

People with Down's syndrome

Bereavement

Myths:

People with Down's syndrome do not experience grief

People with Down's syndrome do not recognise or comprehend loss

Facts:

The loss of a loved one is perhaps one of life's most stressful events. After the death of someone you love you experience bereavement, which literally means to be deprived by death. For example, you may experience bereavement at the loss of a family member, a friend or a pet.

In the past, people with Down's syndrome (DS) were denied the right to grieve because other people mistakenly assumed that they lacked the capacity to do so. The life expectancy of people with DS is steadily increasing and as a result of this, many are experiencing the death of their friends and parents. When people with DS are bereaved, their reactions to the loss are frequently misunderstood.

Grieving is a highly individual process and people respond to bereavement and express their grief in different ways. The person with DS experiences the same processes as the rest of the population. The grieving process for those with DS may however take longer and it may manifest itself in ways that are not instantly recognisable. Usually people can work through their feelings about an unhappy event and come to terms with it. People with DS will probably need help to do this.

Many people with DS find change of any kind difficult to cope with. Routine can be particularly important to people with DS providing individuals with an important sense of order and structure to their lives. However, it has often been the experience of people with DS that other people make decisions that affect their lives without any warning, any element of personal choice or of control.

Common Responses To Grief

Whether or not they have DS, people react individually 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, sense of being abandoned.

Physical: Symptoms such as pain, appetite disturbance, breathlessness and illness. The person with DS, who is less able to express himself or herself 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 DS, in unexpected forms. Although depression sometimes strikes out of the blue, it is often triggered by some unhappy event such as bereavement. These unhappy events affect most people with DS 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, after parents have died, people with DS are often moved to emergency residential care. This means that they lose 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 DS 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. You may obtain a copy of a publication entitled 'Depression in People with Learning Disability' from the Down's Syndrome Association or you can download the leaflet free of charge at the website of The Royal College Of Psychiatrists (www.rcpsych.ac.uk).

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 individual. The news of a death should not be kept from an individual in an attempt to protect him or her.
- Always use straightforward language in order to avoid misinterpretation by the person with DS. The use of terms such as 'death' and 'died' are preferable to terms such as 'passed on' or 'gone to sleep'.
- The person with learning disabilities should be given the choice as to whether or not they wish to take part in the rituals associated with death. If the person is unable to choose directly, it is advisable to involve the person as fully as possible. Non-verbal rituals may be particularly helpful to people with DS.

- 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 with DS may find it comforting to take refuge in their daily routines and familiar surroundings. Helping the bereaved person to maintain some continuity and connection with life before the bereavement is essential to recovery.
- Always give the individual with DS 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 learning difficulties to communicate their feelings to someone outside of the family. You may wish to consider specialist bereavement counselling for the person with learning disabilities. You can obtain further information about this from your local Social Services (Learning Disabilities Team) or from an organisation called CRUSE (see Useful Organisations). CRUSE should be able to provide you with an appropriate local contact.
- Remember that everyone with DS 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 very quickly after someone dies. This might be because they knew that the person was going to die and had worked through their feeling 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 DS 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 DS 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 place where the person is interred can be helpful.

Resources

Literature

Loss And Learning Disability

By Noelle Blackman (Worth Publishing Ltd, 2003)

ISBN 1-903269-02-4

(£12.00)

The emotional life of people with learning disabilities is a subject that has only begun to be thought about during the last decade. This book by Noelle Blackman addresses the central issue of how people with learning disabilities can be affected by bereavement

Am I Allowed To Cry? : Study Of Bereavement Amongst People Who Have Learning Difficulties

By Maureen Oswin (Souvenir Press Ltd, 1991)

ISBN 0-285-65096-3

(£9.00)

A practical guide with plenty of facts and advice mixed with real life stories and experiences. This book is a definite must read for all those working with people with learning disabilities. Although staff attitudes to people with learning disabilities have vastly improved since this book's publication, bereavement of people with learning disabilities is still often overlooked.

Talking Together About Death - A Bereavement Pack For People With Learning Disabilities, Their Carers And Families

By Joan Cooley & Frankie McGauran (Speechmark Publishing Ltd, 2000)

ISBN 086388265X

(£53.00)

A bereavement pack containing five sets of illustrated cards and a user's guide. Designed for both families and carers to share the experience of death and bereavement with people with learning disabilities.

Interventions With Bereaved Children

Edited by Susan C. Smith & Sister Margaret Pennells (Jessica Kingsley, 1995)
ISBN: 1-85302-285-3
(£16.95)

A useful resource with lots of practical ideas. Twenty contributors share effective ways of supporting and helping bereaved children. Chapter 13 is entitled "Helping Families and Professionals to Work with Children who have Learning Difficulties."

Training Pack

Understanding Grief: Working With Grief And People Who Have Learning Disabilities

By Sheila Hollins & Lester Sireling

The Pack may be used in formal staff training or as an educational tool for families and carers of a bereaved person with a learning disability. The Pack includes a video entitled **When People Die** and a copy of the book **When Dad Died**.

The Pack may be purchased from the Department of Mental Health - Learning Disability, St. George's Hospital Medical School (Tel: 020 8725 5496) (£70.00 inc p&p)

Accessible Information For People With Down's Syndrome

When Someone Dies - An Accessible Guide To Bereavement For People With Learning Disabilities And Their Carers

By Michelle Mansfield, Peter Aukland & Anita Evans (Speaking Up, 2006)
(£5.00)

Speaking Up have designed an accessible booklet to enable people with learning disabilities bereaved by death to understand their grief and cope with their loss and to give them greater confidence to access support and to help each other.

Over 40 people with learning disabilities were consulted to write this booklet and a steering group of three people developed this great new resource.

This booklet is a must have resource for all those working with people with learning disabilities, it is designed to be used either with a carer or worked through individually. It contains a pull out 'Mood Chart' so that individuals can explain how they are feeling through their grieving process.

Tel: 01223 566258
Website: www.speakingup.org
Email: sales@speakingup.org

Let's Talk About Death - A Booklet About Deaths And Funerals For Adults Who Have A Learning Disability

(Down's Syndrome Scotland, Tel: 0131 313 4225)
(£1.50)

The booklet may be purchased from DS Scotland or downloaded from the Internet free of charge at: www.dsscotland.org.uk

Understanding Death And Dying - Your Feelings

By Fiona Cathcart (British Institute Of Learning Disabilities (BILD), Third Print 2001)
ISBN: 1-873791-11-9
(£3.50)

BILD also produce two other booklets in the 'Understanding Death And Dying Series' aimed at families, friends, professionals and carers.

These booklets are a valuable resource for general education and social development and can be used in a preparatory way if a relative or friend is diagnosed as having a terminal illness; and to help someone with a learning disability come to terms with bereavement. Designed for children and adults.

The Journey Of Life - How People Change From Babies To Older People

By Karen Dodd, Vicky Turk & Michelle Christmas (British Institute Of Learning Disabilities (BILD), 2005)
ISBN 1-904082-91-2
(£10.00)

The '**Journey Of Life**' will be useful for helping people with learning disabilities understand the human life cycle. The booklet includes pictures of a man with Down's syndrome showing how he changes over time.

The booklets may be purchased from BILD either from the Internet at www.bild.org.uk or by calling 'BookSource' on Tel: 08702 402 182.

All About Feeling Down - A Booklet For People With Learning Disabilities

ISBN 1-903645-395

Foundation for People With Learning Disabilities (FPLD), 2003

This booklet is for young people with learning disabilities aged 14 to 25 and contains information about what you can do if you feel down.

Single copies are usually free to individuals. Either call FPLD on Tel: 020 7802 0300 or download the booklet at FPLD's website: www.learningdisabilities.org.uk

Books Beyond Words Series

When Mum Died

By Sheila Hollins & Lester Sireling (Gaskell & St George's Hospital Medical School, Third Print 2004)

ISBN 1-904671-03-9

(£10.00)

When Dad Died

By Sheila Hollins & Lester Sireling (Gaskell & St George's Hospital Medical School, Third Print 2004)

ISBN 1-904671-04-7

(£10.00)

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.

When Mum Died and When Dad Died take a gentle, honest and straightforward approach to death and grief in the family. The pictures tell the story of the death of a parent in a simple but moving way. The approach is non-denominational. When Dad Died illustrates a burial, while When Mum Died shows a cremation.

The greatly expanded text in these third editions includes information on how people are likely to react when someone is very ill and to their death. It explores difficult emotions, possible physical feelings and behaviour changes. Guidance is given on how to relate to a bereaved person and how to answer the questions 'How do we feel when someone dies?', 'What happens after someone dies?' and 'How long does it take to get back to normal?'. There is advice for support staff and carers of those with learning disabilities (including how to formulate guidelines and a sample bereavement questionnaire), plus information on useful written resources and bereavement organisations that can offer further help.

These books will be helpful to adolescents and adults with learning disabilities as well as for their carers and supporters. In addition, children without learning disabilities will appreciate these books as they adopt a more direct approach to death than is usual.

When Somebody Dies

By Sheila Hollins, Sandra Dowling & Noelle Blackman (Gaskell & St George's Hospital Medical School, 2003)

ISBN 1-901242-90-0

(£10.00)

Everyone feels sad when someone dies. People with learning disabilities have the same feelings of grief as anyone else, but they are seldom offered the help and support that other people are given.

This book tells the story of Mary who is very upset when someone she loves dies. She is encouraged by a friend to go to regular bereavement counselling sessions, which help her to feel less sad. Later on in the book, John also loses someone he is close to. He is given comfort and companionship by his friends, and is shown learning to cope with life better and better as time passes.

This book shows people with learning disabilities that they need not be alone when they feel sad about someone's death, and that talking about it to a friend or to a counsellor can help them get through this difficult time.

Books from the 'Books Beyond Words' series may be ordered from the Royal College Of Psychiatrists either by calling Tel: 020 7235 2351 (extension 146) or via the Internet (www.rcpsych.ac.uk).

Video

Coping With Death

Explains what happens when somebody dies and shows adults with learning disabilities coping with death.

The video may be purchased from 'Speak Up Self Advocacy', Tel: 01709 7100199 (£28.00 inc. p&p).

Books For Children

When Someone Very Special Dies

By Marge Heegaard (Woodland Press, 1991)

ISBN: 0-9620502-0-2

(£8.99)

A simple workbook that can be adapted for children and young people with Down's syndrome. With adult help, users are invited to illustrate and personalise their loss. It also encourages the identification of support systems and personal strengths.

The Down's Syndrome Association does not sell these resources. However, all these titles can be ordered through any large book retailer, via the Internet (e.g. www.amazon.co.uk) or direct from the relevant learning disabilities organisation. Prices may vary according to retailer and availability.

Useful Organisations

CRUSE Bereavement Care

CRUSE House
126 Sheen Road
Richmond
Surrey
TW9 1UR

Tel. 0870 167 1677
e-mail: info@crusebereavementcare.org.uk
Web Site: www.crusebereavementcare.org.uk

A national organisation offering help to all bereaved people.

National Association Of Bereavement Services

20 Norton Folgate
London
E1 6DB

Tel. 020 77099090

Puts callers in touch with their nearest service. Co-ordinates and supports bereavement services.

The Compassionate Friends

53 North Street
Bristol
BS3 1EN

Tel: 0117 953 9639
e-mail: info@tcf.org.uk
Web Site: www.tcf.org.uk

An organisation of bereaved parents and their families offering support to others after the death of a child or children. The organisation also offers support, advice and information to other relatives, friends and professionals who are helping the family.

British Association For Counselling

1 Regent Place
Rugby
Warwickshire
CV21 2PJ

Tel. 0870 443 5252
e-mail: bac@bac.co.uk
Web Site: www.bac.co.uk

Mind

Tel: 0845 766 0163

Web Site: www.mind.org.uk

Stuart Mills, Information Office, DSA (updated Dec 2006)