



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Dementia - Alzheimer's disease



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

Dementia is not a disease in its own right.

Dementia is an umbrella term covering more than 100 different conditions associated with progressive cognitive decline. Alzheimer's disease is the most common form of dementia that affects people with Down's syndrome. People with Down's syndrome can develop other dementias separately or alongside Alzheimer's disease.

Dementia – A common worry

Family-carers and professionals supporting people with Down's syndrome sometimes contact us because they have heard that everyone with Down's syndrome will develop dementia. It is important to be aware of the link between dementia and people with Down's syndrome, but it is certainly not inevitable that everyone with Down's syndrome will develop it. There are a number of physical and psychological conditions that singly, or in combination, can result in symptoms that are similar to those seen in dementia. It is therefore really important to talk through your concerns with the person's GP or someone from the Community Learning Disability Team and ensure that other causes for changes in behaviour and ability are ruled out before dementia is considered as a possibility. This process is often referred to as a "*differential diagnosis*".

Although we have heard of a very small number of cases where people with Down's syndrome have developed dementia very early on in life, if you are noticing changes in a person before the age of 40 years the greater likelihood is that what you are seeing is not as a result of dementia. If you have concerns about the person for whom you care, the first step is to talk to their GP.

What is Alzheimer's disease?

Alzheimer's disease is a type of dementia that gradually destroys brain cells, affecting a person's memory and their ability to learn, make judgments, communicate and carry out basic daily activities. When the brain tissue of someone who had Alzheimer's disease is examined (after they have died), it can be seen that it had abnormal numbers of plaques (clusters of protein fragments that build up between nerve cells) and tangles (dead and dying nerve cells, which are made up of twisted strands of another protein) and the brain size has atrophied (shrunk) considerably. It is these changes in the structure of the brain tissue that leads to the loss of skills.

Is Alzheimer's disease inevitable for people with Down's syndrome?

We all celebrate the fact that people with Down's syndrome are now living much longer. Mean life expectancy for people with Down's syndrome increased from <10 in the early 1900s to a median of 58 by 2011. Wu et al (2011). Alzheimer's disease is not inevitable in people with Down's syndrome, but all people with Down's syndrome are at risk. Many adults with Down's syndrome will not manifest the changes of Alzheimer's disease in their lifetime. Risk increases with each decade of life, at no point does it reach 100%. This is why it is especially important to be careful about assigning a diagnosis of dementia before looking at all other possible causes for why changes are taking place with ageing.

In studies of prevalence of dementia in adults with Down's syndrome, it has been estimated that this rises from 9% of adults with Down's syndrome aged between 40-49 years to 32% of adults aged 50-59 years (Coppus et al, 2006).

Wu J, Morris JK. The population prevalence of Down's syndrome in England and Wales in 2011. *European Journal of Human Genetics*. 2013;21(9):1016-1019. doi:10.1038/ejhg.2012.294.

Coppus, A., Evenhuis, H., Verberne, G. J., Visser, F., Van Gool, P., Eikelenboom, P., et al. (2006). Dementia and mortality in persons with Down's syndrome. *Journal of Intellectual Disability Research*, 50(Pt 10), 768-777

What is the connection between Down's syndrome and Alzheimer's disease?

Down's syndrome occurs when a person has a full or partial third copy of chromosome 21. The higher rates of Alzheimer's disease in people with Down's syndrome were previously thought to be caused by a particular gene on chromosome 21 called APP. Chromosome 21 contains 231 genes, but APP was the prime suspect because it produces amyloid precursor proteins. These are involved in generating amyloid beta proteins, which build up in the brain in Alzheimer's patients.

In a study published in the *Journal Brain* (June 2018) '*Trisomy of human chromosome 21 enhances amyloid- β deposition independently of an extra copy of APP*' researchers found that extra copies of other genes on chromosome 21 increase Alzheimer's-like brain pathology and cognitive impairments in a mouse model of Down's syndrome.

Dr Frances Wiseman, Senior Research Fellow at UCL, and first author of this study, said:

"We've shown for the first time that genes other than APP are playing a role in early-onset Alzheimer's disease in our model of Down's syndrome. Identifying what these genes are, and what pathways are involved in the earliest stages of neurodegeneration, could help us to one day intervene with these pathways to prevent the disease in people with Down's syndrome."

It might not be Alzheimer's disease

Very often someone with Down's syndrome who is showing a deterioration in their abilities will not be developing Alzheimer's disease. It is always important to first discount other reasons behind an individual's decline before Alzheimer's disease is considered as a possibility. This is sometimes referred to as a 'differential diagnosis'.

If you notice a decline in abilities, a loss of skills, changes in personality/behaviour or poor memory and confusion, here are some examples of issues for consideration/investigation:

- **Hearing and vision loss which inhibit social engagement/lead to decline of skills.**
- **Thyroid disorder.**
- **Life changes e.g. reaction to a bereavement, changes in an individual's day service / staff / support, retirement.**
- **Depression.**
- **Menopause.**
- **Side effects of medications / drug interactions.**
- **Urinary infection (if sudden onset of confusion).**
- **Breathing problems during sleep (sleep apnoea)**
- **Vitamin B12 deficiency.**

This is not an exhaustive list.

Since interventions/treatments are available for these issues, it is vitally important to have a full medical assessment at an early stage in order to rule them out. There is further information about differential diagnosis in the 'Assessment and diagnosis' section of this resource.

Is Alzheimer's disease difficult to diagnose in people with Down's syndrome?

Diagnosis of Alzheimer's disease can be made with a high degree of certainty in situations where there is good and reliable information available about how someone has changed and how they are now. Alzheimer's disease can affect a person's cognitive ability (especially their executive function: the ability to break down a task into smaller steps and then sequence these into the correct order). Memory, language and communication skills may also be affected. Whilst a decline in memory or the slow loss of specific abilities may be readily apparent in those without a pre-existing disability, it may be less easily noticed in people with Down's syndrome. There are two main reasons for this. Firstly, unless someone has known that person for some time and has observed the changes, the inability to do something is all too easily put down to his or her learning disability. The crucial question, in the case of an older person with Down's syndrome, is have they been able to do this in the past and now cannot? If so, why has this change occurred? It can be more difficult to track long-term changes in a person with Down's

syndrome who is living in the community due to changes in staff, changes in where an individual is living and a lack of long-term record keeping about the person's skills. Secondly, loss of ability may go unnoticed if the person is leading a life where they are, for example, not expected to take part in household activities or do tasks that require good memory. The fact that someone's memory may have deteriorated would, under these circumstances, go unnoticed.

'Masking' of deterioration can sometimes be an unintended consequence of motivated support staff who seamlessly increase their level of prompting and assistance without recording the fact that the individual is now managing to do less independently than they once were.

The importance of baseline assessments

Alzheimer's disease is suspected when there is a change or a series of changes seen in an individual's function. Thus, in order to observe change effectively, one must first be informed about what the individual was capable of doing at his or her very best. This could be considered the individual's "baseline." The primary importance of having a good description and understanding of an individual's baseline is so it can be used as a basis of comparison if changes are observed as the individual grows older. It is extremely helpful to record baseline information throughout adulthood – noting basic self-care skills, personal achievements, academic and employment milestones, talents, skills and hobbies. A formal baseline assessment can be arranged by a GP or the Community Learning Disability Team (CLDT). Ideally the baseline of an adult with Down's syndrome should be established at around age 30 years with annual reassessments thereafter.

The British Psychological Society issued guidance on baseline assessments in their Division of Clinical Psychology, faculty for People with Intellectual Disabilities publication *"Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia"* April 2015.

Is the progress of Alzheimer's disease different for people with Down's syndrome?

Alzheimer's disease is characterized by a gradual decline that generally progresses through three stages: early, middle and late stage disease. In the general population short-term memory loss is often the first early indicator of the onset of Alzheimer's disease. Research suggests that people with Down's syndrome may exhibit changes in personality and behaviour in the early stages of Alzheimer's disease before memory loss becomes evident.

Often, it is small changes in routine and the person's usual activities of daily life that indicate the possible onset of Alzheimer's disease. Alzheimer's disease in people with Down's syndrome may be associated with the onset of seizures for the first time in that person's life.

The time course of Alzheimer's disease in people with Down's syndrome has been reported to be more rapid than in the general population. Whether this is the case or not is uncertain as it may be a manifestation of the difficulties and delay in making an early diagnosis. By the time the diagnosis is made the dementia may already be advanced.

The later course of Alzheimer's disease in people with Down's syndrome appears to be very similar to the general population.

In people with Down's syndrome, the course of Alzheimer's disease is usually as follows:

Stage 1

Changes in behaviour and personality, such as unexplained and uncharacteristic stubbornness, changeable moods, oddities in behaviour, together with subtle evidence of deterioration in memory for recent events and deterioration in general mental functioning, often together with changes in behaviour and personality. These would be noticeable changes in the individual's usual pattern of behaviour and additional to particular traits that might always have been part of the individual's personality.

Stage 2

Obvious deterioration in memory and evidence for a significant deterioration in general mental functioning, specifically in the areas of ability and communication. Inability to spontaneously recognise familiar people. Onset of problems such as incontinence and evidence of obvious disorientation and confusion.

Stage 3

Complete loss of self-care, living skills, and ability to communicate effectively, leading to the need for 24-hour care and help with all basic aspects of day-to-day life such as eating, drinking and swallowing, use of the toilet, hygiene etc. Inability to recognise familiar people or surroundings.

Getting a diagnosis

It is often the individual's family and/or paid carers that will invariably be the people who first observe changes. This should trigger an assessment, initially by the GP and, if necessary, through a referral to a local specialist service. The diagnosis of dementia, and specifically of Alzheimer's disease, depends on the following:

- Evidence of a pattern of change in personality and general functioning that is characteristic of dementia, such as evidence of a deterioration in memory, general mental functioning, living skills, and personality.
- The exclusion, through a detailed history, clinical examination, and the undertaking of appropriate investigations, of other causes of dementia or of other disorders that might mimic dementia (differential diagnosis).

Assessments

The diagnosis of dementia and the exclusion of those disorders that might mimic dementia depend upon a detailed description of what has been observed by those that know the person well and also a full medical and psychological assessment of the person themselves.

Information from those closest to the person

People who are developing dementia may be able to describe some of the changes that have occurred to them (such as an awareness of memory loss), but many may not be able to remember sufficient details about exactly what has happened over time. This may particularly be the case for people with learning disability and dementia. Information from someone who has known the person with Down's syndrome, ideally for a number of years, is therefore very important. If the person with Down's syndrome is no longer able to describe for themselves what they were able to do in the past, the observations of someone who knows them will be the main source of that information. Sometimes information in life-story books or from other sources can help supplement the observations of others. You can see an example of a life-story book at the following link:

<http://www.bild.org.uk/our-services/books/communication-is-a-human-right/life-story-books/>

When determining whether the changes observed in the person with Down's syndrome might be due to dementia or to any other illness the clinician undertaking the assessment will want to know about whether deterioration or change of any sort has been observed in the following areas:

- **Memory**
- **General cognitive functioning**
- **Specific abilities and living skills**
- **Personality**
- **Mood and general behaviour**
- **General physical health**
- **The person's living and family circumstances**

Assessment of the person with Down's syndrome

The following broad areas of assessment are required:

- The person's own description of any changes in their mood and general well-being and physical state.
- An assessment of his/her cognitive abilities (such as memory) using an established neuropsychological test developed for assessing those suspected as having developed dementia which is deemed appropriate for people with a learning disability (e.g., CAMDEX-DS and DSQIID are the most commonly used in community settings.)

- Physical examination

Investigations

The exact investigations arranged will be guided by the results of the above assessments but may include:

- A blood test to check thyroid function, to rule out conditions such as anaemia or problems with kidney or liver function, or vitamin B12 deficiency, which in rare cases can cause a dementia-like illness;
- Vision and hearing assessments if sensory impairments are suspected;
- MRI or CT brain scan if there is uncertainty about whether the changes are due to dementia, or if the emerging picture is unusual, or suggests the very rare possibility of some other brain problem that might explain the observed changes (e.g., brain tumour).

Given the types of changes described earlier, these are the main problems that should be considered. This is referred to as the differential diagnosis. 'Differential diagnosis' of behavioural and functional change in later life in people with Down's syndrome.

- Depression
- Under-active thyroid gland (hypothyroidism)
- Sensory impairments (visual and hearing loss)
- Impact of major life events such as bereavement
- Other rare illnesses
- An investigation of medications the individual takes to check for possible side effects or interactions that might cause symptoms similar to onset of dementia.

The process that ultimately leads to a diagnosis of Alzheimer's disease and what happens next is illustrated on the next page:

Changes reported by a person with DS or observed by family/carers that cause concern



Contact with GP for assessment and screening for other possible causes for the observed changes. (For example vision and hearing assessment, blood test to exclude thyroid disorder, etc.). Comparison of any assessment data against baseline data (where this exists)



Referral to local Community Learning Disability Team (CLDT) (or to other specialist services) if diagnosis is uncertain or if advice is needed with respect to future support and treatment. Detailed history from someone who knows the person with DS and cognitive assessments of that person, further assessments and investigations, such as a brain scan or blood test, to exclude other possible explanations for the observed changes.



If the diagnosis of Alzheimer's disease is made, the possible use of 'anti-dementia' medication and the development of appropriate support to minimize the impact of the loss of skills, etc. and to maximise the person's quality of life.

Supporting a person with Down's syndrome and dementia

Support should be based around minimising the impact of increasing impairments and maximising the quality of life of the person during the course of their illness. The key to effective support of a person with Down's syndrome who has dementia is understanding both the person and the disease enough to be able to anticipate his/her difficulties. For example, if the person's memory is deteriorating, then this might be compensated for in various ways, such as sensitively and regularly reminding the person who you are and where he/she is. Gesture, signing, and pictures, in addition to using spoken language, may improve the person's understanding and communication thereby helping him/her participate and in turn reduce any anxiety he/she might experience because of his/her confusion and inability to understand.

What often comes up in our dementia training sessions (further information towards the end of this resource) is how to support the individual in the early stages of dementia and explain to them about the changes they may be experiencing. We are also asked about resources to help explain to the person's friends what is happening.

BILD has produced the following easy read resources:

About dementia for people with learning disabilities

About my friend: for friends of people with Down's syndrome and dementia

The journey of life: how people change from babies to older people

<http://www.bild.org.uk/our-services/books/health-and-wellbeing/about-dementia/>

The Alzheimer's Society and BILD have produced the following easy read resource:

What is dementia?

https://www.alzheimers.org.uk/info/20111/publications_about_dementia/772/easy_read_factsheet_what_is_dementia

Medication

As yet there are no treatments that reverse or significantly arrest the plaque and tangle formation and the brain atrophy that cause Alzheimer's disease. Treatment is therefore aimed at slowing down the progression of the brain deterioration. There are now medications that can bring temporary benefits in terms of some improvement in functioning and slowing of the deterioration.

Until relatively recently there has been very little clinical research exploring the effectiveness and safety of these medications in people with Down's syndrome. Some of the research studies carried out used small sample sizes and/or there were problems in the way the studies were designed and carried out. This meant it was difficult to draw conclusions about the use of these medications in people with Down's syndrome.

The results of a research study, led by Professor André Strydom (King's College London), published in the *British Journal of Psychiatry* (2018) show that people with Down's syndrome who develop dementia can benefit from drugs commonly used to treat the condition. The study, which was not a clinical trial, is nonetheless the largest investigation into the clinical effect of drugs used to treat dementia in people with Down's syndrome. The researchers found that people who had been prescribed anti-cholinesterase inhibitors or memantine after a diagnosis of dementia may live longer and demonstrated a slower rate of decline than people who did not take the drugs.

Professor Strydom said "Our results are good news for individuals with Down's syndrome and their caregivers, but it also suggests that having Down's syndrome should not be a barrier to treatment with drugs for dementia. More needs to be done to ensure all individuals with Down's syndrome who have dementia are considered for treatment".

The researchers analysed a cohort of over a thousand people with Down's syndrome who were regularly assessed and followed-up. Those with dementia who were treated with anti-dementia drugs lived on average 5.59 years after diagnosis, whereas those who were not given drug treatment lived for an average of 3.45 years. The researchers also

observed a positive effect on maintaining cognitive function (memory and orientation) in people who were prescribed the drugs. However, the data also showed that there were significant differences in the proportions of people with Down's syndrome and dementia receiving these drugs across different regions of the country.

The DSA advocates for equality of access to medication that may slow the progression of dementia and no person with Down's syndrome should experience less favourable prescribing terms because of their learning disability. As with all medications there is always a balance to be struck between the potential for side effects and the likelihood of benefit. Careful use of medications, usually starting at lower than normal doses, can be justified.

General physical and mental health

Dementia usually develops at a time in a person's life when they are also at risk of other physical and mental disorders. The occurrence of such disorders will compound any difficulties that are a consequence of the person's dementia. In addition, the presence of dementia itself (particularly in the advanced stages) may result in poor physical health due to poor fluid and food intake, or the risk of urinary and chest infections. Regular reviews of both physical and mental health are therefore essential.

In the early stages of dementia it is frequently the case that individuals experience depression, as they recognise that they are losing skills or finding tasks more difficult (people with Down's syndrome being no different from other people in this regard). Appropriate support and interventions should be provided to help the person develop suitable coping strategies and have opportunities to talk about their feelings.

Keeping as healthy as possible helps to minimise the impact of dementia. Infections (such as urinary or chest infections) can cause the person in the early stages of dementia to get even more confused. A sudden deterioration in the person's general mental state should therefore raise the possibility that they have acquired a physical illness. Similarly, the use of certain medications (such as sedatives or for the treatment, for example, of heart problems) may be associated with increased states of confusion when a person has the additional problem of dementia. Thus, all medication must be used with caution and regularly reviewed.

Changes to the living environment

People with dementia have increasing difficulties remembering new information. What happened yesterday or first thing that morning, who people are or where he/she lives, may all be a mystery to the person with dementia. It is memory that gives structure and meaning to our lives and without it, or if it is patchy, the world becomes confusing and frightening. For this reason, in general, people with dementia are best supported in places where they have lived for some time and supported by people who would be familiar to them. This of course may not always be possible.

The environment is not only important because of the person's deteriorating memory, but also because of other problems that arise. Confusion is often worse at night because people cannot use visual clues to help orientate themselves – so lighting is important. The type of carpet, whether doors to rooms are easily distinguished from one another

and whether electrical and other appliances are safe are all important questions. These issues are summarised below:

- Are there any physical or other hazards in the kitchen, bedroom or other rooms that require changes to be made? Perception of depth is often a function that is affected early in the development of dementia and so a person may be uneasy or distressed by changes in floor coverings or by shiny or patterned flooring. Neutral and matt floor coverings may be much more suitable.
- Are there changes that can help the individual to remain orientated in the living space and recognise his/her room, the toilet etc.?
- Can lighting and safety be improved at night-time?
- Are the living and other relevant environments reviewed regularly in the light of the person's changing needs?

Mental Capacity Act (MCA) (2005) and Code of Practice

This law, which applies in England and Wales, sets out what should happen if someone is unable to make a decision for themselves. Its purpose is:

- To support individuals to make their own decisions wherever possible
- To protect those who cannot.

The Act is supported by a Code of Practice with specific guidance for professionals (e.g. social care, health, paid carers) who work with people who lack capacity. It is important for family carers to be aware of what the Code says.

The Act has five key principles to guide carers who have concerns over someone's capacity to make a decision:

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.
- People must have support to help them make their own decisions. This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability. Types of support could include using a different form of communication, providing information in different formats (photographs, drawings, tapes) or having a structured programme to improve a person's capacity to make particular decisions (e.g. a healthy eating programme)
- People have the right to make decisions others might think are unwise - it does not mean they lack capacity. They may need further support to help them understand the consequences of their decision.
- It is important that any decision made on behalf of someone is made in their 'best interests' and that the person themselves and those who know them best are involved in the decision-making.
- A person making a decision on behalf of someone must always ask themselves if there is another option that would interfere less with the person's rights and freedoms.

There is further information about making every day financial, health and welfare decisions post 16 years old at the 'families and carers' section of our website

If you would prefer a hard copy of this information, please call our Helpline 0333 1212 300.

Where should people with Down's syndrome and Alzheimer's disease live?

Preferred option: 'Staying at home' where the person can stay where they are currently living with appropriate supports adapted and provided. This means that the person stays with what is familiar in their long-term memory.

Compromise option: 'Moving to more specialist learning disability provision' where the person has had to move from their current home, but moves into provision supported by learning disabilities services.

Least preferred option: 'Referral out of learning disability services' where the person will be moved to services for older people, either residential or nursing.

By staying where they are, the person will stay with familiar people (family, peers, and familiar carers or friends that they have shared supported living with for some time) and in an environment that they know. Although their needs will change as the dementia progresses, every effort should be made to maintain their home life. This may necessitate environmental changes and adaptations to support the person, increases in staffing levels and careful thinking about the supports required.

Sources of support

GP

Your GP will probably be, certainly initially after diagnosis of dementia has been made, your main source of information and support. Your GP can make referrals for you to social services, other relevant health services and local support/information services. If you are being cared for at home or in a care facility, it is the GP who will overall responsibility for your care. Generic support for individuals experiencing dementia and their family carers differs widely from one location to another, but ask your GP for a referral or list of providers of support in your area, this will include provision from the voluntary sector. In most areas, Dementia Support Workers, affiliated to The Alzheimer's Society <https://www.alzheimers.org.uk/> can advise on what is available in a given location.

Community Learning Disability Team (CLDT)

CLDTs have been set up to serve the particular health needs of people with a learning disability and their family members, family carers and paid staff. CLDTs vary in size and make up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist. If you are not already involved with your CLDT, you can discuss with your GP whether or not a referral to the local CLDT is appropriate. Some CLDTs take direct referrals from people with learning disabilities, their families or paid supporters, thus cutting out the need to ask your GP to make a referral. You can find your local CLDT by searching online.

NHS continuing healthcare funding

It may be possible to obtain funding from the NHS for your care package (to cover health and social care needs) if you have dementia and your care needs are mainly related to your health. You can ask for funding if you live in your own home or in a care home. Your GP, nurse or social worker will carry out an initial checklist assessment to ascertain whether or not you meet the criteria for a full assessment from a multidisciplinary team of healthcare professionals. Your eligibility for NHS funding will depend on your assessed needs. Having a multidisciplinary assessment is not a guarantee that you will receive NHS funding.

There is information about NHS continuing healthcare at the link below:

<https://www.nhs.uk/conditions/social-care-and-support/nhs-continuing-care/>

If the person for whom you care qualifies for NHS funding, you can ask for the funding in the form of a personal health budget. A personal health budget is an amount of money to support your health and wellbeing needs, which is planned and agreed between you (or someone who represents you), and your local NHS team.

Admiral Nurses

In some parts of the UK, the NHS provides Admiral Nurses in partnership with the charity DementiaUK. Admiral Nurses are specialist dementia nurses who give expert practical, clinical and emotional support to families living with dementia. In addition to face-to-face support in some parts of the UK, DementiaUK also operate a Helpline staffed by Admiral Nurses. Helpline staff can provide one-to-one support, practical solutions and guidance.

Helpline: 0800 888 6678

Email: helpline@dementiauk.org

Website: <https://www.dementiauk.org/>

Palliative Care Team

Palliative care teams are made up of different health professionals and they can co-ordinate the care of people with an incurable illness.

In many areas individuals with dementia can access excellent support (including 'hospice at home' care) from their palliative care team. Palliative care services may be provided by the NHS, a local hospice or by a charity.

Further information about palliative care for people with a learning disability can be found at the website of the 'Palliative Care for People with Learning Disabilities' (PCPLD) Network website.

<http://www.pcpld.org/>

PCPLD and NHS England produced a guide 'Delivering high quality end of life care for people who have a learning disability – Resources and tips for commissioners, service providers and health and social care staff' (2017). Available to download at the link below:

<https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>

Social Care

The first step to getting additional day to day support for the person for whom you care is to ask your local authority to carry out a needs assessment. In addition, if you are an unpaid carer, you can ask your local authority for a carers assessment of your needs. Your GP can organise these assessments on your behalf if you wish.

There are factsheets about asking and preparing for these assessments at the 'families and carers' section of our website under 'day to day support for adults'.

If you would prefer hard copies of any of the factsheets, please call us Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk

Our Helpline team (Tel: 0333 1212 300 or email info@downs-syndrome.org.uk) can answer any questions you have about social care.

Research

There is a lot of research taking place in to the link between Down's syndrome and Alzheimer's disease. There are two major hubs in the UK carrying out research in this area:

London Down Syndrome Consortium

A multidisciplinary team of clinicians, human geneticists, developmental psychologists, mouse geneticists, psychiatrists and cellular scientists. The project aims to explore the cognitive, genetic and cellular factors underlying individual differences in susceptibility to Alzheimer's disease.

Website: <http://www.ucl.ac.uk/london-down-syndrome-consortium>

Email: downsyndrome@ucl.ac.uk

Cambridge Intellectual & Developmental Disabilities Research Group – Dementia in Down's syndrome

The long term objective of this research group is to understand why people with Down's syndrome are at risk for Alzheimer's disease so that safe treatments can be developed. They hope that their research will inform a clinical trial, so that scientists can find a drug to prevent this type of dementia from developing in people with Down's syndrome, and in the general population.

Website: <http://www.psychiatry.cam.ac.uk/ciddrg/research/dementia-in-downs-syndrome-dids/>

Email: dh-admin@medschl.cam.ac.uk

The Dementia Action Alliance

The Alliance is a network of organisations, partly funded by Public Health England, whose aim is to connect, share best practice and take action on dementia.

We are working with the Alliance and Public Health England to make sure that the needs of adults with Down's syndrome who are **ageing** are better understood.

For further information about the Alliance go to <http://www.dementiaaction.org.uk/>

University of South Wales

In 2017 Dr Stuart Todd carried out research (not written up at the time this resource was updated) looking at end of life care for people with a learning disability '*Hidden lives and deaths: the last months of life of older people with learning disabilities living in long term care settings for older people in England and Wales*'.

The study aims to identify the characteristics of people with learning disabilities living in generic long term care settings and their end of life care needs. Initial findings indicate that there is a hidden group of people with a learning disability who may experience the end of their lives in generic, long term care homes. In order to improve care in these areas, the needs of people with a learning disability and the needs of those who support them, in this care sector need to be highlighted. These settings may be providing a substantial level of end of life care to this population but we seldom think about their needs or the expertise they might have developed.

How we can help

Helpline

You can call our Helpline team Tel 0333 1212 300 or email us info@downs-syndrome.org.uk if you have any questions about people with Down's syndrome and Alzheimer's disease

Training

We offer a one-day course for health and social care staff involved in assessing and providing for the care-needs of adults with Down's syndrome who have a diagnosis of dementia or work in services where they may attend. We work in partnership with service providers or support groups to organise a day at a venue and date of your choice. We also offer a bespoke training service whereby we can provide a training package to meet your specific needs. For further information please see our website <https://www.downs-syndrome.org.uk/about/training/> You can also call our training team Tel: 0333 1212 300 or email using training@downs-syndrome.org.uk

Benefits

You can call Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk to find out if the person for whom you care is receiving the benefits they are entitled to. If you call us, please ask to speak to a benefits adviser.

DSA Resources

Ageing and its Consequences – A Guide for Parents and Carers

This resource can be found at the health and wellbeing section of our website <https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/>

If you would prefer hard copy of this resource please call us Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk

Other resources

Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia (Royal College of Psychiatrists and British Psychological Society)

http://www.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf

NICE guideline on Dementia: assessment, management and support for people living with dementia and their carers (2018)

<https://www.nice.org.uk/guidance/ng97>

Making reasonable adjustments to dementia services to enable fair access for people who have a learning disability

<https://www.gov.uk/government/publications/people-with-dementia-and-learning-disabilities-reasonable-adjustments>

Supporting Derek – A practice development guide to support staff working with people who have a learning difficulty and dementia

<https://www.pavpub.com/supporting-derek/>

The training film which accompanies this guide may be found at www.youtube.com

Macintyre dementia project

The Macintyre dementia project has made some videos about dementia and people with learning disabilities. The videos look at the impact dementia has on people's emotions and how family, friends and staff can support someone with dementia.

<http://www.macintyrecharity.org/the-emotional-impact-of-dementia-on-everyone/>

Reviewed and updated 2018 by Stuart Mills (DSA Information Officer)

Publication date 2013

Acknowledgement to Professor Tony Holland, Health Foundation Chair in Learning Disabilities, Section of Developmental Psychiatry, University of Cambridge as the original author this resource.

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

Down's Syndrome Association

National Office

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

t. 0333 1212 300

e. wales@downs-syndrome.org.uk

Northern Ireland

Unit 2, Marlborough House,
348 Lisburn Road,
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. enquiriesni@downs-syndrome.org.uk



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of Marcel Jancovic on www.shutterstock.com.



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



© Down's Syndrome Association 2018