# 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

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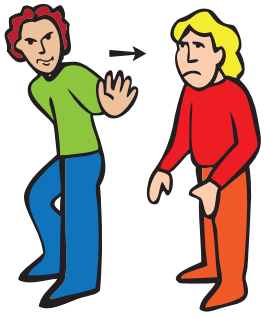
# What is grief?

Grief is what we may feel after a major loss.

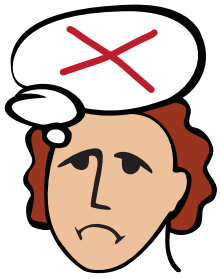
# A major loss could be:

Someone dying

A pet dying



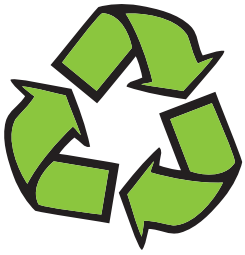
A relationship ending



An important life goal not being reached

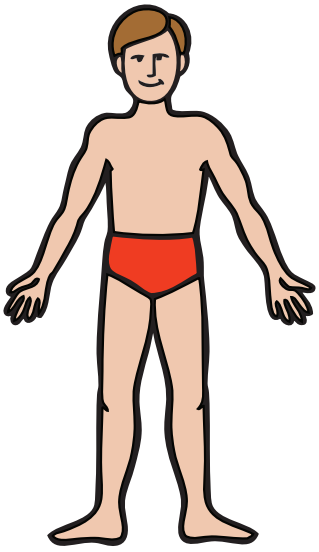
Not being able to do the things you used to

# The cycle of life

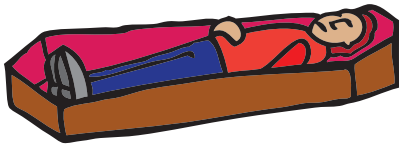


## All living things:

Are born



Grow



Die

# Why do people die?

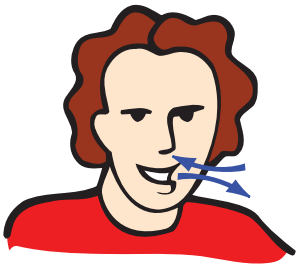
Some people get very old and die.

Some people die after an accident.

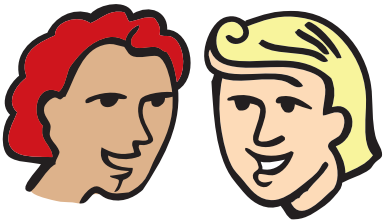
Some people die because they are very sick.

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

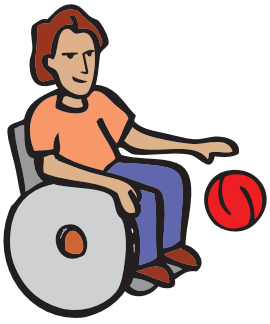
# When people are alive they can:



Breathe



Communicate



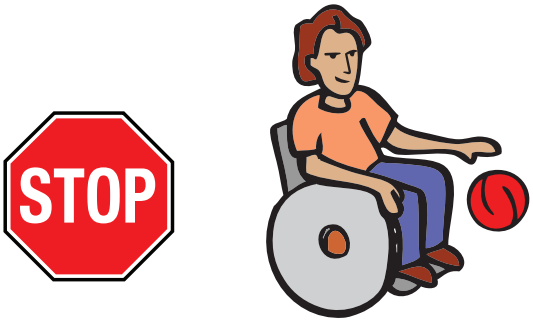
Move

Feel

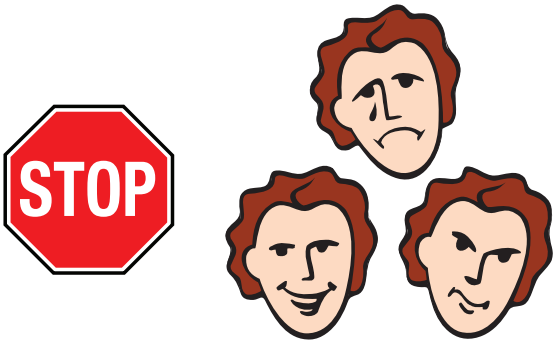
# When people are dead they:

Breathing

Communicating

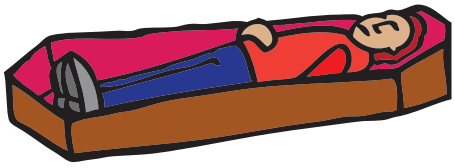


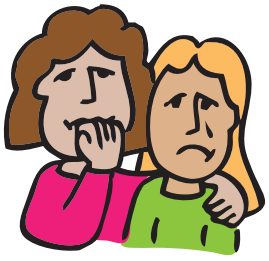

Moving




Feeling

# A Funeral





A funeral is a get-together when someone dies.

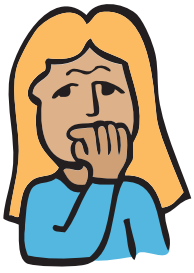
People come together to remember and talk about the person they loved.

They may sing songs and say prayers.

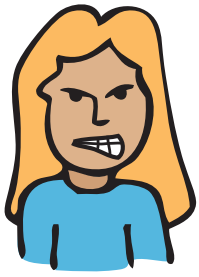
It usually helps to go to the funeral, but it is OK if you don't want to go.

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

Sad

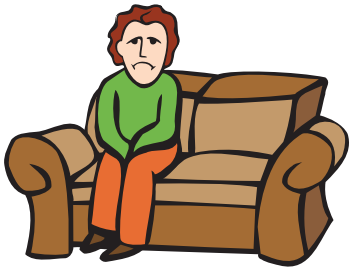


Like you did something wrong



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?"

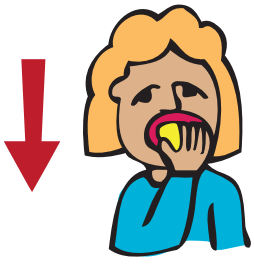
# You may behave differently. You may:

Spend time on your own

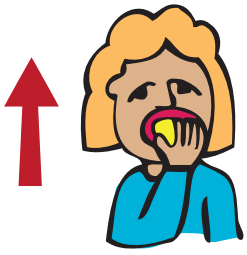
Get angry with others

Lose interest in things

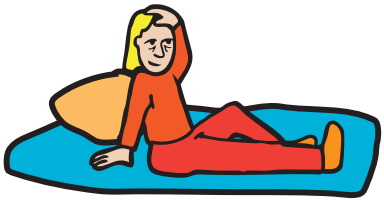
Cry more



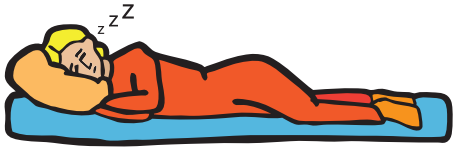
Eat less



Eat more



Sleep less

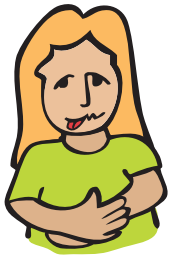


Sleep more

# Your body may be affected. You may:

Get headaches

Feel pain

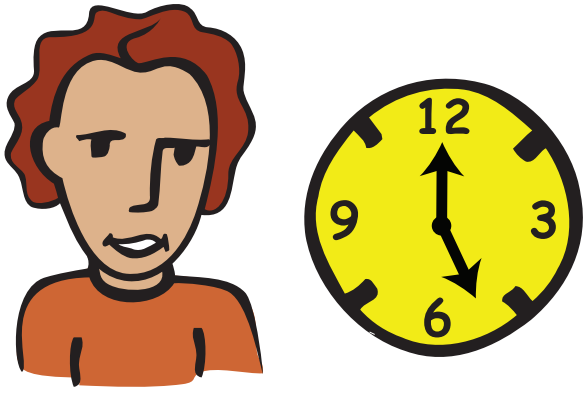


Feel sick

Find it hard to breathe

Feel tired

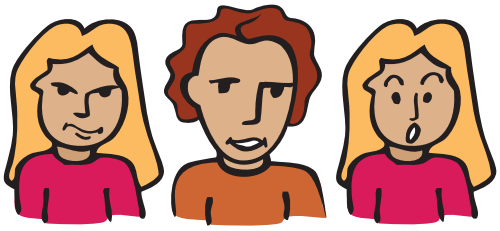
# During grief it's normal to have these feelings, thoughts, behaviours and bodily sensations.




Give yourself time and you may start to feel better.

# It's OK

## It's OK to:



Have lots of different feelings

Cry

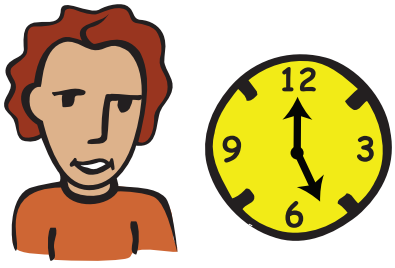
Talk about it if you want

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.



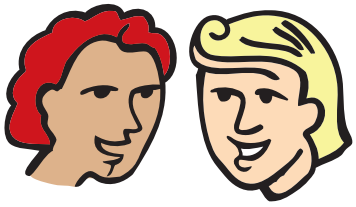

Give yourself time.

It usually gets easier.

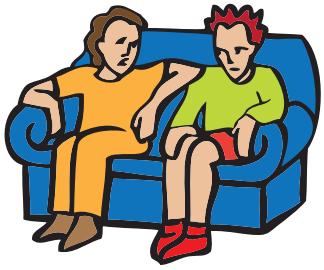
# What helps?

## Always remember there are people who can help you.

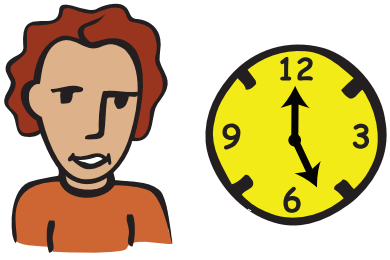
## Here are some ideas that can help many people.



Share your feelings with someone you are comfortable with.



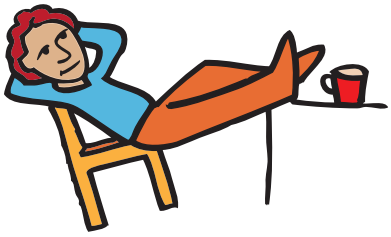
Spend time with others who have experienced a similar loss.




Give yourself time.

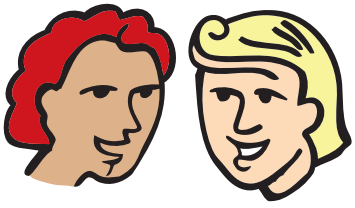
# Other ideas that may help:

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.



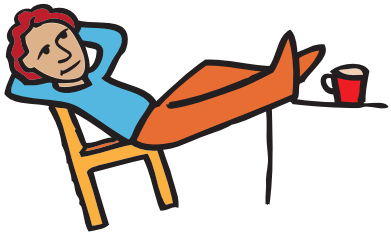
Tell someone about any fears or worries you might have.

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

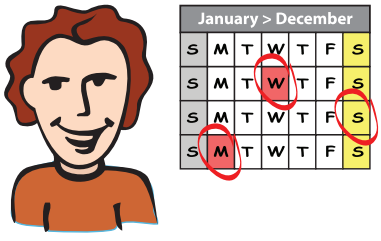
If there are things you want to say to the person who has died you can write a letter. You don't have to send the letter.

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.



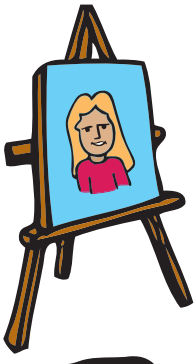

You can put together a calendar that helps you plan and look forward to coming events.

# 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.

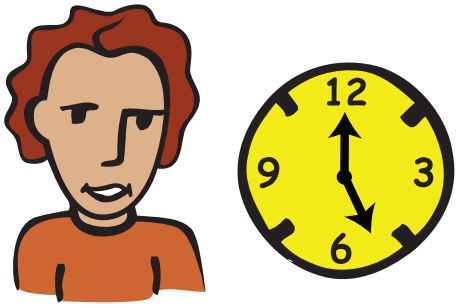
A memory garden where you plant a plant and look after it.



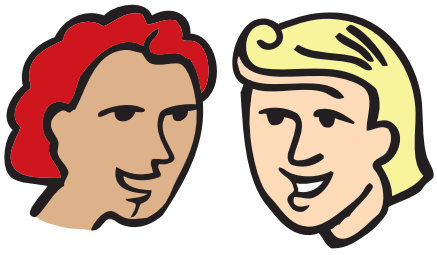
A painting or collage of the person.

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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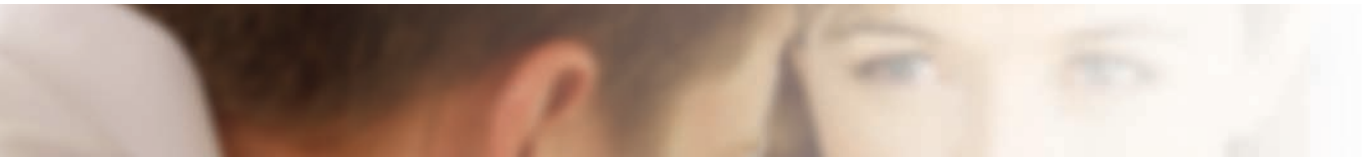


## Introduction

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.

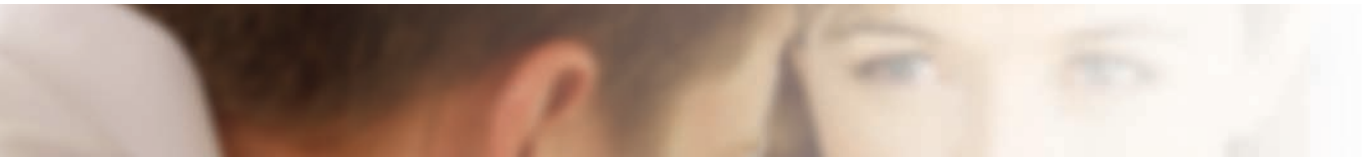
Additionally, the person may experience particular thoughts that may include:

- " 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.

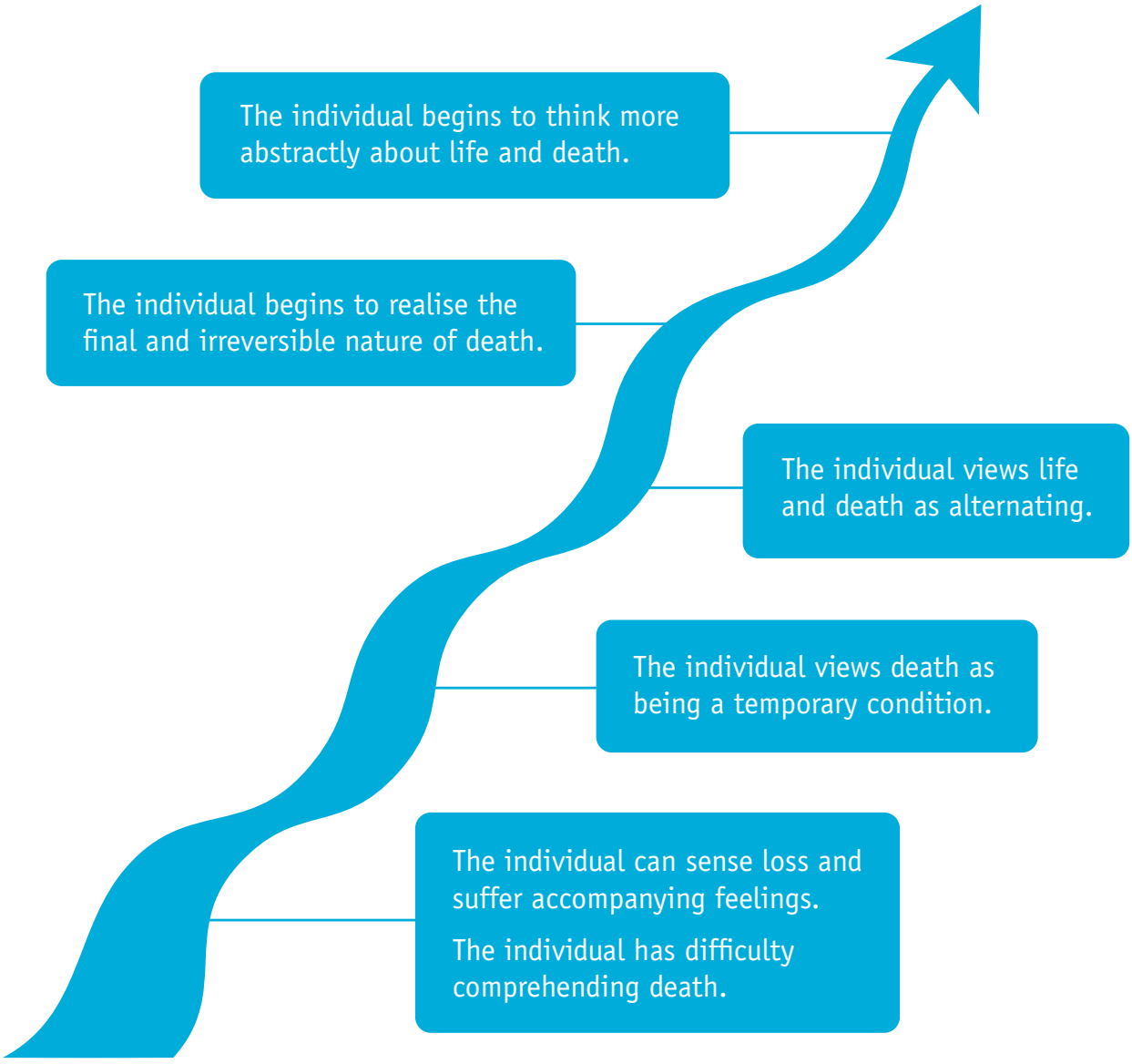
## Cognitive Factors

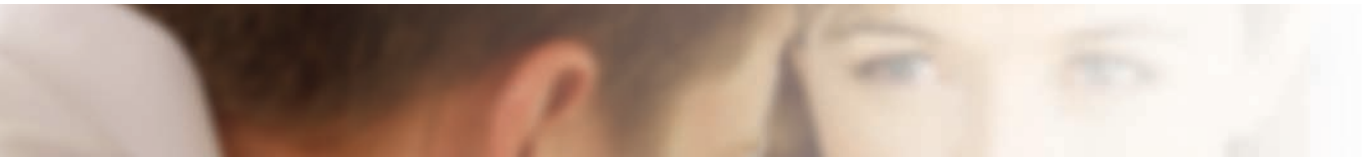
People with disabilities present with a range of cognitive skills. Where a person has difficulties with learning or comprehension, others may draw assumptions about that person's ability to deal with loss and grief. This may lead support people to think that the person with the disability may not have 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:





## 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.

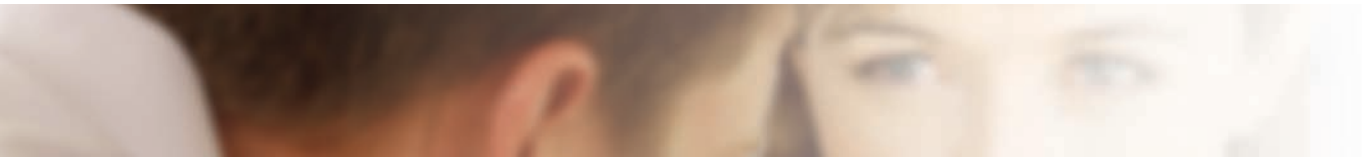
Most importantly, inform the person openly and honestly that death has occurred. This may seem a fairly obvious idea, but is often overlooked, with the person often finding out through here-say or other indirect channels of communication. If a person is not told about the death openly and honestly, then:

- 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

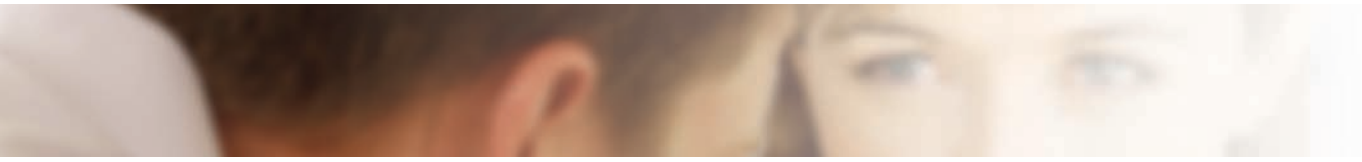
- Listen, rather than try to 'fix'. Be aware that it is difficult to 'take the pain away'. The person will need to work through this process themselves. The role of the support person is being there when needed.

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.

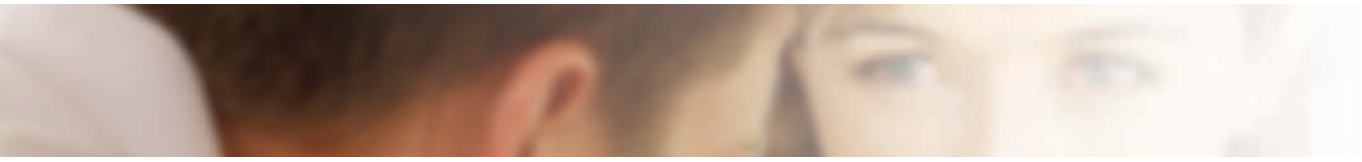
Try to ensure that people are supported in their various environments and are given consistent messages across these environments.

- 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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Luchterhand, C., & Murphy, N. (1998). Helping adults with mental retardation grieve a death loss. Philadelphia: Taylor & Francis.


## Other Resources


Luchterhand, C. (l998). Mental retardation and grief following a death loss: Information for families and other caregivers. Arlington, TX: The Arc.

Hollins, S. (1995). Managing grief better: People with developmental disabilities. Habilitative Mental Healthcare Newsletter 14/3. Available at: http://www.thearc.org/faqs/grief.html.

Watchman, K. (2000). Let's talk about death : a booklet about death and funerals for adults who have a learning disability. Edinburgh, UK: Scottish Down's Syndrome Association.

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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