SUPPORTING PEOPLE WITH DISABILITIES COPING WITH GRIEF AND LOSS

An easy-to-read booklet

HREPSIME GULBENKOGLU

2007

scope
Disability Means Possibility

ACKNOWLEDGEMENTS

The author would like to first acknowledge the contribution of the many people with disabilities who over the years have shared their very personal experiences which have provided the basis for this booklet. The author would specially like to thank Dr Nick Hagiliassis for his ongoing input and support in the development and publication phases of this booklet. Thanks to Helen Larkin and Merrin McCracken for their support in the inception and early development phases and to Joanne Watson for her support with the easy English aspects of this publication. She would also like to extend her appreciation to the members of the Bridging Project and Statewide Specialist Services team at Scope for their support along the way.

Finally, the author would like to acknowledge the donor support of Ms Barbara Haynes.

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Disclaimer: This booklet has been developed for clients and carers who support people with disabilities to deal with grief and loss. It has been developed based on information from available research and clinical publications as well as clinical experience based on working with people with disabilities. However, the material is not definitive or exhaustive. Attention has been given to ensure that the information included in this booklet is relevant to many people with disabilities and complex communication needs. However, decisions regarding seeking specific therapeutic services remain the responsibility of the person and/or their carer and/or their advocate. The information provided through this publication is not intended to provide or substitute for professional mental health services or advice, including grief counselling or therapy. In no event shall the author or the various collaborators be liable for any damages or consequences resulting from direct, indirect, correct or incorrect use of this booklet.

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Background

The aim of this booklet is:

- To provide people with disabilities and their support people with an overview and an understanding of the grief process.
- To highlight the range of needs of people with disabilities who may be grieving.
- To provide effective strategies for supporting people with disabilities in dealing with grief and loss.

Why this booklet?

It is imperative that all people have access to appropriate supports, where required and where requested, for dealing with grief and loss. People with disabilities, may require additional supports that are sensitive to and cater for their specific needs. The provision of appropriate support needs to take into account the social factors, cognitive factors and communication factors, that may have an impact on how a person with a disability experiences and expresses grief and loss.

This booklet has been written with the needs of people with disabilities in mind and includes information and strategies that will be readily accessible to many people.

Who is this booklet for?

This booklet is organised in two sections. The first section has been developed for people with disabilities themselves, written in easy English and using pictures. This section provides information about grief and loss, and strategies for dealing with grief, in an easy-to-read format.

This resource makes use of pictures that have been developed to aid understanding and expression for people with a range of communication and cognitive abilities. They have been designed specifically for this publication, in consultation with people with disabilities, by a graphic designer. It is felt that these pictures most accurately represent the concepts associated with grief and loss. However, some users of this resource may be familier with and therefore more comfortable with commercial symbol sets. If this is the case, they are encouraged to supplement it with the symbols/pictures they are most comfortable with.

The second section has been developed for people who support people with disabilities to deal with grief and loss. They are written as guidelines that may be helpful to families and service providers who wish to actively assist the grieving person with disability.

How to use this booklet.

This booklet maybe used in several ways:

- As a photocopiable resource in its entirety or in sections.
- By the person with a disability, independently or with support.
- By support people as a resource to build their awareness and capacity in this area.

SUPPORTING PEOPLE WITH DISABILITIES COPING WITH GRIEF AND LOSS

Easy-to-read information

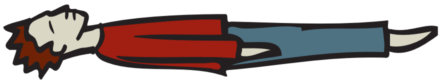
CONTENTS

Easy-to-read information

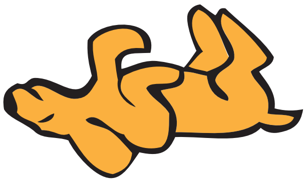
What is grief?

Grief is what we may feel after a major loss.

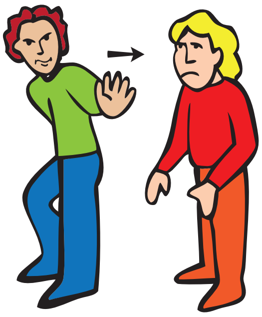
A major loss could be:



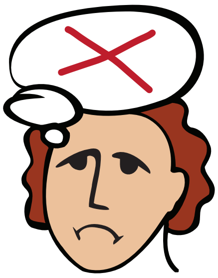
Someone dying



A pet dying



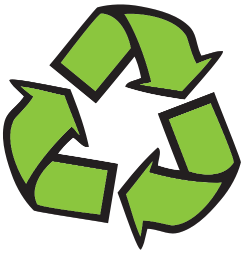
A relationship ending



An important life goal not being reached

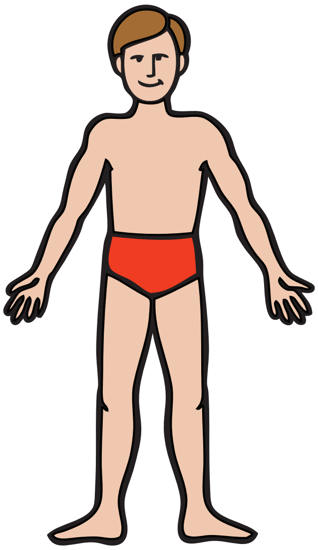
Not being able to do the things you used to

The cycle of life

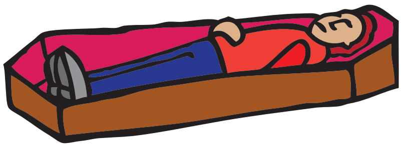


All living things:

Are born

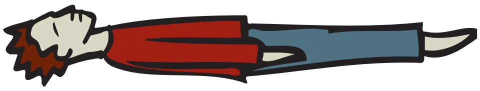


Grow



Die

Why do people die?



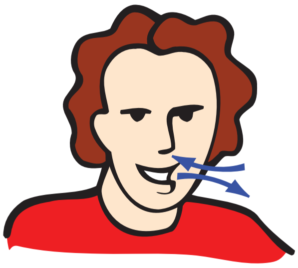
Some people get very old and die.

Some people die after an accident.

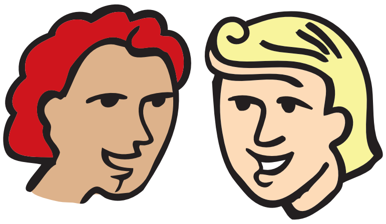
Some people die because they are very sick.

But not all people who get sick die. Most people get well.

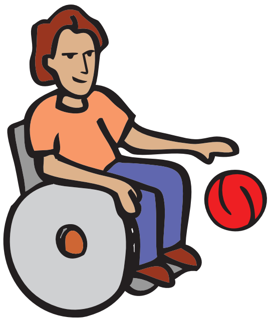
When people are alive they can:



Breathe



Communicate



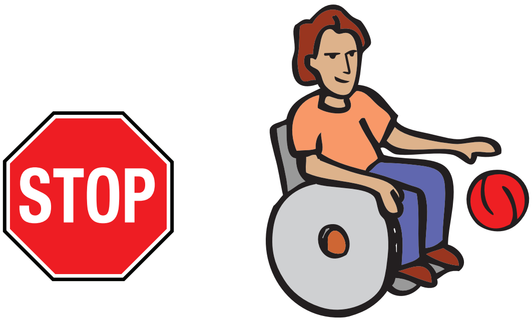
Move

Feel

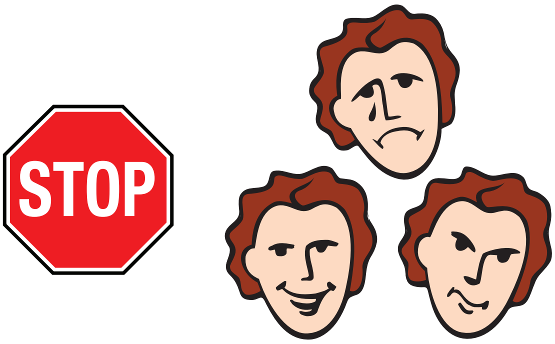
When people are dead they:

Breathing

Communicating

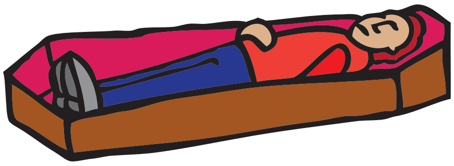


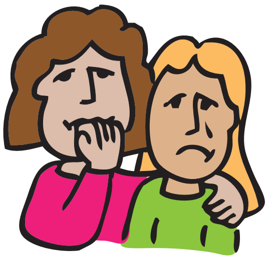
Moving



Feeling

A Funeral





A funeral is a get-together when someone dies.

People come together to remember and talk about the person they loved.

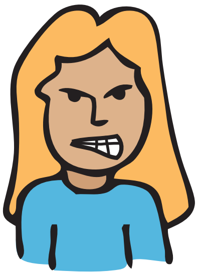
They may sing songs and say prayers.

It usually helps to go to the funeral, but it is OK if you don't want to go.

When someone dies you may have many different feelings. You may feel:

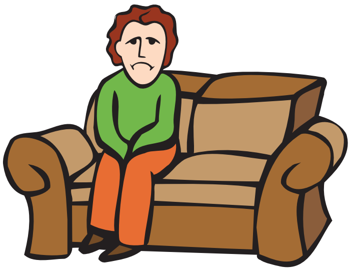
Sad

Like you did
something wrong



Angry

Upset



Lonely

Confused

Your thinking may change.
You may:

Find it hard to concentrate

Feel confused

Find it hard to make decisions

You may have thoughts, like:

"It's not true"

"Why me?"

"I feel scared and lonely."

"I will never get over this."

"Am I always going to feel like this?"

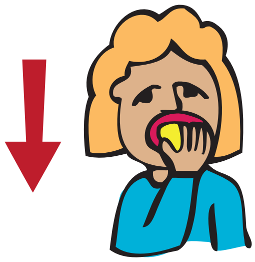
You may behave differently.
You may:

Spend time on
your own

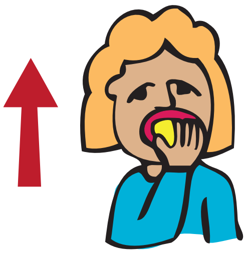
Get angry
with others

Lose interest in things

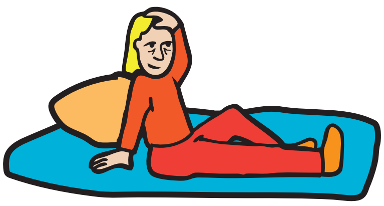
Cry more



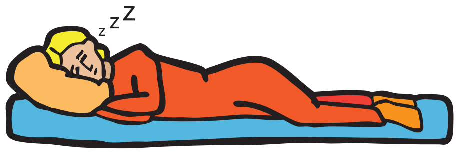
Eat less



Eat more



Sleep less

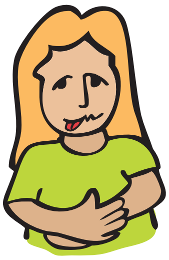


Sleep more

Your body may be affected.
You may:

Get headaches

Feel pain

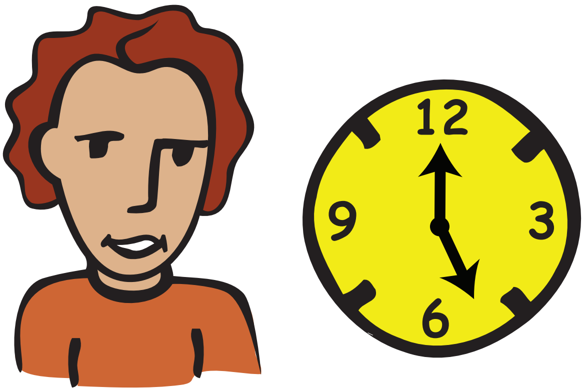


Feel sick

Find it hard to breathe

Feel tired

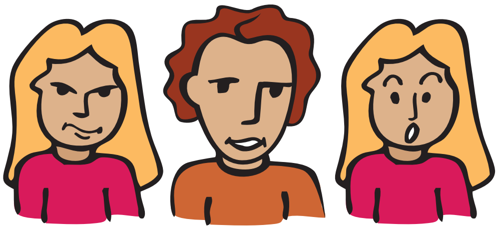
During grief it’s normal to have these feelings, thoughts, behaviours and bodily sensations.



Give yourself time and you may start to feel better.

It’s OK

It’s OK to:



Have lots of different feelings

Cry

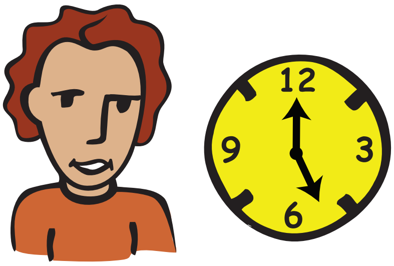
Talk about it if you want

Not talk about it if you don’t want

Special days:

You may feel sad on special anniversaries and special days like Christmas and Birthdays.

It's OK to have sad days.



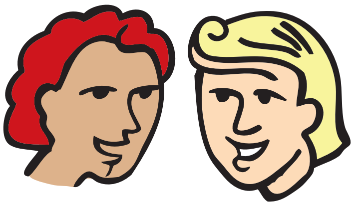
Give yourself time.

It usually gets easier.

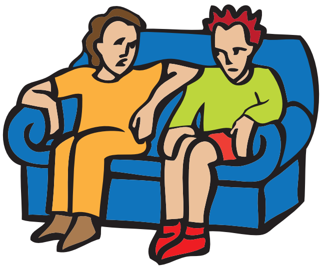
What helps?

Always remember there are people who can help you.

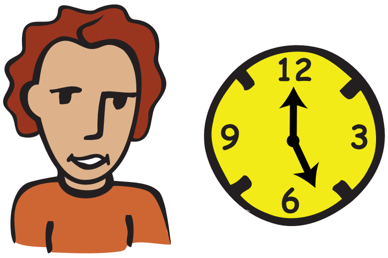
Here are some ideas that can help many people.



Share your feelings with someone you are comfortable with.



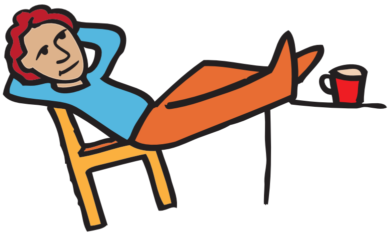
Spend time with others who have experienced a similar loss.



Give yourself time.

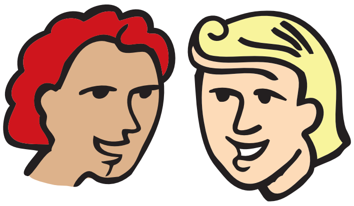
Other ideas that may help:

Accept that you are going through a hard time.



Go on doing the things you normally do. But take a break if you need it.

Try not to make big decisions when you are feeling a lot of grief.



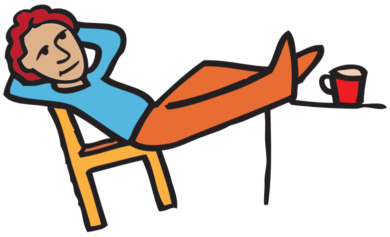
Tell someone about any fears or worries you might have.

Do things that give you comfort, like visiting the cemetery or a place that holds special memories.

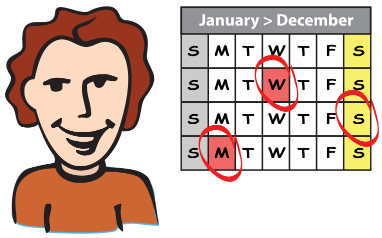
If there are things you want to say to the person who has died you can write a letter. You don’t have to send the letter.

You can make a book of any sympathy cards you get.

You can find a poem, saying or song that helps you remember the person.



You can look for a comfortable place to relax.



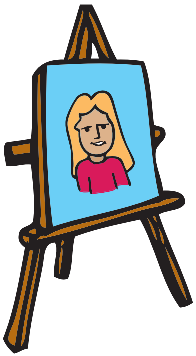
You can put together a calendar that helps you plan and look forward to coming events.

You may keep reminders of the person who has died. You may keep:

Photos or a memory book of the things the person liked.

A memory box where a favorite thing from the person is kept.

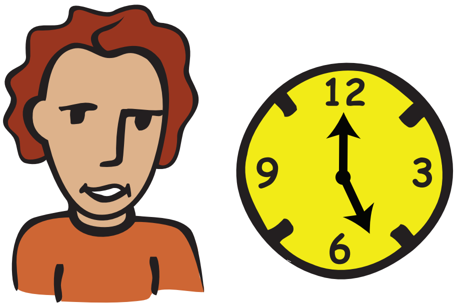
A memory garden where you plant a plant and look after it.



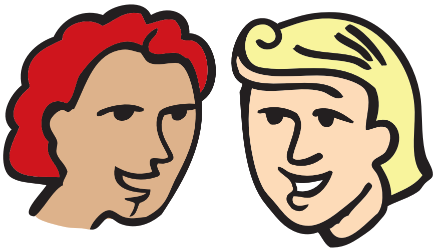
A painting or collage of the person.

A tape of the person's favorite songs.

But, remember, what you decide to do will be up to you.



Remember you will probably feel better with time.



If you don't begin to feel better, ask for help.

SUPPORTING PEOPLE WITH DISABILITIES COPING WITH GRIEF AND LOSS

Information for support people

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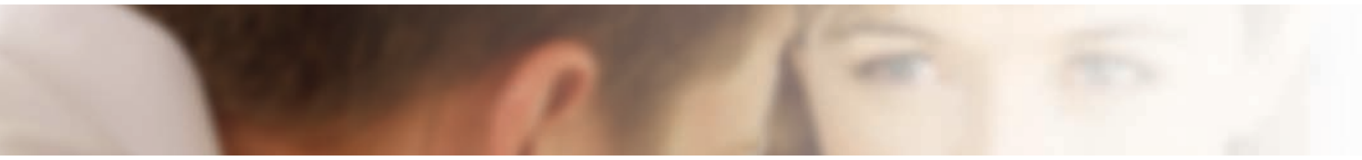


Introduction

Grief is a normal human emotion or set of emotions that occur in response to a significant loss. It is a universal emotion and applies to all human beings regardless of their abilities or disabilities. Grief is our emotional response to loss. It can emerge as a result of death, bereavement or a multitude of everyday experiences related to loss in life. These losses can be actual or perceived. Actual losses can include the death of a loved one, or the loss of a significant relationship in one's life. A perceived loss can include something that was hoped or planned for, that was never realised. This booklet talks about a range of losses, but mainly focuses on feelings of grief and loss as it relates to the death of someone special for the person.

Although grief is a universal emotion, the experience of grief is individual and unique. In other words, while there are characteristics of grief and bereavement that are common to most people, each person will experience grief differently. The life experiences a person has, along with some characteristics sometimes associated with disability, can have an effect on how a person grieves, and also how others interpret their grief responses.

The literature in this area is very limited, particularly in relation to grief issues for people with complex communication needs. However, there is certainly a shift in the way we view the grief responses of people with disabilities. Whereas it was once believed that people with disabilities were 'protected' from grief, there is now increased acknowledgment that people with disabilities also experience grief reactions. There is a clear and growing awareness that the capacity to grieve is not only based on our ability to understand the concept of grief, but also our ability to feel the loss incurred. In other words, the experience of loss and the subsequent grief can occur, regardless of our understanding of death. Our approach to supporting people with disabilities needs to stem from this notion of 'experience of loss' rather than just 'understanding the concept of death'.

Worden (1991), who has done substantial work in the area of grief and loss, suggests that grief consist of four dimensions, namely, feelings, thoughts, behaviours and physical sensations.

Feelings

Feelings associated with grief and loss may include:

- Sadness,
- Anger,
- Emptiness,

This booklet has been written with the needs of people with disabilities in mind and includes information and strategies that will be readily accessible to many people.

- Loneliness,
- Shock,
- Numbness,
- Confusion,
- Disbelief,
- Resentment,
- Denial,
- Frustration,
- Irritability.

Thoughts

Changes in a person's thinking processes may include:

- Difficulty in attending or concentrating,
- Difficulty making decisions,
- Concerned and confused thoughts about self and others,
- Pre-occupation with the person who has died.

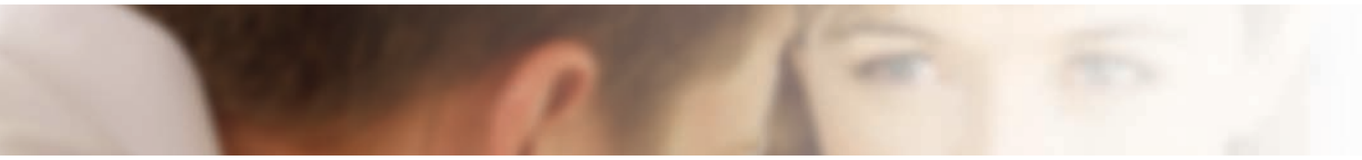
Additionally, the person may experience particular thoughts that may include:

- " It can't be true",
- " Why me?",
- "Am I always going to feel like this",
- " I will never get over this",
- " I feel scared and lonely."

Behaviours

Grief and loss can also be associated with changes in a persons behaviour and may include:

- Withdrawal,
- Physical aggression,
- Verbal aggression,
- Crying,
- Changes in eating and toiletting,
- Changes in appetite,
- Loss of interest in activities,
- Sleep disturbance.



Physical Sensations

Grief and loss may also be associated with changes in body functions including:

- Shortness of breath,
- Pounding heart,
- Hypertension,
- Dizziness,
- Shaking,
- Sweating,
- Pain reactions,
- Tingling and numbness,
- Fatigue,
- Previous illnesses flaring up.

The Impact Of Disability On Grieving

People with disabilities are like everyone else. They may experience a range of losses through their lives, which might set grief reactions.

There are a number of factors that can impact on the grieving of the person with a disability. Although we know that grief reactions are very individual and unique and differ from one person to the other, there are some characteristics that can be seen in some people with disability. These may relate to cognitive, communication and learning experience factors.

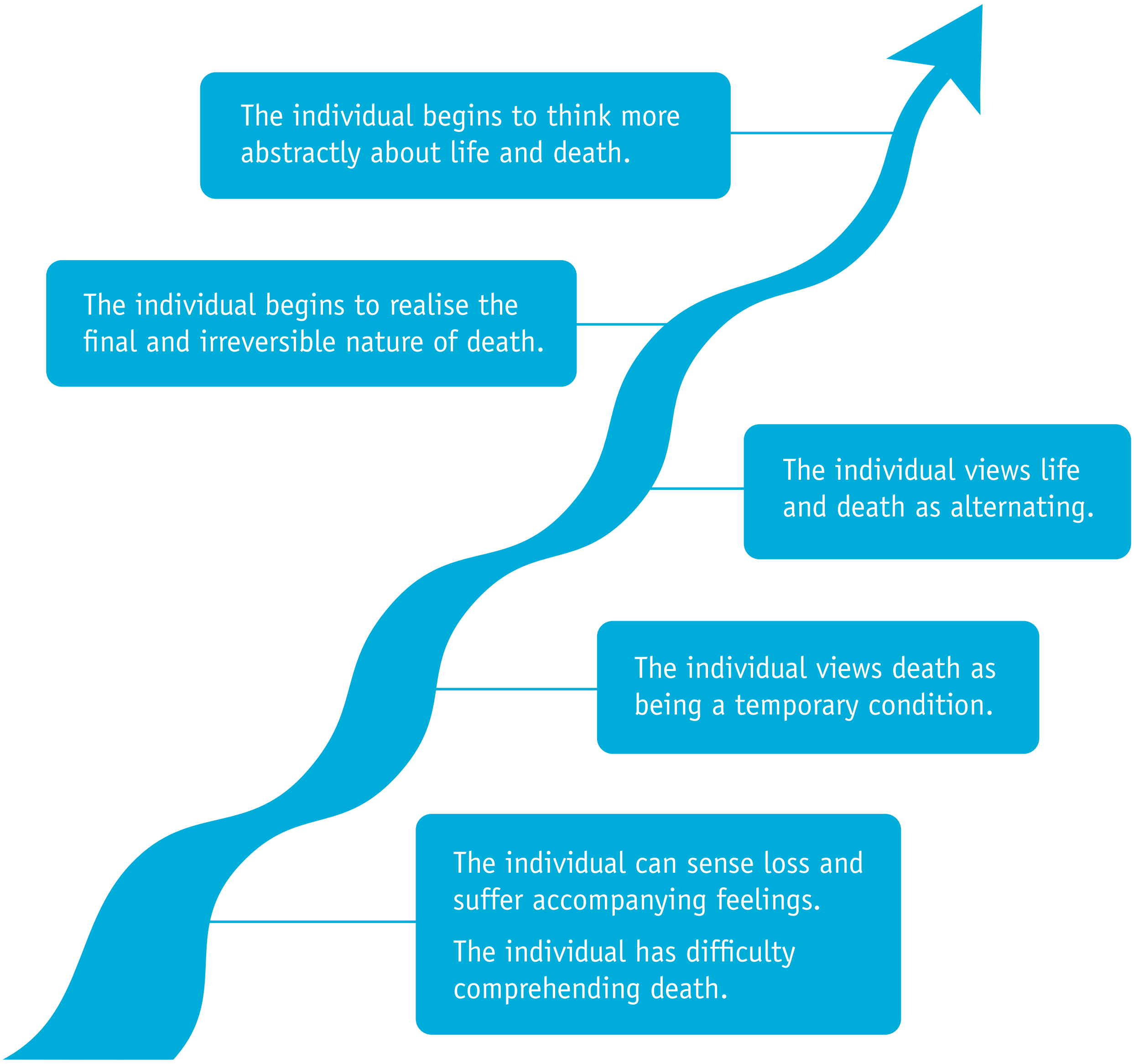
Cognitive Factors

People with disabilities present with a range of cognitive skills. Where a person has difficulties with learning or comprehension, others may draw assumptions about that person's ability to deal with loss and grief. This may lead support people to think that the person with the disability may not have understood what has happened. They may also assume that the person does not feel the loss, or that they need to be protected from the truth, or that by not talking about the issue, the loss will be less obvious to them. However, it is important to realise that people with disabilities don't need to have a full understanding of the concept of death to feel the loss. They may feel the loss by virtue of the fact that an important person in their life is no longer there.

People can have varying degrees of understanding of loss, represented in the figure appearing on the next page. As this figure shows, a person's understanding can range from a 'sense' of loss, to a realisation of the permanency of the loss, to a more abstract understanding about life and death. But regardless of where a person is on this continuum, the person is likely to feel the loss in some way.

> It is important to realise that people with disabilities don't need to have a full understanding of the concept of death to feel the loss. They may feel the loss and the grief by virtue of the fact that an important person in their life is no longer there.

Continuum of understanding of loss:



The individual begins to think more abstractly about life and death.

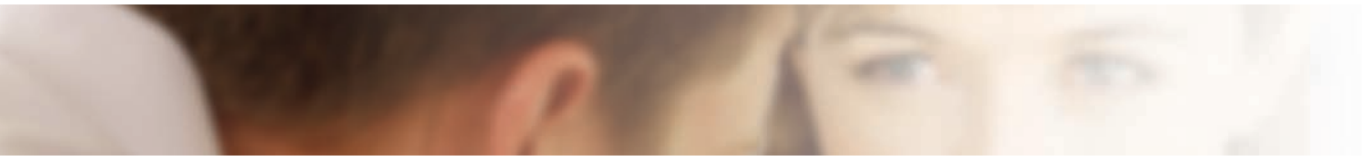
The individual begins to realise the final and irreversible nature of death.

The individual views life and death as alternating.

The individual views death as being a temporary condition.

The individual can sense loss and suffer accompanying feelings.

The individual has difficulty comprehending death.



Communication Factors

Some people with disabilities have complex communication needs. That is, they may be unable to use speech to meet their daily communication needs. They may rely, to varying degrees, on augmentative communication methods, like vocalisations, gestures, and facial expression. They may also rely on alternative communication systems. A person with complex communication needs may have difficulty expressing their emotions, asking questions and conveying information about grief and loss.

Some people may show difficulty expressing negative emotions because over time they may have developed an attitude of trying to please others. They may not feel they have the right or the 'permission' to express negative emotions.

For some people with disabilities, a change in behaviour might be a better indicator of grief and loss than what the person communicates directly through speech or through other means. It is also important to be sensitive to any changes in eating or sleeping patterns, or interest or participation in activities and social interactions. These may indicate how the person is coping with the loss.

Learning Experiences

The life experiences of people with disabilities can make it difficult for them to deal effectively with loss and grief. Parents and staff may treat them differently. For example, parents and staff at times may try to shield them from the harsh realities of life with the fear that they may not be able to cope.

People with disabilities might have experienced multiple losses over time. They may have seen a number of friends or people they have known die. They may have also experienced ongoing staff turnover and changes in residential settings and living arrangements, many of which are beyond their control.

If the person has a limited number of close relationships and social supports, the impact of these losses may be more magnified than would otherwise be the case.

If the person who has died is the primary care giver, then the loss can be experienced at multiple levels. As a result of the death, the person with a disability may not only experience the loss of someone they care very much about, but potentially also experience major changes in their daily routine, living arrangements and financial circumstances. Hence, the loss may also trigger anxiety reactions about their own day-to-day living, care and future.

Because each person and the way they grieve is unique, the kinds of supports and assistance offered will also need to be individualised.

What To Do

Because each person and the way they grieve is unique, the kinds of supports and the assistance offered will also need to be individualised. However, there are some general guidelines that may be helpful to many people with disabilities who are experiencing grief.

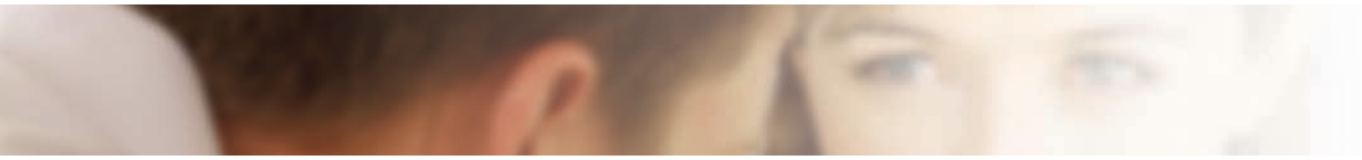
Most importantly, inform the person openly and honestly that death has occurred. This may seem a fairly obvious idea, but is often overlooked, with the person often finding out through here-say or other indirect channels of communication. If a person is not told about the death openly and honestly, then:

- The person's 'right to know' has not been respected.
- The person is denied the opportunity to learn about life and death.
- The person is once again 'shielded' from bad news.
- The person is denied the opportunity to be part of 'normal' grief activities, such as attending the funeral.
- The person may perceive the loss, but not in an accurate way. They may comprehend the loss to be something different than what it actually is, and attach an interpretation of death that is much worse than the reality.

It is important, where possible, that someone who is close to the person with disability gives the sad news. This can help to ease the pain of hearing distressing news.

There is no "good " way of telling a person about the death of someone close. Each individual and each situation is unique. People with disabilities will have different experiences in relation to death and loss. Some may have already experienced the death of someone close and might have dealt with it effectively. Others might have been protected from this concept. The knowledge you have of the person and your relationship with them will very much determine the manner in which you tell the person of the sad news. Some general ideas are:

- Tell the person that death has occurred.
- Explain the death with words that you think he or she will understand.
- Allow and encourage expression of feelings.
- Provide reassurance that the person is not alone and help is available.
- Provide company or space as requested.



General strategies to support people with disabilities deal effectively with grief and loss

Described below are some general strategies that are helpful to consider as you support people with disabilities to deal with grief and loss. These strategies may be helpful for many people, not just those with disabilities. As stated earlier all people grieve differently and their needs for support will be different. So it is important to remember that these strategies are to be used as guidelines only.

Encourage open and honest communication

- Give explanations appropriate to the person's level of comprehension. Make sure that you use words that the person can easily understand.
- Refrain from abstract explanations. Use clear, simple and concrete phrases.
- Use words that describe death in real terms. For example, "(the person) died" rather than "(the person) passed away", or "(the person) has gone to a better place", or "we've lost (the person)". However, if the person has words that describe death in a way that is meaningful to them, based on their previous experiences, then these words can be used.
- Talk about the deceased, ask and allow questions. This gives the person the opportunity to understand that loss has happened, it also reinforces the idea that it is OK to talk about the death, while also giving the listener an opportunity to identify and address any inaccuracies in the person's understanding of the death.
- Accept short conversations. Some people may not feel like communicating their thoughts at the time, or they may not know what to say. However, it is important for the person to know that they can talk about it at some later stage if they feel like it.
- Tolerate silences. Don't be afraid of silences. They are a natural part of the listening process, and can also be useful in terms of giving the person a chance to collect their thoughts. Sometimes, the fact that you are there with the person may be sufficiently reassuring.

Encourage and allow expression of emotion

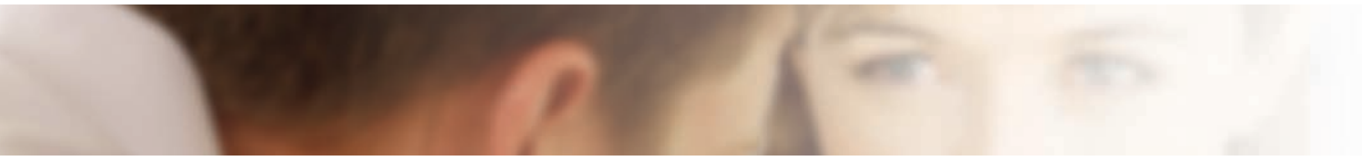
- Listen, rather than try to 'fix'. Be aware that it is difficult to 'take the pain away'. The person will need to work through this process themselves. The role of the support person is being there when needed.

Tolerate silences. Don't be afraid of silences. They are a natural part of the listening process, and can also be useful in terms of giving the person a chance to collect their thoughts.

- Don't judge. Be aware that we all have our own set of values and beliefs. Particularly in relation to grief and loss, people can have a wide range of belief systems, such as varied spiritual beliefs, rituals and other ways of expressing grief.
- Reassure that it is OK to have a range of feelings. This is important in terms of normalising different feelings, and also conflicting types of feelings, such as when someone experiences both deep sadness, but also anger toward the person who has died.
- Reassure that it is OK to cry. Crying is a normal human response to a significant loss, and can be useful as an emotional outlet.
- Validate the person's feelings. Let the person know that you can see that they are experiencing emotional pain, and acknowledge that they are going through a difficult experience, but that also, they will work through this.
- Address fears and anxieties. Listen carefully for any specific fears, such as fear that the person themselves will die, or that their support needs will no longer be met, and reassure the person appropriately.

Help the person to understand the reality of the loss

- Talk about the deceased. It is OK and indeed healthy to talk about the person who has died, and this should be encouraged. However, be led by the person who you are supporting in this, and do not force this topic of conversation if the person is not ready or willing.
- Encourage the person to participate in the rituals (viewing, funeral, visiting gravesite etc.). Taking part in rituals can contribute to the person's sense of belonging and connectedness, as well as helping the person's own recovery from grief. However, this should always be presented as an option to the person, or their advocate. Do not force the person to attend a funeral or participate in other rituals if they do not wish to do so.
- Keep the reminders of the dead person present. This is important in terms of acknowledging and confronting the loss, but also as a reminder of the deceased person and their legacy. Once again, be led by the person, because concrete reminders can sometimes be profoundly painful, particularly in the early stages of grief. In these cases, you may wish to offer these reminders again at a later date.



Provide reassurance and support

- Be available, patient and accommodating. Grief is a complex emotion, and can take time to work through.
- Provide care, comfort and practical support. A sensitive and flexible approach to support will be required. Some times may be more difficult than other times, and the person may require extra support at these moments.
- Encourage routine activities. Routine gives a sense of stability at times of emotional turmoil.
- Encourage the person to minimise change. When a person has experienced significant loss, there is usually significant disruption to their life, so it is important to avoid any further and unnecessary changes.
- Discourage the grieving person from making major decisions. Because of the changes in thinking processes associated with grief, people can have difficulty in concentrating on all the relevant factors for making significant life decisions. If possible, delay big decisions for a time in the future.
- Provide continuity of support in different settings. Try to ensure that people are supported in their various environments and are given consistent messages across these environments.
- Encourage the person to use their local support networks. Talking with someone, such as a friend or family member, who knows the person well and who is familiar with the person's circumstances is often the best and most natural type of support.
- Additionally, the person may be encouraged to communicate with others who they may not know so well, but who have been through a similar loss in their life.
- Support structures that are helpful for people with more complex needs who don't have a formal communication system may need to draw less on strategies based on language and draw more heavily on environment based strategies. Startegies may need to focus on providing a sense of secutrity, stability, comfort, routine and continuity for the person. They may also include relaxation supports, such as sensory activities, based on the person's preferences that are conducive to a calm state and/or expression of emotion.
- Grief responses can sometimes be associated with challenging behaviours, particularly when a person's communication channels are limited and they have difficulty expressing their grief in any other way. In this case, the involvement of a behavioural support practitioner (e.g., psychologist) may be useful. This person can explore the underlying functions of this behaviour and develop strategies for addressing the challenging behaviour.

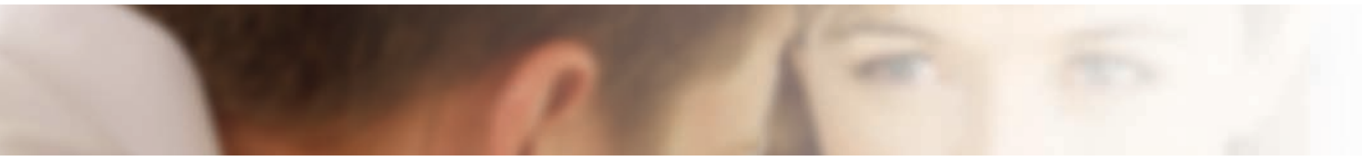
Try to ensure that people are supported in their various environments and are given consistent messages across these environments.

- Offer seeking specialist services, such as counselling, to people with disabilities who display more complicated grief reactions. People whose grief reactions are of an intense or severe nature, take a significant period of time and impact on their daily functioning may require specialist and individualised support to assist them in dealing with their grief.

Creative ideas and activities to assist the person with disability through the grief process

Contained in this section are some ideas that have been found to be useful when assisting people with disabilities to deal with grief and loss. As stated earlier each person's way of dealing with grief is unique and individual and so are their support needs. So it is very important that support people consider these ideas in the light of their knowledge of the person and what that person may wish. Once you feel the person is ready, some possibilities to consider and offer are:

- Creating a memory box where a favourite item or a few items of the deceased is kept .
- Creating a memory garden where a plant is planted and looked after.
- Creating a memory workbook where the person can choose to include things like photos of the person, a list of favourite things such as foods and places etc.
- Helping the person create a painting or a collage or another piece of artwork that represents the deceased person.
- Assisting the person to write an unsent letter to the deceased if they felt they had things to say that they couldn't say at the time, or did not have an opportunity to say.
- Helping the person make a book of sympathy cards that were received.
- Helping the person find a comfortable place to relax if they need some personal quiet time.
- Making a tape of the deceased person's favourite songs.
- Helping the person to find a poem, saying or a song that helps them remember the deceased person, but that also brings a sense of comfort.
- Assisting the person to explore a new leisure activity.
- Assisting the person to develop and use a calender as a way of planning and looking forward to coming events.
- Some of these ideas also appear in Luchterhand and Murphy (1998), which is a recommended resource in this area.



Further information

In this booklet, we have presented information for people with disabilities and support people about grief and loss. While many people who have experienced a loss will be supported effectively by their local support, some may require additional support to deal with their grief, such as people experiencing complex or prolonged grief reactions. In this case, contact with a local service provider experienced in working in this field is recommended.

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THE
BRIDGING
PROJECT

This publication is linked to the work of the Bridging Project. The Bridging Project is being undertaken by Scope in collaboration with the Centre for Developmental Disability Health Victoria, Monash University. The mission of the Bridging Project is to progress the knowledge and resource base to ensure that people with complex communication and mental health needs have access to quality services. The project has two complimentary streams, Building Evidence (increasing the evidence base in relation to individuals with complex communication and mental health needs through research and related activities) and Building Capacity (building the capacity of services to address the mental health needs and preferences of individuals with complex communication needs). The project is designed around the needs of people who are 18 years or older.

More information regarding The Bridging Project can be found at the Scope Web Page, http://www.scopevic.org.au

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Dealing with Death

In the past, people with Down syndrome were denied the right to grieve because others mistakenly assumed that they had no capacity to do so. It was thought that people with Down syndrome did not experience grief, or recognise or comprehend loss.
The following three real-life stories clearly show grief felt by children with DS and this adaptation of an article from the DSA of the UK (Stuart Mills, April 2002) gives more information.

Bereavement

- Bereavement literally means to be deprived by death. When experienced after the death of someone loved, bereavement is perhaps one of life's most stressful events.
- In the past people with Down syndrome would often die before their parents.
  Life expectancy for people with Down syndrome has increased dramatically, so now many adults with Down syndrome experience the death of their parents, who in many cases have been their main carers.
- When people with learning difficulties 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 learning disabilities experiences the same processes as the rest of the population.
- The grieving process for those with learning disabilities may however take longer.
- Grief may manifest itself in ways that are not instantly recognisable.
- Usually people with Down syndrome can work through their feelings about an unhappy event and come to terms with it, but will probably need help to do this.
- Bereaved people with learning disabilities may find that other people make decisions that affect their lives without any warning, or any element of personal choice or of control.

Common responses

- Whether or not they have learning disabilities, people react individually to grief.
- 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, 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. People with learning disabilities, who are less able to express themselves verbally, may experience and exhibit increased physical symptoms of grief.
- **Behavioural:** Low vitality, need for more sleep, sleeplessness, hyperactivity, withdrawal and a lack of interest in normal activities.
- **Mental:** Confusion, hallucinations, nightmares, insecurity, searching for the deceased, poor concentration, regression and loss of skills.

Resolution

- Resolution 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 is not always a continuous or direct one. It may take a considerable time.
- 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 a learning disability, in unexpected forms.

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 a learning disability 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 learning disability because carers often miss the early signs of depression.

The time to get help is when any changes in behaviour or mental state persist for a lengthy period of time.

You should then seek professional help for further information.

pain, appetite disturbance, breathlessness and illness may occur

How to help

- 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 learning disabilities. 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 learning disabilities.
- It is important to allow the bereaved person to have the opportunity to choose a memento 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. Many people with learning disabilities find change of any kind difficult to cope with.
- Routine can be particularly important, providing an important sense of order and structure. The person with learning disabilities 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 learning disabilities 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 his or her feelings to someone outside of the family.
- You may wish to consider specialist bereavement counselling for the person with learning disabilities.

"Dad's Got Gone"

"At a time of loss and grief and sorrow, there is no one way. There is no right way and no wrong way. This is part of our journey. It is not a work of research, rather some words from the heart and born of great love."

Written in memory of a very special father, husband, friend and mentor, Brian Shaw

A large part of parenting involves preparing our children for important life experiences. Preparing them for the first day at kindergarten, the first day at school, the first day at college, and ultimately, helping prepare them for living as well-adjusted adults in society - and the myriad of smaller events inbetween.

Along the way, as part of family living, we also model behaviours, reactions and interactions according to our personalities, family structure, faith, culture, past experiences and personal creeds.

However, when the sudden, the tragic and the totally unexpected happens, disrupting the rhythm of everyday life, you can find yourself fighting a desperate rear guard action of trying to support those you love during a time of shock and bereavement, with little or no preparation.

I would like to share you with you, my family's story and, in particular, how we helped and supported Kendall during a time of great sadness and confusion in her life.

At a time of loss and grief and sorrow, there is no one way. There is no right way and no wrong way. This is part of our journey. It is not a work of research, rather some words from the heart and born of great love.

They are written in memory of a very special father, husband, friend and mentor, Brian Shaw

For the funeral, Kendall wrote a special 'story' for Dad and read it out. It was rather short "I love you Dad. Goodbye"

It seems these days everybody knows about Nelson. Two years ago, when we decided Auckland was no longer where we wanted to live, Nelson was still relatively 'undiscovered'. After a long successful banking career my husband chose early retirement, and we decided to return to his hometown of Nelson. We found our dream home, complete with its own small olive grove, in the foothills of Ruby Bay. This was to be our little piece of paradise. However much it was a diamond in the rough, we saw the potential and planned, plotted, dreamed and schemed of how to make our dream a reality.

Realistically, we were fully aware relocating our family was going to involve sacrifices. We were all leaving behind close friends, and living at Ruby Bay meant adapting to a completely different life style. We discussed this as a family and included the children in our planning. Kendall was going to get a flying fox and a swing - two of her passions - and a puppy. Kendall and her Dad had even drawn up a shortlist of names for their 'brown dog'. We were all excited and looking forward to a new stage in our lives. The only challenge we faced in the immediate future was farewelling Chris who was leaving home to commence tertiary studies - and the multi-syllabic word 'university' entered Kendall's vocab.

Tragically, it was only one month after our arrival in Nelson, and just four days after Chris's departure, that our lives took a sudden, tragic and totally unexpected turn. From Kendall's perspective she went to bed one night and her life was everything it had ever been; she woke up to an entirely different world, a world that no longer held her father. He had died suddenly during the night. Surprisingly, Kendall, a normally light sleeper, had slept through the noisy arrival of ambulance officers, police, doctors, neighbours and family members. In those first hours one of my foremost concerns was, how do I tell Kendall? How do I put the unspeakable into words? I can't now recall the exact words I used when she woke, and I don't think Kendall could fully grasp the meaning of my message anyhow, but she did understand something of our grief and our tears and she did realise her Dad was not to be found.

Later that morning the funeral director returned to our home. I asked him for help and his words and guidance formed the cornerstone for what was to follow. I will always be grateful to Stephen Day for the compassion he displayed, the wisdom he shared and the care and respect he showed my family.

He suggested that I break everything down into very simple steps and explain in words that Kendall would understand exactly what we were doing and why. In retrospect it sounds so sensible but at the time shock seemed to rid me of coherent thought. All I could think was that the old euphemism "Daddy's gone to sleep" was not at all appropriate and was simply an evasion of the painful truth.

So, we told Kendall that the part of Dad that walked and talked and played games and gave Kendall prickly kisses and hugs and laughed and sang and read stories, that part had gone to heaven. We then went on to tell her that when people go to heaven we don't get to see them any more, they can't come home on holiday and they can't phone home, but we still love them and they know we still love them. And they still love us just as much as ever. We told her that heaven was a good place to be.

We were careful to differentiate between Chris leaving home and going to university and her father dying. Both events, superficially at least, had a similar impact on Kendall's daily life in that neither lived at home any more.

Kendall's carer family, the Giddeys from Auckland, with whom we share a very special, very close relationship, flew down to be with us and we discussed what we were telling Kendall so she was getting the same, consistent message from those close to her. This proved to be of immense value to Chris and Jenah (Kendall's siblings) and Steven and Laura (Giddey), none of whom had prior experience of funerals. Explaining the service in uncomplicated terms made it easier for them to prepare, in part, for the funeral service.

At this time the thought occurred to me that we have no control over some things that happen to us in this life but we do have control over our reactions and responses. It followed therefore and was important to me that we honour Brian in a personal and positive manner, worthy of such a kind and gentle man, and in a way that celebrated his life and his many fine attributes.

We all made contributions to the funeral service. Kendall for some time had had a piece of what we called her 'comfort' music - 'Hallelujah' by Rufus Wainwright. Whenever she got angry, was told off or scolded, off she would storm to her bedroom, on would go Rufus, way too loud, and she would emerge a little later, calmer and comforted. So it seemed appropriate that 'Hallelujah' was her contribution.

I decided to speak at the service and as a mark of solidarity, which I greatly admired and appreciated, Chris and Jenah also decided to pay tribute to their father. I asked Kendall if she would like to write a special 'story' for Dad and read it out. She did. It was rather short "I love you Dad. Goodbye" but she did it.

About the same time she drew a picture of her father with some balloons sailing overhead so we incorporated that theme into the service and we each released a helium balloon at the conclusion of his burial, symbolically sending our love heavenwards.

Kendall was remarkable during the church service and again at the burial. She wanted to stay by the grave for sometime after the burial and so she and I sat close together, hugging, until she was ready to leave. Not perhaps the most orthodox behaviour but her needs at that stage were more important.

Sadly, several weeks later Kendall's Nan, my husband's mother, died. She had become very ill and frail and her passing was not altogether unexpected, so I had been able to prepare the children for the possibility of this sad event occuring. Nan's funeral service was held at the same church and conducted by one of the priests who had led Brian's service. Kendall knew what to expect, she sang with gusto (without knowing the words of the hymn), screwed up her eyes very conscientiously in prayer at the appropriate times and I later came across her telling the priest that, "Dad and Nan were in heaven together eating sausages". Our message about heaven being such a good place had obviously made its mark!

The period following two such close bereavements was, naturally, very difficult for us all. Kendall found it extremely difficult separating from me and became very insecure about leaving home. There was an unfortunate incident at school in the first week of term so I removed her for two weeks, reason for considerable concern at the time, but in hindsight, a wise thing to do.

I was worried about Kendall's insecurity and separation anxiety and sought help though the paediatrician at the local hospital. Being in new territory I was totally without a support network and hadn't had the opportunity to meet the health care personnel who would supervise Kendall's ongoing medical care. I was referred at that time to Christine O'Neil of Tautoko (a community based organisation which assists people with intellectual disabilities) who has been of immense practical support to Kendall throughout this year and who has liased with both school and home.

Early on, I put together a book entitled "Kendall's Dad" and for a time, Kendall read this again and again. For Kendall, understanding comes through repetition. The message of the book reinforced what we had been telling her. It talks about sad things happening, how people react, how we can remember happy times and how it's okay to feel sad and to cry. I described the funeral service and the burial and explained words like coffin, burial and cemetery. Kendall also unearthed an old 'You and Me' videotape where Suzie's gold fish dies and gets a dignified burial in the garden and for a while that was played and replayed.

Sadly, I realised our beautiful lifestyle section was much too large for one person to maintain so I decided to sell and move into Richmond. This decision was not made without a great deal of consideration and soul-searching as I was very aware I was disrupting our lives at a time when we were all still so very vulnerable. One night, shortly before we left Ruby Bay, Kendall collapsed emotionally. All she would say is "Dad's got gone. Dad's got gone". It was as if the ghastly realisation of her father's death had finally touched her soul. It was heart wrenching holding her little body as great sobs wracked her. She was inconsolable.

During the first two terms Kendall literally fell apart, school became a nightmare and I watched helplessly as the daughter I loved receded behind some truly horrendous behaviours. Lacking the skills to verbalise her feelings and emotions, Kendall's grief and sorrow found outlet in extreme behaviours. Realising this was beyond what I could cope with, I again called in Christine O'Neil who set in place a behaviour plan. Term three saw a marked improvement and term four has seen Kendall emerge the calm, happy, contributing, amusing, sometimes obstinate student she always was. At the same time, she is different. The sad events of this year have left a mark; she appears sadder and quieter at times but she had also developed a new maturity.

I wish I could end this with a happy ever after paragraph but we have some way to go before any happy ever afters. Our journey through grief is not yet over. My two girls and I are trying our best to adjust to a very different life. It isn't easy. We have had all those 'first' birthdays without Dad and, at the time of writing, we face our next big 'first' - Christmas.

I choose to focus on the positive and remember what we had and the love we all shared rather than focus solely on our loss. I believe by showing my children how to do this, together we can look towards a new tomorrow albeit a very different tomorrow from what we had ever hoped for. We can learn to accept what life gives and what life takes away and value each day and each person we meet along the way. Together, we have discovered the power of love and how it is all that really matters when life is indeed, harder.

Diane Shaw,
mother of Chris, Jenah and Kendall
Nelson

“Grandma’s not *really* dead?”

I’ve written about our experiences helping our daughter Biddy to understand death, and process and cope with the loss of a Grandma. My partner Paul and I have two children: Biddy aged 11 who has Down syndrome, and Laura aged 8.

My mother died in May 2003, and for the final five months of her life needed someone with her all the time. I am the youngest of eight children and we all felt strongly that we wanted to keep Mum at home. At the end of January we employed a carer to look after Mum from 8am – 5.30pm Monday to Friday, and the family covered the rest of the time.

The girls had visited Grandma lots when she was more able, when she would whip up a batch of scones or pikelets if she knew you were visiting. There was always a warm quiche if we visited near lunchtime. From when Mum began deteriorating we visited two or three times weekly. This enabled the girls to slowly adjust to the changes in her health. I was often staying the night and occasionally the girls would stay on a weekend or holidays. I spent quite a lot of time away from home during this period. I was still working as an independent midwife, helping to care for Mum and trying to keep things going at home.

Life was quite disrupted at this time for Biddy and Laura, but my partner Paul was fantastic and coped with home life when I was working or at Mum’s.

From when Grandma began to ‘slow down’ and need assistance, we began to discuss that Grandma was getting old and unwell, and that she may die soon. Each time we went to Grandma’s we would talk about her in the car on the way home. I would point out the changes and encourage the girls to ask questions. I would explain each time that life wasn’t much fun for Grandma, that she couldn’t eat much, that she couldn’t see her garden so well [she had cataracts] and that movement was painful.

Biddy loved helping .She used to jump on Grandma’s bed and talk to her .It was difficult to explain that she needed to be careful, as Grandma was very thin and quite sensitive to movement and touch. [She had lost about 15 kg over 5 months.]. Grandma had a soft spot for Biddy. Some days Biddy would be the only one to get a smile from her.

In addition to frequent visits to Grandma, we would talk about age and dying. We talked about our cat that had died a couple of years previously, ‘Winnie One Eye” as the girls fondly knew him. He was old and developed a large tumour and died at the vets. We brought him home and the girls decorated the box and wrote a message for Winnie on it, then we buried him in the garden. We had said at that time that Winnie was old and it was OK for him to die.

In early March we had some devastating news. My twenty-two year old nephew John had been killed in a climbing accident on Mt. Rolleston.

Biddy and grandma celebrate her 87th birthday, 4 months before her death

This presented another challenge. We had been preparing the girls for Grandma’s death and now trying to get Biddy to understand that John had fallen on the mountain and died, was difficult. I found I had to repeat the same thing in different ways to get Biddy to understand.

John was at his home for a few days before the funeral. Biddy saw John and touched his hand. She told everyone in the room that “John’s died. He fell down a mountain and hurt his head. He’s got a sore head.” I think she wanted to get reassurance that she understood things correctly. I used these times to explain in more detail.

I’m aware that some people can’t cope with seeing dead people themselves, but it certainly helped Biddy to understand death. All my family talked to Biddy over this time and helped her to understand.

Laura (Biddy’s eight year old sister) responded quite differently to Biddy. She didn’t share her feelings at all. She also chose not to see John.

The girls went to the funeral and burial. Family and friends filled in the grave and I thought Biddy was going to fall in at one stage. All the children seemed to find helping quite therapeutic and fun. Children certainly provided some distraction and humour at this sad time [especially Biddy]. After the funeral we went back to my sister’s house and the children had lots of fun with their cousins, and it extended to a barbeque and late night.

Laura and Biddy found that week very difficult and it made me realise that death is a very difficult concept for ALL children to cope with. They are trying to understand what has happened, while coping with their routine being shattered and us being upset.

Mum died on May 4th, 8 weeks after John’s death. I had been away for the weekend and went straight to Mum’s house. Paul hadn’t said anything to the girls so we told them together the next morning.

Family and friends filled in the grave and I thought Biddy was going to fall in at one stage. All the children seemed to find helping quite therapeutic and fun.

Biddy would often say, "Lets go and see Grandma". I would have to remind her that Grandma was dead. She would then suggest we could take some flowers to her grave.

I told them that we had some sad news for them. That Grandma had died yesterday and that it's really sad for us because we are going to miss Grandma lots. I also said that life was no fun for her anymore, and its OK for people to die when they get old.

I then told them that we would go and see Grandma that morning.

The girls reacted quite differently. Biddy asked lots of questions and made lots of statements. She repeated what I told her. It was like she wanted me to say it wasn't really happening. Laura was very quiet and I had to keep asking if she was all right and did she understand what was going to happen.

We are lucky in that my brother in law is an undertaker and I asked that Mum be left at home on her bed until the girls had seen her. We spent some time alone as a family with Grandma. The girls then played around and came in and out as family visited. Biddy insisted on helping when Grandma was taken to the car to go to the undertaker's.

Also I thought it would be helpful for the girls to be there when Mum was brought home again, and requested that Mum go back onto her bed, as I felt the girls would find that better. [My thirty year old niece commented that she found it much nicer also.]

There were some hilarious moments when Biddy would copy people's behaviour. We were sitting in Mum's room, talking about when we were children. There was lots of talking, laughing and crying. I looked over and saw Biddy dropping her glasses and dabbing her eyes. Initially I thought she was sad, but I soon realised as I watched her, she was copying everyone's behaviour and emotions – it certainly lightened the moment!

She seemed to sense when we needed to laugh.

Biddy didn't understand totally. On one stressful trip home from Mum's Biddy commented "Isn't it sad Grandma died". "Yes Biddy. It is sad, but Grandma wasn't well and she needed to die". Silence for a few minutes and then "Grandma's not dead". "Yes Biddy Grandmas dead." A few repetitions later, she finally said, very distressed "Grandma's not *really* dead?" I needed a stiff gin by the time I got home!

I found it very draining having to repeat everything. It wasn't easy trying to cope with my emotions and remain patient with Biddy. Laura was really helpful with reinforcing the message, but at 8 was struggling to understand it all herself.

The girls both saw Grandma go into the coffin and put in a special flower for her.

The funeral had lots of family involvement. My brother is a priest and conducted the service. He talked about Mum and Grandma, which made it more relevant for the girls.

At the cemetery Biddy was standing near the hearse "keeping an eye on Grandma"[her words]. She heard my brother in law say we should start soon. Biddy hopped up and in a very loud voice said "Let's get this show on the road". As we carried the coffin over she called out to everyone "make way for Grandma". This certainly lightened the moment and caused everyone to laugh. As soon as the burial was over Biddy said, "Right - now we can have a barbeque." She had remembered what had happened after my nephew's funeral.

I have tried to decide what helped Biddy most. I think the repetition, and explaining in different ways to try and ensure more understanding. Biddy would often say, "Lets go and see Grandma". I would have to remind her that Grandma was dead. She would then suggest we could take some flowers to her grave. I commented on January 13th that it was Grandma's birthday, and made the mistake of saying that if Grandma had been alive she would have been 88 years old. Biddy thought about it for a minute and said "When Grandma becomes alive we could have a surprise birthday party for her".

I have worked in the past as a nurse and am presently a midwife and have seen the importance of talking openly and honestly with children about death. I have used opportunities to discuss death with the girls, for example newspaper articles, and friends' grandparents dying. Both girls have accepted old age and dying as a natural process. For Biddy, conceptualising death has been harder than for Laura, and repetition seems to help the message get across. Biddy still has limited understanding of the finality of death – perhaps as time passes, and with repeated discussion, she will understand that Grandma won't come back.

Anne O'Connor
Christchurch

"Dad goes in a heaven car."

Hamish and his dad, Alistair, had a great relationship. They watched the rugby together, fished off the boat together and played cricket together. They laughed together, they joked together, they sat in church together, they prayed together. Hamish and Alistair loved each other dearly.

Those days are gone now.. On November 1st, 2002, Alistair was diagnosed with a brain tumour. The doctors hadn't been concerned that Alistair's headaches were anything serious, but thought at CT scan would soon dispel that theory and then they would find the root of the problem. Hamish and I visited Alistair that evening to see how the scan had gone. As soon as we walked into the room and I saw Alistair's face…. I knew he had some news for us. He patted the side of the bed and asked me to sit down. "I've got something to tell you ....they found something on the scan. I have a brain tumour." Our world suddenly turned upside down, never to be the same again. Changed forever. We sat in shock, not really comprehending what was truly happening.

Hamish, at 17 years old, sat silently in the hospital room. As yet he didn't understand or have any knowledge of what we were talking about and even in the days ahead, as we told family members, cried, talked, prayed, Hamish seemed to be unaffected by what was going on. The tumour needed immediate surgery, so within a few days, Alistair was sent to Wellington hospital for the operation. The morning he was due to be taken to Wellington, Alistair phoned me early. He asked me, with emotion in his voice, "Could you please bring Hamish in to see me before I leave for Wellington. Also would you bring a cauliflower and mushroom for me." I didn't ask the reason why, but felt I knew….


Hamish with dad Alistair before the brain tumour was discovered

We arrived at the hospital and Alistair asked Hamish to come and sit up on the bed with him. Alistair, a primary teacher for many years, explained how his brain, the cauliflower, had something growing in it, the mushroom, that shouldn't be there. "The doctors are going to try and take the mushroom part out." Alistair worked away at the cauliflower with his Swiss army knife. "But when they try and cut the mushroom out they may take out little bits of the cauliflower, so when I wake up again, I may not be able to walk or talk or even know who you are." He told Hamish how much he really loved him.

The operation was initially considered to be very successful and most of the tumour had been removed. But within a week we were told that the tumour was "Glioblastoma Multiforme", grade IV malignant and the operation had only removed about half the tumour. We were told Alistair's prognosis was 8-10 months. With weeks of radiotherapy, dreadful headaches, dizziness and appointments, our lives revolved around Alistair's illness. Hamish just kept being Hamish. He watched his videos; he talked about his birthday and asked what was for dinner. But slowly, he began to take it in. I remember so clearly a night when Alistair and I were sitting on the sofa. I started crying as we talked and without a word Hamish walked out of the room, I thought to leave us alone. But not at all, hearing his footsteps and heavy breathing return, he had the box of tissues in his hands. He lay the box down and then proceeded to pull a tissue from the box and began to wipe my eyes. " You sad because dad is sick", he said. He repeated this many times over the next months.

By March 2003, Alistair's health had deteriorated to the stage that he was admitted to the hospice and we were told that there was nothing more they could do. The pain of loss and grief was extreme as we faced a future without him. Did Hamish really understand that his dad might die? I sat on his bed one night and said to him that dad was very sick and could die. Hamish had prayed, and did so every morning and night. Hamish had watched his dad on the radiotherapy machine, seen his dad in hospital, but did he really understand that dad could die? That night, the reality of Alistair's illness was beginning to sink in. We talked, cried and prayed together. Yes – he asked God everyday to please heal Dad, and also talked about the reality that Dad might be going to heaven soon. Heaven, death, grief…. they were all things we were well accustomed to talking about. Close family friends had died in the previous few years and we had talked a lot to Hamish about what happened. He'd seen our friends after their death and he'd been to their funerals. Death was not a stranger to him.

Death had been a much talked about subject for us as a family, as from when Hamish was just 2 ½ months old, we were told of his heart condition (Eisenmenger syndrome). We knew that everyday with him would be a bonus. Yes- we'd lived with a death sentence over Hamish all his life. But not Alistair. Not Dad, the big strong one, the hunter, the fisherman, the teacher, the principal….we'd never talked about him dying.

The months went on, and Alistair's health stabilized for a few months. He spent his days either sitting or lying down. His ability to do anything physical was minimal…. he could walk around the house and go for the occasional walk pushing his wheelchair. Hamish thought it was cool because now dad had a wheelchair too! But Alistair was an invalid. Seizures, headaches, tiredness, vomiting, shakiness, dizziness…. all became part of our normal life. Hamish continued to do all the things he'd always done. Off to school in the morning, calling out to Alistair as he left - "Bye Dad." Arriving home in the taxi…. "How's Dad?" he would ask. "Go and see him and tell him about your day", I'd respond. It was routine for us. Dad was sick. Hamish would get him a drink and have a little talk to him, but often the headaches or tiredness meant even the talks they used to have diminished.

As Alistair's eyesight deteriorated, he could no longer watch the rugby. He began to become confused about whether day was night or night was day. Hamish went into our bedroom less. Alistair didn't often talk when Hamish spoke to him. The headaches became more and more severe. Another admission to the hospice. Alistair was sleeping most of the time by now and when he was awake he was often confused and disorientated. Hamish went to stay with his "second parents" for a few days. I was exhausted from caring for Alistair. Alistair had short times of being very coherent, but mostly was highly drugged and asleep. Hamish would visit his dad at the hospice, and watch him try to feed himself, but need help ; watch him try to stand up, but fall over; hear him speak but not make sense; watch him sleep and not talk. As the days went on Alistair became more and more ill. By the middle of November we were told that Alistair only had 2-3 weeks left. Over the months, I told Hamish that Dad might die, Dad probably will die, Dad will die soon, Dad will die very soon. Hamish was not protected from the truth but rather we faced it together. He never judged the situation but accepted it as part of life.

Alistair's 47th birthday was the 22nd November and we wanted him home. He came home in the ambulance, confused and very ill. He managed to stay awake off and on, all day for his birthday and we sang happy birthday, talked to him, held his hand, loved him, knowing that there was only such a short time left. Yet Hamish took it all in his stride – never asking why, just like his father…. Alistair never asked why, but rather made the most of the life he had. Like father like son!

Alistair was nearly blind, unable to do anything for himself, needing 24 hour care. Then he stopped eating. On Wednesday 3rd December, Alistair only had hours left. He was deteriorating very quickly. The boys and I sat and held Alistair and we were with him as he passed away. I was aware only that Hamish was hugging and supporting others as we had an outpouring of grief, realizing Alistair had taken his last breath.

The hospice nurse arrived, the pastor, the funeral director, family and friends. Hamish remained open and honest. "My dad died." He cried with us when we cried. He knew his dad had gone even though his body still lay on the bed. Hamish accepted death as part of life. We had Alistair's body brought home for the days between his passing and the funeral. Hamish saw him, Hamish touched him, Hamish wrote him a long letter and put it beside his dad. Hamish spoke to his friends on the phone and told me they were sad because his dad died.

The day of the funeral came. Although Hamish is much shorter than Alistair, at 5 ft, and Alistair was 6ft 1", Alistair's suits fit Hamish well in width! Hamish wore Alistair's college tie. Alistair would have been so proud of him as he stood in his suit and tie. Hamish attended the funeral in full confidence… even greeting people with handshakes as he entered the church. More than I could do by far! He sat quietly as the service commenced but each time he looked and saw me crying, an arm would come over towards me and rub my shoulder, then a tissue. Looking at the white casket, the photo of a younger, healthier Alistair, some McNeill tartan fabric and a floral tribute of red and white roses, we listened as people gave their tributes to a life well lived. After our older son, Callum, spoke, he called Hamish up. Hamish spoke into the microphone clearly but with emotion…

"Dad is go to heaven. God is good. Dad is a good father."

There may have been dry eyes in the church until then, but there weren't any after Hamish had spoken. He returned to his seat with tears in his eyes and a sad but proud look on his face. Alistair would have been so proud of him, as I was that day. As the casket was carried from the church with Renton(17) and Callum (21) as the leading pall-bearers, Hamish held my hand and supported me, as we left the church. Without his heart condition, Hamish would also have been a pall-bearer. But he did a great job of looking after his mother! At the graveside, Hamish again attended to me and mixed with our many friends. Hamish, Callum, Renton and I knelt and prayed as the casket awaiting lowering. Together we farewelled a dear and well-loved father and husband. "Loved and cherished husband of Christina, patient, humourous and much loved father of Callum, Hamish and Renton." The death notice words were so true.

It's not long since Alistair passed away. It is still very very fresh and new for us. An empty seat at the table, an empty place in my bed, his voice no longer heard, his presence no longer physically felt… a huge emptiness in our lives. As I continue to grieve the loss of my husband and soul-mate, Hamish continues with me in my journey. In his acceptance of death, he is able to support and care for those around him. He cries sometimes, he talks about his dad, he hugs me when I need a hug, he wipes my eyes with tissues and says – "It is too hard for you. You miss Dad." And he counts down the days before his birthday. He plans his birthday, he talks to his friends on the phone, he watched his videos, and he asks me what we're having for dinner tonight. He loves his life. He loves his dad. He never asks why but makes the most of each and every day.

In Hamish's own words… **"I love Dad. He is cool. He goes in a heaven car. Dad is alive in heaven. I will see him again. We'll all die."**

Christina McNeill
Palmerston North

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 onoe 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 woth 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)