

Loss

Bereavement support for people
who work with adults with a
learning difficulty



common knowledge

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About the workshop

Welcome to this practical course for those who support adults with learning difficulties at times of loss and bereavement.

After this workshop you will know more about:

- The history and experience of adults with learning difficulties in relation to death and loss
- The importance of ritual
- The grief process
- Different types of death and reactions to them
- The role of the support worker
- Breaking bad news
- The practicalities around death
- Practical resources that you can use to help you guide mourning
- Grief counselling - more help for you and for the people you support
- Death and ritual in different traditions, cultures and faiths

Common Knowledge

Common Knowledge is a partnership between people with a learning difficulty, families, statutory and voluntary sector organisations, further education colleges and Social Inclusion Partnerships.

The project is managed by SHS and jointly funded by the European Social Fund, Glasgow Learning Disability Partnership and the NHS in Glasgow.

**This information is available in different formats
please contact us for details (0141 276 3641) or
visit our web site (www.ckglasgow.org.uk)**

We have worked with some of our partners to produce this pack. We are grateful for the work of Fair Deal for One in One Hundred, Meldi, Pamis, Planning Together, Yorkhill Family Bereavement Project, Area Learning Disability Team, North West, Glasgow Learning Disability Partnership.

We would also like to thank Alistair Lawson who helped us by explaining some of the practicalities. We are also most grateful to Noelle Blackman from ROC whose experience and insight helped us to shape this pack.

On bereavement, grief and mourning

"In grief we veer from coping to not coping, from vivid clear memories to surprise at forgetting"

Maureen Oswin

"No one ever told me that grief felt so much like fear, I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning"

CS Lewis

"Our feelings after a loss are the price we pay for our attachment to other people"

S. Lieberman

"Grief will occur in everyone as it does not rely on cognitive understanding"

Deborah Davis, Living with Loss

"I dreamt of you again last night and when I woke it was as if you had died afresh"

Dora Carrington

Loss

DAY ONE Programme

9.30 Welcome and introduction

9.45 Hopes and fears

10.00 Groundrules

10.15 Euphemisms and taboos

10.30 Break

10.45 Reactions and experiences:
grief and mourning

11.15 A history of death and disability

11.30 Other losses

11.50 Models of grief

12.05 The four tasks of mourning
and an introduction to how
we can support people

12.20 Hopes and fears: learning log

12.30 Lunch

1.30 The memory exercise

1.50 the needs of the bereaved

2.10 Case study: zara the role of the
support worker

2.40 Break

3.00 Breaking bad news
Precious object
Learning log
Relaxation

Bereavement training

'Bereavement is what happens to you, grief is what you feel, mourning is what you do'

Bereavement

The word bereavement is thought to derive from the old English word 'breafian', which meant, 'to deprive'. Bereavement can best be defined as the state of being emotionally deprived. The word bereavement is commonly used to describe a person's condition in the months that follow the loss of a relative or friend by death.

Grief

When we grieve we experience deep and intense sorrow. This is apparent in our physical and emotional responses.

Mourning

Mourning is the process, which occurs after a significant loss, especially of a loved one. Grief is a process; individual expression of grief is determined in part by an individual's family and cultural background.

Group groundrules

why

This exercise gives the group an opportunity to agree groundrules for how they will work together in an inclusive and empowering way.

The theme of loss and bereavement is a particularly sensitive one and we want to create a supportive and affirming environment, in which people feel able to express themselves to the extent that they wish, whilst ensuring that the workshop remains a learning and beneficial experience for all.

This is also an opportunity for individual participants to check out any concerns they have at this point about the workshop.

how

We will give you between 5 and 10 minutes in small groups to agree groundrules. To help you come up with groundrules, it might be useful to think about the kinds of things the trainers and other participants would have to do to make you feel at ease and part of the group.

Another way of doing this is to think about the things the trainers or other participants might do which would make you feel uncomfortable and anxious - and make sure we all know not to do them.

Someone in the small group will have to take a note of the groundrules your group agree and report them back to the big group. You can take a note on the next page of the final list of groundrules agreed.

Our groundrules

1.....

2.....

3.....

4.....

5.....

6.....

7.....

8.....

9.....

10

Euphemisms and taboos

Think about, and list all of the words and phrases that we use instead of the words 'death' or 'dead'.

What are the words?

Any you haven't heard?

Does anyone know where any of these phrases come from?

Why do you think it is so hard for us to say 'death' or 'dead'?

What do you think these terms would mean to someone with a learning difficulty?

What impact might using these terms have on a person with a learning difficulty?

Reactions and experiences

Think of your experience of working with a person or people with a learning difficulty.

Were they told of the death?

Were they involved in the funeral preparations?

What do you think their experience of the mourning process was?

How was their grief handled?

How were they supported through the grief process?

Grief and mourning

why

To we explore loss as experienced by people with learning difficulties.

To consider people with learning difficulties' experiences in relation to loss and bereavement. To consider how people with learning difficulties are supported through the grief process at times of loss.

To become conscious of blocks to participation in the grief process.

To become more aware of how people with learning difficulties are excluded from full participation in the grief process.

how

We will work in small groups of 3 or 4. Take 20 minutes to reflect on your experience of supporting adults with learning difficulties in times of bereavement.

What might make it more difficult for a person with a learning disability to grieve?

In your experience, are people with learning difficulties treated in an inclusive way?

Someone should take notes summarising the discussions that have taken place in the small groups. The person who has taken the notes should then be able to give feedback to the whole group.

We kindly thank Noelle Blackman for this contribution

A history of death and disability

Take a couple of minutes to read through this text. Talk to your neighbour about the things that strike you.

The way in which a society deals with death illustrates a lot about that society and its beliefs and value systems. Contemporary society, at least on the surface, is somewhat uncomfortable with talking about death, mortality and issues of bereavement. People avoid talking about death. It is an awkward and difficult subject. To talk about death risks being accused of morbidity or of being overly fascinated with religion and the after-life. To be interested in what happens when you die suggests to some a lack of interest in, or ability to cope with, life as it is.

Maureen Oswin is one of the few people who have written about the experience of people with learning difficulties and bereavement. She noted that "despite all the advances made in changing attitudes towards people with learning difficulties, it appears that in the area of loss and bereavement they are still not receiving enough consideration, nor the appropriate support that they require". She attributed this to poor attitudes to people with learning difficulties, which have meant that their bereavement problems have been largely ignored. At the root of poor or inappropriate treatment was the belief that "they do not have the same feelings as the rest of us".

She points out that "death and grief create fears and uncertainties for most people, and the combination of bereavement and people with learning difficulties, a double taboo, has usually been considered so fraught that the problems have been swept under the carpet".

The history of death in learning difficulties is closely allied to the way in which adults with disabilities have been viewed and treated. So to begin with we will use that history as the framework for what we say.

Disabled people as an economic burden

Disabled people have often been seen as a drain on society, as people who do not contribute but require other people to pay for and support them. The 'colonies' and 'farm schools' set up to provide for people from 1870 onwards were organised to be as self-sufficient as possible, in order to reduce the

costs to the public purse. This was one of the pressures that encouraged very large establishments in rural settings to achieve economies of scale. Many hospitals in the UK had farms until recent years. These became virtually self-contained communities, with their own churches and clubs. When someone died in such an environment one of the primary concerns was that the whole process of death and the handling of the death should be as economic as possible and should not add to the cost of the institution. For this reason many individuals were buried in graveyards within the vicinity of the grounds of the hospital. The emphasis was on doing things cheaply.

Even before such colonies arose most people who would now be categorised as having a learning difficulty were buried by the Poor Fund or through proceeds from the Poor Law, many in the environs of workhouses and almshouses. Little physical evidence of these practices remain both for the reason that parish records often did not record the deaths of the 'febrile and simple' and if they did the graves were usually unmarked. Around the middle of the nineteenth century, there was a real shortage of graves in London. Graves were re-used; among the first to be 're-used' were those where the 'poor, feckless, halt and lame' had been buried.

Disabled people as eternal children

The belief that people with learning difficulties are eternal children is central to understanding the way in which people have sought to protect them from an awareness of death and mortality.

In previous generations, and in many cultures today, death is something that is hidden from children. The same attitudes have persisted for adults with learning difficulties. Individuals are often not told what is happening because it is thought that they do not understand the significance of the events around them. Adults with learning difficulties have often been denied their basic human right of being allowed to grieve for those important to them in their lives.

Maureen Oswin, in her work, recounts numerous instances of this sort of overt protectionism based on the view that the disabled are children or that they are unable to express appropriate emotions at difficult times. They are denied information, responsibility, and personal choice resulting in dis-empowerment and a lack of protection. The following two quotations illustrate this type of protectionism:

"After Mrs Z was widowed, the doctor advised: 'don't tell your son'. He had enough problems. 'He might make more problems for you, and anyway he

won't understand'. Acting on his advice Mrs Z kept the death of her husband a secret for several months and merely told her mentally handicapped son that father had 'gone away'. It was a dreadful strain for her, grieving for her husband and at the same time having to keep the death a secret from her adult son who was sharing the same house." (Oswin, The Grief That Does Not Speak, p6)

"One reason they (adults with learning difficulties) do not get much sympathy is that they may be labelled as 'not having the same emotions as the rest of us'. This can cause inaccurate judgements to be made about their normal reactions to a death. A sad-faced, unresponsive woman sitting glumly in a corner staff described as a 'typically dull mentally handicapped person' after she had been admitted to hospital following the sudden death of her widowed mother. They failed to see her as a person suffering from a bereavement." (Oswin, Alive To Death, p14)

Expressions of opinion by people with learning difficulties can be discounted. They are often not involved in the planning and organisation of funerals, in the family's grieving and practical decisions taken at the time of death. These activities are a key part of the grieving process. The sense of isolation and confusion is therefore exacerbated by their being often 'shut out' or 'removed' from their grieving families.

Research has shown that only about 50% of people with learning disabilities attend their parents' funerals (Hollings and Esterhuyzen 1997). There are many anecdotes of individuals being removed to enable the family to get on with their grieving.

"John came home from the day centre one day and discovered that his mother was cold and wasn't able to say anything to him. He knew that something was wrong and so he picked up the phone and dialled 999. After the police officers came they phoned the local social worker who arrived and told John not to worry and that everything would be okay.

John was very worried and not sure what was wrong with mum. He was confused by all the people who kept arriving in the house and was very upset when two men came and carried a big black bag out of the house because after they left he couldn't find his mum.

A few hours later someone else came and took John with them. He went with this person and stayed with them for two weeks. No one mentioned or talked about his mum. After that time he went back to his day centre, again no-one mentioned mum."

The use of respite care has often been used to help families at a difficult time. The reality for adults with learning difficulties is that being shut out, taken away, and kept quiet - all actions once routine in our response to children around death - are highly damaging and traumatic.

Disabled people as objects of charity and holy innocents

Disabled people may also be seen as objects of charity and some are seen "as gifts from God". The connection between disability and religious beliefs is not always consistent - sometimes serving such people brought the carer closer to God in some way and at others times the person was seen as a form of punishment for some previous sin.

The association with religious professionals and religious belief is a complex one in the history of learning difficulties. In a largely and ostensibly Christian culture in Britain, in pre-industrial times, disabled people were often supported in monasteries, by wealthy benefactors or through charitable donations from the parish. To some extent the development of modern 'hospitals' was a result of the need to care for those born disabled as well as those injured in 'holy battles'.

The word 'hospital' itself suggests a place of 'hospes', welcome and hospitality. It is probably true to say that many people with disabilities received a degree of protection and support in these religious communities. The Reformation (in the 16th century) resulted in the closure of the monasteries in Britain; many thousands of individuals were left to fend for themselves or thrown back on the care of their families.

Ambivalent attitudes have existed from medieval and early industrial times, with some people being cared for within their own communities, often in a paternalistic and protective way. Other people with learning difficulties became scapegoats or were accused of magic, witchcraft, or anti-religious belief and practice, and suffered as a result.

Throughout this period adults with learning difficulties were assumed to not understand what death was really about, although religious professionals did administer Christian sacraments to such individuals.

The Reformation, with its emphasis on intellectual knowledge and assent to religious belief led to the further marginalisation of people with learning difficulties. It is from this period that many people with learning difficulties were excluded from involvement in Christian practices and this would often

mean an exclusion from the rights of Christian burial within consecrated ground. Up until relatively recently only those who were 'Christian' were allowed to be buried within church grounds, and the churches held control over burial practices until the late 19th century.

With the secularisation of culture in Britain in the 20th century public burial grounds were developed and became the domain of local government. As a result of the increasing multi-ethnicity of communities facilities which were appropriate for non-Christians also became common from the 1960s onwards.

Many people with learning difficulties exercise their own religious beliefs and are part of religious communities. Evidence suggests that someone with a learning difficulty is more likely to be associated with a religious group. Given this, the role of religious professionals in and around death and bereavement is important, and those who support adults with learning difficulties need to be aware of different cultural and religious responses to death and bereavement.

Disabled people as having a life not worth living

The psychoanalyst Valerie Sinason has written "many learning disabled babies and children grow up breathing in an infanticidal wish. What is it like knowing you are dying when you have lived your whole life in the shadow of a death wish?"

The death of a person with a learning difficulty may be seen as a release for the family. In addition, people might minimise the loss, making glib or casual comments - as if they have not valued and thought the person's life to be as worthwhile as anyone else's.

Towards inclusion

From 1930 onwards in the UK, there has been a shift in official policy away from detention in institutions to life in the community. At the start of the 21st century the majority of people with a learning difficulty now live their lives in the community with family members or in supported or individual accommodation

Whether they are appropriately included and involved within those communities is open to debate. The experience of death and bereavement has become less institutionalised. Although an emphasis on protectionism

and avoidance of the issue remains, people with learning difficulties are increasingly aware of the nature of death as it impacts upon their lives within their local communities.

People with learning difficulties often lead lives that are characterised by loss. A person with a learning difficulty still dies at a much earlier age than average. Their experience of death is often much more frequent. People with learning difficulties suffer other losses too, often experiencing the early loss of parents on admission to institutional care. On leaving long stay hospitals people lose friends and acquaintances. The death of a parent can lead to the loss of everything familiar, a home, acquaintances, pets, and possessions.

The need to support people appropriately in and through that process is self-evident. People with learning disabilities have the right to be treated with dignity at times of death, not to have their behaviour medicalised or minimised, but valued and respected.

Other losses

why

To raise our awareness of the extent of the losses experienced by people with learning disabilities. To explore issues around multiple loss.

how

Work in small groups of 3 or 4. Take 20 minutes to write down what losses someone with a learning difficulty would experience on:

Leaving the family home?

Leaving a long stay hospital?

Someone should take notes summarising the discussions that have taken place in the small groups. The person who has taken the notes should then be able to give feedback to the whole group.

We kindly thank Noelle Blackman for this contribution

How we respond to bereavement

why

To give the group the opportunity to consider the signs and symptoms of grief and to understand the importance of recognising that people while there are common signs and symptoms of grief, people should be given space to grieve in their own way.

how

The whole group will watch a video.

Make a note of:

- How each character responds to the loss
- Compare the responses

The video will then be discussed with the whole group.

video notes

What reactions do you notice?

Make a note of features of the process of grief.

Signs and symptoms of normal grief

“An inability to recognise the person’s grief will make them lonely at the very time that they need other people and love and friendship.”

Maureen Oswin

Some of the most commonly experienced symptoms do not feel normal. They feel frightening and complicated. The stages of grief can co-exist, and come and go. There is a range of natural, physical and emotional responses to grief.

The following symptoms can be part of normal grief:

Physically

- Crying
- Sleep disturbance
- Tightness in chest
- Racing heart
- Over-sensitivity to noise
- Dry mouth
- Breathlessness
- Weakness
- Tightness in the throat
- Choking
- Shortness of breath
- Lack of energy, loss of sexual desire
- Hallucinations
- Difficulty concentrating
- Loss of appetite/sudden weight loss
- Use of psychotropic drugs
- Pain

Thoughts

- Disbelief

- Confusion
- Preoccupation with the deceased
- Sensing deceased's presence
- Wishing you were dead so you could be with the dead person
- Thinking life is not worth living or it will never be the same again

Actions

- Absent-minded/forgetful
- Social withdrawal/going out all the time
- Sleep disturbances
- Restlessness/over-activity
- Searching, visiting remembered places and the grave of the deceased
- Calling out for the deceased/dreaming about the deceased
- Not wanting to talk to people
- Not wanting to eat
- Bottling up feelings

Feelings

- Sadness
- Fear
- Yearning, pining
- Anger
- Relief
- Guilt or self-reproach
- Anxiety
- Worry that someone else you love will die
- Loneliness
- Numbness
- Spaced out
- Helplessness
- Shock
- Rapid mood changes
- Stuck
- Panic
- Stress
- Weak
- You want to run away
- Suicidal

Further notes

Models of grief: signs and symptoms

It can be helpful to think about the experience of grief as a series of stages. The grief process is usually described as having four or five stages.

Until recently, models of the process were based on the idea that everyone goes through the same sequence of stages in the recovery from grief, and at relatively the same speed. Departure from these stages, in either the type of mourning behaviour or the length of the period of mourning, was taken to be indicative of abnormal or pathological grief.

We now realise that grief is different for every individual. We do not necessarily go through all of the stages in the same sequence and with the same degree of ease or difficulty.

It's more helpful to think of grief as wheels and a whirlpool. Then you are less likely to expect someone to be at a certain stage by a certain time.

The 'Grief Wheel' (Grief Education Institute, Denver, 1986) - see diagram on page 22 - provides a simple framework to aid understanding of the experience of grief. The 'Grief Wheel' can be applied to any loss. It suggests that people need to go through four phases in the process of coming to terms with a loss. There are no clear dividing lines between phases, they merge, with some movement backward and forward. No time-scale is given for the grieving process either for each phase or as a whole. The four phases are:

Shock: the reality of the loss has not sunk in.

Protest: the person protests that the loss cannot be real, whilst at the same time being confronted with evidence that it is.

Disorganization: the reality of the loss becomes real.

Reorganization: the person begins to rebuild their life. The wheel is shown as being completed at a higher level than it began because many people do

report that, through the process of adjusting to a loss, they have, in some way, grown and become a stronger person.

Grief is individual; a wide range of feelings and changes may be experienced at each phase of the 'Grief Wheel', for example:

Shock

Numbness: a lack of feelings, probably because to acknowledge all the feelings would be overwhelming

Disbelief: "It hasn't really happened"; "It must be a mistake"

Hysteria: uncontrolled emotional excitement

Euphoria: an irrational feeling of happiness

Unemotional: apparently unaffected

Thinking: slow, chaotic or unaffected

Activity: slow, hyperactive, or unaffected

Suicidal thoughts: wanting to join the deceased

Protest

Sadness: an all-pervading feeling

Anger: may be directed at the deceased for leaving, or at others who may be blamed for the loss; or may be a general feeling of anger and irritability

Guilt: "if only": taking the blame for words spoken or not spoken, for actions done or not done

Fear: of own death, of survival, of inability to cope, of the future

Relief: perhaps after long illness

Yearning: the longing for the return of the lost person; may include a sense of presence, or seeing, hearing, smelling or feeling them

Searching: looking for the deceased, calling them or mistaking others for them

Preoccupation: with memories related to the loss; often includes thoughts of how to recover the lost person, dreams and nightmares

Physical distress: chest pains, fatigue, tensions, nausea, sleep disturbance, panic

Disorganisation

Confusion: often a mass of conflicting feelings and thoughts

Apathy: void of feeling, indifferent to what is happening

Aimlessness: no sense of purpose, not knowing where to go, lacking motivation

Loss of interest: not wanting to do anything

Loss of confidence: fear of failure, fear of not coping

Low self-esteem: somehow of less worth without the deceased, and less able

Anguish: deep emotional and often physical pain

Depression: low, flat, despairing

Anxiety: may be related to own mortality, or to feeling there is no way out and no way of coping

Loneliness: often not assuaged just by the company of others, which may in fact be avoided

Concentration and Memory: often poor for the task at hand

Sadness: sometimes described as a better feeling, if it is following a recovery from more intense depression

Loss of meaning: "Why are we here?"; "What's it all for?"

Loss of faith: may be damaged - "How can God do this?"

Hopelessness: unable to see a good future and perhaps feeling stuck, with no sign of change

Suicidal ideas: overwhelmed by hopelessness, depression and despair

Decreased resistance to illness: susceptibility to all sorts of minor, and possibly more major, illnesses

Reorganisation

Developing balanced memories: developing a more realistic memory of the deceased, both the good and bad aspects of their personality

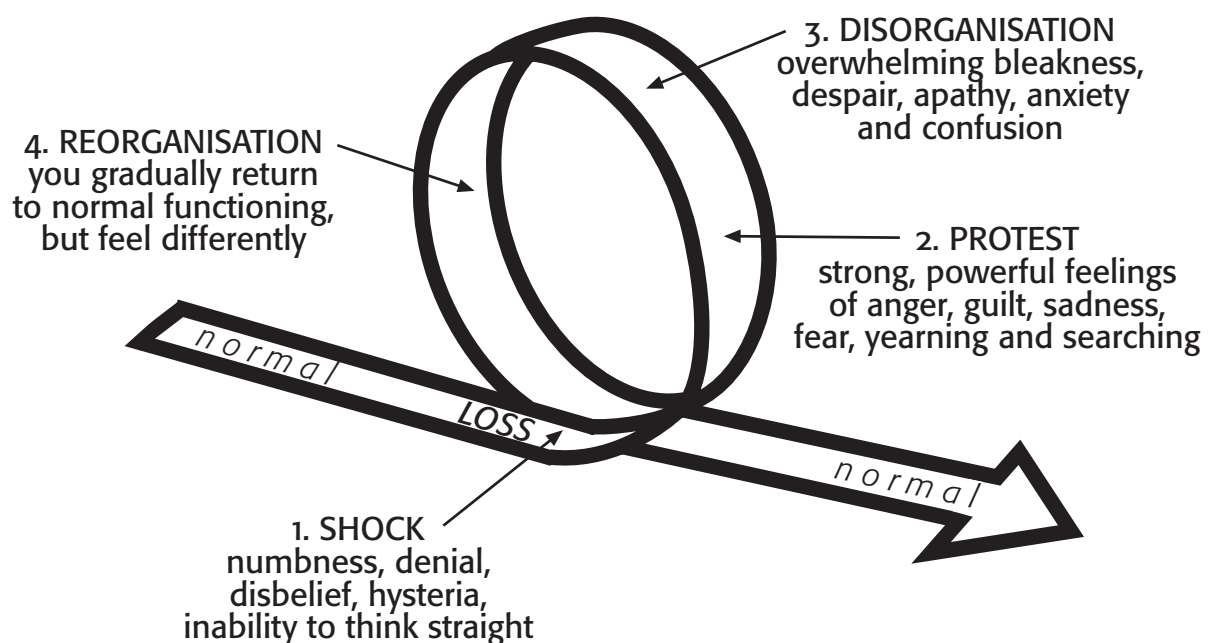
Pleasure in remembering: enjoying memories, although still sad as well, but no longer just painful

Control over remembering: some choice over when and what to remember; no longer preoccupied with memories

Return to previous levels of functioning: a resumption of activities, interest, motivation and ability

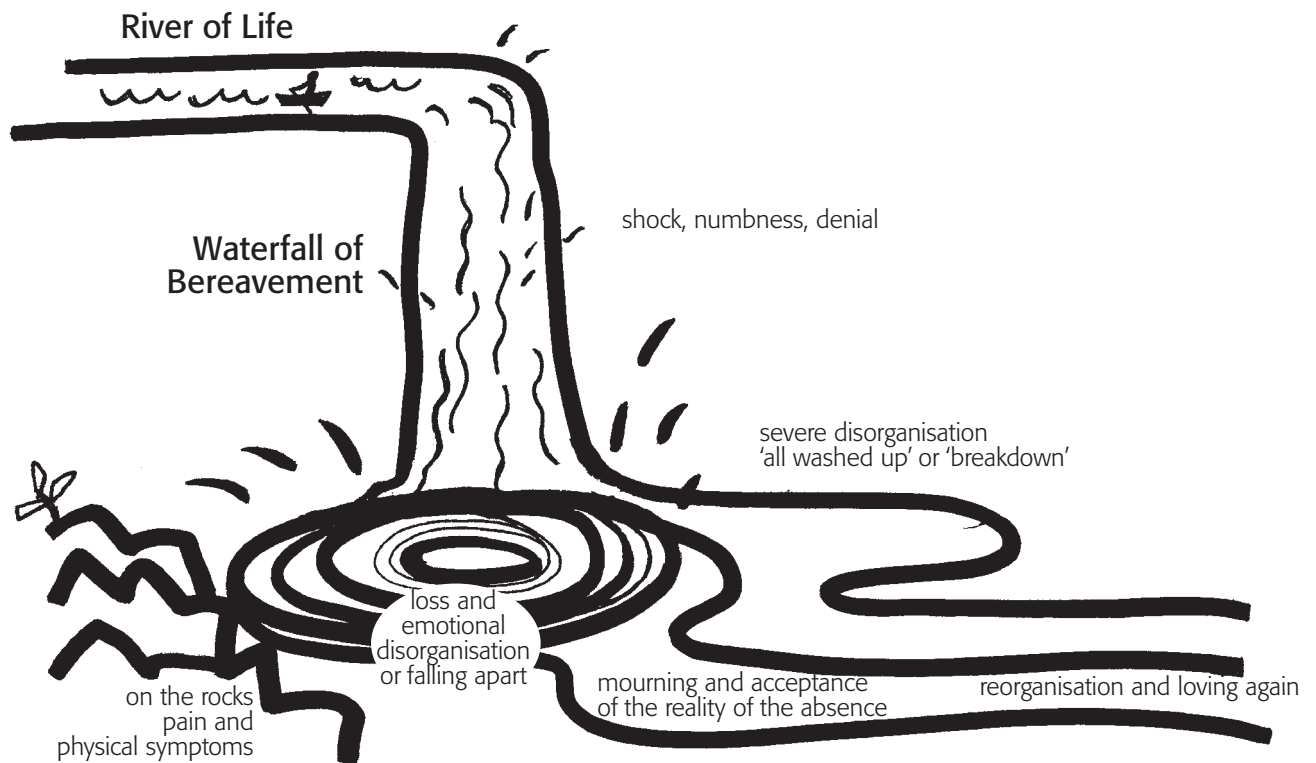
Changed values: a different view of the relative importance of things; new insight

New meaning in life: a new sense of purpose



An alternative model

This is a pictorial approach to grief developed by Dr Richard Wilson, a consultant Paediatrician at Kingston Hospital. It shows an oarsman rowing along the 'river of life' that is suddenly plunged down into the 'waterfall of bereavement' to the 'whirlpool of grief' below. The whirlpool whirls you around, sometimes you visit the calm shallows, and at other times you are cast against the rocks of despair.



The four tasks of mourning

Dr J William Worden, author and researcher on bereavement issues, has identified four tasks of mourning:

Task One: To Accept the Reality of the Loss

People often deny their loss. People will keep the person's clothing or possessions as if waiting for them to return. Alternatively, a person might try to deny how important the person was to them, or minimise the significance of the relationship.

Task Two: To Experience the Pain of Grief

It is important to feel the pain of sorrow and to express these sorrowful feelings. People often try to avoid the pain, for example, moving from a place that has many memories, or drinking to numb their senses.

Task Three: To Adapt to an Environment Without the Deceased

In our acceptance of the reality of our loss, we must develop new skills and interests and to develop new relationships to fill the void.

Task Four: To Withdraw Emotional Energy and Reinvest it in Other Activities

While they were living, much of our energy will have been focused on our loved one. Now that they are gone, we must direct that energy into new places - new interests, new friends. We will prioritise other relationships. People should be directing some of their energies toward taking good care of their emotional and physical health.

Memory exercise

why

We do this exercise to give us a better understanding of the grief process by relating it to our own experiences of loss.

how

Think back to a close relationship in your past, which ended. You may find it easier to think about a relationship which you chose to end.

Now, without giving any details of the relationship itself, describe:

- How you felt initially.
- How you felt after a few months.
- What helped you feel better.

Now, working in pairs, take a couple of minutes each to share your experience of what helped with your partner.

This is a time to be listened to.

There are two parts to this exercise:

What do people who have experienced a loss need?

What support is helpful or useful?

Compare your lists with the ones in your pack. Is there anything that surprises you?

The needs of the bereaved

Bereaved people need:

- The truth in words which are specific and appropriate
- Comfort
- Reassurance
- Routine
- To know that they will continue to be cared for
- Consistent care
- The opportunity to revisit the story
- Time
- Someone to listen and answer questions
- To feel safe
- To be allowed to cry
- Acceptance
- To be enabled to do whatever is appropriate and safe

...and the role of the support worker

Support workers can help people to complete the 'tasks of mourning.' They can offer support and comfort to a person.

A support worker can help people complete the four tasks of mourning by:

- Providing adequate and clear information
- Directly addressing fears and anxieties
- Offering reassurance that they are not to blame
- Helping people to say goodbye/ attend the funeral
- Listening carefully
- Validating feelings
- Helping deal with overwhelming feelings
- Involving and including the family
- Continuing with routines
- Modelling grief behaviour if appropriate
- Facilitating opportunities to remember
- Understanding normal and abnormal reactions
- Recognising the need for additional support

The needs of the bereaved

The personal history of Zara, a Muslim Woman

why

To give the group the opportunity to consider how support staff might be able to help individuals to complete the four tasks of mourning.

how

Work in small groups of three or four.

The group should appoint a scribe. This person should take a note of the small group discussions and be able to relay these discussions to the main group.

Consider what has been said in relation to the Four Tasks of Mourning, then:

- Read each paragraph carefully; has Zara undertaken any of the tasks of mourning? If so which tasks has she undertaken?
- If you were Zara's support worker, how might you help her in her efforts to undertake the tasks of mourning?
- Ignore the importance of practical needs.

Personal histories

This is the personal history of Zara, a Muslim woman

Zara was a middle aged Muslim woman. She lived at home with her family. She did not attend a day service. During the day Zara sat in the kitchen, helping her mother. In the evening she watched TV with her father. Zara was quite sociable, she enjoyed the company of her nieces and nephews. She loved music and liked to go out with the family when they went shopping.

One evening Zara's father had a heart attack. He had not told anyone about the pains in his chest. He died before the ambulance arrived. Zara witnessed the paramedic trying to resuscitate her father. She knew that he was dead. Zara's mother and sister were distressed and unable to accept their father's death. Zara stared at her father's body but did not cry.

At the mosque, Zara's brother and brother-in-law washed the body and wrapped it in the traditional way in a white cloth. When the body is washed and placed in the coffin, no one is allowed to touch it. Usually in Britain, the friends and family will come to the mosque and read a funeral prayer. Men perform this prayer. People come to see the body for the last time.

In the Muslim tradition the body is buried as soon as possible, ideally this is done within 24 hours. The mosque deals with all of the burial arrangements. Muslim graves are separate from non Muslim. The body is pointed towards Kabah, the house of God. The men of Zara's family went to the graveyard for the burial.

The women of Zara's family did not go to the burial. As part of a wife's mourning process she stays at home for 90 days. Zara saw her father for the last time when his body was brought back to the house. Zara's mother, sisters, family friends and relatives paid their last respects at home. Zara was very quiet.

It is customary that friends or relatives cook for the family for three days after the death. On the afternoon of the funeral neighbours cooked lunch and brought it to the family. Zara did not eat anything.

Zara was deeply hurt by her father's death. She sat in the living room and she would shout and swear. She would not sleep or eat. She started to lose a lot of weight. She did not go out, she would not walk. Zara's health deteriorated rapidly. The family were very concerned about Zara and they tried to talk to her, but she found it very hard to talk about her feelings.

Personal histories

These are comments from a support worker who worked with Susan, aged 29, who has Down's Syndrome:

'Susan had been coming to the club for about 10 years and had made lots of friends. Her favourite support worker was Alan. She was a lively, active and helpful person to have around. Always in a positive mood she really kept everything going when at times things got difficult.

In December we noticed that Susan began to get a lot quieter, she wouldn't join in any of the group activities. She began to sit on her own and turn away from others in the group. She didn't even want Alan to be with her. One time when a friend, Jane, tried to cuddle her, she shoved her away and ran screaming from the room.

Things seemed to go from bad to worse. In the art classes she kept on drawing clouds and dark pictures and wouldn't draw what we asked her to paint. We even caught her once trying to cut her finger with a knife. We decided not to tell anyone in case she might have got into trouble.

It was only later that we learned from her social worker that Susan's father with whom she lived had been taken to hospital and had died a few weeks earlier'.

Susan's support workers didn't know there was anything wrong in her life. How could this have been prevented?

What do you think the staff could have done to support her better?

When Susan tried to hurt herself did the staff act appropriately? If not, what should they have done?

Breaking Bad News

Do...

- Think carefully about who should break bad news
- Choose an appropriate time and place
- Ensure you have the facts as far as possible
- Be honest
- Take time
- Use direct language not euphemism
- Offer reassurance
- Accept the significance of the loss for the person concerned
- Answer questions honestly
- Be prepared to admit when you cannot find the answers
- Try to address needs
- Explore practical issues
- Explain what will happen next
- Ensure your own emotional safety
- Ensure that you are given support too

Don't...

- Panic
- Withhold information
- Pretend a person is alive if they are dead
- Bring your issues into the process
- Make guesses when facts are unknown
- Use language that might cause confusion
- Dismiss the significance of the news for the person concerned
- Avoid being honest in order to protect
- Ignore the importance of practical needs
- Offer false hope
- Try to move the person on in their grieving
- Accept the initial response as an indication of how the person is coping
- Ignore the impact of this experience upon yourself
- Not able to talk about the person without crying

Homework

What happens when someone dies - the practicalities

The role of the undertaker

This is a transcript of a conversation with Alistair Lawson, undertaker

"First and foremost we must be able to react like an emergency service. That is, at short notice, 24 hours a day, 365 days a year. Our aim is a response time of one hour or less. This feature of our work may not seem the most important until you need it. When that situation arises it is all that you want. If a minister or priest is called to a house of a death he/she should be able to rely on this back up. The quicker we can react to a difficult death in a private house the more confidence a family will have in our ability to co-ordinate, arrange and conduct the events leading up to the funeral and, of course, the funeral itself.

Gaining the confidence is a large part of taking the pressure and strain from our clients, leaving them to get on with the complex emotions of loss. This is done, as you know, with a combination of experience, knowledge and personality, most of which can be learned. However, it is probably better for everyone if it is felt. This aspect of our work has parallels with your own - Funeral Directing has a degree of vocation about it.

Once the initial contact has been made we must progress quickly. This is what our clients want. Our goal on the first day of contact is to set a time, date and a place for the Funeral Service. This is not always possible, but progress can always be made in the right direction. The goal, when achieved, seems to help families settle down. A palpable relief can be felt. It lets people spread the news. When the telephone starts to ring in the evening, concerned people can be told in one call instead of many return calls. Obviously early contact with whoever is likely to be taking the Service is vital (mobile phone anybody). It helps people feel connected. It can solve problems with commitments before they arise.

The benefits of early communication are many for all concerned. It may even be the secret to helping families approach the way they are feeling as opposed to what they still have to do. Our relationship with local clergy comes sharply into focus at this point. We do not take for granted the fact that we feel confident to call on a Minister or Priest in the district.

I hope that this confidence is reflected in the accurate feedback and reliable help we can provide to any of the local churches up to and on the day of a funeral (besides our funeral services, we provide a sounding board for people, an information and advice service and free pre-planning service, alongside our pre-paid Funeral Plans).

Once the three big questions have been answered (when, where and who?) the detailed planning can begin.

We always arrange: the collection of the deceased, collection, production and delivery of all relevant documentation, we pay out disbursements on peoples' behalf (that is, costs to them directly - flowers, catering, gratuities and fees). We give out our best advice on all aspects of our proposed service, guiding people away from the inappropriate and unworkable whilst encouraging individuality and attention to detail. Our knowledge of the various needs, conditions, rules and limitations at all local Churches, Cemeteries, Crematoriums, Hotels and our own premises can help bring together smooth and dignified service. Circumstances and personal change and a constant evolution takes place, to the point that over a ten-year period, big changes are felt.

We often arrange flowers, catering, transport, newspaper notices, hymn sheets, organisers, viewing of the deceased, headstones and ashes interments.

We sometimes arrange for international transportation (import and export), embalming of deceased and for funerals to take place anywhere in Britain (mostly Scotland). It is achieved largely through the co-operation of all concerned, something that we should look after as it is quite a rarity these days.

Over the years I have arranged accommodation; worn a top hat as requested; buried someone in a home made coffin; placed a giant (and I mean giant) leek and two huge onions on a coffin at the Crematorium instead of flowers; played "Goodness Gracious Great Balls of Fire" at Daldowie and a lot more besides. That is what keeps it interesting. Ours is a

fantastic job, small scale but important, people-based with a polished end product (no, not the coffin silly - the Funeral Day itself)".

We kindly thank Alistair Lawson for his contribution (2002)

**Remember to
bring a treasured
object with you
tomorrow!**

My learning log

what we did

what I learned
from this

what I will now
do differently

how I might apply
this

how I applied this

Loss

DAY TWO

Programme

9.30 Learning to listen

9.50 Reflection and listening
qualities of a good listener

10. 05 Techniques for active listening:
setting the scene

Boundaries:
ask yourself the right questions
before you start

10.15 Role play
Responding

10.25 Techniques for active listening:
open questions

10.40 Break

11.00 Techniques for active listening:
open questions

Role play

12.30 Lunch

1.30 Some tools and techniques for
helping people come to terms with
their loss

A break will be included at some point during the afternoon

3.30 Learning Log

4.00 Close and evaluation

Learning to listen

why

To give every participant the opportunity to share their views with others.

how

Work in pairs. The trainers will ask participants to reflect on all or part of the work they have undertaken on the course. Each person, in turn, should take two minutes. Remember you don't have to speak continually. You can pause and you can reflect.

The trainers will then ask for a general feedback on what was discussed in each group.

Listening

This is not always appropriate, but if these skills can be used they can be extremely effective.

Showing the speaker that you are listening to what is being said helps to build trust and makes it more likely that an individual will be open. You can help by:

- Noticing when a person needs help.
- Intervening - if there are signs that a person is having problems.
- You don't have to offer solutions.

The following techniques can help you to help a person to feel better:

- Listening actively.
- Responding effectively.

Reflection and listening

Qualities of a good listener

why

To give the group an opportunity to consider 'what makes a good listener?'

how

Have you ever had an experience when you were really listened to?
How did that feel?

Working individually, think about someone you have known who was a good listener - why were they so good, what skills and personal qualities did they have?

Now move into groups of 3. The group should draw up a list of all of the skills and qualities that make a good listener.

Techniques for active listening: setting the scene

The treasured object

Have a look at how Adrienne uses active listening techniques.

Note what you observe being done that is helpful.

Is there anything that was unusual about what Adrienne did?

Using questions well

Boundaries

Ask yourself some questions before you start doing this. Do you feel able/willing to do it?

- Select a place to talk that is quiet, free from interruption and distraction and not open to view.
- Plan for time to talk.
- Remember - quality not quantity of time. Convey a sense of being unhurried by using appropriate body language.

Responding

Some things to think about when responding:

- Maintain eye contact.
- Continuation behaviour -use nodding, use encouraging language (for example "go on", "uh-uh").
- Tolerating phrases - let a person gather their thoughts - do not jump in with questions or comments.
- Reflect facts - clarity and understanding.
- Reflect feelings - 'you felt let down?' and 'you felt angry'. Identify the emotions behind what the speaker is saying.
- Paraphrase and summarise - show you are listening and understanding their viewpoint.

Techniques for active listening: open questions

Work in pairs. Person 'A' hides something belonging to person 'B' somewhere in the training room. 'B' then uses open questions to find out where his/her belonging is hidden. If 'B' asks a closed question 'A' simply answers, "That is a closed question".

In the large group, quick think all the words which can be used to start an open question.

Supporting information Using questions well

Avoid:

- Leading questions - "Wouldn't you agree that...?" "Wouldn't you admit that...?"
- Multiple questions
- Multiple-choice questions - "do you think you would prefer to do... or...?"

Open Questions

Open questions relax people and encourage them to talk. The simplest way to ask an 'open question' is to ask questions beginning with words such as:

WHAT, WHERE, WHEN, WHY, HOW, WHO

The way that you ask questions influences the way that they are answered.

Examples:

Closed question: Did the interview go well?

(Alternative) Open question: How did you feel after the interview?

Closed: Do you enjoy the job you are doing?

Open: What do you most like about your job?

Closed: Are you getting on with your work colleagues?

Open: How are you getting on with your work colleagues?

Using questions well

Different kinds of questions

- Elaboration
- Specific
- Feelings
- Opinion

Elaboration - encourages openness

Examples"

"Tell me about..."

"Can you describe..."

Specific - for clarification, for confirmation of understanding

Examples:

"When exactly did this happen?"

"Can I just check?"

Feeling - to gain insight and understanding

Example:

"How did you feel...?"

Opinion - non-threatening, reveal views, move sessions forward when people are hesitant

Example:

"What do you think about...?"

Techniques for active listening

Your treasured object

why

To give the group an opportunity to practice the listening skills that are so important when supporting a bereaved person.

To reflect on the meaning and importance of objects in relation to memory.

how

Work in groups of three. One person should take the role of the speaker, another the listener and another the observer. Identify a speaker first - the speaker should take 10 minutes to talk about an object that is important to them.

The listener should practice their active listening skills.

The observer should make a note of how the listener demonstrates the active listening skills we have been discussing. The observer should record their observations on the sheet provided. The observer should give comment to the listener on how well they demonstrated the basic listening skills.

Each person in the group should take a turn of being the listener, the observer and the speaker.

Using resources

why

To help support staff to feel comfortable when they are trying to convey the concept of death.

how

We will discuss books and videos which will help to convey the concept of death. The death education resources help to convey all the components of the concept of death. The components of the concept of death are:

- Realisation – the awareness of death as a state of being, as something which happens
- Separation – the location of the dead, are they in the sky or under the ground?
- Immobility – are the dead active or inactive?
- Irrevocability – whether death is permanent or reversible
- Causality – external or internal causes, an accident or a heart attack?
- Dysfunctionality – the lack of body functions of the dead
- Insensitivity - the lack of sensory function
- Appearance – how someone may look when they are dead
- Universality – everyone dies
- Personification – the Bogeyman, the Grim Reaper

This has been adapted from Kane (1979)

Supporting John through bereavement - a support workers' experience

I was in the house alone with John, who has a complex and profound learning disability, when I received the phone call. It was his step-mum to say his Dad had died very suddenly from a heart attack - he was 46 years old. I was shocked, very upset and couldn't believe it. I wondered how I could tell John - he is deaf and uses signalong to communicate. I knew we were going to have great difficulty explaining to him and making it meaningful. But I never at any time thought he shouldn't be told. John is an adult and an equal. He had a right to know and to have the opportunity to grieve.

The other staff and I agreed that signing would not be the right way to explain what had happened, as John doesn't understand the sign for death. So I borrowed a book called 'When Dad died' and went through it with him. We spoke to the local undertaker and asked if we could bring John to the chapel of rest to see a coffin. they were very helpful. Beforehand I went through the book again with John.

Two staff members went with John to support him. We all went into the room and asked John to come over to the coffin and put a photo of his Dad on top. We kissed the photo and John did the same. We all waved goodbye. John lifted a hymn book - we did the same. We sang 'All things bright and beautiful'. We wanted to show John what people would be doing at the funeral service.

John is normally impatient and we thought he would want to go. But he sat

down and looked at the coffin for a short time. We moved away to give him time to himself. When we left he put his arm through my colleague's and took my hand. This may have been for security or comfort but we don't know.

To protect John, his step-mum felt it would be better for him if he didn't see his Dad at the chapel of rest and I respected this. We spoke about him going to the funeral and decided he should go and say goodbye to his Dad. If John wasn't involved, he might go through the rest of his life thinking his dad had rejected him because he didn't visit as before. It would be a traumatic experience but I knew that the people who knew John, and wanted to be there with him, would support him.

To help prepare John I video-taped a programme on television showing part of a funeral. When my colleague prepared his communication board the next day she put up a photo of the coffin, John's Dad and the staff who would be going to the funeral with him. After breakfast she showed the video. Then she showed John the black tie and white shirt he would be wearing and her own outfit.

When the rest of the staff arrived John looked at what we were wearing. Someone brought in candles to try and create an atmosphere of peace, and a different feeling from normal. I asked John if I could take a photo of him - he stood up immediately, almost to attention. It was as if the clothes he was wearing made him sense the seriousness of the situation.

We arrived at the crematorium early to let John see the building and to take some photos for a book that we would put together about his Dad and his death. We waited until most people were in and stopped to wave to the coffin. We sat near the back to allow John to go out if he wanted. During the service, when the curtain was closing, we all waved again and I showed John the photo of his Dad. When his family were leaving at the end John looked amazed that he knew so many people. He was probably looking for his Dad as well. I walked to the front with John and we waved again. We went back to John's house where one of the other men, with support from staff, had made a small buffet. We sat for a short time until John went and changed his clothes.

After a few days we went through the book again. I showed John a picture of someone planting a tree. We bought a small bush which he helped to plant and buried the picture of his Dad there. A few weeks later I was sitting

outside with John. He was looking at the bush and I noticed tears on his face. I took his hand and signed Dad - he signed Dad back. It was very emotional and I had tears in my eyes. I took John's hand and let him feel my tears to let him know I was trying to understand.

I feel that by involving John and trying different ways to explain to him about his Dad, he now has some understanding of what has happened and can grieve. Of course he hurts - but he would have hurt more if he had thought his Dad had rejected him. We are now gathering photos of his Dad and putting them in a book that John will have in his room to look at.

I would like people to reflect on this sometimes taboo and emotional subject and to talk to their families or the people who support their sons or daughters about their wishes in the same situation. I have since talked with the parents of the other men I support. They would both like their sons to be told of their parents' death and want them to attend their funerals. They realise that we all have to go through this to understand the finality of it all.

Belinda Paris, ENABLE Scotland

All names have been changed

From ENABLE's newsletter 'Newslink', Autumn 2001 issue

Referring on

Grief Counselling - is used to help people deal with normal or uncomplicated grief.

Grief Therapy - is used to help people deal with abnormal or pathological grief.

Who should receive grief counselling?

There are two main approaches to offering grief counselling:

1. Wait until the bereaved person gets into difficulties
2. Identify those at risk and make an early offer of support.

Who do you turn to when a person needs more help than you feel able to give?

Red flag Indicators

If you find that even after a very long time the person you support is still experiencing:

- Self-destructive behaviour/desire to die
- Marked social withdrawal
- Aggressive behaviour
- Somatic complaints
- Appetite disturbance
- Sleeping difficulties

- Not able to talk about the person without crying
- Neglecting themselves
- Reversal in behaviour patterns
- Persistent self-blame/guilt

Then think about accessing additional support

Who is at risk?

Not every bereaved person will need grief counselling.

There are several factors which have been shown to contribute to poor outcome following bereavement:

1. **Type of death**

Sudden or unexpected death - people recover less well if they have only had a short time to prepare for death. Often, there has been no chance to say goodbye. Disbelief about the loss interferes with the mourner's ability to come to terms with the reality of the death and its implications. Sometimes, the mourner will obsessively reconstruct events.

2. **Characteristics of the relationship**

If the relationship was poor, people can find a death particularly difficult to come to terms with.

The level of inter-dependence is also a factor; if people were heavily dependent on each other, especially when the person who has been very dependent dies, the bereaved person can struggle to come to terms with a changed identity.

3. **Characteristics of the survivor**

Those who are over anxious or insecure or who have had a previous mental illness are more at risk of running into difficulties. People who are excessively angry or self-reproachful also have a poorer outcome.

4. **Social Circumstances**

Lack of, or a perceived lack of, family support has also been associated with poor outcome, especially in situations where the bereaved person's grief is denied.

Type of death

Anticipated Death

Significant illness during old age or terminal illness can allow others to anticipate death and bereavement. Opportunities to prepare for death and funerals should not be ignored and can be very powerful ways of enabling the family to come to terms with the inevitable, and can facilitate the opportunity to say goodbye and to also reach a sense of closure.

Anticipated death can also raise other issues: there can be guilt associated with the sense of relief that the loved one is no longer suffering. There can also be other issues concerning the ways in which anticipated death through prolonged illness might have resulted in a change of responsibilities within the family - this can also produce feelings that need to be addressed. Sometimes, with terminal illness, the grieving begins before death, as often the state, and sometimes appearance of the loved one, changes so significantly. This again can raise issues and confused feelings within the grieving process.

Other types of death can increase the potential for complicated grieving.

Sudden Death: Murder

For the bereaved, there is clearly a sense of having the life of their loved one "stolen" from them. The anger that is a natural part of grieving becomes accentuated, intensified and directed towards the hands of whoever committed the murder. When there is no identified criminal, this can cause displaced anger and confusion. There is sometimes a searching for somewhere to place such anger.

Murder is a tremendous violation. The bereaved also has to face the media attention that this type of death can attract. It can mean that the need to grieve privately can also be "stolen" from them. Murder can delay the possibility of closure when there are legal and criminal implications, which necessarily take time and can delay the grieving process.

Further complications arise when another family member commits the murder. This can cause significant problems for families as they try to come to terms with what has happened and experience divided loyalties and marked conflict of feelings. Those who witness the murder of their loved one

experience very deep trauma and need support for some time. It is sometimes necessary to refer witnesses of such crimes for more specialised psychiatric help.

Suicide

This form of death can again raise feelings of violation for those left behind. Those who discover the deceased will often need specialised support and referral to psychiatric services.

The nature of the suicide can also produce complicated feelings and trauma. If the person has made suicide attempts before, there can be mixed feelings for those left behind.

People can also experience conflict in their religious beliefs with regard to suicide and may also have difficulties understanding the problems which the person who killed themselves might have been struggling with.

If the suicide is not anticipated, there will be questions for the bereaved, which cannot always be answered. If signs have been given that this might happen one day, there may be associated feelings of guilt that nobody acted in time. Death through suicide can intensify anger, rejection and abandonment. The bereaved needs to place such feelings somewhere and can sometimes feel guilty for feeling angry towards the deceased.

Suicide can raise tremendously painful questions of abandonment and wondering if the deceased really loved those left behind. Such questions need careful handling and therapeutic intervention is necessary if they are to work towards closure.

Accidental Death

Such deaths can, like death through suicide or murder, raise significant questions for which there might not be any easy answers. The shock stage of grieving can overwhelm the bereaved. It is vital that those who are caring for the bereaved are aware of this important stage in which denial figures so significantly. Those who are trying to support the bereaved can often misinterpret this.

Death by accident, can, by its very nature, also complicate the grieving process, because the bereaved might not be able to view the deceased, or might not have the opportunity to say goodbye in an appropriate way. Included in this important area are those deaths where bodies are not

found, and this can further complicate the grieving process. The events of September 11th stand as an example of the need for loved ones to have "some fragment" (as one parent said of her daughter who was killed in the second Tower) to lay to rest and to grieve appropriately.

Death as a result of terrorism, death at sea, or any situation where a body is not available for the ritual of burial etc., can cause complications for those who grieve. The bereaved need consistent care and support in being able to say goodbye and reach closure. Once again, if there are issues that continue to traumatise the bereaved, then they should be encouraged to seek psychiatric referral.

We kindly thank Tina Campbell for this contribution

Additional support

Who do you turn to when a person needs more help than you feel able to give?

Referring on:

RESPOND Helpline

Tel: 0808 8080700

A helpline for people with learning difficulties who have experienced a bereavement

Cruse

Tel: 01738 444 178

An organisation which offers bereavement counselling

Some tools and techniques for helping people to come to terms with their loss

why

To give the group an opportunity to try out a range of tools that support staff can use with people. These tools can help people to express themselves and their feelings, to remember things, and can help people to come to terms with their loss.

- Storyboard
- A photo album
- An inner and feelings box
- A mask
- Sympathy cards
- A fear collage
- Christmas baubles
- Emotions cards
- A first aid kit
- Life stories
- A box with mementoes
- A memory jar
- Drawings, paintings, poems

how

We will demonstrate how to make and use each tool then we will give you 20 minutes to experiment with producing some of the tools. Work in groups of three.

Wills and Trusts

What is a will?

A will is a legal document that lists who you want your money and possessions to go to after you die. It's advisable to make a will regardless of whether you think your belongings are worth anything. If you leave money or estate behind and no will it may not go to the people you want it to and cause your family a lot of problems.

Your will can also state what you want to happen to your body, whether you want to be buried or cremated your views on organ donation etc. It may state who you have appointed to be your executors or who you would like to act as guardian to your children. Don't attempt to write your own will or one that has been pre-printed. It is advisable to consult a solicitor to give you advice. Let your family know where your will is kept. This will make it easier for your family to meet your requests as soon after you die as possible.

Parents or carers may want to make a will to provide money for the person they care for. They will be concerned about the care that person will receive after their death and may wish to set up a discretionary trust or a user-controlled trust fund which names those who will help the person manage their money.

People with a disability can also leave a will if they have possessions or money that they would like to see going to someone specific. The person must have an understanding of what they are doing in order for the will to be a legally binding document. The person must be over 16 years old.

Some parents aren't sure whether to leave money to their child who has a disability. This can be a difficult decision especially if the person cannot manage his or her own money. If you leave a will to your other sons and daughters and not your disabled son or daughter they can still make a claim on your estate, as it is their legal right. Trusts are an option of leaving money and ensuring that it is used appropriately.

What is a trust?

A trust is an arrangement where people called trustees manage money for specific purposes. The people for whom the trust has been set up are called beneficiaries. The trust states that the trustee must invest the capital and pay

the income from the investment to the beneficiary. In so doing the beneficiary does not legally belong to the capital and can continue to claim some benefits. The trustees can also take on some other roles. These must be stated in the will. Some of these extra powers can be:

Advancing the capital - this is where the beneficiary requires a major item that costs more than the trusts income.

Accumulating the income - this means that instead of paying the income to the beneficiary the money can be reinvested in the trust fund. This is a discretionary trust. This can only be accumulated for a maximum of 21 years.

It is advisable to have 2 trustees. One of these people should know the beneficiary well and it can be a good move to have someone of a similar age. The other trustee should be someone who is familiar with investments such as a solicitor. It is important to seek legal guidance when setting up a trust.

For further information contact:

ENABLE Legal Services
6th Floor
7 Buchanan Street
Glasgow
G1 3HL

Tel: 0141 226 4541

Death and its rituals in different religions and cultures

Judaism

Jews believe that a Jew is someone who is the child of a Jewish mother, and who has not adopted another faith. Jews, or someone who converts to Judaism, believe that there is a single God who created the universe and with whom every Jew can have a personal relationship. They believe that God continues to work in the world, affecting everything that people do. The Jewish relationship with God is a “covenant” relationship. In exchange for the many good deeds that God has done and continues to do for the Jewish People, the Jews keep God’s laws, seeking to bring holiness into every aspect of their lives.

Jews believe that God appointed the Jews to be his chosen people in order to set an example of holiness and ethical behaviour to the world. Jewish life is very much the life of a community and there are many activities that Jews must do as a community. For example, the Jewish prayer book uses ‘we’ and ‘our’ in prayers rather than ‘I’ and ‘mine’. Jews feel part of a global community. Much of Jewish religious life is based around the home and family activities.

Mourning

There are five stages of mourning in Judaism.

1. Between death and burial.
2. The first three days following burial. Visitors are sometimes discouraged from visiting during this time, since the loss is still too fresh.
3. Shiva - the seven day mourning period following burial (this includes the first three days)
4. Shloshim - 30 days following burial (includes Shiva). The mourner slowly emerges back into society.
5. Twelve month period (includes shloshim) when life becomes more routine.

The mourning period for all relatives, other than the mother and father, ends with Shloshim. The laws from day 31 through to the end of the twelfth month are only exercised by parents.

Shiva

Shiva begins immediately when the casket is covered with earth. Mourners who are unable to go to the cemetery begin Shiva at the approximate time of burial. Shiva ends seven days later after the morning prayer service. The day of burial is counted as the first even though it is not a full day.

If Shiva has begun and there is a major holiday (Rosh Hashanah, Yom Kippur, Passover, Shavout, Sukkot) then Shiva is seen as complete and the rest of the days are nullified, because it is mandatory to be joyful on a holiday. If the death occurred on the holiday itself, then the burial and Shiva begin afterwards. The ideal place to sit Shiva is in the home of the deceased since the spirit continues to dwell there. The mourner washes his hands before entering the house, eats a meal and sets up the house for mourning status.

Shiva restrictions and prohibitions

- Leaving the house of mourning is limited.
- Mirrors are covered.
- The mourner sits on a low stool.
- Leather shoes are prohibited (in ancient times. Leather shoes were a symbol of wealth and comfort).
- Greetings are prohibited from both the mourner and those coming to extend their condolences. The exception is the Sabbath.
- Bathing is prohibited. Dirt may be removed locally with soap and water.
- Haircuts are prohibited. Shaving is prohibited for men.
- Cutting nails is prohibited.
- Washing clothes is prohibited with the exception of clothes to be worn on the Sabbath.
- Wearing new clothes is prohibited. (after the Shiva period until the end of the twelfth, if it is necessary to buy new clothes, the mourner should have someone wear it for him so that it is not considered to be "new" any more).
- Marital relations are forbidden.
- Studying the scriptures is prohibited since it is a source of great delight.
- Conducting business is prohibited.
- Attending parties is prohibited.

On the Sabbath the mourner is allowed to leave the house of mourning to go to the synagogue. Immediately following the evening service on the Saturday night, the mourner resumes his full status of mourning.

Condolence during Shiva

It's a mitzvah or good deed, to make a condolence call. The condolence call is to relieve the mourner of his feeling of loneliness. Yet, at the same time, the visitor waits for the mourner to initiate the conversation. It is up to the mourner to dictate what he wants to talk about and express. The last thing that the visitor says to the mourner before leaving is 'May god comfort you among the other mourners of Zion and Jerusalem'.

Rituals relating to death

The body is tended immediately, to preserve the sanctity of man. Although the body is no longer used, the form must be respected for having once housed the spirit of God. Immediate members of the family should not be present while preparing the body for the burial. The deceased is dressed in a shroud. All human beings are considered equal and are dressed in the same manner. Poor and rich alike are dressed in a simple white garment without pockets. The body is then wrapped in a prayer shawl with one of the fringes cut to symbolise the mourning period and loss. The coffin is simple and made completely of wood (in Israel no coffins are used at all; the body is put into the ground in the prayer shawl). The concept is that wood decomposes at the same rate as the body.

Funerals

The deceased must be buried in the earth, therefore, cremation and embalming are forbidden. There should be a natural decomposition of the body. Usually family and close friends act as pallbearers and they are the ones to start shovelling dirt into the grave. Kaddish, the prayer recited for the deceased, is recited at this time.

All those present at the funeral must wash their hands afterward. There is an emphasis on life since one has just come in contact with the dead. This is like a purification process.

Christianity

The Christian religion acknowledges the divinity of Jesus Christ. Christians believe that some 2 000 years ago God became man on earth in the person of Jesus Christ. He was crucified, rose from the dead and ascended to heaven.

Approximately one third of the world's population professes some form of Christianity. There are many different Christian churches, with differing structures, beliefs and rituals, but the concept of one God who reveals Himself as a Father, a Son and a Holy Spirit (the Trinity), is central to all Christian teaching.

Sacraments are ceremonies, which Christians believe, were ordained by Jesus Christ and confer spiritual gifts on those who receive them. Christian tradition recognises seven sacraments. Baptism, the 'essential' sacrament, marks the entry of a person into the family of Christ. The Eucharist is the 'principal' sacrament (also called Holy Communion, Lord's Supper or Mass), whereby bread and wine, symbolising the body and the blood of Christ, are taken in His memory. The other sacraments are confirmation, penance, the sacrament of the sick, matrimony and priestly ordination. Different churches vary in the importance they attach to the different sacraments, and their relevance to dying and death.

In England the established Church is the Church of England, or the Anglican Church. Its adherents are called Anglicans. Anglican dogma is also common to the church in Wales, the Church in Ireland, and the Episcopalian Church in Scotland. Anglicans account for only 4% of the world's Christians, but they are the majority religious group in the UK, where some 57% of the population consider themselves to be Anglican.

In Scotland the Christian population is almost equally divided between the Church of Scotland (Presbyterian) and the Roman Catholic Church. Presbyterianism or Protestantism is a different way of organising the Church and arose after the Reformation of the 16th century.

Post-mortems, transplants, transfusions, and body donation

Post-mortem examinations are not forbidden on religious grounds. There is no church teaching regarding the disfigurement of a body: only the soul is believed to transcend to the next world. There is no religious objection to the giving or receiving of blood or organs, nor to the donation of the body for teaching or research. In this last case the church would offer a memorial service after the death, and a funeral service later, when the body is finally interred.

Procedure at death

Prayers may be said at the bedside at the point of death, or over the body of the patient after death, in the ward or in the mortuary chapel. The minister offers thanks for the life, which has passed and commends the soul to God's

keeping. Last offices (the washing and laying out of a body) are carried out according to normal ward practice.

Funerals

An Anglican body may be laid in the coffin with the hands crossed over the chest, placed in an attitude of prayer or supine with the hands at the sides. Burial and cremation are equally acceptable.

Roman Catholicism

The Roman Catholic Church is the religious body of Christians that accept the supreme jurisdiction of the Bishop of Rome (the Pope). The Pope is acknowledged to be the true successor to St Peter, claimed to be the apostle appointed by Christ to the head of His church. Catholics make up approximately 57% of the world's total Christian population. Probably almost a fifth of the human race belongs to the Roman Catholic faith, and Catholics constitute about 13% of the total population of the UK.

The Catholic Church teaches that God is the Trinity (Father, Son and Holy Spirit), but also extols the intercessional qualities of Mary, the mother of Christ. It places greater emphasis on the sacraments and the symbolic significance of worship than do many other churches. The Catholic Church teaches that this life is merely a beginning and that death is a step to the 'fullness of life'.

Baptism has great significance for Catholics of all ages. It is of particular importance that a child should be baptised before or even at death. A priest should be called in appropriate situations, but anyone, even a non-believer, may baptise in an emergency. A little water is poured onto the forehead of the patient, with the words 'I baptise you in the name of the Father, the Son and the Holy Spirit'.

For those already baptised, the sacrament of the sick is a symbol of Christ's healing and loving. It can be adapted to the severity of the illness and repeated if circumstances change. If the person is dying, the priest anoints the dying person with consecrated oil on the forehead and hands in a ceremony (sometimes called 'extreme unction') which symbolises forgiveness, healing and reconciliation. These sacraments are of enormous significance to believers.

Post mortems, transfusions, transplant and body donation

There is no religious objection to these but the body should be treated with reverence at all times.

Procedure at death

At the point of death, and up to three hours after death, extreme unction may be given. Routine last offices are appropriate and there is no religious objection to non-Catholics handling the body.

Funerals

Traditionally in the UK and Eire, Catholics are buried rather than cremated, but there is no religious prohibition to cremation. In some communities, particularly among Irish Catholics, it is customary to display the body after death or at the funeral - so the body should be embalmed. Some families, particularly Irish, Italian and Spanish ones may wish to take the body back to their homeland for the funeral. They will require an 'out of UK' certificate to do so. A requiem mass may be held later to pray for the deceased and comfort the family and their mourners.

Other Churches

There are many Christian groups in the UK apart from the Anglican, Presbyterian and Roman Catholic Churches. Some have very distinct beliefs and practices. Some churches have links with ancient mainstream churches of other countries (as for example, the Greek and Russian Orthodox) and are subject to their control. Those churches, which are tied neither to the State, nor to Rome and which do not conform to the Anglican and Catholic tradition of hierarchical church organisation are known as 'free' or 'non-conformist'. Some adherents will describe themselves as Protestants or Chapel. These churches include:

- The Methodist Church (at least 450,000 adherents in the UK).
- Baptists (170,000).
- The Salvation Army (some 924 churches 139 engaged in Evangelistic and social activities in 1987).
- The Society of Friends, or Quakers, with about 18,000 members.
- Seventh Day Adventists (16,500 members).
- The General Assembly of Unitarian and Free Christian Churches, the Free Church of England, the United Reform Church and many others.
- The Lutheran Church has over 70 million members worldwide, but only about 27,000 in the UK. Lutheran services in the immigrant communities here are often held in other languages. All these groups have much in common despite their diversity.

Post-mortems, transfusions, transplants and body donation

There is no religious objection to any of the above.

Procedure at death

For most other churches some form of service at death is often appropriate.

Funerals

Burial and cremation are usually acceptable to most other churches.

Jehovah's Witnesses

Jehovah's Witnesses are deeply religious people who try to live their lives according to the Old and New Testaments. They believe that the Kingdom of God will soon be experienced on earth. At that time God will resurrect many former inhabitants on earth and a number who are so destined will rule in heaven with Christ. Although Jehovah's Witnesses have no belief in the Trinity, they do regard Jesus Christ as the Son of God and declare themselves to be Christians. There are no separate clergy. All Witnesses are committed to spreading the faith, which was formalised in the USA in the 19th century and has now spread all over the world. There are about 117,000 Jehovah's Witnesses in the UK.

Jehovah's Witnesses have fundamental religious objection to the use of blood as part of medical practice, based on teachings from the Bible, which refer to blood as 'the soul of the flesh' (Genesis 9: 3-4, Acts 15:20, 28-29; 21:25). These passages forbid the consumption of it orally and intravenously. To Witnesses, blood represents life itself and must be handled with respect. It is not acceptable for it to be stored.

Baptism is unusual before the age of twelve and a young child is protected by the dedicated state of the parents and would not require urgent baptism even in extremis. Baptised parents will not give consent for a blood transfusion for their child, which they regard as against biblical teaching. Only those Witnesses who know that they are of the heavenly calling take the emblems of the bread and wine, representing Christ's body and blood. The ceremony, the Memorial, takes place only once a year on the anniversary of the death of Christ.

There is dietary prohibition against blood and against the consumption of animals that have been strangled. Each Witness takes responsibility to inquire whether blood or blood products are part of the dish offered. Black pudding, a sausage made from animal blood, would be unacceptable, as would game that had been shot and improperly bled.

Jehovah's Witnesses will want reassurance that blood will not be used against their wishes. Family, friends and elders of the congregation will wish to visit, but there is no formal ritual for the dying.

Post-mortems and body donation

The living body is dedicated to God, but the body has no particular religious significance once the breath of life has left it. Post-mortem examination or body donation would therefore be a matter for individual conscience.

Transplants

In general, there are no religious principles against transplants and many aspects would be left to the individual to decide. Reception of components may be acceptable where no blood is involved, as with corneas. Donation of organs would likewise be a matter for individuals to decide, but because other blood would then flow through that organ. It is unlikely that Witnesses would be willing donors of major organs.

Procedure at death

There are no particular rites at death. Routine last offices are appropriate.

Funerals

Both burial and cremation are acceptable. There is no formal written service; each is prepared as appropriate for the individual Witness. The ceremony may take place in the Kingdom Hall (the meeting place of the congregation) or at the crematorium.

The Afro-Caribbean Community

The major Christian churches in the afro-Caribbean community are Anglican, Methodist and Pentecostal and among the older generations, a high proportion of the followers are church attendees. The church is a social and community centre as well as a religious one. In the UK, the religious background of an Afro-Caribbean community will reflect the culture of the island from which its members came. At death, religious differences are likely to be minimised, and cultural and island identity predominate.

On the whole these communities are likely to be more demonstrative in the practice of religion than their Caucasian counterparts. For example Afro-Caribbean Methodists regard baptism as very important, and the baptismal service for a child is major religious occasion for his or her family and friends. Sometimes, parents do not marry and may not live together. Grandparents

are central in family relationships and often play a major part in the rearing of grandchildren. The extended family structure may be complex but the family influence is strong, good relations are maintained and the family come together at the death of one of its members. Most of the younger members of the Afro-Caribbean community were born in the UK, and the Caribbean influence may be less strong for them than for their parents and grandparents.

Post-mortem and body donation

Older members of the community may believe that the body must be intact for the after life and will be deeply offended by its disfigurement. They are unlikely to give consent for post-mortem except for coroner's cases.

Blood transfusion

There is no religious objection to the giving of blood (except for Jehovah's Witnesses or Rastafarians).

Organ transplants

There are no religious objections to the reception of a transplanted organ, but those who believe in the sanctity of the body are unlikely to agree to organ donation. Younger family members may have different views.

Procedure at death

Routine last offices are appropriate. There are no religious objections to others handling the body as long as respect is shown, although it may be preferred if someone from a similar ethnic background is able to fulfil this duty.

If death occurs at home, family and friends may perform the laying out.

Funerals

In the UK, burial is the preferred method of disposal. The funeral is an important and elaborate occasion for the extended family and for all those who loved the deceased. The entire community will wish to attend. Time will be allowed for the dispersed relatives to gather together. The body may be brought to the home before the funeral service and may be viewed there and also during the singing of a hymn in church. This is a sign of respect, according to the wishes of the family, especially in Pentecostal communities. Ideally the body should be embalmed, especially if the funeral will be delayed. Because of the importance attached to funerals, time off work to attend them is necessary for many people, not just the very close family. The funeral service may be long, varied to suit the individual and characterised

by hymns, tributes, a choir, a steel band or other music, gospel singing and flowers.

At the graveside the family will fill the grave in them selves, while the singing continues. The congregation will probably return to the hall for a gathering after which the family house remains 'open' for people to call on the relatives, and for prayer, for about a week.

Rastafarianism

Rastafarians are followers of a growing movement, which began in the 1930s in the West Indies, mainly in Jamaica and Dominica, among the descendants of slave families who came from Africa. Identification with Africa is central to the Rastafarian doctrine and the movement is linked to the roots of resistance to slavery. The 'Back to Africa' movement led by Marcus Garvey (1887-1940) raised black consciousness and self-respect and has inspired the faith.

The accession of Ras (Prince) Tafari as the Emperor of Ethiopia (Haile Selassie I) in 1930 is central to Rastafarian belief. He is considered to be a divine being, the Messiah of the human race, who will ultimately lead all black people to freedom. Believers claim there is a direct lineage from the biblical King David to Ras Tafari (hence the name Rastafarian). The Emperor also bears the titles of 'King of King' and the 'Lion of Judah'.

The Rastafarian movement has rejected many aspects of the major cultural influences which were predominant in Jamaica and has become a distinct entity. The Old and the New Testaments are still regarded as scriptures, but Rastafarians do not consider themselves to be Christians. For them Christ's spirit has been reborn in Ras Tafari, the New Messiah. Rastafarians believe that they are the true Jews who will eventually be redeemed by repatriation to Africa, their true home and heaven on earth.

Rastafarianism is a personal religion. There are no church buildings, set services or official clergy. All members share in the religious aspects, have a deep love of God and believe that the temple is within each individual.

Rastafarians will be unwilling to receive any treatment which might contaminate the body, and some may reject Western-style treatments. Members of the faith are readily identified by their distinctive hairstyles. 'Dreadlocks' or 'locks' are a symbol of the faith and a sign of black pride. Orthodox members may not permit their hair to be cut. Rastafarian women

dress modestly at all times. There is a taboo on the wearing of second hand clothing.

All forms of pig meat are forbidden. Some feel that all meat is unnecessary and follow a vegetarian diet. Certain foods are regarded as unwholesome; herring and sardines, among others are not acceptable.

The family may pray by the bedside of a dying member, but other than this there are no last rites. Rastafarians believe in the resurrection of the soul after death, but not of the flesh.

Post-mortem and body donation

Both would be extremely distasteful to most Rastafarians. Few would agree to a post-mortem except where it is ordered by the coroner.

Blood transfusion

The fear of contamination of the body will influence the attitude to transfusion. Assurance will be needed that no disease will be transmitted. Objection may be raised to both donation and reception, although donation to and reception from other members of the family may be considered.

Organ transplants

Again the fear of contamination will make willing participation unlikely. There is also a belief that to do so is to interfere with God's plan for mankind.

Procedure at death

Routine last offices are appropriate.

Funerals

Burial is preferred but cremation is not forbidden. The funeral is plain and simple, unlike the elaborate occasions seen in the funerals of other Afro-Caribbean groups. Only the intimate family and friends will attend the funeral. There is no special mourning ritual but family and friends are very supportive of the bereaved.

Islam

Islam is the Arabic name for the Mohammedan religion. The term means 'surrender to God's will', and includes acceptance of those articles of faith, commands and ordinances revealed through the Prophet Mohammed.

Mecca, near the Red Sea coast of Saudi Arabia, is the religious centre for Muslims and a place of pilgrimage from all over the Islamic world. It was here that Mohammed was born and began his teaching.

There are four chief religious duties for a Muslim. These are prayer (five times a day, with purification rituals), alms giving, fasting, and a pilgrimage to Mecca.

Halal lamb, beef and chicken are eaten, but pork meat, carrion and blood are forbidden. Fish and eggs are allowed, but must not be cooked where pork and other non-Halal meat is cooked. During the month of Ramadan a Muslim fasts between sunrise and sunset.

Post-mortems and body donation

In Islam, the body is considered to belong to God - strictly speaking no part of a dead body should be cut out, harmed, or donated to anyone else. Post-mortems are therefore forbidden unless ordered by the coroner, in which case the reasons for it must be clearly explained to the family. Strict Muslims will not agree to organ transplants, and the subject should not be raised unless the family initiated the discussion.

Procedure at death

After death the body should not be touched by non-Muslims; health workers who need to touch the body should wear disposable gloves.

A Muslim funeral should take place as soon as practical, preferably within 24 hours. Delay can cause distress to the relatives but if unavoidable, the reasons should be explained carefully to them.

Under normal circumstances, where a death certificate has been issued by the attending doctor, the body should be prepared according to the wishes of the family. Normal Muslim procedure is that the body is straightened immediately after death to facilitate the washing and shrouding of it. The head is turned towards the right shoulder, so the body can be buried with the face towards Mecca. Muslims of the same gender should wash the body in the ritual way. The hair and nails are not cut. The body is wrapped in a white sheet, 40 yards long, which conceals the whole of the body.

Funeral

Muslims are always buried, never cremated, and the body should be buried pointing eastward, toward East Mecca. Some families take their dead back to their country of origin for burial.

Hinduism

Hinduism is the title given to the religion of the vast majority of the population of India. It is inextricably bound up with culture and social structure. It encompasses a great tolerance of beliefs and practices, and different Hindu communities have different ways of expressing their faith, and usually have their own local temple.

Hindus believe there is one God, who can be understood and worshipped, in many different forms. Every Hindu should pray, revere the old, and offer generous hospitality to any visitor. Many are vegetarian, refusing to take the lives of animals for food. Most Hindus do not eat meat, and some will not eat eggs; however, milk from cows is acceptable to most Hindus. In India, where a caste system exists, castes vary in how strictly they follow the laws of diet, prayer, and ritual purification.

There is also a belief in reincarnation in which the status, condition and caste of each life is determined by the behaviour in the last life - making each person responsible for who he is and what he does.

Post-mortems and body donation

There may be religious objections to blood transfusions or organ transplantation, and permission must be sought. Post-mortems are not accepted, and permission must be sought.

Procedures at Death

The person's family may wish to call a Hindu priest to perform holy rites. The priest may tie a thread around the neck or wrist of the dying person, to bless him or her. The priest may also sprinkle blessed water from the Ganges over the dying person, or place a sacred tulsi leaf in his or her mouth. The dying person's relatives may wish to bring money or clothes for him or her to touch, before distribution to the needy. If they cannot go to the bedside themselves, they will appreciate it if a care worker will do this for them.

Under normal circumstances - where the attending doctor has issued a death certificate - the family should, if available, be consulted before the body is handled. Funerals should ideally take place as soon as possible and in India would take place within 24 hours. In Britain there is likely to be a delay of several days because of pressure on crematorium services.

Jewellery, sacred threads and other religious objects should not be removed. The body is wrapped in a plain white sheet, without religious emblem. In

most cases it should not be washed, as this is part of the funeral rites and will usually be carried out by relatives later.

Funeral

All adult Hindus are cremated, but infants and young children may be buried.

Coping with the unfamiliar organisational side of death and cremation in Britain can be extremely distressing to bereaved relatives and careful explanation and practical help may be needed to contact undertakers and deal with the paperwork.

Before the body is taken to be cremated, the body must be taken past the front entry of the local Hindu Temple.

After the service, the family may hold a 'turban ceremony' or Havan, which is the reading of the 'mantra', from the holy book, accompanied by ritual cleaning with fire. These prayers are for the peace of the soul of the departed and for a new beginning for the rest of the family.

The ashes should be handed to the family to be taken back to India.

Sikhism

Sikhs, (disciples) are members of a religious faith which originated in the 16th century in the Punjab in Northern India, as a reformist movement of Hinduism. After much persecution, Sikhs eventually became a people with a military organisation, (Khalsa Panth), in defence of their faith.

Their founder, Guru Nanak, tried to combine the best features of Hinduism and Islam. He and the nine succeeding Sikh gurus are revered as saints. The Sikh holy book, the Guru Grant Sahab, is a collection of writings of the 10 gurus, the last of whom commanded that Sikhs should use the Guru Grant Sahab as their teacher.

Sikhs believe in God. Each makes his personal relationship with God and worships in his own way, aiming after many cycles of rebirth, to achieve true understanding and unity with God. Sikhism preaches the equality of all people, irrespective of caste, colour or creed.

Some Sikhs have chosen to, 'take Amrit', (a kind of confirmation), and are then bound to observe special rule, such as daily attendance at the temple, special prayers, dietary rules, and the wearing of the 'five Ks'. These are:

Kesh - uncut hair, Kangha - the wooden comb, Kara - iron wristband, Kirpan - a short sword, and Kach - short trousers/breeches. These symbols should not be disturbed unless it is absolutely necessary.

Most male Sikhs have the second name 'Singh' (lion) and females have the name 'Kaur', (princess).

Many Sikhs, especially women, are vegetarians. They may also exclude eggs and fish from their diet.

Post-mortems and Organ Transplants

There are no religious objections by Sikhs to blood transfusion, organ transplant, or post-mortem examination.

Procedure at Death

Generally Sikhs are happy for non-Sikhs to tend the body and perform the normal last offices if the family wishes it. In Sikh tradition the family is responsible for all ceremonies and rites connected with death, and many families will wish to wash and lay out the body themselves.

Special regard should be given to the five Ks. In particular Kesh (unshaven hair) is felt to contribute to a Sikh's personality and should be left intact at all costs. The hair on the head is sanctified at an initiation ceremony and must be kept covered. Beards are not trimmed. The face of the deceased may be displayed on numerous occasions prior to the funeral, and a peaceful expression is desired. The body is covered in a plain white sheet or shroud without religious emblems.

Funeral

Adult Sikhs are always cremated. Sikhs are cremated wearing the five symbols of the faith. The cremation should take place as early as possible, and in India would take place within 24 hours of death. In Britain there is likely to be a delay of several days because of pressure on crematorium services. Sikhs are cremated wearing the five symbols of the faith. Before the body is taken to be cremated, it must be taken past the front entry of the local Sikh Temple.

At the service in the crematorium, a priest must recite special prayers from the Guru Granth Sahib. Normally the son or closest male relative starts the cremation. On the following day, the ashes will be ceremonially sprinkled into flowing water. Some families may take the ashes to India, to the river KeeratPur Sahib. During the days and nights before the funeral, all the adult

members of the family will attend a complete reading of the Guru Granth Sahib. On the day of burial the last verses of the reading will take place (Ardaas).

Buddhism

The majority of Chinese people in the West of Scotland are from Hong Kong but an increasing number of Chinese immigrants are from Mainland China. The main language spoken is Cantonese; there are also many Hakka speakers.

In Scotland, Buddhism is associated with the Chinese community, but many Chinese believe in Confucianism, Taoism or are Christians or Muslims. Some Chinese belief systems are complex mixtures of Buddhist, Confucianism, Taoism and ancestor worship. Many also live by an ethnical code governed by Ying (human kindness), Yi (integrity), Li (courtesy) and Tse (wisdom). Therefore, it is vital to ask the family what practices and religious rites they want for their relative.

To a Buddhist, life is an opportunity to work for transcendence. People who have achieved transcendental states in life are no longer subject to transmigration although they may choose rebirth in order to further their training on the Buddhist path.

The state of mind of a dying person is considered crucial to his/her transcendence. In Chinese Buddhist culture final thoughts should be free from worldly attachments and directed toward Buddha, Pureland, Bodhicitta and Enlightenment. One's family, relatives and friends may withhold expressions of grief so as not to disturb the peace of mind of the dying person; they may feel that this will help strengthen the dying person's Buddhists' aspirations. Chinese Buddhists want the dying person to be in a peaceful and comfortable environment.

Nowadays, one is pronounced dead by a doctor when the pulse and brain waves are gone. From the Buddhist point of view, the consciousness is still in the process of separating from the body - movement of the body and abrupt environmental changes that can disturb the process. It is taught that the body should not be disturbed in any way for a few additional hours. This dying process is accompanied by chanting.

Post-mortems and Organ Transplant

According to Buddhist teaching surgical procedure done before the body is

completely cold will inflict pain and suffering on the dying person and will hinder a good rebirth. Nevertheless, when the dying person has made a will donating his or her organs, he or she is thought to be protected by Buddha and will become free from transmigration as a result of this selfless act of offering.

Rituals related to death

The body is washed, dressed and eyes are closed. Usually a set of new clothes, new shoes, jewellery and ornaments are used to adorn the deceased. Rituals are performed. Under the guidance of a Buddhist monk, the deceased is placed in a coffin. Usually the coffin remains with the undertaker.

A piece of white paper, with announcement of a death in the family, is posted on the main entrance of the family home. In the house, a temporary altar is set up with the deceased's photo and a lotus seat is placed at the centre. A lotus seat is rectangular block of paper or wood, with the name of the deceased. The consciousness is thought to reside here temporarily. Offering of flowers, candles, incense, food and drink are placed here and are replenished. This is the main place for rituals and for visitors to show respect.

The date for memorial service or farewell ceremony is usually chosen according to Chinese lunar calendar. This service involves the same offerings and rituals but on a larger scale. It is customary for all relatives and friends to gather to show respect and listen to eulogies. The immediate family members wear traditional clothing of mourning; the traditional colour is white - however, black has become acceptable.

At the conclusion of the memorial service, paper models of a house are burned for the deceased. In rituals relating to death, paper currencies are burned as offerings to deities. These currencies are made of paper and gold or silver foil; they are printed with auspicious signs and words and images of auspicious deities. They are known as hell bank notes.

Funeral

After the memorial service, the coffin, accompanied by family members, relatives and friends, will be taken to the burial ground. Ashes are gathered in a container and are either buried or stored in a 'pagoda', maintained by cemeteries or monasteries. Alternatively ashes are scattered into a river or ocean.

The family continues to make offerings at the lotus seat on the first and fifteenth of every lunar month. One to three years later, the lotus seat is removed - at this point, it is believed to have merged with the ancestral lotus seat.

My learning log

what we did

what I learned
from this

what I will now
do differently

how I might apply
this

how I applied this

Further reading

Bereavement Studies in Adult Life, by Colin Murray Parkes, published by Tavistock Publications

On Death and Dying by Elisabeth Kübler-Ross, published by Tavistock Publications

Grief Counselling and Grief Therapy by William Worden, published by Routledge

Attachment and Loss Vol 3. Loss: Sadness and Depression by John Bowlby, written by Hogarth Press

All in the end is Harvest, produced by CRUSE, edited by Agnes Whittaker, published by Darton, Longman and Todd

A Grief Observed by C.S. Lewis, published by Faber

Thro' Grief by Elizabeth Collick, published by CRUSE

Am I allowed to Cry? by Maureen Oswin, published by Souvenir Press

Living with Loss, helping people with learning disabilities cope with bereavement and loss, by Noelle Blackman, published by Pavilion

Mental Handicap and the Human Condition: New Approaches from the Tavistock by Valerie Sinason, published by Free Association Books

Books and resources you can use with the person you support

Books

When Dad Died by S Hollins., L Sireling and B Webb, published by Sovereign Press

When Mum Died by S Hollins., L Sireling and B Webb, published by Sovereign Press

Understanding Death and Dying by F Cathcart, published by the British Institute of Learning Disabilities

When Someone Very Special Dies by M Heegaard, published by Woodland Press

Exploring Your Emotions by Holland, Payne, A and Vickery, L, published by British Institute of Learning Disabilities

Video

Coping with Death by Speak Up Self Advocacy Project
website: committee@speakup.org.uk

Useful Articles

Fiona Cathcart, Coping with Distress, in Nursing Times, October 25th, vol 85, no 42, and 1989: pp 33-35.

Death: coping with distress, in Nursing Times, 85, 1989, pp 33-35.

Death and people with learning disabilities: Interventions to support clients and carers, in British Journal of Clinical Psychology, vol. 34, 1995: pp 165-175.

Understanding Death and Dying, 1994, Bild Publications. Series of 3.

Lorraine Crick, Facing Grief, in Nursing Times, July 13, vol. 84, no 28, 1988: pp 61-63.

French and Kuczaj, Working through Loss and Change with People with Learning Difficulties, in Mental Handicap, vol. 20, September 1992: 108-111.

Ian A James, Helping People with Learning Disability to Cope with Bereavement, in British Journal of Learning Disabilities, vol. 23, 1995: pp 74-77.

Rosemary Jenkinson, Death of A Friend, in Nursing Times, 15, vol. 89, no 50, 1993: pp 65-66

John Kennedy, Bereavement and the person with a mental handicap, in Mental Health Bulletin 78/11, 1989: pp 36-38.

Maureen Oswin, Alive to Death, in Community Care, 28 November 1991, 14-16.

Don't ask us to dance: Some aspects of bereavement for people who have learning disabilities. in Clinical Psychology Forum, 44 June 1992: pp 16-21.

The Grief That Does Not Speak, in Mental Handicap Bulletin, 78/10, winter 1990: pp5-7.

Materials List

- Crayons
- Scissors
- Chalk
- Salt
- Felt tips
- Glue
- Ribbon
- Wool
- Card
- Little jars
- Balloons
- Christmas baubles
- Finger paints
- Clay/Plasticine
- Masks
- Music

Evaluation

Loss

DATE

- 1 What did you think of this workshop?
- 2 Which part of the training did you find most useful?
- 3 What did you think the trainers did well?
- 4 What could they have done better?
- 5 Is there anything they could have done differently?

Thank you for your time in completing this form.

