



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Bereavement



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

Myths

- People with Down's syndrome do not recognise or understand death
- People with Down's syndrome do not experience grief

Facts

The loss of a loved one is one of life's most stressful events. When someone close to you dies, you experience bereavement, which literally means to be deprived by death. For example, you may experience deep and lasting sorrow at the loss of a family member, a friend or carer or a pet. You are in grief.

People with Down's syndrome may be denied the opportunity to grieve because other people mistakenly assume that they don't have the capacity to understand about death or to feel real sadness.

As the life expectancy of people with Down's syndrome has increased many more are experiencing the death of their friends and parents. When they are bereaved, their emotional and physical reactions to the loss are sometimes misunderstood or denied.

People respond to bereavement and express their grief in many different ways. Usually there is a process of working through their feelings, coming to terms with the loss and adjusting to life without their loved one. The grieving process for those with Down's syndrome may however take longer and may show itself in ways that are not instantly recognisable. They will probably need support to work through the process.

Routines can be important to people with Down's syndrome in that they provide a sense of order and structure to their lives. As well as dealing with the grief of the loss of someone close, some people may also have to cope with significant and unsettling change to their routines.

Before the passing of the Mental Capacity Act (MCA) 2005 (England and Wales) people with Down's syndrome might have found themselves in situations where, after the death of a loved one, other people were making decisions that affected their lives. We hope that since the passing of the MCA people with Down's syndrome are being supported to make decisions about their own lives as a matter of course. According to the law anyone aged 16 years or over must be assumed to have capacity to make decisions for themselves. The law says a person must be given relevant information in an appropriate format and time to understand it before a decision on their capacity is made. There is

information about making every day financial, health and welfare decisions post 16 at our website (families and carers section).

Common responses to grief

Everyone reacts differently to grief, but most people experience at least some of the common responses to bereavement. These are summarised below:

An initial sense of shock, numbness, disbelief and denial accompanied by one or more physical symptoms such as lack of energy, trouble in concentrating, remembering and making decisions, hyperactivity, thinking about wanting to die and a sense of unreality.

As the early shock wears off and the impact of the reality of the death is felt, people may experience the following reactions:

Emotional: Anger with the deceased or with those who it is believed could have prevented the loss, guilt, anxiety, fear, panic, depression, despair, mood swings, irritability, crying, sadness, yearning and pining, a sense of being abandoned.

Physical: Symptoms such as pain, appetite disturbance, breathlessness and illness. People with Down's syndrome, who are less able to express themselves verbally, may experience and exhibit increased physical symptoms of grief.

Behavioural: Low vitality, more than usual need for sleep, sleeplessness, hyperactivity, withdrawal and a lack of interest in normal activities.

Mental: Confusion, hallucinations, nightmares, searching for the deceased, poor concentration, regression, loss of skills and insecurity.

Resolution of grief occurs when the bereaved is able to think of the deceased without pain or anger and can recall the times they had together in a positive way. The journey towards resolution of grief is not always a continuous or direct one. It is also a journey that may take a considerable period of time.

It is important to note that not everyone will experience all of the symptoms detailed above.

Depression

Sometimes grief can continue into depression and this may well show itself, in someone with Down's syndrome, in unexpected forms. Although depression sometimes strikes out of the blue, it is often triggered by some type of unhappy event such as bereavement. These unhappy events affect most people with Down's syndrome at some stage of their lives. However, not everyone will get depressed.

Sometimes one loss can then lead on to other major changes that may result in depression. For example, we have heard of cases where parents have died and their adult son or daughter has been immediately moved to emergency residential care. In moving, they have experienced the loss of their home, their familiar possessions and routines, as well as their parent and carer. Sometimes a more serious and persistent depression develops. This is a particular risk for people with Down's syndrome because

carers often miss the early signs of depression. The time to get help is when any changes in behaviour, withdrawal or gloom persist for a lengthy period of time. You should then seek professional help.

See also the DSA's Health Series resource on Depression.

Common features of grief in people with Down's syndrome

Some people with Down's syndrome will experience a delayed response to grief; this can be up to six months or more after their loss. It may be that some people with Down's syndrome struggle, and therefore take longer, to understand the finality of death and their own thoughts and feelings.

"Interestingly, some of our patients have not initially appeared to grieve after a significant loss such as a parent. Later after another loss – often one that seems less significant – the person will experience and express the grief that he did not with the first and more significant loss."

The Guide to Good Health for Teens & Adults with Down Syndrome – Chicoine and McGuire (Woodbine House, 2010)

The grieving process in people with Down's syndrome may be complicated by difference in how time is perceived along with the presence of a strong visual memory.

Even though T's mother died over ten years ago, T often speaks about her mother's death in very current and immediate terms. To an outside observer it would appear as if T is vividly experiencing the loss of her mother. People who do not know T very well have assumed that the loss of her mother is a recent occurrence.

Helping the person with Down's syndrome through the process of bereavement

Always give the news of a death with honesty and at a pace suited to the person. The news of a death should not be kept from a person in an attempt to protect him or her.

Always use straightforward language in order to avoid misinterpretation. The use of terms such as 'death' and 'died' are preferable to terms such as 'passed on' or 'gone to sleep'. Visual aids such as pictures or drawings and easy read written materials will help.

The person should be given the choice as to whether or not they wish to take part in the rituals associated with death, such as attending a funeral. If the person is unable to

choose directly, it is advisable to involve them as fully as possible. Involvement in non-verbal rituals may be particularly helpful for someone with Down's syndrome.

It is important to allow the bereaved person to have the opportunity to choose mementoes by which to remember the deceased person and to act as a focus for their feelings.

Avoid major change at this confusing and distressing time. The person may find it comforting to take refuge in their daily routines and familiar surroundings. Helping them to maintain some continuity and connection with life before the bereavement is essential to recovery.

Always give the person space and time in which to express their feelings. If the deceased is a family member, it may be helpful to create opportunities for the person with Down's syndrome to communicate their feelings to someone outside of the family. Your local Community Learning Disability Team may be able to offer advice and support (see below).

Remember that everyone with Down's syndrome is different. It may take many months for some people to realise that the dead person will not come back. For some people life will get back to normal quite soon after someone dies. This might be because they knew that the person was going to die and had worked through their feelings before the death. Some people may experience strong feelings of loss for months or even years. As time passes, as with all of us, the person with Down's syndrome should reach a point where they can remember good things about the dead person without being very sad at the same time. Naturally, dates such as the dead person's birthday or the date when the person died will sometimes bring back the feelings of sadness. Memories are important and it can help for the person with Down's syndrome to talk about the person who died, what they were like and what they used to do together when anniversaries arise.

Non-verbal rituals and visiting familiar areas or the person's grave can be helpful.

Community Learning Disability Teams (CLDTs)

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. 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.

Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record

(SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it means. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.

Resources

Adams, J. (2008). *Children with Special Needs and their Grief*. Child Bereavement UK. Available at: <https://childbereavementuk.org/for-families/info-sheets/>

Blackman, N. (2003). *Loss And Learning Disability*. Worth Publishing Ltd.

Chicoine, B. & McGuire, D. (2010). *The Guide to Good Health For Teens & Adults with Down Syndrome*. Woodbine House. pp351-353.

Cottis, T. (Ed). (2009). *Intellectual Disability, Trauma and Psychotherapy*. Routledge.

Hollins, S. (2012). *Managing Grief Better: People with Intellectual Disabilities*. In Understanding Intellectual Disability and Health, St George's, University of London, 2012. (online) Available at: <http://www.intellectualdisability.info/mental-health/managing-grief-better-people-withintellectual-disabilities>

Koehler, K. (2011). Supporting bereaved children and young people with Autism Spectrum Difficulties (ASD). Child Bereavement UK. (online) Available at: <https://childbereavementuk.org/for-families/info-sheets/>

McGuire, D. & Chicoine, B. (2006). *Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioural Strengths and Challenges*. Woodbine House, pp197-203.

Hand-In-Hand. (2007). SeeSaw. Supporting bereaved children who have special needs (online). Available at: <http://seesaworguk.eweb801.discountasp.net/Schools/Training-for-schools>

Tuffrey-Wijne, I. (2013). *How to Break Bad News to People with Intellectual Disabilities*. Jessica Kingsley Publishers. <http://www.breakingbadnews.org/>

Easy read information

All About Feeling Down – A Booklet For People With Learning Disabilities Foundation for People With Learning Disabilities (FPLD), 2003. (online) Available free to download at: <http://www.learningdisabilities.org.uk/publications/all-about-feeling-down/>

Coping With Loss. Down Syndrome Scotland. (online) Available free to download at: <http://www.easyhealth.org.uk/sites/default/files/coping%20with%20loss.pdf>

Dodd, K., Turk, V. & Christmas, M. (2005). *The Journey Of Life: How People Change From Babies To Older People*. British Institute of Learning Disabilities (BILD). Available from: <http://www.bild.org.uk/our-services/books/health-and-well-being/the-journey-of-life/>

Let's Talk About Death – A Booklet About Deaths And Funerals For Adults Who Have A Learning Disability. Down's Syndrome Scotland. (online) Available free to download at: <http://www.easyhealth.org.uk/sites/default/files/lets%20talk%20about%20death.pdf>

Books Beyond Words Series

Many people understand pictures better than words. This series of picture books is for use by people with learning disabilities. They help people to understand and deal with difficult situations and emotions.

Hollins, S. Dowling, S. & Blackman, N. (2014) When Somebody Dies.

Hollins, S. & Sireling, L. (2004). *When Dad Died*.

Hollins, S. & Sireling, L. (2004). *When Mum Died*.

Available from: <http://www.booksbeyondwords.co.uk>

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Author: Stuart Mills (Information Office, DSA)

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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



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