporting may need help to communicate about their health or may need someone to communicate for them. There are some useful tools that can be prepared in advance (like a communication passport or a health passport), or that can help you in stressful times (like a structured communication tool). The medical signing board may also be helpful by providing visual cues for a person with ID to talk to a health professional about their health - see [**Medical Signing Board**](#)

Communication is complex, with many different aspects. Receptive language is how a person understands language. Some people may have difficulty understanding language that uses a lot of jargon, acronyms, slang words, or is about abstract concepts. It is helpful to communicate with simple words, in clear, short sentences. Some people may also have difficulty processing the language - so speaking slowly and leaving time between sentences can also be helpful. Questions should be asked one at a time, allowing enough time for a person to process what is being asked, think about an answer, and communicate their response. Visual cues can be useful to help a person understand, as pictures support the words they are hearing. If a person doesn't understand what you are telling them, keep trying - but consider saying it in another way, using different words or visual supports.

Expressive language is how a person uses words to show their thoughts or feelings. This is a complicated process. The person first needs to identify their thoughts/feelings, then come up with words to use, then be able to communicate the words (i.e. verbalise, sign, use a communication device). The person may need additional time to do all the steps required to produce their communication output.

Visual cues, facial expression and body language may all be useful to help clarify meaning. If you don't understand what a person is trying to say, keep trying - but consider alternative strategies, like asking if they could say it again, can think of another way to say it, or if there is a different way they could show you. If you are going to involve another person to help decipher the communication, then ask permission first.



When you've been supporting a person who has communication difficulties for a while, you build a relationship and can pick up on the various forms of communication they may use in different situations. Ability WA have developed a 'Communication Skills Checklist', used to identify methods a person may use to communicate for different reasons, and can be found here:

Fact Sheets

The following communication tips may also be helpful:

Communication Tips

If you would like to learn more about how to support communication, the learning module 'Supporting and understanding communication' can be found **here**.



COMMUNICATION PARTNERS

There are different ways to support the person to communicate, through whichever means of communication they use. As a communication partner, you are not speaking on someone's behalf. Rather, you are facilitating the person's involvement to communicate as much as possible. You wait, listen, and respond. You may also help to clarify meaning of the words.

It is important to know that people will want different things in their communication partner.

For example, people who use augmented and alternative communication (AAC) have individual preferences regarding how they want their communication partner to act. However, there are some key strategies that are common, which are useful for people with communication difficulties whether they are AAC users or not³⁴:

- **Respect the effort that communication can take**
– for people with communication difficulties, whatever form of communication is being used, can take a lot of effort.
- **Be patient and wait**
– it can take time to produce the message, let alone think about what you want to say. You need to wait as long as necessary to hear a response to your question.
- **Help manage the noise**
– an AAC device has a limited volume range. Processing speech can be difficult for people in loud environments. Consider whether you can move to a quieter place and if the conversation needs to occur face-to-face or could occur online (i.e. email, social media).
- **Help manage the physical space**
– find a space accessible to the person. If they need to use an AAC device, consider whether it needs a power outlet, or the lighting needed to support its use (i.e. no bright sunlight).
- **Watch the person, not the device**
– facial expressions provide contextual information. An AAC user might form the message, then activate the speech – and activate facial expressions as the message plays.
- **Pay attention to message and other cues**
– rather than jump to a conclusion about what a person means to say, look for different cues. Consider whether there are different meanings and ask clarifying questions if needed. Tone of voice and rate of speech provide cues which may not be present in digital voices, or for people who may have limited verbal speech.
- **Don't dominate the conversation.**
Conversation is a dialogue constructed between two or more people. Usually, it is not an interrogation with one person asking all the questions and the other one answering them. It is also not a monologue where one person just listens. As a person with communication difficulties may need additional time, a good communication partner finds ways to give them control, allowing time for them to take their turn before the conversation moves on.
- **Accept what a person has to say,** however it is expressed, and however long it takes to say.



A good communication partner has some core values. They presume competence. They are flexible, ready to adapt and change in response to the situation and the person's communication. They are persistent with communication and try different ways to engage with the person. They are patient and allow time for communication.

There are several ways that a communication partner can help a person build communication skills:

- **Model the language.**
At times, you may want to show different types of communication functions – asking questions, giving opinions, telling news, and having conversations. Some people may want you to model how words sound so they can work on their clarity of speech and pronunciation; others may be offended if they think you are correcting them.
- **Pause and wait.**
Sometimes it can take time to initiate the movement, or do the mental processing needed for communication. A communication partner should pause expectantly, keeping an open expression that invites the person to take their turn in the conversation if they wish to. Don't jump in with prompts or help if they haven't responded immediately.
- **Make comments rather than ask questions.**
A conversation partner needs to be careful not to ask too many questions that we know the answer to, or ask yes/no questions. It is important a person has opportunities to initiate conversation and isn't worried about getting an answer wrong. A communication partner is effective if they make comments, describe things or provide opportunities for the person to discuss the topic further.
- **Be consistent with how you respond to communication attempts.**
Acknowledge the attempt and treat the communication as meaningful. You may be able to expand on what has been said, or restate what has been said. This can be a useful way to confirm the message that is intended.

Thinking about how you can improve your skills as a communication partner, you may want to consider the following checklist: ***Person Centred Communication Partner Checklist.pdf***

While developed specifically for augmentative and alternate communication (AAC) users, many strategies are useful for anyone with communication difficulties.

At times, you may need to provide advice and support to a health professional with respect to how they may communicate effectively with the person you support. The following fact sheet may be helpful: ***Communicating with People with Complex Communication Needs.***





COMMUNICATION PROFILE

Communication profiles are generally developed by a speech pathologist or a neuropsychologist. They are developed after a series of assessments testing different aspects important to communication. The assessments may include sensory-motor capabilities, attentiveness, receptive and expressive language, pragmatic or social language, speech, fluency, voice, oral issues, and non-oral communication. A range of assessments may be used, and a summary can be found here:

Communication Assessments for People with Behaviours of Concern

A communication profile can be very useful to support a health professional to understand what social, physical and environmental supports are needed to best support a person in the context of a health appointment. The profile can also help identify areas of opportunity where the person may benefit from specific goals to enhance their communication ability. The profile can also support the health professional to understand how they may need to change their communication style in order to support the person with disability in their communication and/or decision-making.

COMMUNICATION PASSPORT

A communication passport is a practical approach, giving people important information about how a person with complex communication difficulties can communicate and how they like to be supported to communicate. The passport draws on information from people who know the person with disability, and different contexts to create an understanding of how to support the person to communicate as effectively as possible. The person is presented in a positive way as an individual, not as a disability diagnosis.

The communication passport can provide a wide range of information beyond the way a person communicates, how you can help them to communicate, and what help they want. The passport often contains information about the important things a person wants you to know about them, and the context of their lives (their family, their friends, where they live and work). The passports may also include information about things the person likes to talk about (e.g. hobbies, teams), and what they like to do. The passport often includes information relevant to the person's mental wellbeing, such as what makes them upset, cross, calm, and happy. Templates to create a communication passport can be found here: ***Creating Passports***

Communication passports are important during times of transition, when the person with disability meets new people who may not have time to get to know the person properly. The person with disability owns the communication passport, and it is their likes and dislikes that are identified – not the person who helps develop the passport!

COMMUNICATION DICTIONARY

A communication dictionary is a document outlining ways the person communicates and is mainly for people who use non-verbal communication. Communication dictionaries link different vocalisations, body language, facial expressions, gestures, and signs that people use to add meaning. Photos of specific movements can be used rather than words. The dictionary also tells the communication partner what they should do for each type of information. A template to create a communication dictionary can be found here: [*Personal Communication Dictionary*](#)



STRUCTURED COMMUNICATION TOOLS

At times, the person may not be able to communicate about their own health. It can be challenging to communicate effectively about someone else's health. There may be a lot of different things to remember, and a lot of different people who need to hear the same message. It also may be challenging to communicate in stressful situations, or when you are tired. In an ideal situation, there would be time to plan what to say, and how to say it.

A structured communication tool is useful to help get your message across, especially when talking on the phone. One example of a tool is the 'SBARD', which stands for:

- **Situation** – what is the current situation?
 - Explain who you are, your role, and where you are calling from. If you are on the phone, provide a direct phone number in case you get cut off
 - Provide information about the person you are supporting – name, date of birth, Medicare number
 - Explain why you are concerned about the person you are supporting
- **Background** – what is the relevant medical history for the person you are supporting?
 - State what medical conditions the person has
 - Detail the treatment or medicines the person takes routinely
 - Identify any new treatment or medicines the person is taking (e.g. antibiotics, pain medication)
 - Say what test results you are waiting for (if relevant)
 - Mention when the person was last seen by a doctor, and who their doctor is (if relevant)
 - Discuss the last set of observations taken for the person (if taken recently), and what is 'normal' for the person
- **Assessment** – what action have you taken so far?
 - Detail the soft signs or symptoms you have observed
 - Outline the pain relief or other medications that have been given to the person
 - Mention if you moved the person, and how
 - Detail the observations that have been taken (and when)
- **Recommendation** – what would you like to happen next?
 - Ask whether you need a medical appointment for the person you are supporting, and how quickly it should occur
 - Do you need someone to do something? ('Please could you...' or 'I need you to...')
 - What should you do to help manage the person's health, or while you wait for help to arrive? ('What do I need to do next?' or 'Is there anything I need to do in the meantime?')
- **Decision** – summarise the agreed plan for what will happen next. This should be documented in the care plan for the person you support.
 - Outline what you need to do ('if there is no improvement within XX time, then I will take YY action' or 'I understand that I need to...')
 - Outline your understanding of what they will do ('we have agreed that you will do...')
 - Outline your understanding of what others need to do ('we have discussed that so-and-so will...')

The Academic Health Science Network for the Northeast and North Cumbria developed a good template to support structured communication in residential aged care homes. The template would also be useful in supporting a person with disability with high support needs. The template can be found here: ***Is My Resident Unwell?***

The SBARD approach can be very helpful to guide the person with ID through their conversation with health professionals. While all the different components of the tool may not always be needed, the structure of the tool can help the person remember all the important details they want to communicate to the doctor, and the questions that they want to ask.



MY HEALTH RECORD

What information is on the electronic 'My Health Record'?

The 'My Health Record' is a digital summary of people's individual health information. A My Health Record has been created for all Australians who did not opt out by February 2019. It is possible to set privacy and security settings, choosing who can access the information, or different parts of the record. For example, you can choose which healthcare providers can see your record and be notified when they first access your record.

People can add their own relevant information, like emergency contact details, current medications, advance care directives, and information about allergic reactions. They may also choose to add whether they are Indigenous, and/or in the Australian Defence Force (or a veteran).

If access is given, health providers involved in care of the person can access important health information like medications, medical conditions, pathology test results, and information about allergies and immunisations. This can be very important if people see more than one doctor. Permission can also be given to healthcare professionals (doctors and pharmacists) to add clinical documents to the My Health Record. This might include an overview of a person's health (called a shared health

summary), hospital discharge summaries, reports from tests or scans, medications that have been prescribed, and referral letters. This type of information gives a doctor a more detailed picture of a person's medical history over time, which may help their clinical decision-making.

Information can also be added from government sources. This includes information from Medicare, and the Pharmaceutical Benefits Scheme (see Section 14 for a description of these). The My Health Record can also detail information about immunisations that are included in the Australian Immunisation Register, including childhood immunisations and vaccinations including Flu and COVID-19. The record contains information about a person's organ donation decision. The record can also detail relevant medical information from the Department of Veterans Affairs (if a person has been or is currently in the military).

A good explanation of the My Health Record can be found here:

My Health Record Plain English Booklet

How to use the My Health Record to support a person

Even though you are providing support for someone with ID, you may not have access to their My Health Record. Only a nominated or an authorised representative can access someone else's My Health Record. There is a difference between the two:

- A nominated representative is usually a family member, close friend, or carer of a person. If you are a nominated representative, you can view or help manage another person's My Health Record and see their previous tests and prescribed medicines. A nominated representative with full access can upload documents for the person they are caring for, including a person's health summary or an advanced care plan. The person who owns the My Health Record can control the level of access the nominated representative has.
- An authorised representative is responsible for managing the My Health Record of someone who is not able to make decisions for themselves. The authorised representative has complete access and control over the record, as if it were their own. The authorised representative may be a parent, carer, family member, legal guardian, or someone with enduring power of attorney.

How the My Health Record can be used in an emergency

Health care providers can access information within a person's My Health Record for the purpose of reducing or preventing a serious threat. Information about allergies, medicines and immunisations can help clinicians deliver safer treatment and care. Called 'emergency access', this lasts for up to five days and is recorded in the Access History. In this type of access, restricted information and documents can be seen by the health care provider; they will not be able to see documents that have been removed or hidden, or personal health notes.

HEALTH PASSPORTS

Health passports prepare important information to share with others in a care team, including health professionals, supporters, or others. A health passport contains a wide range of information about an individual, beyond their illness or their disability. This tool helps the care team see the person rather than the disability. It also provides information to the care team about how to interact and communicate with, and support the person to make decisions about their own health. Health passports are suited to situations where health professionals have time to look at the document – for example, at the GP or specialist, or during a planned admission. In an emergency, the health professional's priority is to meet the person's immediate health needs.

Helping a person with ID develop their health passport provides an opportunity to identify what they think is important for people to know, and how they would like to be communicated with and cared for. It is a good idea to discuss the health passport when the person is in a relatively healthy state, as you can plan for what should happen when the person becomes unwell and needs medical care. This process will also identify opportunities to help the person learn more about their health and how they can advocate for themselves. It also helps you know what circumstances you will need to be an advocate for them.

There are many different examples of health passports – see Appendix E for the information that needs to be in a passport, and for a link to different styles. One approach to health passports uses a traffic light system. Using '**Julian's key passport**' as an example, the passport is structured as follows:

1. **RED** – Things you must know about the person
 - a. Information for forms (name and contact details, next of kin, Medicare number insurance details, relevant health documents, GP details)
 - b. Health-related information (allergies, medical problems/history, current medications)
 - c. Personal details (communication style, personal beliefs, normal behaviours, how the person reacts to pain)
2. **YELLOW** – Things that are useful to know about the person
 - a. Type of disability
 - b. Information about support (level of support required, names/roles of support people)
 - c. Details about personal care (toileting, feeding, drinking, sleeping)
 - d. Details about safety and reducing anxiety
3. **GREEN** – The person's likes and dislikes
 - a. Things that make a person comfortable/uncomfortable

Another example of a health passport identifies the five most important things a person needs the health professional to know about their disability, health, behaviour, and communication (see Appendix E for the My Health Matters Folder, Council for Intellectual Disability). This approach provides the care team with information that will assist them to provide care more effectively to the person with disability.

It is important to recognise that health passports are valuable when people have time to look at them. At times health care is provided in a rushed and chaotic environment, and the care team may not have time to consider the information. The team may change from one shift to the next, and there may not be an opportunity to pass on the information. As a supporter of someone with disability, you may need to continue to communicate the important information contained in the document, and not assume that it has been read by all nurses and doctors.





CARE PLANS

Perspective from the disability sector

A care plan is a written record of the support and care a person requires. Care plans are required for people with disability who live in supported accommodation. They are also useful for people living with family, or in other community settings. The plan outlines the views, preferences, needs and actions to be carried out by all who provide care, to meet the person's needs, and any risk-mitigation or emergency measures that may be required.

Ideally, the care plan is created with the person with disability and includes information about the person's personal routines, goals, or support needs, that may get reviewed annually. However, the care plan needs to be a living document, with other details (e.g. medical information, medication management and other treatments) needing to be updated more regularly. It is critically important the care plan includes information about proactive health care (e.g. health checks and screenings), together with reactive health care (e.g. medication regime, rehabilitation program, etc.).

The care plan should also outline communication expectations, including who has the authority and responsibility to contact various people like family members, guardian (if appropriate), and the person's GP. If a person is at risk of an adverse reaction to medication, the care plan should include clear guidance about who has responsibility for notifying the Therapeutic Goods Administration's adverse events line. Similarly, the care plan should detail who has responsibility for notifying the NDIS Commission about all reportable incidents.

The care plan may also need to outline how the person will be supported in the event of an emergency (e.g. flood, fire). The Person-Centred Emergency Preparedness framework,³⁵ and workbook offers step-by-step guidance on what needs to be considered in the event of an emergency. The workbook can be found here: **[Person-Centred Emergency Preparedness Workbook](#)**

Perspective from the health sector

In primary health, a GP may often develop an advance care plan for their patients. In this context, the care plan describes the agreed goals of care, and outlines the planned medical, nursing, and allied health activities for the person. The care plan reflects the shared decisions made by the patient (and families/carers when relevant) about the tests, interventions, treatments, and other activities needed to meet the goals of care.

The medical care plan will depend on each person's individual circumstances. Some of the components may include the following:

- **Personal identifiers and preferences** – these may include support needs, spiritual/cultural needs, and legal status.
- **Clinical assessment and diagnoses** – these may include diagnoses, comorbidities (other diagnoses), allergies and reactions, medications, and other relevant medical history.
- **Goals of care** – these include both clinical and personal goals (in the short, medium, and long term), when the goals will be reviewed, and preferences for care in the future (e.g. advance care directives).
- **Risk screening and assessment** – identified risks, the planned prevention strategies, and timeline for review.
- **Planned interventions** – these may include diagnostic tests or different types of treatments.
- **Activities of daily living** – this relates to a person's functional status, and may include the assistive devices they need, dietary needs, bowel/bladder habits, mobility, and work or recreational activities they participate in.
- **Monitoring plans** – these include the frequency of monitoring, review dates, and the plan for escalation if required.
- **People involved in care** – the support people (family, carers, and other relevant people) that are involved in care decisions and delivery of care.
- **Transition of care** – this is important when transitioning from one health service to another, and includes services and resources for the transition process, referrals, and discharge instructions.

People with ID are eligible for a yearly GP care plan (called a GP Management Plan). For people who also have complex health conditions, their GP can review the plan every three to six months. When two or more others are providing a service, GPs can organise a meeting to help coordinate care - called a Coordination of Team Care Arrangement. Depending on the person's circumstances, a GP is also able to develop a Mental Health Plan, and/or a Chronic Disease Management Plan.

SECTION 10 - Decision-making in health

People with ID should be involved in all decisions about their health and wellbeing. Some people can make decisions alone while others will need support. It is important to recognise that some decisions can be very simple, while others very complex. The level and type of support a person requires for decision-making depends on the situation. For some decisions, people may need additional time and repetition of discussions about their choices. It is critical that supporters provide information in an accessible way, adequate time so that the person is comfortable making their decision, and the level and type of support that the person prefers and needs.

Developmental Disability WA produced a workbook to support decision-making, found here: [**Decision workbook**](#)

Can people with ID give consent to health interventions? This depends on the person's legal capacity, and the complexity of the decision that needs to be made. It is important to not assume a person does not have legal capacity – and instead, consider how they may be supported to provide consent. However, at times there may be some people who need a substitute decision-maker to act on their behalf. There are different laws in each Australian state or territory regarding guardianship, how substitute consent is obtained, and how an authorised representative or guardian should make those decisions. It is always important for the substitute decision-maker to consider the person's will and preferences when making decisions on their behalf, with the involvement of an independent advocate if needed. See Appendix D for information relating to the legal framework that underpins decision-making in health care.



THE DECISION-MAKING PROCESS

People make decisions every day – at times the choice is easy, with a clear yes or no answer. At other times, people may need to go through a process to make their decision, with their choice depending on several things. People may need different levels of support, depending on the complexity and importance of the decision. It is important to consider how a person with ID can be supported in each of the following steps because that person may be able to make their own decisions when provided with sufficient support:

- **Identify what decision needs to be made.** As a supporter, you may help a person to understand what the decision is, why they need to make it, and a timeframe to make the decision. At this point, it is important to consider what support the person would like in making the decision.
- **Gather relevant information.** You may need to find further information about the topic to help with the decision-making. It is important you help a person know which source of information is evidence-based (i.e. that has been scientifically proven), and which is opinion (i.e. someone's point of view). See Section 13 for more detail. In health care, the type of information you may need to look for depends on the situation. For treatments, you may be looking for information about success rates, side effects, cost, and recovery times. You may need to find information about different procedures or processes, or where a person can access the care or intervention they are looking for. For health-related lifestyle goals, you may need to find information about how the person can progress towards the goal and what needs to be put in place to support that.

- **Identify alternatives.**

In some circumstances, there may be only one option being decided upon. However, in other situations there may be a range of options to consider. This is where a person may like to talk to other people who have experienced a similar situation about the choices they made or ask for a second opinion from another health professional.

- **Weigh up the options.**

With all the information that has been collected, you can help a person go through each alternative and consider the benefits, risks, and cost associated with each choice. A person's values and beliefs influence the weight we put on different choices.

- **Choose!**

Out of available options, a person now decides. If a person is unsure, it is a good idea to ask if they would like to go through any of the previous steps again. They may need additional time or want more information to make the decision. They may also want to seek advice on what someone else would choose. It is important you provide a person with decision-making support, but always come back to asking them what they want to decide.

- **Taking action.**

Sometimes, this may be as simple as receiving a particular treatment or procedure. There still may be a lot of organising required for that to occur, such as making an appointment, organising transport, etc. For more complicated things, there may need to be an action plan developed, outlining who is responsible for what. A person may need a care plan updated, to ensure actions occur.

- **Review.**

This step is not always needed but is important for things occurring over a period of time. For example, if a person has taken a new medicine, it is important to review the treatment is effective (benefit), and side effects are manageable (often considered a cost), or even whether the treatment is needed anymore. For many health-related decisions, the person's GP can help with this review.



DIGNITY OF RISK

Dignity of risk refers to the legal right of every person, including those with ID, to make choices and take risks. This helps people learn and is important for a good quality of life. Sometimes, a person with ID may be stopped from doing something, because a caregiver wants to protect them – however, this is not allowing them dignity of risk. For example, a person may want to ride their bike to the local park for exercise. There can be a tension between duty of care in safeguarding (protecting people from the presumed risk of navigating the roads, stranger danger, falling off the bike), and the benefits that come from the activity (exercise, increased self-esteem, social connection). The NDIS Quality and Safeguarding Framework requires people to be supported to take informed risks to improve the quality of their lives, where caregivers recognise when positive risk-taking is something the person can decide on.³⁶ In the example given above, the tension can be resolved by supporting the person to build the skills to perform the bike ride while managing real and perceived risks.

In your role supporting a person with ID, you may often be told they have the right to choose. This is correct. However, it is also important you consider how you can provide information to the person, so they make an informed choice and understand potential risks where possible. If a choice has potential for short- or long-term harm, it is good to talk about the possible outcomes to help a person understand the difference between a **WANT**, and an **INFORMED CHOICE**. For example, many people enjoy eating a hamburger, and they are tasty to eat every now and again. However, if a person was to eat a hamburger every day, they risk developing poor health. While a person may **WANT** the hamburger, they know they ate one yesterday so the **INFORMED CHOICE** may be to have a hamburger once a month rather than daily.

INFORMED CONSENT

Informed consent is a person's voluntary decision to agree to a health care treatment, procedure, or some other health intervention. The word '**INFORMED**' is important, as it means that accurate and relevant information about the health care intervention has been provided to the person, and that the person has had time to think about the decision. Information generally includes details about benefits, risks, alternative options, and what might happen if a person doesn't have treatment.

The person should also be told about the costs of any health care intervention. These are all summed up by the **CHOOSE WISELY** questions, so you can help the person you support ask the following questions:

- **Do I really need this test, treatment, or procedure?**
Tests may help find out what the problem is. Treatments (like medicine), or procedures may help treat the problem.
- **What are the risks?**
It is important to know whether there are side effects to the test or treatment. It is also important to understand whether the results will be accurate, or whether there is possibility that what is done will lead to more testing, additional treatments, or another procedure.
- **Are there simpler, safer options?**
It is good to understand whether there are alternative options to treatment that could work. These might include lifestyle changes which can be safe and effective options, depending on the situation (for example, exercising more, eating different foods, changing sleep habits).
- **What happens if I don't do anything?**
Ask whether the condition or the symptoms get worse or better if the test, treatment, or procedure is not done right away.
- **What are the costs?**
Costs can be physical (e.g. side effects), financial, emotional, or a time. It is okay to ask when there is a cost, whether it is reasonable, or whether there is a cheaper alternative.



Making an informed decision does not mean that a person can't change their mind. In most circumstances, a person has the right to refuse treatment or withdraw consent. An Easy Read guide to making choices about health can be found here: ***Making Choices Easy***. While the legal information relates to UK laws, other information is relevant to Australia.

At times, it is good to ask whether a decision can be reviewed. This might be after a treatment has been tried for a while. For some medicines, it is a good idea to ask for a review after 4-12 weeks, so the doctor can discuss whether the treatment is working, the side effects are manageable, and if there is something else that should be considered. Some people with disability may take several different medications and asking for a medication review with a doctor or pharmacist is a good idea, especially if the medicines have been prescribed by more than one doctor.

RESPONSIBILITY FOR CLINICIANS TO SUPPORT INFORMED DECISION-MAKING

Health professionals have a responsibility to make sure the person understands the nature and consequences of any proposed medical treatment and can decide about medical treatment. Some health professionals might make assumptions about a person's capacity for decision-making, so supporters may need to advocate for the person with ID to be involved as much as possible and provide the tools that a person needs to support their decision-making. There is a useful Canadian resource showing doctors the steps they can take to support health-based decision-making for a person with ID. Although they refer to Canadian laws, the tips are useful for Australian doctors, and can be found here: ***Decision Making Approaches***

Sometimes the person with disability may need the health service to remove barriers preventing them from understanding the information and deciding; this is called making a reasonable adjustment. It can be a simple change made by one health professional, e.g. a doctor can provide information about a person's health and care in a way that makes it easier to understand, like speaking clearly and using simple words, allowing extra time for people to process information, and providing written information that is easy to read. Adjustments may be more complicated, needing extra people, e.g. bringing in an interpreter or communication specialist.

It is important that where possible, a doctor gets to know the person with ID (and their main caregivers), building a relationship based on effective communication and trust.³⁷ This allows the doctor to understand the person's need for accommodation and support. A GP is often the most important person in a health care team for a person with ID, as they can develop a good relationship over time, and help the person develop confidence to participate in decision-making about their health. Doctors may find the guidelines for effective communication with a person with disability outlined in Section 10 helpful.

YOUR ROLE IN SUPPORTING DECISION-MAKING

What is supported decision-making? It is a way to provide people with ID the support they need to make their own choices. If you are supporting a person with ID, you need to learn about what kind of support they want – it may be to help them understand what their choices are, to make decisions, or communicate those choices. It is important to remember that a supporter is not making choices for the person with disability, even if you think the person isn't making the best choice. We all learn by making bad choices (see 'Dignity of Risk' on p.123). People are safer and better protected if they learn decision-making skills and can make their own choices, so it is important to respect this.

What do you need to do to support decision-making? Ultimately, that depends on what the person wants and needs. There are many different examples of the type of support you can give³⁸:

- **Helping the person access information about their choices, by**
 - o Finding accessible information, like Easy Read pamphlets or videos
 - o Researching available choices
 - o Explaining different options, and brainstorming with the person to help them decide
 - o Finding classes to help the person learn about self-advocacy and decision-making
- **Providing advice, by**
 - o Helping to make lists of pros and cons of each option
 - o Reminding the person with disability about their values and preferences, and discuss how the choices align with their values and preferences
 - o Advising the person about their choice
- **Logistics and scheduling**
 - o Organising appointments and visits to look at different options
 - o Keeping a calendar reminder of important dates, appointments, and schedules
 - o Attending appointments or meetings with the person you are supporting
 - o Arranging transportation for appointments
- **Communication**
 - o Helping the person plan what their choice is, and how they want to talk about it
 - o Making sure the person has plenty of time to think and talk about their choice
 - o Helping the person communicate their choice, making sure the choice is understood, recognised, and respected

If you would like to learn more about how you can support people to make decisions, the learning module 'Supported Decision Making' can be found [here](#).

TOOLS TO SUPPORT DECISION-MAKING

Decision aids in health are helpful – they do not tell people what to do but set out the facts and help people consider their options. For people with ID, decision aids may include illustrations to make the information more accessible and help with understanding. Decision aids need to be specific to the situation, but may include the following:

- A description of the condition and symptoms
- The likely prognosis with and without treatment
- The treatment and self-management support options (and the probability of different outcomes)
- What is known from the available research and what is unknown or uncertain
- The most frequent side effects or complications of the treatment options
- A way to help people clarify what their preferences are
- Where more information can be found

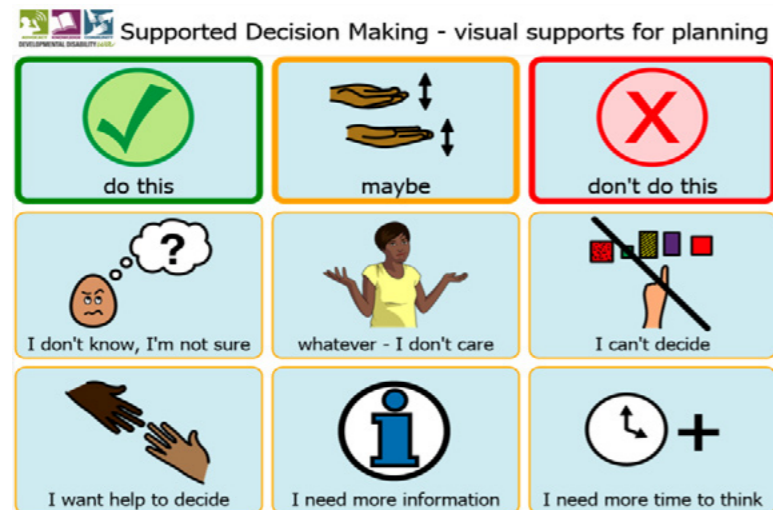
It is important to realise that sometimes people may need help with decision-making in some areas, but not others. It is good to explore the decision-making supports a person would like in different domains of life. The tool for exploring decision-making supports includes a part on healthy living, and can be found here: [***Tool for Exploring Decision-Making Supports***](#)



Another tool that can help support decision-making is a 'Talking Mat'. A Talking Mat is a visual communication framework supporting people with communication difficulties to express their feelings and views. The Talking Mat is made up of three sets of picture communication symbols – a topic, the options, and a visual scale of how the person feels about the options (for example, don't like, don't know, like). Once the topic is chosen, the person is given the options one at a time and asked to think about each one. They place it on the mat, depending on how they feel about the option. The Talking Mat can help with the following:

- **Understanding relevant information.**
The topic is provided in visual format, with symbols graded according to complexity. The images focus on the essential words and can help people process concepts by breaking information into small manageable components, which do not require literacy. The Talking Mat provides a structured framework for open questions. People have time to respond.
- **Retaining information.**
Information is presented simply, reducing memory demands. The result can be made into a permanent visual record of their views.
- **Weighing up information.**
The person has time to process information and respond in their own time. The process allows people to say no, or to change their mind, with no direct confrontation.
- **Communicating decisions.**
The Talking Mat allows the person to express their own views whether they are right or wrong, giving them control. It provides a visual space, where a more complex and composite perspective can be built. The process can work in parallel with other communication systems.

Sometimes people may like to use pictures to show their answer. This is called having visual support for decision-making. The support can be as simple as a traffic-light system, with green for 'yes', yellow for 'I'm not sure', and red for 'no'. Making decisions can be more complicated than that, so Developmental Disability WA created the following decision matrix to help people communicate choices.



SECTION 11 - Setting health-related goals

It is important to empower people, so they have greater control over decisions and actions affecting their health. This can be facilitated by helping the person you support set specific health-related goals important to them. With this approach, a person may consider specific health behaviours related to poor health and those linked to improved health and wellbeing. While some factors influencing health may not be modifiable, there are other factors that can be changed, including some that we may not automatically associate with health (e.g. employment status, or the physical environment and access to nature).



IDENTIFYING WHAT COULD BE CHANGED

Sometimes people think they live a healthy lifestyle but don't notice everything they do that may be harmful to their health. It can be useful to keep a diary related to healthy lifestyle behaviours. There are many different examples of diary templates and apps available online, from simple food intake diaries (*e.g. Food Diary*), through to tracking symptoms (*e.g. Food Lifestyle Symptom Diary*), or activity levels (*e.g. My Fitness Pal*).

Depending on the person's needs, the diary might include any of the following:

- **diet** (e.g. what they ate each day for breakfast, lunch, dinner, and snacks)
- **activity** (e.g. what exercise they did, and for how long)
- **sleep** (e.g. how much, and what quality)
- **hydration** (e.g. how much water they drank)
- **feelings** (e.g. mood, energy levels, anxiety)
- **social connection** (e.g. relationships, opportunities to connect with people in person or virtually)
- **risk behaviours** (e.g. alcohol, smoking)
- **health issues** (e.g. weight, headaches, seizures, dental issues).

A diary kept for a period (e.g. a week or a month) becomes a good starting point for conversations around health-related goals. Some calculators have been developed to provide ideas about goals to help a person be healthier, which can be found here: ***Tools and Resources***

WA Individualised Services has a good planning toolkit helping guide conversations around discovering goals important to another person. The toolkit can be found here: ***Planning Card Set***

Another very useful tool to help initiate discussions about health and wellbeing is the 'Is There a Better Way?' (ITaBW) card set from Microboards Australia, found here (scroll down for the ITaBW Card Set): ***Learning Hub***

SETTING A GOAL

Many people can think of what might help them live a healthier lifestyle. In your role supporting a person with ID, you are perfectly placed to encourage them to consider habits they could change, or new habits they might like to adopt. Appendix A is a checklist modified from the Healthy Me resource (developed by Brightwater), used to guide conversations around potential healthy lifestyle improvements. Alternatively, you can find male and female health action plan templates here: [My Health Action Plan](#)

It is helpful to talk about setting health-related goals – and then consider how to help them achieve those goals. It is important to make **SMART** goals:

- **Specific** – it is useful to consider the following:
 - o Why is the goal important to the person?
 - o What needs to be accomplished (e.g. changing a habit or behaviour, learning skills, or completing a task)?
 - o Who needs to be involved to achieve the goal (e.g. can the person do this by themselves, or do different people need to be involved for different steps)?
 - o Where will the activity happen (e.g. at home or a different location or at a particular event)?
- **Measurable** – how will you measure progress towards the goal, and how will you know if the goal has been achieved? If the goal is going to take some time (e.g. working towards exercising the recommended amount), what milestones can be set to break the bigger goal into smaller, measurable steps?
- **Achievable** – what skills, support, or resources are required to reach the goal? If the person doesn't have the skills, what would it take to develop the skills? If there is a cost involved, does the person have enough money to fund it (or if not, what needs to happen to get the funding)? What type of support is required, and who is going to provide the support?
- **Relevant** – the goal needs to suit the person's values, and what they want to do and achieve.
- **Time-bound** – how long should the goal take to achieve, or what is the deadline for achieving the goal? What needs to happen by what timeframe? For bigger goals, the milestone components can also have a timeframe.

You also have a role in supporting progress towards the goal/s. It is important to remember it is the person's goal and consider what sort of support they might like. You may need to consider what might stop a person from achieving their goal, and how you can help reduce those barriers. For example, if a person's goal is to lose weight, then providing healthy food options is helpful, whereas taking them to a fast-food outlet every day is not helpful for that goal.

MAKING A HEALTH ACTION PLAN

Once a goal has been set, it is important to act! A health action plan is a checklist for the different things that need to happen to achieve the goal. When a person has different people supporting them, an action plan is a good way to make sure everyone understands what the goal is, and what their responsibilities are in helping the person achieve the goal. Action plans also mean that people can prioritise what is important to them. Action plans can be included in the care plan.

Action plans need to include the following components:

- **A good description of the goal that the person wants to achieve**
- **All the tasks that need to be carried out to reach the goal**
- **The people who are responsible for each of the tasks**
- **When the tasks need to be completed by (including any deadlines, and milestone tasks)**
- **What resources are needed to complete the tasks (including money and a person's time)**
- **How progress will be measured.**

Remember – action plans are not written in stone. Sometimes, they need to be revised as more information becomes available, or people's priorities change.

WA Individualised Services have a good resource to help with your action plan here: [Plan Implementation](#)

An Easy Read description of an action plan can be found here: [Health Action Plans](#)





SECTION 12 - Building coping skills to manage health (and health appointments)

All behaviour has meaning – it is a form of communication particularly important for people who may have communication difficulties. It is important to try and understand what the cause of the behaviour is, so you can help the person you support to develop strategies to cope with things that may be distressing. When a person has a health issue, there may be behaviours occurring as a side effect of medication, pain, their mental health, or because of the environment is noisy, too small/large a space, or because the person has been waiting a long time and is really bored! Communication problems can also cause frustration because a person is not being understood, or because someone isn't taking the time to explain what is happening. Behaviours may also occur because someone is trying to let you know that they are hungry, thirsty, tired, or anxious about what is going to happen.

TIPS TO IMPROVE WAITING FOR AN APPOINTMENT

Having to wait for an appointment can be stressful. If the person you support finds new environments difficult, or struggles with the sensory load of being in noisy and crowded waiting rooms, then consider whether any of the following ideas would be useful:

- Book the first appointment in the morning, or the first appointment after lunch. At times, doctors may be running late with their appointments for several reasons, particularly when people book a standard consult, but really need a long one. By booking the first appointment, you are more likely to have the appointment at that time. Note – if the appointment is likely to take longer than the standard consult, then make sure you book the longer consult so you have enough time.
- Ring the clinic 20 minutes before the appointment to see if the doctor is running on schedule. If they aren't, then you can either leave for the appointment a little later or make a detour and do the waiting in a nice place (e.g. grab a drink and sit in a park).
- If you have arrived and you find the doctor is behind schedule, ask the receptionist whether there is a quiet place you can wait. Alternatively, ask if there is a place nearby where you can wait, and have them text you when it is time for the appointment. Some people prefer to wait in their car.
- Ask when the anticipated appointment time will be – it is much easier to fill time if you know how much time you have. Remember to be polite – the time delays are beyond the control of the receptionist as well.
- Always have something enjoyable for the person to do. Being engaged in an activity, watching something on a tablet, or being able to fiddle with a toy can all distract from the waiting. See the information about developing a safety plan below.
- Ask whether the health professional will come and see the person you support in another environment (e.g. in the car while outside the health service, at home).

SOCIAL STORIES

Social stories are a good tool to help a person with ID learn how to do new things, understand what is going to happen in new situations, or explain how to act in different environments. A good social story will describe what the situation requires in detail, including when and where it occurs, who is involved, what to do, and why people behave in certain ways.

A social story should focus on one topic. The story should be written from a first-person perspective and personalised by including photos of people involved, supporting the text of the story. The language should be positive (e.g. avoiding terms like “do not” or “shouldn't”), and in the present tense. The social story uses descriptive sentences, answering questions like who, what, when, where, and how. The social story should include directive sentences, describing how the person

should feel or react to the situation, and what behaviour is needed. The stories may also have perspective sentences, describing the feelings, thoughts, or moods of someone else. A general rule for a successful social story is to have 2-5 descriptive or perspective sentences for each directive sentence.

The layout of the social story should use a simple font with white background, allowing the text and pictures to be the highlight of each page. Each page has 1-2 sentences, so it is not cluttered. You can find more detail about how to write a social story here: ***What Are Social Stories?***

At times, a generic social story can be helpful. Some common social stories about accessing health care can be found here:

- ***Say Less, Show More***



EASY READ RESOURCES

The aim of Easy Read resources is to give people more access to information. Easy Read uses images to complement the text, as the meaning is carried by both text and images. The language is simple, but not childish. The font size is large. If a difficult word is needed, it is written in bold. The next sentence or phrase then defines the difficult word. If there are a lot of difficult words in the text, a word list can be included at the end of the document. Depending on a person's reading level, they may be able to read it themselves, or follow along when it is being read to them. The resource may need to be read through multiple times.

Many government services now provide Easy Read leaflets. It is okay to ask for them. Many health-related Easy Read documents from the UK can be found here:

- ***easyhealth.org.uk/pages/easy-read-health-leaflets-and-films***
- ***mcht.nhs.uk/information-for-patients/patient-leaflets/easy-read-leaflets/***
- ***sth.nhs.uk/patients/patient-information/find-a-leaflet/view-all-easy-read***

While some are only relevant to the UK, there are a lot of useful leaflets for the Australian context. There are many Easy Read leaflets that are about a specific health procedure (e.g. having blood pressure measured, taking a specific drug, etc.) While some people with ID may not be able to read all the words, they will be able to follow pictures. A series of free health-related picture books can be found ***here***. Additional books with no words are available to buy.

At times, you may not be able to find a suitable Easy Read document that suits the needs of the person you are supporting. If you decide to make your own version, think of it as a summary of the source material so you can plan the structure and decide on the level of detail to include. Identify the main points you want to cover and think of the best ways to explain them. Examples are useful to help explain ideas and concepts. Choose relatable images the person understands. Questions should only be used in headings, as they can make people anxious. You may find useful information for designing an Easy Read document ***here***.

HAVE A SAFETY PLAN

At times, it can be very stressful to be in the environment of a health service, or when a person does not feel well. For some people, it may be useful to develop a plan for different activities they might like to do when dealing with frustration, fear or worry. Depending on personal preferences, there are a range of activities to help them cope with the situation – for example, some people may like to do a sensory activity, while another may like to do a meditation activity. The idea of safety plans originated from mental health services.

A safety plan is a document that reminds you what type of signs you will see when the person you are supporting is under a mild, moderate, or severe level of stress, what activities are most effective to help them cope, and what supplies you need for the activities. The plan does not need to be complicated, and you can develop it with the person with ID. It is a way to talk about helpful coping skills which can be built over time. The safety plan is NOT a set-and-forget document – it can change over time as a person builds coping skills. It helps the person build self-awareness and resilience.

The types of activities that may be useful vary and will depend on a person's preferences. They include:

- **Artistic activities** – e.g. drawing, colouring in
- **Meditation or relaxation activities** – e.g. breathing exercises, progressive muscle relaxation
- **Movement** – e.g. chair exercises, walking, stretches
- **Reading or writing**
- **Sensory activities** – e.g. hand massage, fidget toys, weighted blanket

If you are supporting a person with ID, you may like to develop a safety plan with the person that can be used when you notice the first signs of distress. Examples of useful activities can be found here: [Wellness Guide](#)

MANAGING TRAUMATIC EXPERIENCES

Trauma is an event or series of events that a person has experienced, which has lasting impact on their wellbeing – but it is defined by the impact of that experience, rather than the event itself.³⁹ The person you support may have previously had a bad health care experience. This can influence future care – it can change a person's willingness to participate in procedures or engage with health staff. Trauma can impact a person's emotional state and manifest in behaviour that may be considered challenging, as the person is communicating about their trauma. It is important to recognise that all people participating in an event may experience trauma from that event. If the person you support has experienced trauma, it is important to recognise the signs of trauma. There are no right or wrong ways to respond to events, so people may experience a wide range of physical and/or emotional reactions to the event (see the table below).

Common symptoms of trauma

Emotional and Psychological Symptoms	Physical Symptoms
<ul style="list-style-type: none"> • Guilt, shame, self-blame • Withdrawal from others • Shock, denial, disbelief • Anxiety and fear • Feeling sad and hopeless • Anger, irritability, mood swings • Confusion or trouble concentrating • Feeling numb 	<ul style="list-style-type: none"> • Aches and pains • Muscle tension • Troubles sleeping (insomnia, nightmares) • Elevated heart rate • Feeling agitated • Feeling fatigued • Feeling unsettled or starting easily

Symptoms of trauma usually last from a few days to a few months and gradually fade. However, the symptoms can reappear if something reminds the person of the trauma – this is a problem when accessing health care becomes a trigger. For some people, the trauma symptoms don't reduce or can even become worse as the nervous system is unable to process the event properly. When this happens, the person may be experiencing Post Traumatic Stress Disorder, and should seek professional psychological help.

Trauma-Informed Care

It is important to consider how to prevent the person being retraumatised and help them to recover from the trauma so they can access health care as needed. Trauma-informed care has five important principles that can help to reduce trauma for all involved:

1. **Safety** – both physical and emotional safety of the person is important.
2. **Choice** – the person has choice and control over the situation. Their rights and responsibilities are clear.
3. **Collaboration** – the person is involved in decision-making about themselves.
4. **Trustworthiness** – the person can trust providers, with boundaries and expectations clear and consistent.
5. **Empowerment** – there is a focus on the person's strengths, and on building those strengths while also developing stronger skills to cope.

In your role supporting a person who may have experienced trauma, it may be helpful to let health professionals know the key details of the traumatising event, and how it has impacted the person. Advocate for what works best for the person but recognise that it may not always be possible for that to happen depending on the situation. You can access a learning module on 'Trauma-informed care' [here](#).



Critical Incident Debriefing

Experiencing a traumatic event can be overwhelming and can lead to ongoing distress which can be harmful if a person doesn't have the skills or strategies to cope. It is important to consider the following steps in the context of both the person you support, and yourself⁴⁰:

- **Step 1 – Demobilisation.** Calm the situation and make sure that a person's immediate needs are met. It is often helpful to have someone who was not involved supporting this step, and it is carried out as soon as possible after the event. Some strategies include:
 - o Summarise what happened and clarify the details
 - o Show care and support, and consider mental health first aid
 - o Make an action plan, considering the needs of all involved people. This includes making short-term arrangements for another person to provide support to the person with disability if required.
- **Step 2 – Defusing.** This stage should occur within 12 hours of the incident and should be conducted by someone with psychological training if possible. The aim is to bring the experience to a conclusion and provide immediate personal support. This stage provides a safe and non-judgemental place and time to talk about the event, discussing thoughts and emotions that are associated with the event. It is important that each person's unique experience and reactions are validated, as that helps with processing the event. Immediate support needs should be identified. It may also be useful to discuss the potential of other possible reactions that may be experienced in the future to empower planning to build additional coping strategies if needed. Consider what psychological supports may be needed, and how they can be accessed.
- **Step 3 – Debriefing.** When everyone has had time to take in and process the experience, it is good to have a structured discussion to put the event into perspective. Debriefing should be conducted by a person with appropriate training and is done 3-7 days after the event. The debrief is useful to understand the sequence of events, the causes and consequences, and each person's experience. It can also help people to understand the normal psychological reactions to the event and consider methods and strategies to help cope with the emotional responses to the event. Debriefing with the person with disability is important as it helps to identify the specific supports or interventions that may need to be put in place prior to accessing a similar health service again (e.g. see 'Desensitisation. on p.142).
- **Step 4 – Seek counselling if required.** Counselling for trauma supports a person to identify the feelings and emotions felt after a traumatic experience and to develop strategies to come to terms with the event and cope. There are psychologists with specific expertise in trauma counselling.

Tips to Recover from Trauma

Many of the healthy lifestyle suggestions are helpful in recovering from trauma, including eating well and getting good quality sleep. Other strategies to help recover from trauma include supporting the person to:

- **Exercise.** Trauma can disrupt the body's natural equilibrium, keeping a person in a hyper-aroused state with too many stress hormones circulating in the body. Exercise burns off excess adrenaline and releases endorphins which help repair the nervous system. Rhythmic exercise using arms and legs works best. Helping the person you support to focus on how their body feels as it is moving is a way to add mindfulness to the exercise, distracting from the thoughts and emotions connected to the traumatic experience.
- **Connect with other people.** While it is normal that people may want to withdraw from others, isolation only makes things worse. It is important for people to avoid spending too much time alone and to connect with friends face-to-face if possible. Remind the person you support that they don't have to talk about their traumatic experience – but that if they want to share their feelings about it that you will listen. Support them to do normal activities that don't have anything to do with the traumatic experience. They may also benefit from joining a peer support group.
- **Use known self-regulation strategies.** There are a range of different strategies people can use to self-regulate, which changes the level of their stress hormones, reducing arousal and anxiety. For example, some people like a particular sensory experience, such as listening to music, using a weighted blanket, or petting an animal. Others may like to use relaxation techniques, such as mindful breathing (focusing on how the exhalation of breath feels), yoga, or meditative sitting. Favourite hobbies are also a good way to reduce stress and self-regulate.



DESENSITISATION

Sometimes, a person may develop a fear about a particular medical process. A common example is a fear about needles and having injections. This may be because of a previous experience which was not good, a lack of explanation of what is happening, poor support, or for no identifiable reason. Sometimes the phobia is so extreme, that it is also associated with specific health care professionals, so the person with disability becomes anxious, distressed, and/or aggressive if they see anyone in that role.

It is important to balance the health need against the risk. This means asking how necessary the procedure is versus what the impact will be for the person. It may also mean asking whether the procedure can happen another way, or whether there are any practical steps to minimise the discomfort of the procedure (e.g. using an anaesthetic cream prior to a vaccination). However, there are some procedures which occur on a routine basis and there is no other way to do them. In these instances, desensitisation may be useful.

Desensitisation is a process.⁴¹ The first step is to understand all the fear-inducing factors related to a procedure. This may be related to pain, or previous experience (e.g. from being held down for a procedure, or being yelled at), or some other trigger for anxiety. Some people can develop anticipatory fear over time, which is more generalised and not necessarily directly related to the procedure. For example, the person may anticipate what is going to happen, and be fearful of items associated with the procedure (e.g. latex gloves, alcohol wipes), or even where it happens (e.g. doctor's office). These triggers are then ordered by how anxious they make the person feel, from least to the most stressed.

The second step in desensitisation is to identify things that help the person become calmer and self-regulate the anxiety. For example, a person may become less anxious when listening to music, playing with a specific toy, or even in the company of a particular person.

The third step in desensitisation is to expose the person gradually and repeatedly to factors that cause anxiety over time, while using the anxiety-decreasing strategies identified in the second step. The factors are ordered from the ones that cause the least to the most stress, so those factors lose power to cause anxiety and distress. Depending on the situation, innovation may be required as the real-world scenario can be confronting. Less realistic and play-based activities may be useful, including recreating the scenario using Lego or other toys, role-playing the scenario with people, using video clip examples, social stories, and Easy Read resources. As the person becomes more comfortable at one level of exposure, more realistic props and sounds are added, and more anti-anxiety measures are added. The goal is to keep the person's interest, without scaring them.

Desensitisation should be done with the support of a psychologist or occupational therapist. The process may need time, and very small steps in exposure. For people who have NDIS plans, desensitisation is an appropriate goal to discuss in the planning meeting so sufficient support is resourced for the process.



SECTION 13 - Finding good information

There are many places you can find good information – doctors and other health professionals, the internet, and from friends and family. Trustworthy health information should be evidence based, rather than opinion. It is good to look for information from more than one source and use your judgement about whether the information is accurate. In your role supporting a person with ID, you can help the person to consider whether health information is right for them and understand when something is ‘too good to be true’. Remind them that any changes to health care need to be discussed with their doctor.

INTERNET INFORMATION

There is a lot of information available online, but it can be difficult to determine whether it is reliable and trustworthy. While many websites say they are ‘medical’, some do not provide reliable health information or current health information. It can be difficult to sort out what is likely to be trustworthy, especially when there are names of different organisations that you’ve never heard of before. The person you support may find the following Easy Read fact sheet helpful:

Find Good Health Information Online Easy English Booklet

The following questions can help you choose websites that are trustworthy, as you search for reliable health information:

- **Who hosts the website?**
 - o Sometimes there is a clue in the website name:
 - .com is a commercial website (e.g. business or company that sells a product)
 - .gov in the web address is a government agency, and .gov.au is Australian
 - .edu in the web address is an educational institution (e.g. a university)
 - .org is usually a non-profit organisation (e.g. a professional group, a support group, or an advocacy group).
 - o Sometimes there can be information in an "About Us" page of the website, where you can find out who is running the website (e.g. a board of directors, a panel of experts), and why (e.g. a mission statement).
 - o Can you find contact details for the organisation hosting the website? Is it clear about who the organisation is – or does it talk about unnamed ‘individuals’, ‘groups’, or ‘businesses’? Trustworthy websites will have contact information that you can use to reach the site’s sponsors and authors.
 - o Who funds the website? Is advertising for products clearly labelled, or is it difficult to see the difference between the advertisement and the website content?
- **What is the purpose of the website?**
 - o **Providing information** – how is the information chosen? Is the information reviewed by experts? Where is the information from? Does the website have information about an editorial board or review process? How do they keep information up to date? Is the information from scientific evidence, or is it an opinion or testimonial?
 - o **Providing services** – are the services free? Is the information unbiased, or biased towards the service on offer?
 - o **Providing products** – does the website favour a particular company and its products (which is often the case of a sponsored website)? Is the information biased or unbiased?
 - o **Asking for personal information** – does the website ask you for personal information? Are you comfortable with what information you are being asked to provide, and how it will be used? How is your privacy protected?



WWW.

There is no guarantee that information you find on websites will be accurate and evidence based. However, you can look at different high-quality websites to see if information is similar. Some websites have 'Health on the Net' (HON) Foundation certification, which means the health and medical websites are accountable to basic ethical standards in how information has been presented, how information is sourced (i.e. from trained and qualified professionals), privacy is respected, evidence is provided to support any claims, and financial interests are disclosed. There are several websites containing trustworthy information, and are a good starting point:

- In Australia, try healthdirect.gov.au/
- From the UK, try patient.info/ or evidence.nhs.uk/
- From the US, try medlineplus.gov/
- HON certified websites can be searched from here: hon.ch/HONsearch/Patients/index.html

Using search engines (e.g. Google) is another way to find information if you aren't quite sure what you are looking for, or do not know exactly where to find the information. However, when you type in a few words or a phrase, you will often get thousands of results. The ones first on the list may not necessarily be the best sources of reliable information, as organisations can pay money to have their web page appear higher in search results. Be as specific as possible with your search terms. For example, searching for 'Carer', returns about 1,680,000,000 results; 'Carer support', returns about 124,000,000 results; and 'Carer support Australia', returns about 8,870,000 results. Using quotation marks is another way to limit results further, with "Carer support Australia" returning eight results.

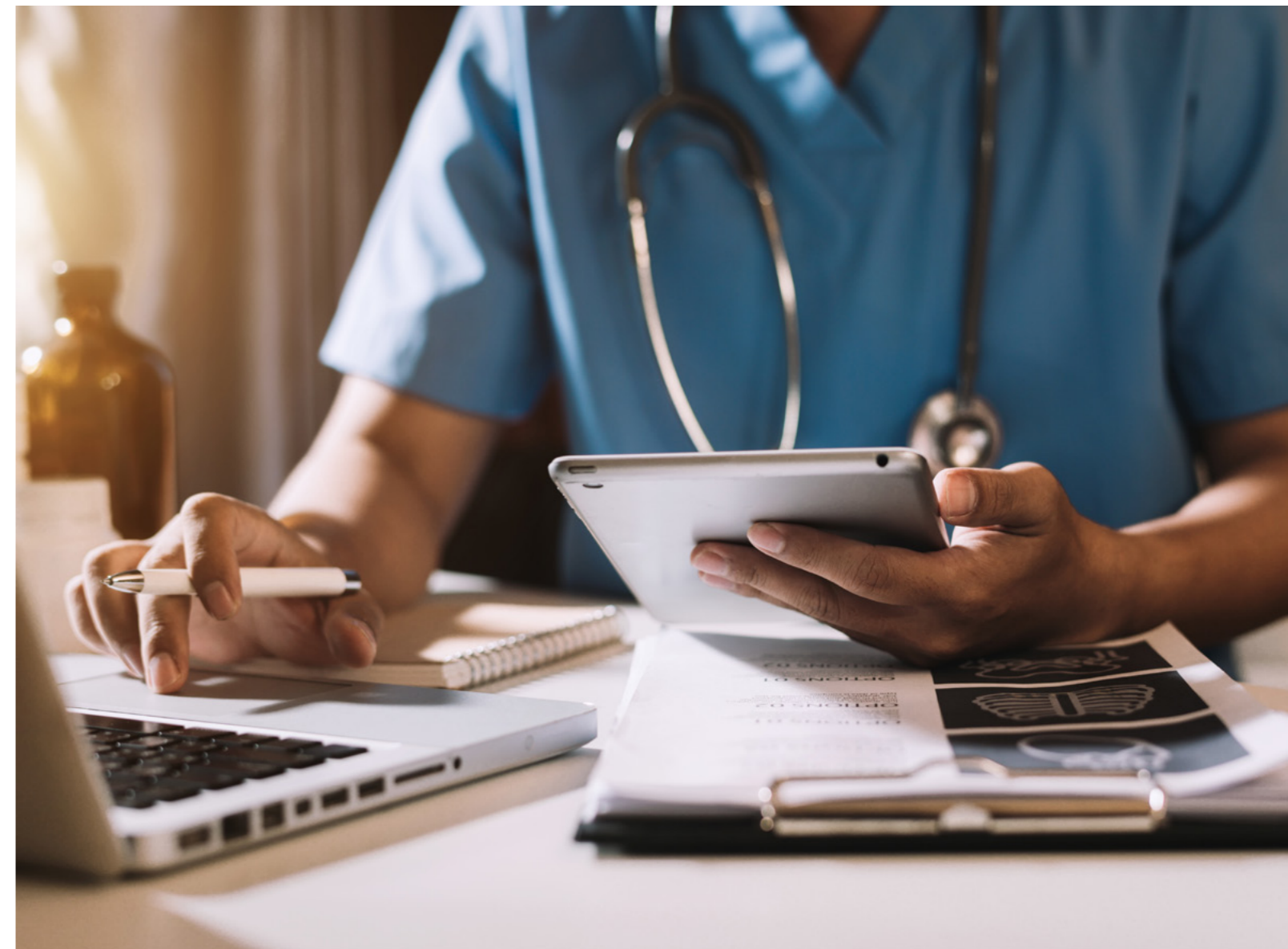
People often find information on social media. It is important to know there is very little safeguarding against misinformation, and you can find both high- and low-quality health information. This means it is important to make a judgement on whether the information is trustworthy. Often, information may be opinion rather than fact, or could be taken out of context. It is important to look for the citation (where the information came from) and try to go back to the original source material for the information if possible. Remember that people will often 'cherry-pick' the information which means selectively using only the information that confirms their opinion, while ignoring any information that contradicts their opinion.

OTHER INFORMATION SOURCES

You can often get brochures and DVDs related to health conditions or treatments. The doctor is a good person to ask about what information sources they recommend. They can often suggest condition-specific organisations who may also have different ways of providing information (e.g. support groups, newsletters, trained educators, or peers). The library is another place to go to, as librarians can help find a range of different information sources.

If the person you support needs Easy Read resources, then many of the UK resources here may be useful:

- <https://www.easyhealth.org.uk/pages/easy-read-health-leaflets-and-films>
- <https://www.mcht.nhs.uk/information-for-patients/patient-leaflets/easy-read-leaflets/>
- <https://www.sth.nhs.uk/patients/patient-information/find-a-leaflet/view-all-easy-read>



PART E

UNDERSTANDING THE HEALTH SYSTEM

Navigating the health system can be difficult. It is useful to know what rights people have, and how the health system is organised. The following sections give an overview of:

- Different aspects of the health system
- How the health and disability systems work together
- How to provide feedback or make a complaint.

SECTION 14 - The Australian Health System

THE AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

People in Australia have health care rights wherever they access health care. Everyone who works in a health service must respect the health care rights of all people who use the health service. However, at times there may be a need for you, in your role of a supporter of someone with disability, to ensure those rights are maintained.

In Australia, a person with ID has the right to:

- **Access** – this means a right to obtain health care services and treatment that meet their needs. Access includes getting good advice from health care providers, having appropriate medical tests, as well as receiving treatment for any health problem.
- **Safety** – a person with ID should receive safe and high-quality health care that meets national standards. They should feel and be safe in the environment where care is being provided.
- **Respect** – everyone should be treated as an individual, with dignity and respect. This also includes having their culture, identity, beliefs, and choices recognised and respected. A person with ID should be treated fairly, and know their needs are important.
- **Partnership** – when accessing health care, people have a right to ask questions and be involved in open and honest communication. Sometimes this may mean that you as a supporter are helping a person with ID decide what questions they want to ask their health care provider or asking questions on their behalf (if they would prefer). A person with ID should be included in the shared decision-making process, meaning they are making decisions with their health care provider should they choose, and are able, to. They can also choose which people they want involved in planning and decision-making.

- **Information** – people with ID should receive clear information about their health condition. This information includes the possible benefits and risks of different tests and treatments, how much it costs, and how long they may need to wait. This information is important so that the person with ID can give informed consent or be supported to be involved in the consent process as much as possible. If a person needs help to understand and use health information, they have a right to be given that assistance. They have a right to access their own health information. They also have a right to be told if something has gone wrong during their health care, how it happened, how it may affect them, and what is being done to make care safe.

Informed consent means that a person knows both the potential good and bad things that might come from the test or treatment, and they get to say yes or no to the test or treatment.

- **Privacy** – health care services must respect the privacy of a person with ID. Any information about them and their health must be kept secure and confidential. This means that as a supporter of someone with ID, you do not have the right to know everything about someone's health unless you have the legal right through medical guardianship.
- **Give feedback** – a person with ID has the right to say what they think about the health service, or someone who works there. They can provide feedback or make a complaint without it affecting the way they are treated. If they make a complaint, health care providers must listen, and address their concerns in a transparent and timely way. Providing feedback and sharing their experience is a way to participate in improving the quality of care and health services.

To support a person with ID to understand their health care rights, an Easy Read version of the Australian Charter of Healthcare Rights can be found here: [**Charter of Healthcare Rights**](#)

HEALTH SECTOR GOVERNANCE

Governance of the health system is important. There are standards health services must meet, set by the Australian Commission on Safety and Quality in Healthcare. This gives consumers or health care services a consistent statement of the level of care that can be expected from health service organisations. The standards most relevant to consumers are:

- **Standard 1** provides a framework for safety and quality, outlining what a safe organisation needs to have in place for their governance structure and processes
- **Standard 2** outlines how health services should partner with consumers. Partnerships need systems in place for them to work effectively
- **Standard 3** is about medication safety, and the processes a health service needs to have in place for safe use of medication
- **Standard 4** is about medication safety, and the processes a health service needs to have in place for safe use of medication
- **Standard 5** has a focus on comprehensive care, and on minimising patient harm
- **Standard 6** is about communicating for safety and supports effective communication between the health service and patients, carers, and families

Other standards (not outlined) focus on specific health service processes relating to preventing and controlling infections, blood management, and recognising and responding to acute deterioration.

More information about the National Safety and Quality Health Service Standards can be found here: **NSQHS Standards**

An Easy Read fact sheet on health care rights from the Council on Intellectual Disability can be found here: **Your Right to Good Health Care**

DISABILITY SECTOR GOVERNANCE

The NDIS Quality and Safeguards Commission is an independent agency from the National Disability Insurance Agency. It was established to improve the quality and safety of NDIS supports and services. It regulates NDIS providers, aiming for consistency across all Australian states. It is also responsible for managing complaints and identifying areas for service improvement.

The Commission is guided by the NDIS Quality and Safeguarding Framework. The objectives of the framework are to ensure that NDIS funded supports:

- Uphold the rights of people with disability, including their rights as consumers
- Facilitate informed decision-making by people with disability
- Are effective in achieving person-centred outcomes for people with disability in ways that support and reflect their preferences and expectations
- Are safe and fit for purpose
- Allow participants to live free from abuse, violence, neglect, and exploitation
- Enable effective monitoring and responses to emerging issues as the NDIS develops.

A BRIEF OVERVIEW OF THE STRUCTURE OF THE AUSTRALIAN HEALTH SYSTEM

The Australian health system can be difficult to understand and navigate. The state and federal governments share responsibility for funding, managing, operating, and regulating many components of the health system. Government, for-profit and not-for-profit organisations are part of the health system, providing various services, including private hospitals, GP clinics or practices, and other community services.

There are different types of services available to support health:

- **Public health services** – are broad, focused on the whole community, and include services like health promotion and disease prevention programs. These services are often called preventative care and include screening and vaccination which occur in the community (e.g. at pharmacies, GP clinics, schools). Healthy lifestyle and health education initiatives may also be run through a range of different community organisations, not necessarily by health care organisations.
- **Primary health care** - generally occurs in the community in a private practice, a community health organisation, or a local government organisation. Many people will access health care from their local GP or nurse practitioner. Pharmacists, dentists, and allied health professionals also provide primary care. Primary health services are broad – they often provide the prevention and screening highlighted above, but also early intervention, treatment, and management of chronic conditions. There are also urgent care clinics which are for urgent, but not life-threatening medical conditions, which have longer opening hours than most GP clinics. Some primary health organisations are for specific population groups (e.g. age-related, refugees, Aboriginal and Torres Strait Islander people), or specific services (e.g. oral health, sexual health, drug, and alcohol services). Ambulance and the Royal Flying Doctor Service are also part of primary health care.
- **Specialist health care** - provides services for specific or complex health issues, and includes services for diagnosing conditions (e.g. imaging, pathology), as well as specialist care (e.g. oncology for cancer treatment, psychiatry for mental health treatment, surgery). Generally, a person needs a referral from another medical practitioner to access specialists.
- **Hospital care** - includes the emergency department, outpatient clinics, as well as health care in the hospital for admitted patients. There are different types of hospitals in Western Australia. Tertiary public hospitals are larger teaching hospitals, providing emergency, general, and specialist health care, with three tertiary hospitals specifically for mental health, obstetric, or paediatric services. General public hospitals are smaller, with varied services, depending on the hospital. Regional hospitals are like general public hospitals, except they also offer emergency services. Specialist hospitals provide specialist services, often with a mental health, aged care, and rehabilitation focus. Private Public partnership hospitals provide a mix of free public and private health services, including emergency, general and specialist care. Private hospitals do not offer free public services but offer a range of specialist care.



HOW HEALTH CARE IS PAID FOR

Medicare is a universal health insurance scheme in Australia, paid for by federal collected taxes and a Medicare levy. This scheme provides access to free hospital services in public hospitals and pays rebates for a range of medical services and procedures provided by medical practitioners in the community. It also provides a range of subsidised prescription medicines, under the Pharmaceuticals Benefit Scheme, at this [link for more detail](#).

For example, a visit to the GP will generally attract a Medicare rebate. While some clinics will 'bulk-bill' so there is no out-of-pocket payment, it is common that an extra 'gap' or 'out-of-pocket' payment will be required, depending on what service was provided by the doctor or nurse at the clinic. The services subsidised by Medicare are listed in the Medicare Benefits Scheme, available online [here](#).

Private health insurance is paid for by consumers. Depending on the type of insurance policy, it may pay for medical and allied health services that are not funded by Medicare. When purchasing a policy, it is important to look carefully at the waiting times that apply (before being covered), what procedures or services are covered and excluded, the amount of co-payment required, and the limit of cover. There are three different types of health insurance:

1. Hospital cover gives someone the right to choose their own doctor and decide whether to be treated at a private or public hospital if their doctor works at both.
2. General treatment (or ancillary) cover provides insurance against the cost of treatment by ancillary health service providers, such as a dentist, optician, or allied health therapist.
3. Ambulance cover provides funding for ambulance services, including an emergency service.

Health care is not the responsibility of the NDIA. However, for some people, their NDIS plan may include limited disability-related health supports purchased using NDIS funding. These supports can include consumables (things that get used), funding for a suitably trained and competent worker to perform specific tasks, the development and review of management plans, and training for a suitably trained and competent worker to implement developed plans. It is important to discuss the need for funding with the NDIS planner during the NDIS plan development, specific to the eight categories of supports, which include:

- Continence
- Diabetic management
- Dysphagia
- Epilepsy
- Nutrition
- Podiatry
- Respiratory
- Wound and pressure care

While the need for health services is often unplanned for acute care when a person is sick or injured, preventative care and management of chronic conditions can often be planned. It is important to consider what level of support a person with disability may need for planned access to health services so this can be adequately funded through a NDIS plan (e.g. requesting additional support worker hours if required to support access to a twice-yearly check-up by a GP).

There is additional assistance for people who are entitled to Centrelink payments (for example, on a Disability Support Pension). A person receiving a Centrelink payment is eligible to have a Health Care Card, which means they are considered concessional patients under the Medicare Safety Net and Pharmaceutical Benefits Scheme Safety Net so will get cheaper medicines and some discounts on services. More information can be found here: [Health Care Card](#)





SECTION 15 - The health care team

Health care is a team effort. There are many different people who will be part of the team, depending on the circumstances. In your role as a supporter, you are a very important part of the team. You may need to be an advocate for a person with ID with different members of the health care team, for different reasons, at different times. You may also need to help manage various health issues for the person you support, as well as provide support for preventative care. The UK's Core Capabilities Framework for Supporting People with a Learning Disability highlights the different ways you can provide health-related supports, and can be found here:

Learning Disability Framework

While the legislation component is based on UK law, other information is relevant to the Australian context. The health care team is often thought of as those who deliver clinical care. These are people like doctors, nurses, pharmacists, dentists, and therapists. However, there are many other roles within the team, such as administrative and support staff (e.g. the receptionist at a clinic), people who provide emotional or spiritual support (e.g. chaplain, counsellor), other staff (e.g. social workers, community health workers), and technicians who may perform tests. For a person with ID, carers and support workers are also key people in the health care team.

ROLES IN THE HEALTH CARE TEAM

The health care team includes people who can support a person to improve health and wellbeing, and to prevent illness, as well as people who provide care when a person needs treatment of some sort. The health care team can be thought of as follows:

- **The individual (and support network)** – has a personal responsibility to be part of the health care team. As a supporter of someone with ID, you can support a person to set health-related goals (e.g. exercise, eating well, moderating alcohol intake), and to manage any health conditions. You can also support a person to find information that meets their needs, so they are able to make informed decisions about their health choices.
- **The primary health care team** – people that a person can see for general health issues or problems.
 - o The General Practitioner (GP) can give health advice, guide preventative care, help manage chronic conditions, treat illness and injuries, provide referrals to specialised health services, and coordinate care across the health care team. It is valuable to find a doctor the person with disability likes and build a relationship over time, so the doctor gets to know them well. Doctors like to see people for annual health checks, vaccinations, and other preventative care because it helps them learn how a person appears when well, which is helpful to them noticing when someone is becoming unwell. Seeing a person more frequently helps the doctor to understand the communication needs of a person, so they can communicate more effectively.
 - o The dentist can provide dental check-ups, provide advice about oral hygiene, treat dental problems, and provide emergency dental care. Oral health is often poor for people with ID, for several reasons. Unrecognised dental problems can cause pain, resulting in changed behaviour if a person has communication difficulties. See the dental care component of Section 2 to find more information about how to support a person's oral health.
 - o The pharmacist (or chemist) can provide advice about medicines, and health conditions that can be treated with over-the-counter medication. For people with a complicated medication regime, the pharmacist can provide Webster packs which help the person take the right dose at the right time. The pharmacist can often help a person manage their scripts, letting them know when they need the doctor to provide a new script.
 - o The nurse practitioner is a Registered Nurse who has additional training and experience so can diagnose and treat people with a variety of health conditions. Nurse practitioners can prescribe most medicines, order diagnostic tests, and refer people to specialists.
 - o Nurses care for people through health and illness. They may have several different responsibilities, including recording medical history and symptoms, monitoring health, administering treatment, performing diagnostic tests, and providing education, support, and advice to people.

- **The second-tier health care team** – these are the people that a person may need to see, depending on their age, and whether they develop specific medical conditions, or need other types of treatment.

o Medical specialists are experts in specific areas of medicine. For example, a person may need to see a surgeon, seeing a specific type depending on their needs (i.e. orthopaedic surgeon for bones, neurosurgeon for brain, and cardiothoracic surgeon for heart/lungs). Other specialists have expertise in different body systems (i.e. haematologist treats conditions that affect the blood, endocrinologist treats conditions caused by hormones, and psychiatrists treat mental health conditions). There are many different types of specialists, and the GP can direct the person to the right one.

o Allied health professionals do a range of different things⁴²:

- **Arts therapists** use visual art-making, drama, dance, and movement to improve physical, mental, and emotional wellbeing.
- **Audiologists** are experts in hearing loss. Regular hearing checks can be important for a person with ID.
- **Chiropractors** diagnose and treat back pain and disorders of the musculoskeletal system. They may provide treatment like manipulation, massage, or provide ergonomic advice.
- **Dietitians** are experts in food and nutrition. They provide advice on diet and nutrition for people who may have health conditions or need help in maintaining a healthy weight.
- **Exercise physiologists** provide clinical exercise programs for people with different health issues. The aim of the exercise is to prevent or manage chronic disease or injury, and assist in restoring a person's optimal physical function, health, or wellness.
- **Genetic counsellors** have specialist understanding of human genetics. They provide information to people about genetic conditions, as well as emotional and practical support to help people adjust to living with, or being at risk of a genetic condition.
- **Medical radiation** includes a range of different disciplines such as radiographer, medical imaging technologist, radiation therapist, or nuclear medicine technologist. They produce medical images that help describe, diagnose, monitor, and treat a person's injury or illness.
- **Music therapist** uses music to support people to improve their health, functioning and wellbeing, depending on the person's individual goals. Music therapists may often help with physical, communication, or cognitive impairments, grief, and loss, or to help pain management.

- **Occupational therapists** promote health and wellbeing by enabling people to participate in everyday life. This might include supporting self-care activities, modifying an activity or environment, and identifying strategies to participate in the community.
- **Optometrists and orthoptists** are experts in eye health. Optometrists are trained to test vision, prescribe glasses, and may also treat a range of eye conditions. Orthoptists are trained in assessment, diagnosis, treatment, and rehabilitation of people with eye disorders.
- **Orthotists and prosthetists** provide orthoses (splints and braces) and prostheses (artificial limbs) to help a person increase mobility and independence.
- **Osteopaths** have a clinical focus on the way the body works in human movement. They provide manual therapy interventions which can include exercise prescription, needling, education, and lifestyle advice to improve a person's movement, reduce pain, and manage or treat a range of physical impairments.
- **Paramedics** can respond to emergencies, and are often the first responder (for example, with the ambulance). Paramedic practitioners have additional skills in primary care and may provide follow-up and ongoing care for people they encounter.
- **Physiotherapists** are experts in the structure of the body and its movement. They treat a range of injuries, musculoskeletal conditions, and chronic health conditions. They are involved in the assessment, diagnosis, planning and management of a person's care.
- **Podiatrists** are experts in foot care. They treat bone and joint disorders and provide general foot care which is important to people with circulatory problems, or who are elderly.
- **Psychologists** are experts in human behaviour, and can help people change the way they think, feel, behave, and react. Psychologists can assess and diagnose a range of problems, and help a person develop skills and strategies to manage their emotions and mental wellbeing. Neuropsychologists are different from a psychologist, as they focus more on neurobehavioural disorders, cognitive processes, and brain disorders.
- **Social workers** support people to make changes in their lives which will improve the person's personal and social wellbeing. The social worker helps a person identify issues that need change and connect the person to different types of support in the community. Social workers may provide counselling, advocacy, and service coordination.
- **Speech pathologists** diagnose and treat communication disorders, which may mean a person has difficulties with speaking, listening, understanding language, reading, and writing, and the skills needed for communicating in social settings. Speech pathologists are experts in supporting people who are unable to communicate verbally and can support the use of augmentative or alternative communication devices. They also help people who have difficulties swallowing food and drink safely.

- o There are other people that may support emotional health and wellbeing. Apart from the allied health professions (e.g. psychologists, occupational therapists, and social workers), counsellors and mental health nurses may also support mental wellbeing. Some people may also want to access support from their chaplain or spiritual leader (e.g. priest, minister, imam, rabbi, etc.).

You may need to explain the different roles to the person you are supporting. Easy Read descriptions of different health care occupations can be found here: [People Who Can Help You](#)



PERSON-CENTRED CARE

The way the health team works together is very important. Person-centred care is the foundation to safe, high-quality health care. It is essential to understand what is important to the person with disability. The team should work with a person in a way that is respectful and develops and maintains trust. The person is included in making decisions and planning their care. Person-centred care is supported by the standards set by the Australian Commission on Safety and Quality in Healthcare (see Health Governance).

Person-centred care is simple – here is a useful acronym to summarise it:

- C** - Communication on a regular and ongoing basis, at a level, and in a language that X can understand. It will enable X to be an active participant in their health and wellbeing. It will empower X to engage in shared decision-making, and informed consent.
- A** - Access to health care that X needs in the right place and at the right time.
- R** - Respect X's values, beliefs and needs in a person-centred manner. That includes carers and support workers.
- E** - Experience health care in a way that leads to health and wellbeing outcomes that X is seeking.

- Debra Letica, 2021

The Australian Commission on Quality and Safety in Healthcare has identified principles of person-centred care. As a supporter, you have an important role in helping these principles work:

- **Respect for patients' preferences and values** – often, a person with ID may not have their preferences respected. In fact, there are many instances when they are excluded from decision-making, as the care team makes assumptions they are not capable or do not mind what happens. A supporter's role is to ensure the person is central to all decisions being made, the person's preferences are known to the care team, and that the person is supported to be part of the decision-making process as much as possible.
- **Emotional support** – through the health care journey there are many times when a person may need emotional support. As a supporter, you may be the one to provide the support. Sometimes you may need to speak up and ask what opportunities there are for additional emotional support (e.g. facilitating access to a chaplain or a counsellor).
- **Physical comfort** – it may be difficult to recognise when a person who has communication difficulties is experiencing physical discomfort. You may understand the signs of the person, and let the care team know if the person is uncomfortable, in pain, becoming more anxious, etc.
- **Information, communication, and education** – everyone has the right to know what is happening to them, with information provided in a way that they understand. As a supporter, you may have a role in explaining to both the person you are supporting, and at times, members of the care team. Keeping calm and open conversation going is very important.
- **Continuity and transition** – a relationship exists between the person and the health care team. Ideally, when relationships develop over time, we are building understanding and knowledge about a person's needs. If there is a need to move to a different doctor/clinic, there is communication about what will happen to the person you are supporting, and effective communication about the situation to the new doctor/clinic. Sometimes there may need to be planning for what is going to happen with the care team.
- **Care coordination** – this is when patient care activities are deliberately organised, and information is shared amongst all the relevant members of the health care team at the right time. There are many care coordination activities you may be involved with, such as monitoring and helping with follow-up care, supporting self-management, and/or communicating and sharing knowledge with the care team.
- **Involvement of carers, family, and friends** – this means you are allowed to support a person on their health care journey, should they want that. It is important to remember you may not necessarily be authorised to access to the person's health information. That is a different process.
- **Access to care** – you may need to support a person to access health care. This may mean you are advocating on their behalf or providing suggestions on how to improve access (if required).

SECTION 16 - Making complaints in the health and disability systems

Sometimes, a person may feel that they did not get the best service or have problems in the way a service was provided. Making a complaint can be good feedback for service providers. At times, it may lead to service improvement.

In the first instance, it is best to raise the complaint directly with the service provider. This is often the best way to have the issue resolved quickly. Registered health and disability providers have complaints systems in place. You can find more information about how to make a complaint directly to the health service from the Health Consumers Council (see hconc.org.au/ for contact details).

If the service provider is not able to resolve your complaint, you can contact:

- the NDIS Quality and Safeguarding Commission if it is about a funded NDIS service
- the WA Health and Disability Services Complaints Office (HaDSCO) if it is about other disability-related services, or health services.

If the complaint is about a health practitioner, HaDSCO is required to consult with the Australian Health Practitioner Regulatory Agency to determine who will manage it. Complaints about discrimination are heard by the Australian Human Rights Commission.

Where to make a complaint

NDIS Quality and Safeguarding Commission: ndiscommission.gov.au/about/complaint

HaDSCO: hadsco.wa.gov.au/Make-a-Complaint

Australian Human Rights Commission: humanrights.gov.au/complaints#main-content

What complaints may be about

The NDIS Commission can take complaints about NDIS services or supports that were not provided in a safe and respectful way or delivered to an appropriate standard. They will also take complaints about how the NDIS provider managed a complaint from a NDIS participant.

The Health and Disability Services (Complaints) Act 1995 identifies the types of complaints that HaDSCO is allowed to accept. These include the following:

- Refusing to provide a service
- Breaching confidentiality
- Providing a service that should not have been provided
- Charging an excessive fee
- The manner of providing a service
- Not effectively dealing with a complaint
- Denying or restricting the person's access to records
- Failing to comply with the Carers Charter, Disability Services Standards or Charter of Mental Health Care Principles.

If a person feels discriminated against because of their disability (or age, gender, or race), they may also make a complaint to the Australian Human Rights Commission.

Who can make a complaint?

A complaint can be made by the person who received the service, a representative or carer, or a provider on behalf of the person that received the service from another provider.

Support to make a complaint

Advocacy support helps people have their voice heard on issues important to them and helps them protect their rights. For people with ID and carers, advocacy support can be provided to support the person throughout the complaint process.

Depending on the circumstances, there are several organisations that are funded to provide individual advocacy. These include:

- People With Disability WA - pwdwa.org/how_we_can_help/individual_advocacy.html
- Health Consumers Council WA - hconc.org.au/individual-advocacy/
- Mental Health Advocacy Service - mhas.wa.gov.au/
- Developmental Disability WA - ddwa.org.au/services/individual-advocacy/
- Kin (formerly Ethnic Disability Advocacy Centre) - kinadvocacy.org.au/
- Explorability - explorability.org.au/

REFERENCES

1. AIHW, Health status and risk factors of Australians with disability 2007-08 and 2011-12. 2016.
2. Weise, J., Pollack A, Britt H, & Trollor JN, Primary health care for people with an intellectual disability: an exploration of consultations, problems identified, and their management in Australia. *Journal of Intellectual Disability Research*, 2017. 61(5): p. 399- 410.
3. Cooper, S., McLean, G, Guthrie, B, McConnachie, A, Mercer, S, Sullivan, F, & Morrison, J, Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice*, 2015. 16.
4. World Health Organisation. Health Promotion Glossary. https://www.who.int/healthpromotion/about/HPR_Glossary_1998.pdf
5. Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. No. AUS 199. Canberra: AIHW.
6. Batterham et al. (2016) Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health*, 132:3-12
7. https://www.eatforhealth.gov.au/sites/default/files/content/n55_australian_dietary_guidelines.pdf
8. <https://www.ebnutritionconsulting.com/portion-size-guide>
9. <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/health/health-risk-factors-and-behaviours>
10. <https://www.health.gov.au/health-topics/physical-activity-and-exercise/physical-activity-and-exercise-guidelines-for-all-australians/for-adults-18-to-64-years>
11. <https://gdhr.wa.gov.au/-/protective-behaviours>
12. https://www.esafety.gov.au/sites/default/files/2020-12/Online_safety_for_young_people_with_intellectual_disability_report.pdf
13. Medicare Benefits Schedule Book (2018), Commonwealth of Australia, ISBN: 978-1-76007-348-0
14. <https://www.healthdirect.gov.au/blood-tests-a-z>
15. <https://www.asha.org/articles/intellectual-disabilities-and-hearing-loss/>
16. <https://www.teeth.org.au/three-tips-to-prevent-tooth-decay>
17. [https://www1.health.gov.au/internet/main/publishing.nsf/content/EEA5B39AA0A63F18CA257BF-0001DAE08/\\$File/Guiding-principles-for-medication-management-in-the-community.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/content/EEA5B39AA0A63F18CA257BF-0001DAE08/$File/Guiding-principles-for-medication-management-in-the-community.pdf)
18. <https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports/disability-related-health-supports-providers>
19. <https://asthmawa.org.au/emergency/>
20. Mental Health First Aid Australia. Considerations when offering mental health first aid to a person with an Intellectual Disability. Melbourne: Mental Health First Aid Australia; 2019. https://mhfa.com.au/sites/default/files/mhfa_id-guidelines_sept_2019.pdf
21. <https://www.healthdirect.gov.au/heart-attack>
22. <https://www.healthdirect.gov.au/stroke>
23. Pain – a guide for parents. <https://cerebra.org.uk/wp-content/uploads/2019/11/pain-Aug19-web-1.pdf>
24. https://palliativecare.org.au/wp-content/uploads/2015/05/PCA002_The-Dying-Process_FA.pdf
25. <https://palliativecare.org.au/publication/standards/>
26. https://acpopc.csp.org.uk/system/files/documents/2021-05/FINAL_Ambitions-for-Palliative-and-End-of-Life-Care_2nd_edition.pdf
27. Foo B, Wiese M, Curryer B, Stancliffe RJ, Wilson NJ, Clayton JM (2021) Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and their death: a thematic analysis of in-depth interviews. *Palliative Medicine*, 35(4): 738-749.
28. <https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>
29. Werner S, Yalon-Chamovitz S, Tenne Rinde M, & Heymann AD (2017) Principles of effective communication with patients who have an intellectual disability among primary care physicians. *Patient Education and Counselling*, 100(7): 134-1321.
30. My Health Care Visit: Understanding Today's Visit and Follow-up. Malhas M, Hermans H, Orr E, Zaretsky L & Lunsky Y. Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019. <https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/>

31. Western Australian Department of Health. Hospital Stay Guideline for Hospitals and Disability Service Organisations. Perth: Health Networks Directorate, Western Australian Department of Health; 2016.
32. <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/communicating-your-healthcare-provider-when-you-are-hospital-information-sheet-consumers>
33. <https://www.acma.gov.au/emergency-calls>
34. <https://www.assistiveware.com/learn-aac/follow-their-lead-how-to-be-a-respectful-communication-partner>
35. https://collaborating4inclusion.org/wp-content/uploads/2019/05/UOS_PrepareNSW_user_guide_FINAL_v2.pdf
36. NDIS Quality and Safeguarding Framework, 2016. https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_framework_final.pdf
37. Sullivan WF & Heng J (2018) Supporting adults with intellectual and developmental disabilities to participate in health care decision-making. *Canadian Family Physician*, 64(S2):S32-S36
38. https://www.aclu.org/sites/default/files/field_document/supported_decision-making_for_supporters_-_pamphlet.pdf
39. <https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/trauma-informed.aspx>
40. <https://www.betterhealth.vic.gov.au/health/healthyliving/workplace-safety-coping-with-a-critical-incident>
41. Levine K (2013) Treating fears and phobias in children with ASD. *Autism Spectrum Quarterly*. Fall issue, 8-10.
42. <https://ahpa.com.au/allied-health-professions/>
43. <https://medication.challengingbehaviour.org.uk/>
44. Sinclair C, Field S, & Blake M (2018) Supported decision-making in aged care: a policy development guideline for aged care providers in Australia. (2nd Edition) Sydney: Cognitive Decline Partnership Centre.

APPENDICES

APPENDIX A Healthy Living Checklist

Note – this checklist was adapted from the Brightwater Healthy Me resource.

To use these checklists, look at the different areas of your life where you might need some extra support. If you tick yes, then you may want to take action. Taking action may mean that you get an appointment to have something checked. Taking action may also mean that you set a goal and change something. You may like to talk about what you can do for each of the different areas with your health professional, carer, or family member.

Ears and Hearing	YES	NO
Do you find it hard to hear when people talk to you?		
Do you hear some things people say but miss other things?		
Do you have trouble hearing when you are in noisy places like a shopping centre?		
Do people who live with you think you have the television or music up too loud?		
If you have a hearing aid, do you have any problems with it?		
Does anyone think you need your hearing checked?		

Eyes and Eyesight	YES	NO
Do you have trouble reading small writing in a magazine, book, or newspaper?		
Was your last eye test more than two years ago?		
If you have glasses, do you have any problems with them?		
Are your eyes dry or itchy a lot of the time?		
Does anyone think you need your eyes checked?		
If you have problems with your vision, do you need more support to enjoy life and be more independent?		

Communication	YES	NO
Do people say it's hard to understand you when you talk?		
Do you need more support to improve how you communicate?		
Do you often feel like you don't understand when people talk to you?		
If you use a communication aid, is it broken or not working properly?		
Do you have problems letting people know when you are sick or in pain?		

Mental health	YES	NO
Do you regularly feel sad or lonely?		
Do you feel like you have no energy most of the time?		
Is something happening that is making you feel worried or scared?		
Do you regularly have trouble sleeping for no reason, or want to sleep all day?		
Do you sometimes see or hear things other people can't see or hear?		
Do you sometimes feel so nervous nothing will calm you down?		
Do other people think you have a mental health problem?		
Has a doctor ever told you that you might have a mental health problem?		
Do you need more support for your mental health?		

Relationships	YES	NO
Are you in a relationship (or possibly starting one) and would like to speak to someone for support of this?		
If this person comes to visit, do you prefer to see them privately in your room?		
Do you have trouble hearing when you are in noisy places like a shopping centre?		
Do you often get very upset about your relationship?		
Do you think there are parts of your relationship which are not good?		
Would you like more support around any worries or concerns you have about your sexuality?		
Do you have enough opportunities to meet new people?		
Would you like more support to look good or with your self-esteem so you feel ready to meet someone?		

Getting Around	YES	NO
If you use a wheelchair or a walker, is it broken or uncomfortable?		
If you have equipment to help you in the kitchen or bathroom, is it broken or uncomfortable?		
Have you been having more falls lately?		
Are you finding it more difficult to do transfers you could do in the past?		
Do you feel confident catching the bus or train?		
Do you have a plan for what to do if you are out in the community and something goes wrong?		
Do you need more support to access the community?		

Chewing and Swallowing	YES	NO
Do you sometimes cough or choke when you are eating?		
Have you had lots of chest infections?		
Does anyone think you have a problem swallowing food or drinks?		
Do you sometimes find food leftover in your mouth after mealtimes?		
Do people tell you to slow down when you are eating or drinking?		
Does your voice sound “gurgly” or wet a lot these days?		

Teeth and gums	YES	NO
Do your gums bleed when you brush your teeth?		
Does your mouth hurt when you eat or drink?		
Do you get mouth ulcers?		
Does anyone think your breath smells bad?		
Do you need to know how to clean your teeth (or dentures) better?		
If you have false teeth, are they comfortable when you chew?		
Does your jaw hurt when you chew?		
Do you grind your teeth?		

Skin and Hair	YES	NO
Do you need more support with a skin condition (like keeping your skin clean and dry)?		
Are you unsure how to check your skin for signs of pressure ulcers?		
Does your head often get itchy, or do you have dandruff?		
Do you take medication that makes you more sensitive to sun and sunburn?		
Do you need to be reminded to move into the shade if you are hot?		
Do you need to be reminded to wear a hat and sunscreen before you go out in the sun?		
Is it more than a year since any moles or spots on your skin have been checked by a doctor?		

Going to the Toilet	YES	NO
Do you think you have constipation (can't do a poo)?		
Do you have accidents when you can't get to the toilet on time?		
Do you have pain or stinging when you pee?		
Do you need to pee a lot more than you used to?		
Does your pee look dark yellow in colour, or smell different to usual?		
Do you have trouble remembering to wash your hands with soap and water after you have gone to the toilet?		

Women's Health	YES	NO
If you are aged 50 or older, you should have a breast examination every two years. Do you need to have a breast examination?		
All women over 25 who have ever had sex should have a cervical screening test every five years. Do you need to have this test?		
Do you want a support person to stay with you and explain what is happening when you go for a breast examination or cervical screening test?		
If you are aged 50 years or older, you should do the bowel screening test every two years. Do you need to do the bowel screening test?		
Are your periods very heavy (lots of blood) and painful?		
Do you need more support to manage your periods?		
If you are aged 45 or over, your periods might be different to before – heavier, lighter, or not as regular. This is called menopause. Do you think you might be going through menopause?		
Does your vagina sting, get itchy, or have a smelly discharge?		
Do you want more advice on safe sex?		
Do you want more advice on contraception?		
Would you prefer to see a female doctor about women's health?		
Do you think you might have a sexually transmitted infection (STI)?		

Men's Health	YES	NO
If you are aged 50 years or older, you should do the bowel screening test every two years. Do you need to do the bowel screening test?		
Have you found it difficult to pee (e.g. trouble starting, or being unable to pee even though you feel you need to, or poor flow)?		
Have you had discomfort when you pee?		
Have you needed to pee frequently or suddenly?		
Have you found blood in your pee or semen?		
Does your penis sting, get itchy, or have a smelly discharge?		
Do you want more advice on safe sex?		
Do you think you might have a sexually transmitted infection (STI)?		

Pain	YES	NO
Do you feel a lot of pain in any part of your body today?		
Do you ever have pain that wakes you up at night?		
If you take medication for pain, do you still feel pain most of the time?		
Is there a position which is more comfortable for you, but people forget to assist you to get into this position?		
Do you need more support to manage pain in your body?		

Diabetes	YES	NO
Do you need more support to work towards being a healthy weight?		
Do you need to pee a lot more than you used to?		
Do you get thirsty a lot?		
If you have diabetes:	YES	NO
Do you need more help to manage it well?		
Do you know the signs of low blood sugar (a 'hypo') and what to do if you feel that way?		
Do you know what food to eat?		

Sleep	YES	NO
Do you go to bed and wake up at different times each day (e.g. not have regular sleep patterns)?		
Do you take medicine to help you go to sleep?		
Is your bedroom uncomfortable (too noisy, too hot/cold, too much light, uncomfortable bed)?		
Do you drink alcohol or tea/coffee before bed?		
Do you nap a lot during the day?		
Do you wake up at night and have a hard time going back to sleep?		
Do you find it difficult to get to sleep?		
Do you find it difficult to wake up and get up in the morning?		
Do you wake up feeling tired, even when you've slept?		
Are you sleeping at night for less than six hours, or more than nine hours?		

APPENDIX B

Medication pathway

(information for caregivers and family of people who are prescribed or may be prescribed psychotropic medication)⁴³

Note: see the link in footnote below for more detailed information about psychotropic medicines.

Psychotropic medication is medicine which affects the mind. They are medicines that are usually given to help with mental health needs and can be very effective in treating mental illness when used appropriately. Sometimes the medicines may be used to manage behaviour that is challenging. It is important that the medicine is used appropriately, as sometimes people can be prescribed too much medicine, or medicine they don't need for their health. This is called over-medication.

There are different types of medicines. The psychotropic class of drugs include antidepressants, antipsychotics, mood stabilisers, stimulants, anti-anxiety, and epilepsy medication. These medicines all need a prescription from the doctor.

People with ID are sometimes prescribed psychotropic medicine without being diagnosed with the mental health problems that the drugs are for. While they are appropriate for some people, it is important to avoid inappropriate medicine because:

- Side effects of psychotropic medicine can have a negative impact on a person's quality of life and health. The person can be at risk of organ failure, and significant weight gain.
- Side effects of psychotropic medicine can be serious and even life-threatening if it is not monitored closely.
- It can be difficult for someone to stop taking psychotropic medicine, especially if they have been taking it for a long time. The medicine can have long-term effects on the body.
- Once psychotropic medicine is prescribed, there can be less motivation to explore alternative solutions, like modifying the person's environment, or Positive Behaviour Support.
- Inappropriate or over-medication is a restrictive practice.

IMPORTANT NOTE: As a caregiver, it is important that you don't stop a person from taking any medicines or changing the dosage without professional medical advice. If you are worried about the medicines being taken, then speak to the person who is responsible for prescribing the medicines as soon as possible and ask for them to be reviewed. You may also like to talk to the person's doctor or pharmacist to let them know about your concerns.

Before a medicine is prescribed, it is good for the person to have the following checks to help decide whether the medicine is the best option. It also helps set a baseline, so it is easier to see if the medicine is beneficial for the person. The checks include:

1. **Physical health check.** This helps identify whether a person's behaviour is caused by them being in physical pain or discomfort. Baseline measures also help identify what side effects are being experienced, and may include blood pressure, weight, blood tests, and even an echocardiogram (ECG) test, depending on the medicine being considered.
2. **Behaviour baseline.** If a person can experience challenging behaviours, then recording the behaviours can help identify whether the medicine is having a positive or negative impact on the behaviours. An example of how behaviours can be recorded can be found here:
Finding the Reasons for Challenging Behaviour
3. **Functional assessment.** This can help identify the causes of challenging behaviour and provide suggestions on how to best respond to the behaviour.
4. **Quality of life measure.** Psychotropic medication can affect a person's quality of life, so it is important to check whether the medicine is making someone sleepy, changing their energy levels, making them gain a lot of weight, or some other change to their life quality. Checking the quality of life again after the medicine has been tried for a period helps you see whether it is making a difference to the person's wellbeing.

In your role supporting a person with ID, you may need to help the person ask questions about the drug that is going to be prescribed. Some of the following questions may be helpful:

- What medicine is being suggested? (Please write down the name of the medication, and the name of the generic version)
- Why is the medicine being suggested?
- What is the diagnosis that has been made, and how was it made?
- What change do you think the medicine will make?
- How will we know if the medicine is working?
- Is this medicine the least restrictive option?
- What are the alternative options to this medicine?
- How long will the medicine be prescribed for?
- What side effects are possible, and how are they monitored?
- What would happen if side effects have a negative impact on the quality of life?
- How often will this medicine be reviewed?
- How will the medicine be reduced and removed if it is not effective? Are there any withdrawal symptoms that caregivers need to know about?
- Where is accurate and clear information about this medicine found?
- Will this medicine interact with another medicine the person is taking?

If the decision has been made that the person is going to try the medicine, there are other questions that may be helpful to ask the doctor:

- What dose will be given? How was this set?
- What options are there for taking the medicine? (Tablet or liquid form)
- When should the medicine be taken?
- What should be done if a dose is missed?
- How often will this medicine be reviewed, and when is the next review date?
- What side effects are important to look for, and how should these be recorded and monitored?
- Who should be contacted if side effects are noticed?
- How long will the person continue taking this medicine?
- If the medicine is not showing to be effective, or if the person has side effects, how will the medicine be stopped, and will there be any withdrawal symptoms to manage?

Medication reviews are important. When antipsychotic medicine is prescribed for challenging behaviour, the effectiveness and side effects of the medicine should be reviewed after three to four weeks. If there has been no improvement after six weeks, the guidance recommends that the medicine should be safely withdrawn, and other options considered. For other psychotropic medicines, if there has been no improvement in three months, then the medicine should be safely withdrawn. Questions a person may like to ask when the medicine is being reviewed include:

- Is the medicine making a positive difference?
 - Is the person experiencing any side effects? If yes, how can these be addressed?
 - What alternative interventions could also be helpful alongside the medication?
 - Is the person finding it easy to take the medicine?
 - Have there been any changes to the person's physical health?
 - Is the medicine needed at all?
 - What is the plan for eventual reduction or withdrawal of the medicine?
-

APPENDIX C

The NEWS2 Scoring System and Thresholds

Chart 1: The NEWS2 scoring system

Physiological Parameter	3	2	1	0	1	2	3
Respiration rate (per minute)	≤ 8		9-11	12-20		21-24	≥25
SpO ₂ Scale 1 (%)	≤91	92-93	94-95	≥96			
SpO ₂ Scale 2 (%)	≤83	84-85	86-87	88-92 ≥93 on air	93-94 on oxygen	95-96 on oxygen	≥97 on oxygen
Air or Oxygen?		Oxygen		Air			
Systolic Blood Pressure (mmHg)	≤90	91-100	101-110	111-219			≥220
Pulse (per minute)	≤40		41-50	51-90	91-110	111-130	≥131
Consciousness				Alert			CVPU
Temperature (°C)	≤35.0		35.1-36.0	36.1-38.0	38.1-39.0	≥39.1	

Chart 2: NEWS2 thresholds and triggers

NEW score	Clinical risk	Response
Aggregate score 0-4	Low	Ward-based response
Red Score Score of 3 in any individual parameter	Low-medium	Urgent ward-based response*
Aggregate score 5-6	Medium	Key threshold for urgent revsponse*
Aggregate score 7 or more	High	Urgent or emergency response**

*Response by a clinician or team with competence in the assessment and treatment of acutely ill patients and in recognising when the escalation of care to a critical care team is appropriate.

**The response team must also include staff with critical care skills, including airway management.

Chart 3: example of NEWS2 chart

	DATE	TIME		DATE	TIME
A+B Respirations Breaths/min	≥25		3	≥25	
	21-24		2	21-24	
	18-20			18-20	
	15-17			15-17	
	12-14			12-14	
	9-11		1	9-11	
≤8		3	≤8		
A+B SpO ₂ Scale 1 Oxygen saturation (%)	≥96			≥96	
	94-95		1	94-95	
	92-93		2	92-93	
	≤91		3	≤91	
SpO₂ Scale 2† Oxygen saturation (%) <small>Use Scale 2 if target range is 88-92%, eg in hypercapnic respiratory failure</small>	≥97 on O ₂		3	≥97 on O ₂	
	95-96 on O ₂		2	95-96 on O ₂	
	93-94 on O ₂		1	93-94 on O ₂	
	≥93 on air			≥93 on air	
	88-92			88-92	
	86-87		1	86-87	
84-85		2	84-85		
≤83%		3	≤83%		
Air or oxygen?	A=Air			A=Air	
	O ₂ L/min Device		2	O ₂ L/min Device	
C Blood pressure mmHg <small>Score uses systolic BP only</small>	≥220		3	≥220	
	201-219			201-219	
	181-200			181-200	
	161-180			161-180	
	141-160			141-160	
	121-140			121-140	
	111-120			111-120	
	101-110		1	101-110	
	91-100		2	91-100	
	81-90			81-90	
	71-80			71-80	
61-70		3	61-70		
51-60			51-60		
≤50			≤50		
C Pulse Beats/min	≥131		3	≥131	
	121-130		2	121-130	
	111-120			111-120	
	101-110		1	101-110	
	91-100			91-100	
	81-90			81-90	
	71-80			71-80	
	61-70			61-70	
	51-60			51-60	
	41-50		1	41-50	
	31-40		3	31-40	
≤30			≤30		
D Consciousness <small>Score for NEW onset of confusion (no score if chronic)</small>	Alert			Alert	
	Confusion			Confusion	
	V		3	V	
	P U			P U	
E Temperature °C	≥39.1°		2	≥39.1°	
	38.1-39.0°		1	38.1-39.0°	
	37.1-38.0°			37.1-38.0°	
	36.1-37.0°			36.1-37.0°	
	35.1-36.0°		1	35.1-36.0°	
≤35.0°		3	≤35.0°		
NEWS TOTAL				TOTAL	
Monitoring frequency				Monitoring	
Escalation of care Y/N				Escalation	
Initials				Initials	

APPENDIX D

Legal Framework for Decision-making

THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The United Nations Convention on the Rights of Persons with Disabilities states that everyone has equal recognition before the law. This means that everyone has the right to make their own decisions. While Australia signed up to this convention in 2008, sometimes policies still do not allow people with ID make their own decisions. The Australian Law Reform Commission identified four important decision-making principles with reference to the United Nations Convention on the Rights of Persons with Disabilities.⁴⁴ The principles are:

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. People who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of people who may require decision-making support must direct decisions that affect their lives.
4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

A rights-based approach to decision-making means that supporters of a person with ID help the person make decisions about their lives and respect their decision. How the decision-making is facilitated depends on the level of support required for decision-making:

- Independent decision-making is when a person makes their own decisions. They do not need any help to decide.
- Supported decision-making is the process of enabling a person to make and communicate decisions about their own life. The decision-making is supported, but the decision is theirs.
- Representative decision-making is when a representative is appointed to make decisions for a person who requires decision-making support. The decision should be directed by the preferences and rights of the person with disability – everything possible should be done to support the person to make their own decision first, but if this is not possible, the decision should be motivated by ‘what the person would have wanted’ rather than ‘what is in the best interests of the person’.

GUARDIANSHIP

A representative is often called a guardian. A guardian can make decisions about where a person should live and who they should live with, who they spend time with or communicate with, and what medical treatment they should receive. Usually, the application is made by someone who knows the person with ID well (e.g. family member, doctor), but is worried they are not able to look after themselves. In WA, the Guardianship and Administration Act 1990 provides for the appointment of guardians to safeguard the best interests of adults with decision-making disabilities (that may be a result of ID). A guardian is appointed by the State Administrative Tribunal when it is satisfied the person is not able to make life decisions that are in their best interests, are incapable of looking after their own health and safety, unable to make reasonable judgements in respect to personal matters, and need oversight, care or control of their own health and safety or for the protection of others. Guardianship will also be considered an option when there is concern that a person is at risk of neglect, exploitation or abuse, or there is unresolved conflict between family members and/or primary care providers about the person’s best interests. When a guardian is appointed in situations of conflict (i.e. disagreement between treating team and supporters or family), it is critically important to ensure the person with disability is still supported to be involved in the decision-making, and not sidelined with their wishes not being respected.

It is important to note that not all people with ID will have a guardian. It is not necessary when informal support arrangements are working well, and the best interests of the person with a decision-making disability are being met. For example, a guardian is not required when a person is able to manage and maintain a reasonable quality of life for themselves, or they are being adequately supported and cared for by others. It is not necessary when there are no personal or family conflicts about the person’s care and support needs, or no major problems or issues that are a threat to a person’s quality of life.

An enduring power of guardianship allows a person to appoint someone or several people they trust as an enduring guardian to make personal, lifestyle and medical treatment decisions when they are unable to make or communicate those decisions for themselves. This style of guardianship plans for the future, when additional decision-making support may be required.

ADVANCE HEALTH DIRECTIVES

Sometimes there is a need to make decisions about something that will happen in the future. An Advance Health Directive (AHD) is a legal document allowing people to make decisions about future treatment should they become sick or injured and not capable of communicating their wishes. It only comes into effect when applied to the treatment required, and the person is not able to make reasoned judgements about decisions at the time. In WA, if people have been judged as not having the capacity to make medical decisions, they may not be able to make an Advance Health Directive. This means it is very important to have a conversation with the person about their wishes so if you need to advocate for them or support their communication, you are clear about their preferences.

There is a hierarchy of treatment decision-making. For non-urgent treatment, if the person has an Advance Health Directive, and it covers the type of treatment required, the health professional needs to follow the directive. If there is no Advance Health Directive, health professionals go to the first person in the decision-making hierarchy who is 18 years or older, has full legal capacity, is reasonably available and willing to make the decision. The hierarchy order is the enduring guardian (with authority), the guardian (with authority), spouse or de facto partner, adult son or daughter, parent, sibling, primary unpaid caregiver, or other person with a close personal relationship. There is a risk a health professional may assume a person with ID is not able to decide for themselves – it is important to advocate for information in an appropriate way and provide decision-making support if required.

When a person needs urgent medical treatment (to save their life, or to prevent them from suffering significant pain or distress), it may not be possible for the health professional to determine whether an Advance Health Directive has been made, or to obtain a treatment decision from someone in the hierarchy. In this case, the health professional is allowed to provide the necessary treatment. In cases when a person needs urgent treatment that the health professional believes is the result of attempted suicide, the health professional can administer the necessary treatment even if there is an Advance Health Directive which does not consent to the treatment, or if the person's guardian, enduring guardian, or person with authority to decide withholds consent.

APPENDIX E

Health passports

Health passports carry information that can be used in different health settings. The following information may be included:

1. Summary of basic personal and health details:
 - Full name, address, date of birth, and language spoken
 - Medicare number, health care card number, pension number, health insurance details
 - Height, weight, blood group, known allergies
 - Current medication, dosages, and how it is taken
 - Contact details of guardian (if relevant)
 - Contact details of General Practitioner and other relevant health professionals
 - Any emergency information
2. Current health care plan (if there is one)
3. Significant health conditions or support needs
 - Chronic conditions (e.g. diabetes, asthma) if relevant
 - Any serious medical issue (and what the doctor needs to know about it) – e.g. previous reaction to a medication
 - Communication barriers, and how a person communicates to let people know what they need or want, or expresses pain
 - Special swallowing or nutrition needs
4. List of previous medications, when they were on the medications, and the effect they had
5. Immunisation status
6. Family health history (e.g. heart disease, stroke, cancers, cholesterol, etc.)
7. An ongoing record of health services visits, including the name of the health professional, what the health issue was, what tests were done, what medications were prescribed, and any instructions from the health professional
8. Annual health reviews and other health assessments or reports

Examples of health passports can be found here:

Canada – About My Health (Surrey Place) – this tool is a worksheet you can use to help a person with ID write information prior to a health care visit. It is useful when seeing a new provider and can be shared in advance. The tool can be found here: ***About My Health New***

Easy Read examples can be found here: ***My Health Passport***

Council for Intellectual Disability ‘My Health Matters Folder’ (available in pdf): ***My Health Matters Folder***

Down Syndrome Association ‘Health Record - about me’ (available in word or pdf): ***Health Toolkit***

Queensland Department of Health ‘Julians Key Health Passport’ (available in pdf): ***Julians Key Health Passport***

For specific appointments: ***My Health Care Visit***

