

When someone you
know has died...

**a guide for professionals offering
bereavement support**



Bereavement and loss support for
people with learning disabilities

Contents	Page
Acknowledgements	4
Introduction	7
Approaches to understanding grief	8
When to refer on	16
Challenges to bereavement support	17
Meaningful support	18
Communication and bereavement	22
Communication and creativity	26
Media	26
Music	27
Photographs and life story work	28
Artwork	31
Gardening	32
Using games and activities	32
Mementoes	33
Smells	33
Conclusion	34
Useful resources	35
References	38

Tables and case examples	Page
Table 1: Overview of grief responses (Worden, 2009: 18-31)	9
Example One: Making use of television	27
Example Two: Life story work	29
Example Three: Using a photo album	31

Acknowledgements

In addition to parents of people with learning disability and people with learning disability themselves, over the years this booklet has been written in conjunction with a number of representatives from the following organisations:

Reach, part of Asist Advocacy Services

Choices Housing Association

Keele University, Staffordshire

Royal MENCAP Society

North Staffordshire Combined Healthcare NHS Trust
(Speech & Language, Broom Street Resource Centre & Psychological Services)

Staffordshire Social Services

South Staffordshire Healthcare Trust

This is the fourth edition of this booklet, and in addition to updating and expanding the content, we have taken the opportunity to change the format and associated images in keeping with other booklets and leaflets in this series.



This booklet should be used in conjunction with:

When someone you know has died...

clear information

A leaflet to support the bereaved person with a learning disability.

When someone you know has died...

a guide for carers offering bereavement support

A booklet to help family and carers to provide appropriate bereavement support.

Also an additional workbook accompanies this series

When someone you know has died...

people with learning disabilities supporting each other

A workbook to help bereaved people with learning disabilities supporting each other.

Sue Read,
Professor of Learning Disability Nursing,
Keele University,
Staffordshire, UK

October 2014, 4th Edition.



“...no soul
remembered
is ever really
gone.”

(Albom, 2013:308)

Introduction

Although the only real certainty in life, death is one of the hardest losses to accommodate. It's also probably one of the most the most significant and difficult events to support in the lives of people with a learning disability. The emotional needs of people with learning disabilities often remain neglected (Arthur, 2003), particularly in relation to death, dying and bereavement. In recognition of this, a series of booklets have been developed in conjunction with this booklet to highlight the support needs of bereaved people who have a learning disability. They were written and designed by a multi-disciplinary group, incorporating people with a learning disability; carers (personal and professional); and other professionals (from varied backgrounds).

This particular booklet has been designed specifically for those professionals who support people with a learning disability from within a variety of caring contexts. The aims of this booklet are to:

- remind professionals that loss can mean different things to different people, and to never underestimate its impact
- raise the profile of the bereavement support needs of people with learning disabilities
- acknowledge the varied impact that death may generate
- promote understanding about the theoretical concepts of grief
- focus upon the practical approaches which may be used to support people in emotional distress
- encourage formal and informal carers to be creative when supporting people who are bereaved
- ensure that a consistency of support is available to all people with a learning disability regardless of where they live.

This booklet was never developed to substitute education and training around this sensitive topic, but to complement these learning opportunities and other existing resources.

Approaches to understanding grief

Much of the research and current thinking around grief work has evolved from the work of John Bowlby (1980), who identified the role that attachment plays when people experience loss. Usually, (but not always) the nature of the relationship between the deceased and the survivor dictates the impact of grief. A model of grief offers a framework from within which practitioners can facilitate or enable grief work. Such models also affirm the grief process and the diverse ways that individuals might react following the death of a loved one. Over the years, there have been a range of grief models, some more helpful and effective than others. The models and approaches identified here are used to offer a flavour of how such understanding can facilitate the healthy support of bereaved people who have a learning disability.

Bereaved people may respond to death in numerous, multiple ways, which include emotional, physical, behavioural and psychological effects (see Table 1).

Table 1. Overview of grief responses (Worden 2009: 18-31)

Feelings	Sadness, anger, guilt, loneliness, fatigue, anxiety, shock, yearning, helplessness, relief, numbness, emancipation.
Physical sensations	Hollowness in the stomach, tightness in the chest, tightness in the throat, oversensitivity to noise, breathlessness, muscle weakness, lack of energy, dry mouth.
Cognitions	Disbelief, confusion, preoccupation, sense of presence, hallucinations.
Behaviours	Sleep disturbances, appetite disturbances, absent-mindedness, social withdrawal, dreams of the deceased, avoidance behaviours, searching and calling out, sighing and restless hyperactivity, crying, visiting old haunts, carrying objects that remind one of the deceased, treasuring objects that belonged to the deceased.

This table is provided to give an overview of the various common responses to death.

Traditional theories of grief involve the idea of working through and 'resolving' grief, of letting go of the deceased before being able to move on with life. Various stages of grief are described e.g. shock and numbness, yearning and searching, disorganisation and despair and re-organisation (Parkes, 1996). Alternatively, grief is seen as conforming to a series of tasks: to accept the reality of the loss; to process or work through the pain of grief; to adjust to a world without the deceased; and to find an enduring connection with the deceased in the midst of embarking on a new life (Worden,2009: 39-53).

Such tasks take into account theories which suggest that the resolution of grief involves continuing bonds, where the survivors maintain a relationship with the deceased and that these continuing bonds can be a healthy part of the survivor's ongoing life. Klass et al (1996) in their pivotal book on the subject provide some case examples such as:



A 12 year old who still talks to her dead father when she has difficulties at school.

"He'd understand if I screwed up in school. Mom would get real mad. So now when I get a bad grade I 'talk' to him about it."

A widow who still talks to her husband.

"So it's like I'm talking to him the whole time I'm getting myself ready to go to work. It's like this constant conversation he and I have...and it's like even though physically he's not here, that mentally I have this continual conversation going on with him..."



A father who talks to his dead 17 year old daughter while running.

"I often reported silently to her about what I'd been doing lately, about what I thought of the weather, how my conditioning was going, what her younger brothers were up to. Frequently I sensed she was nearby, cruising at my elbow."



Examples involving people with a learning disability include:

A 33 year old woman who often talks to her dead mother when she makes mistakes in the kitchen. "I laugh, look upwards, thinking about how mum would laugh at me burning the gravy."



A 22 year old man, who loved to go back to visit the home where he used to live happily with his parents. He liked to recount stories about his life there and the good and bad times that he shared with his family, "we had good times here".



A 61 year old man, who lives in a community home, who describes how his best friend (who died twelve months previously) visits him at night whilst he is alone. "I tell her everything that I've done during the day, and she smiles but never talks back to me." He finds her visits comforting and looks forward to them.



As the quote at the beginning of this booklet so ably recognises '...no soul remembered is ever really gone'. (Albom, 2013: 308), and life story work, memory books and photographs are all tangible ways of helping people with a learning disability to retain memories and preserve important relationships with their loved ones in accessible and concrete ways.

A sixty-year old lady lost her mother 18 months ago. One day, carers might be surprised to find her distressed, not very well presented and clutching a photo of her mother to her chest. From this snapshot view, one might assume that she was failing to come to terms with her mother's death. However, carers may find that the next day she would be well dressed, chatty and waiting eagerly to attend the Day Centre. The photograph may be back on the windowsill with those of her other friends and family. People may feel overwhelmed by their grief at times, yet at other times emerge bright, cheerful and appearing to be coping well. This is what Stroebe & Schut (1999) describe as the dual process model of grief where bereaved people **oscillate** between the mixed feelings of emotion and coping, to being overwhelmed with grief.

Machin (1998) describes **a range of response to loss** in which people may show bias towards certain dimensions of loss such as feeling overwhelmed or feeling that they need to be in control. A bias towards a balanced dimension suggests that the individual is able to address both the emotional or cognitive elements and the need to be in control of and get on with their lives. In this sense the balanced dimension is similar to the oscillation process in the dual process model.

Doka (1989; 2002) coined the term **disenfranchised grief** to describe grief that is not socially accepted and so may be more difficult to deal with because of the lack of social support or the benefits of participating in rituals. He identified certain groups as being more likely to experience disenfranchised grief, including people with mental health issues; children and young people; older people; prisoners;

and people with a learning disability (Doka, 2001). His approach is helpful because it recognises the importance of the social context in which death occurs. Death never occurs in a vacuum, but within a social context, and that context may have a profound impact on how the death is accommodated (Read, 2014), which other models often fail to include. Doka recognised **three key elements** to disenfranchised grief:

1

The griever can be disenfranchised because of the assumptions that other people make. People with learning disabilities may be assumed not to grieve because “they don’t understand”. Consequently, people with learning disabilities may not be told of the death of their loved ones, so do not attend funerals and as such are completely excluded from the bereavement process and any associated rituals.

2

The relationship may be disenfranchised if the relationship is not recognised or valued. It may be that (for example) a father does not visit his son very often in the home where he is supported. If the father then dies, it would still be important for the son to know. He is still his father. Everyone has a right to know when important people die so that they can acknowledge the death and explore its consequences. Sometimes it appears that people with a learning disability are left wondering where friends and family have gone to, since they are just not there anymore; which Read (2014) describes as having to ‘make sense of nonsense’.

3

The loss itself can be disenfranchised. For example, many losses that are not death related (loss of home, transitional loss, loss of friendships etc.) can be disenfranchised because of the tendency to associate loss mainly with death. Over the years, people with a learning disability may have been exposed to enormous, often multiple losses, that have largely been ignored and subsequently neglected. Carers may have come and gone; friends may have been relocated; individuals may have moved on to community-based homes.

All changes (however positive in the long term) involve loss of some kind. Some carers might think that they are protecting people with learning disabilities from the sadness associated with loss if they do not inform them, and involve them, in loss and death. Eventually the person will discover the loss and not being informed or involved might cause numerous additional problems in how they then deal with their grief, months or even years after the death. It's a missed opportunity to learn about loss and to develop coping styles; and it may cause distrust in the carers who decided not to include them.

The following story of Joan's loss well illustrates the consequences and challenges of disenfranchised death.

Joan's story of loss

Joan was forty-four, and lived at home with her father. Following his sudden death due to a heart attack, Joan had to quickly move into residential care. Her family did not want her to be upset any more than was necessary, and as a result Joan never went to her father's funeral. Joan had difficulty accepting that her father was never coming back, and indeed could not understand where he had gone.

Many months following the death, Joan was referred to a bereavement counsellor, who helped Joan to explore her feelings around the death and to help her to understand what had happened at the funeral. This involved taking Joan to visit the church where the service was held and to the graveside where her father was buried. As a result Joan was grieving separately from the rest of the family, and in isolation, having missed the opportunity to share her grief collectively with others.

Such approaches tell us much about the uniqueness of grief and the range of potential responses involved. People need to have every opportunity to participate in the death and any associated rituals, to affirm the death and to enable them to say their goodbyes in a meaningful way.

If individuals are excluded from grief, then the grief process may be delayed and some individuals may find it difficult to accept the death and subsequently acknowledge and explore their feelings of loss, often resulting in complicated grief (Dodd & Blackman, 2014). People with learning disabilities do experience loss and do grieve, but they need every opportunity to be involved in the death and bereavement experience to do so effectively. This may prove challenging for many different reasons, as illustrated shortly. Such experiences can also help them to develop appropriate coping mechanisms for any future losses.

When to refer on

According to Worden (2009), most grieving people cope with their loss in their own social circle, and only a small percentage of individuals actually require additional, specific help and support, for example counselling or therapy. Elliott (1995) suggests that specific help and support may be required for certain people with learning disabilities, namely those:

- Whose anger is high
- Who seem to be profoundly missing the deceased person
- Who have a restricted social network
- Who are assessed as not coping with bereavement

Additionally, people who have been excluded from the funeral or who have not been told about the death for some time after the event may need the professional help of a bereavement counsellor (Read 2000).

Challenges to bereavement support

Dealing with death and bereavement is often difficult while individuals seek to make sense of the loss, even with the support from those people within their own social circle. For people with learning disabilities there may be additional considerations related to the disability itself and the attitudes of others towards their disability, leading to what Oswin (1991; 2001) described as the “double taboo” of death and disability. People with learning disabilities have often been protected from the true impact of death, by well-meaning carers who want to minimise their distress. As previously identified, people who do not have the opportunities to do what they need to do following a loss, who may not have the chance to openly grieve, and who are not involved in the rituals surrounding death, may be described as disenfranchised grievers (Doka, 1989). Therefore, people with learning disabilities may be vulnerable from a death and bereavement perspective (Read & Elliott, 2003) as they are often reliant upon others to facilitate such opportunities to mourn.

Over-protectiveness often leads to disempowerment. Some individuals may not be encouraged to say goodbye to their loved ones; may not attend the funeral and are often misinformed (or not informed) about the death of their loved ones, until many months or years later. Indeed some people with a learning disability may never be told about the death of a family member. Such attitudes to loss and death do not help bereaved individuals to accommodate their grief.

Professional carers who support people with learning disabilities may find it difficult to facilitate constructive dialogues around death and bereavement because of the sensitivity of the topic area. Whilst others may have limited knowledge and negative attitudes regarding death and bereavement; may not have received adequate training and may not be aware of the resources available to help them in this task. They may also harbour an innate fear of

the individual's responses and reactions during death and bereavement, particularly from people who have a history of behaviours that can be challenging.

Bereavement affects people in different ways, and familiar carers might offer a strong sense of social support whilst also having a pivotal role in anticipating, identifying and acknowledging individual responses and the need for additional specialist input. Support at this time is crucial, both to the bereaved person and those responsible for their care. Service providers need to be mindful of the importance of support at such times and that such support may be needed in the short, medium and long term.

By identifying, acknowledging and addressing such challenges in an open, honest and sensitive way, carers can help the person with a learning disability to confront and deal with the resultant sadness and other associated feelings following the death of a loved one. When death and bereavement is dealt with in a supportive, sensitive and consistent way, individuals learn to develop personal coping strategies helping them to deal with future losses in a more constructive manner. Meaningful support is crucial to this process.

Meaningful support

Support may come from many directions and from many people, and carers may be involved with both offering and facilitating support to the bereaved individual. Finding out what the person knows, and needs, and identifying how such needs can be met are the first steps in the healing and helping process. Carers should **actively listen** to the individual (using body language, eye contact, facial expressions etc.) to look for common responses to loss and perceived difficulties in grieving.

The grief responses of people with learning disabilities are often delayed due to limited cognition, a lack of accurate information and the person's inability to specifically ask for what they may need. Therefore information about the death (and the rituals following the death such as funerals, memorials etc.) needs to be recorded in an accessible and permanent way. Since grief responses may take months and sometimes years to surface, such records will play an important role in providing pertinent information when supporting a person when the grief does surface. Sometimes, carers may not be in the best position to offer support and may need to seek alternative help such as bereavement counselling (see earlier section on when to refer on).



Practical support may involve offering people the **choice** to participate in the rituals surrounding death, thus enabling them to say goodbye to their loved ones in a way in which they feel comfortable. This may include accompanying someone to the Chapel of Rest; finding out about funeral arrangements and explaining these in a way that the person understands, and also contacting appropriate people who need to know about the death. Such approaches would help to minimise the disenfranchising effects described by Doka (1989; 2001).

When accessing additional support, carers may need to contact:

- Religious faith leaders
- Advocates
- Bereavement counsellors
- Community learning disability nurses
- Social workers

Carers should help the bereaved person to establish and maintain tangible, meaningful memories of the deceased in the form of photographs, life books and memory books.

Bereaved people often find comfort in personal keepsakes such as clothing, jewellery, music and perfumes, which are powerful reminders of the deceased. This too is in keeping with the promotion of continuing bonds (Klass et al, 1996); maintaining tangible links with people who are no longer visible. Many people find comfort in visiting the grave, or other similar memorial, and time should be set aside for these important visits or rituals of memorial. Similarly, important information about where the grave is located should be routinely kept in a person's personal file for future reference.

It is also worth remembering that the family and friends of

the person with a learning disability may be grieving too, and may need help and support at this sensitive time. Offering support to bereaved people may be difficult, and the needs of those providing support should not be overlooked. Professional carers may need a regular, shared opportunity to talk about such difficulties in a confidential and supportive environment, or may need to seek individual support, such as clinical supervision. Because of the diverse needs of people with learning disabilities, consistency of support is crucial. This booklet, in conjunction with two accompanying booklets, has been developed to ensure that support is delivered in a holistic, clear, consistent and meaningful way.



Communication and bereavement

Since more than 50% of people with learning disabilities have some form of communication difficulty (Kerr et al., 1996), carers need to be aware of the importance of using effective, clear communication. Allow time for the person to digest the information and repeat information often. Alternative methods of communication such as drawings, photographs and pictures may well be very useful.

Buckman describes bad news as any news that drastically and negatively alters someone's perceptions of their future (Buckman, 1991), and there are guidelines available to support this challenging process (e.g. Tuffrey-Wijne, 2013). Buckman (1991) offers a six-step protocol or framework that has been meaningfully integrated to support people with a learning disability (Read, 1998). This protocol includes:

1

Getting started, by finding an appropriate place or venue. This should be private, comfortable, and if possible, familiar. Ensure sufficient time is available to talk.

2

Finding out how much the person knows and understands. This might involve asking questions to explore understanding and using the booklets to empower the individual to ask appropriate and meaningful questions. Whilst many individuals with a learning disability have limited experience of grief work, McEvoy (1989) believes that they do have an understanding of the concepts of death, although this is variable.

3

Finding out how much the person wants to know. Although some people may not want to know the details surrounding the event, they do have a right to be told when someone has died.



4

Sharing the information, at the individual's own pace. Communicating in a way that the individual is likely to understand. The person should be provided with the basic facts, using language that is truthful and cannot be misunderstood, e.g. the person should be told that a relative/friend has died, not that the relative has left. Otherwise, the person may be left searching for their loved one.



5

Responding to the individual's feelings. Recognising and evaluating responses, offering constructive and reflective feedback, and working at an appropriate pace.



6

Planning and taking action. This involves, informing appropriate others (after Buckman, 1991, cited in Read, 1998).

Carers may be reluctant to inform individuals about someone dying if they have a history of challenging behaviours, for fear of inappropriate, unmanageable responses. Whilst recognising that such challenges may prove problematic, all individuals have the right to know about the death of their loved ones, and planning around staffing issues, immediate and ongoing support is crucial in these circumstances (Read, 1998).

There are now many resources available to enhance communication, such as reminiscence work, life books, symbols, Makaton, picTTalk and a snoezelen environment. It may be useful to refer to other professionals for advice, e.g. Speech and Language therapists and professional counsellors. Carers should also provide information about the bereavement to other agencies involved with the person (consent permitting), enabling those staff to contribute to the ongoing support when appropriate, thus providing consistency for the person. Care staff need to be told exactly what words and symbols have been used to explain the death in order to avoid confusion and promote consistent communication.

Reciprocal communication may be difficult for many reasons (e.g. limited cognition, minimal verbal language and incongruent non-verbal communication) and carers need to be creative in using appropriate resources. These include pictograms, reminiscence work (Stuart, 1999) and memory games to talk about the past. Although it is difficult and can be challenging, it is essential that the person be supported at this difficult time to minimise future recurrent problems.

One element of communication is that of making choices and decision making. Some of the choices following a bereavement can be difficult for anyone, and sometimes have to be made quickly (such as viewing the body to say goodbye prior to cremation or burial). People with a learning disability need to be given the appropriate information using

language that they understand to help them make informed choices. We all find these choices difficult and often want to change our minds, consequently people with a learning disability need to be reassured that it is all right to change their mind at the last moment. Even though it is acceptable for someone to change their mind and go back on a decision, some events have a cut-off point when it is too late, e.g. being able to view the body or go to the funeral (once the funeral has taken place it is too late to say they will go after all). Such choices are reflected in the accompanying leaflets.

People need to be reassured that whatever choices they make they will be given the necessary help and support to carry out these decisions, wherever feasible and possible. One choice they may have to make is whether they wish to see the body (as mentioned previously). For those individuals who wish to view the body, preparation is important. Individuals need to know that the body will not look the same, that it may smell distinctly different. A dead body will feel cold to the touch, will not be breathing, and will normally be in a box called a coffin. Such preparation is crucial in helping the person to make an informed decision and in helping them to anticipate what they might see, hear and smell when viewing a dead body, to minimise excessive distress.

Supporting people with learning disabilities may mean that carers need to be creative in the way they support a person with a learning disability, in order to access the bereaved world of the person, to try and understand and appreciate the bereaved person's needs.

Communication and creativity

Since the majority of people with learning disabilities have some form of communication difficulty, professional carers need to be creative in the design of activities chosen to help individuals work through their bereavement. People of all abilities experience bereavement and it is important that carers tailor their approaches to the individual's needs, abilities and interests. The activities outlined below are not an exhaustive list, but are intended to provide some ideas that may be delivered and adapted by support staff.

Media

Television, radio, and video can all be effective ways of engaging individuals and groups in discussion about their thoughts and feelings around sensitive topics. This can then be developed into a discussion about individual thoughts and feelings surrounding death. Using media in this way can help people with learning disabilities to explore their own thoughts and feelings in a safe, objective way. This may involve listening to a poem or a story and thinking about the emotions one of the characters may have felt following the death of a loved one.

Additionally, television programmes can teach individuals about the process and associated rituals surrounding death and bereavement. Although there are many benefits to using television programmes constructively, people need to be reminded that they are not real and that the characters are acting. It is not uncommon to see an actor die in one television programme only to see the same person apparently alive and well in another programme on a different tv channel some time later. For individuals who are visually impaired, recordings of radio plays or talking books may be used in the same way as television or video.

Example One : Making use of television



A hospital T.V drama may show someone having an illness and then dying. Watching the programme and then discussing its contents may be useful to explore individual feelings. Additionally, it may also be used as a way of helping to prepare someone for what may happen if a relative was terminally ill.

For some, this activity may be used to help them appreciate the feelings and emotions experienced by others. This can help them to understand how (for example) their friend at the Day Centre may be feeling following the death of their mother.

Music

Music is another way of helping people to identify and explore emotions and feelings. People may need help to make CDs of songs or music that bring back memories of their loved one. Or to create a CD that be used to help them relax when they are finding things difficult. Music is accessible to everyone and can be used with people of all abilities. Some individuals may be unable to provide information about the kind of music they like. In this case, when compiling tapes, family members could be approached about the type of music (or music associated with particular television programmes) enjoyed at home by the family.



Photographs and life story work

Photographs are particularly useful when people have expressive language problems and have been used in a variety of contexts (e.g. Jackson & Jackson, 1999). From a bereavement perspective, photos of the person who has died, of family members, that capture holidays, special events and places visited can constructively contribute to life story or memory books. Life story work revolves around the individual, has multiple functions, and provides a unique heritage about that person and can be developed with anyone, regardless of levels of ability. The process of creating a life book can also serve as a vehicle for acknowledging the present, exploring the past and planning for the future. They can be constructed as a book, as a folder or box, involve video or audio footage, and photographs and should involve the contributions from families, friends and carers. Life story work is a valuable and useful resource generally, but when a bereavement occurs information from the life book may be useful in helping the person to deal with the death. Additionally, information about the death can be incorporated in the life book as a natural event. Memory work is similarly developed, but has a specific focus (i.e. is usually based around a person who has died).

Example Two : Life story work

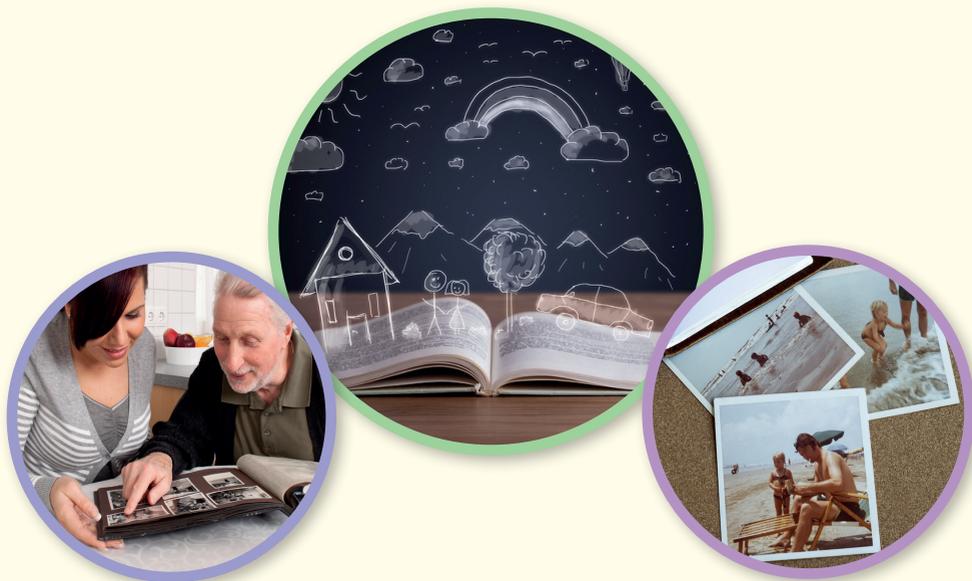


Jane has a learning disability, lives in a unit as part of a large institution for people with learning disabilities and has limited communication skills. Over the years she lost contact with her family, but continues to frequently talk about her father to the care staff.

The institution where she lived was due to close, and in order to help her through the resettlement process, the care staff started to develop a life story book with Jane. The care staff approached her father to get some background information of Jane's family and associated photographs. Her father willingly gave the information and this prompted him to start to visit his daughter again, which pleased her immensely. The staff took lots of photographs of Jane and her father when he visited.

The life book helped Jane when she moved to a new home and new carers. The carers were able to read about her background history and explore the contents of the book with her.

The life book came in useful again at a later date when her father died. The care staff were able to help her to incorporate important details of her father's death, and the process of selecting favourite photographs to put in the life book encouraged her to express her sadness which helped her through her loss. Jane was able to reflect on the photographs taken of her with her father and they helped her to remember the many good times they had shared.



Photographs are a relatively inexpensive but powerful way of retaining memories in a concrete way. With digital cameras, images can be stored and printed off as required if images become lost or damaged over time. Photographs can help the person to maintain a sense of self amidst all the changes that are occurring in their lives. If individuals have to move home or change Day Services, they may find themselves without anyone who knows them or their life history. Life books can therefore be particularly important when considering the multiple losses that are so often experienced by people with learning disabilities following a bereavement and photographs can contribute to these.

When individuals with expressive communication difficulties have suffered a bereavement, a useful approach is to help them make a small album of photos of their loved one, which is always available to them. If they attend a Day Service then a duplicate album should be available there. Such albums can also be used to quickly initiate interaction with staff about what has happened. They may also be useful as a way of gauging how individuals are feeling by assessing their reactions.

Example Three : Using a photo album



John was a young man with autism whose father was diagnosed with an inoperable brain tumour. John has no speech but became acutely aware that his father was very ill.

The family and staff at the Day Service collected photos together so that John could have a permanent reminder of his father. A copy of the album is kept at the Day Centre in a place John can access independently and easily.

Now, three years after his father's death, John will get his album out and smile at the photos of him and his dad doing things together. John also had a collection of amateur films of him and his dad together, which he likes to watch from time to time.

Art work

A range of creative activities can be used to encourage memories in either a group or individual setting. Creative activities can be adapted so that they are accessible to people of all abilities. Collages can be made from mementos of the person who has died, including photos, materials, jewellery etc. This can be a relatively inexpensive, manageable way for individuals to keep a wide variety of special, personal items belonging to their loved ones. Modelling clay and plasticine can be used to create models, which may be a way of creating an accessible, tactile, lasting reminder of someone and can be an enjoyable activity for people who have visual impairments.

Gardening

Gardening is an activity enjoyed by many people and creating a special area of the garden to remember loved ones can be especially useful when someone is unable to visit a grave. This can form a focus for remembering and celebrating important dates. It may be worth thinking about having a particular plant or tree that can grow in a pot, as opposed to planted in the ground, as it would be more portable should the individual move house.



Using games and activities

Table top activities such as jigsaws and board games can act as a diversion when talking about difficult topics. Through doing an activity together, professional carers can talk and offer support without making the person feel pressurised. Exercise (e.g. swimming, football) can be an effective way of releasing emotion and again provide a diversion from the pressures of one-to-one discussion about bereavement. Memory games (i.e. fun games to encourage memory and recall) can be used to initiate discussion and to help individuals retain and articulate their own memories and feelings about a loved one. Such activities can be a useful distractor, creating valuable opportunities to explore latent emotions.

Mementoes

These may be anything that individuals feel may help them to remember their loved one, forging connections as part of promoting continuing bonds (Klass et al, 1996). They may be items of jewellery, clothing or personal items, such as a smoking pipe or favourite hat. It is important to let individuals choose their own mementoes, as what they see as a special item may be very different from what carers may view as a special item. Individuals could be helped to decorate a special box in which their mementos can be kept safe and easily accessible. Mementos can also be used within a collage, as mentioned previously.

Smells

Smells have a very important and powerful link to memories and can be a useful way of keeping the memory of a loved one alive for individuals with more profound disabilities. Smells (e.g. perfumes, soap and other toiletries) may be reminiscent of a person, or may be reminiscent of buildings and places (e.g. furniture polish, washing powder, the smell of baking etc.). When working with people who struggle to communicate well verbally, smells can be used imaginatively and constructively. If possible, talk to relatives to establish a picture of the smells that individuals would have associated with their loved one (e.g. a certain perfume).

Many of the activity ideas outlined here can also be used in a proactive way to introduce and help an individual come to terms with the anticipated death of a loved one (see Examples one and two). Resources to support such positive practice can be found in the resource section of this booklet.

Conclusion

This resource has been designed to support those professionals to help people with learning disabilities who have been bereaved, either proactively (before the loss) or reactively (following the loss). However, professionals may decide to use parts of this booklet (particularly the more practical approaches) to inform and support family and friends too.

The concepts of grief have been gently introduced, specifically in relation to people with learning disabilities. Issues surrounding support, and challenges to offering effective support, are recognised and strategies described to overcome and minimise such barriers. Practical approaches are suggested and examples of good practice provided.

This booklet has been written in conjunction with three other booklets ('When someone you know has died...clear information'; 'When someone you know has died... a guide for carers offering bereavement support': 'When someone you know has died...people with learning disabilities supporting each other') to raise the profile of this sensitive topic and to ensure a consistency of meaningful support to this population. Whilst this booklet will never replace multi-disciplinary education and training, it is hoped that the ethos behind it will serve to complement existing learning opportunities. This booklet may also encourage the development whilst also encouraging the development of new initiatives to support bereavement, loss and people with a learning disability.

Useful resources

Babb, C. (2007). Living with shattered dreams: A parent's perspective of living with learning disability. *Learning Disability Practice*, 10(5): 14-18.

Blackman, N. (2003). *Loss and learning disability*. London: Worth Publ.

Blackman, N. & Todd, S. (2005). *Caring for people with learning disabilities who are dying*. London: Worth Publ.

Cathcart, F. (1994). *Understanding death and dying: Your feelings*. Kidderminster, Worc.: British Institute of Learning Disabilities.

Cathcart, F. (1994). *Understanding death and dying: A guide for families and friends*. Kidderminster, Worc.: British Institute of Learning Disabilities.

Cathcart, F. (1994). *Understanding death and dying: A guide for carers and other professionals*. Kidderminster, Worc.: British Institute of Learning Disabilities

Hatton, C, Turner, S, Shah, R, Rahim, N., Stansfield, J. (2004). *What about faith? A good practice guide to meeting the religious needs of people with learning disabilities*. London: Foundation for People with Learning Disabilities.

Heegaard, M. (1991). *When mum and dad separate: Children can learn to cope with grief from divorce*. U.S.A.: Woodland Press.

Hodges, S. (2003). *Counselling adults with learning disabilities*. New York: Palgrave McMillan.

Hollins, S. and Sireling, L., Webb, B. (2004). *When mum died*. (3rd ed.) London: Books Beyond Words.

- Hollins, S. and Sireling, L., Webb, B.** (2004). *When dad died*. (3rd ed.) London: Books Beyond Words.
- Hollins, S., Cappuccio, F., Adeline, P., Kopper, L.** (2005) *Looking after my heart*. London: Books Beyond Words.
- Hollins, S., Blackman, N., Dowling, S., Brighton, C.** (2003) *When somebody dies*. London: Books Beyond Words
- Hollins, S. & Perez, W.** (2000). *Looking after my breasts*. London: Books Beyond Words.
- Hollins, S. & Downer, J.** (2000). *Keeping healthy 'down below'*. London: Books Beyond Words.
- Hollins, S. & Wilson, J.** (2004). *Looking after my balls*. London: Books Beyond Words.
- Jennings, S.** (2005). *Creative storytelling with adults at risk*. Bicester, Oxon: Speechmark.
- Forrester-Jones, R. & Broadhurst, S.** (2007). *Autism & loss*. London: Jessica Kingsley Publishers.
- Jackson, E. & Jackson, N.** (1999). *Learning disability in focus: The use of photography in the care of people with a learning disability*. London: Jessica Kingsley Publ.
- Read, S. (2014).** *When someone you know has died...clear information*. (2nd edit) Staffordshire: Keele University.
- Read, S. (2014).** *When someone you know has died...A guide for carers offering bereavement support*. (2nd edit) Staffordshire: Keele University.
- Read, S. (2014).** *When someone you know has died...people with learning disabilities supporting each other*. Staffordshire: Keele University.

Read, S. (2014) (edit). *Supporting people with intellectual disabilities experiencing loss and bereavement: Theory and compassionate practice*. London: Jessica Kingsley Publ.

Read, S. (1999). *Bereavement and people with learning disabilities*. London: E-Map healthcare Ltd., Nursing Times Monograph No. 30.

Read, S. (1999). Creative ways of working when exploring the bereavement counselling process. IN: N.Blackman (edit) (1999). *Living with loss: Helping people with learning disabilities cope with loss and bereavement* (pp9-13). Brighton: Pavilion Publ.

Read, S. (2003). Bereavement and loss. IN: A.Markwick & A.Parrish (2003). *Learning disabilities: Themes and perspectives*. Edinburgh: Butterworth Hinemann.

Read, S & Bowler, C. (2007). Life story work and bereavement: Shared reflections on its usefulness. *Learning Disability Practice*,10 (4), 10-15.

Read, S. (2007). *Bereavement counselling for people with learning disabilities*. London: Quay Books.

Strohmer, D.C. & Prout, H.T. (edits) (1994). *Counselling and psychotherapy for persons with mental retardation and borderline intelligence*. Vermont: Clinical Psychology Publishing Co.

Tuffrey-Wijne, I. & Davies, J. (2006). This is my story: I've got cancer. 'The Veronica Project': an ethnographic study of experiences of people with learning disabilities who have cancer. *British Journal of Learning Disabilities*, 35: 7-11.

Tuffrey-Wijne, I. (2009). *Living with learning disabilities, dying with cancer: Thirteen Personal Stories*. London: Jessica Kingsley.

References

- Albom, M.** (2013). *The first phone call from heaven*. GB: Sphere.
- Arthur, A.R.** (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities*, 31, 25-30.
- Bowlby, J.** (1980). *Attachment and loss vol.3: Loss, sadness and depression*. London: The Hogarth Press and Institute of Psychoanalysis.
- Buckman, R.** (1991). *How to break bad news: A guide for health care professionals*. London: Papermac.
- Doka, K.J.** (1989) *Disenfranchised grief: Recognising hidden sorrow*. Toronto, Canada: Lexington Books.
- Doka, K.J.** (2002) (Edit) *Disenfranchised grief: New directions, challenges and strategies for practice*. Illinois: Research Press
- Elliott, D.** (1995). Helping people with learning disabilities to handle grief. *Nursing Times*, 91 (43), 27-29.
- Jackson E. & Jackson, N.** (1999). *Learning disability in focus: The use of photography in the care of people with a learning disability*. London: Jessica Kingsley Publ.
- Kerr M., Fraser W., & Felce, D** (1996). Primary health care for people with a learning disability. *British Journal of Learning Disabilities*, 24, (1), 2-8
- Klass, D., Silverman., P.R., & Nickman, S.L.,** (1996). *Continuing bonds: New understandings of grief*. Washington: Taylor & Francis.
- Machin, L.** (1998) (2nd Edit). *Looking at loss: Bereavement counselling pack*, Longman UK Ltd.
- McEvoy, J.** (1989). Investigating the concept of death in the mentally handicapped. *British Journal of Mental Subnormality*, 35 (2), 115-121.

- Oswin, M.** (1991). *Am I allowed to cry?* London: Souvenir Press.
- Oswin, M.** (2000). *Am I allowed to cry?* (2nd edit). London: Souvenir Press.
- Parkes, C.M.** (1996). (3rd Edit). *Bereavement: Studies of grief in adult life.* London: Routledge.
- Read, S.** (2014) (edit). *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice.* London: Jessica Kingsley Publ.
- Read, S.** (1998). Breaking bad news to people with learning disability. *British Journal of nursing*, 7(2), 86-91.
- Read, S.** (2000). Bereavement and people with learning disabilities. *Nursing and Residential Care*, 2(50), 230-234.
- Read S. & Elliott, D.** (2003). Death and learning disability: A vulnerability perspective. *Journal of Adult Protection*, 5, (1), 5-14.
- Stuart, M.** (1997). *Looking back, looking forward – reminiscence with people with learning disabilities.* Brighton: Pavilion Publ.
- Stroebe M., & Schutt, H.** (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), 197-225.
- Tuffrey-Wijne, I.** (2013). *How to break bad news to people with intellectual disabilities: A guide for carers and professionals.* London: Jessica Kingsley Publishers.
- Worden, W.J.** (2009) (4th Edit) *Grief counselling and grief therapy: A handbook for the mental health practitioner.* London: Tavistock Routledge.



Keele
University

For further information contact:

Sue Read
Professor of Learning Disability Nursing,
School of Nursing and Midwifery,
Clinical Education Centre,
UHNS,
NHS Trust,
Newcastle Road,
Staffordshire.
ST4 6QG
T: 01782 679653
E: s.c.read@keele.ac.uk

Acknowledgments:
Reach, Happy Day Design Ltd.



Happy Day
DESIGN

