



Wellbeing for Life

Loss, Change and Grief



Learning Outcomes

- What is meant by “loss”.
- Practical tips to support people with their loss and how to cope.
- To have an awareness of grief cycles and how they affect people who are dying.
- To acknowledge and embrace change within a person and provide “just right support”.



A Trio Bound Together

Loss, change and grief are inextricably linked and represent feelings and experiences that all of us will have at some point in our lives.

It is often assumed that a person with a learning disability will not react to experiencing loss, change or grief, or their reactions are assumed to be 'behaviours'. Both of these assumptions are wrong.

Never underestimate the power that loss, change and grief can have on a person, and be mindful that - if anything - a person with a learning disability may feel the effects of loss, change and grief even more acutely than you do.

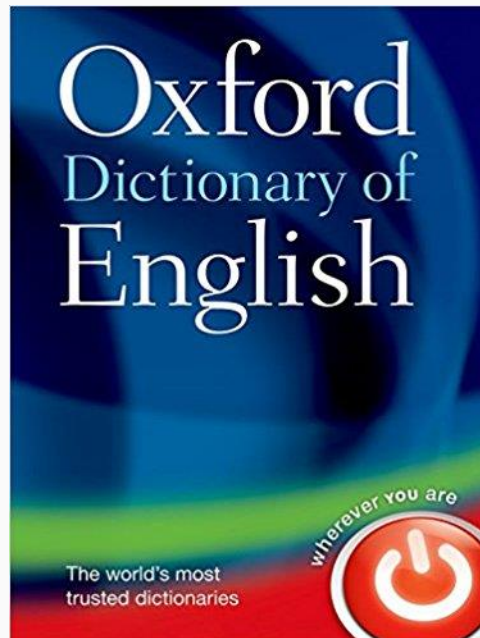


What does “loss” mean?

The Oxford English Dictionary describes loss as:

“The fact or process of losing something or someone”

“The feeling of grief after losing someone or something of value”





How does “loss” manifest itself?

Loss can take on many forms, including:

- The death or terminal diagnosis of a person we know, care about or love
- Being a person who is given a terminal diagnosis
- The loss of the chance to ‘do’ something – for example, to say something to a person who is ill, dying or deceased that is really important, or to spend time with the person
- The loss of our relationship with a person who is ill or dying as it once was, perhaps because the person no longer reacts to us as they once did because of the physical or mental effects of their illness
- The loss of an item that is important, perhaps because it reminds us of something or someone, or represents a purpose we have and value

Remember: Never dismiss any experiences that the person you support has in relation to loss – something that may seem very trivial to you or a distant fleeting relationship with someone could have vital importance to the person.



Supporting a Person's Loss

One of the most important aspects in supporting a person experiencing loss is to use your own personal feelings and emotions in a positive way, rather than allowing them to impact upon your professionalism negatively.

This may be challenging if you are feeling loss keenly yourself, but you need to remember that your role in this moment is to support the person, putting their needs before your own.

Draw on your own feelings and emotions to empathise with the person, perhaps by reminiscing with the person and/or acknowledging the role of the person or item that is the focal point of the person's loss.

Ensure that the person you support knows that they are not alone, and that their feelings are validated, understood and supported.



Supporting a Person's Loss

Practical Tips

- **Give time** – Never attempt to rush a person experiencing loss. Working through these feelings and emotions will take as long as it takes, and this will be entirely individual to each person.
- **Give space** – Ensure the person has the privacy they need to make sense of their loss privately if that is important to them.
- **Listen** – Be there for the person when they need to talk or express themselves through their own preferred communication methods.
- **Comfort** – If the person needs comfort from you, for example a hug or even just to hold your hand, respond warmly.
- **Talk** – If the person you are supporting wants to talk about someone they have lost, or something they have lost, support this exploration sensitively and openly.



Impact of Loss on Daily Life

For some people, keeping to their routine is an important part of how they cope with loss. Keeping routines and the environment as consistent as possible will help. When changes are needed involve the person in a way that makes sense to them.

For other people, they need to take a break from their usual activities to focus on how they are feeling or to do something practical that reflects the emotions they are experiencing.

Knowing what helps the person relax and feel safe is important as this can be introduced at times of distress and sadness.

If the person has lost someone close to them, they may need to do something for that person, for example by writing a 'Miss you' card or buying flowers for the person.

Be guided by the person, what they are telling you they need; what you are observing while supporting them and what you are reflecting upon as an individual and as a team.

Approach each day with an open mind and be flexible in your approach.

Understanding about grief cycles may help you to support the person with a greater level of insight into their feelings and experiences.



The Grief Cycle

The five stages of grief, as outlined by Elisabeth Kübler-Ross in her 1969 book *On Death and Dying* are:

- **Denial** – Refusal to accept facts, information or reality. This is often a defence mechanism.
- **Anger** – This may be linked to wanting to blame someone or something for the grief being felt.
- **Bargaining** – A state of 'if only' when the grieving person wants to try and change the course of events or turns to their religion for help.
- **Depression** – The beginning of accepting the reality that the person finds themselves in, often accompanied with sadness, regret, fear or uncertainty.
- **Acceptance** – Emotional detachment and objectivity.

People who are grieving do not necessarily go through the stages in the same order or experience all of them



The grief cycle and people with a learning disability

When thinking about the grief cycle in relation to a person with a learning disability, be aware that the person may not demonstrate where they are in their own grief cycle in a way that you can immediately understand.

Possible reasons for this include:

- The person's emotions are very conflicting, verging from one extreme to another.
- The person does not feel able to express themselves, perhaps because they do not feel comfortable in their environment or in the company of certain people.
- The person does not know how to express what they are feeling, perhaps because they have not had this feeling before.





The grief cycle and people with a learning disability

- The person associates the way they feel with something negative from their past, perhaps because they remember the feeling they have now from a previously upsetting experience, like losing someone else that they cared about.
- The person's communication ability is compromised by what they are feeling, i.e. their emotions are so overwhelming that they cannot express themselves in their usual way.
- In supporting the person, concentrate on what they are able to communicate to you, and ways you can interpret what they are communicating or additional communication tools that you could utilise to enable the person to express themselves more comprehensively – be aware that they may need more support than usual with communication if they are distressed.



How the grief cycle affects a person who is dying

A person who is dying may have a declining awareness of what is happening to them. They may also be unable to actively demonstrate their emotions due to their physical or mental frailty.

For these reasons, it may be difficult to know if the person is 'coming to terms' or has 'come to terms' with their terminal diagnosis.

Whilst it is thought that person who is dying may move more quickly to the 'acceptance' stage of the grief cycle than those they will leave behind, you may never be able to ascertain if this is the case for a person you support who is dying, or the person's death may happen quicker than expected, perhaps not leaving enough time for the person to find their own acceptance.



Supporting a person who is dying through their grief cycle

Ways you can support the person include:

Support with denial – Offer as much factual information as the person needs, in however much detail the person can cope with, and as frequently as is needed by the person. Do not become frustrated if the person appears stuck in denial – this is a natural reaction

Support with anger – Validate the person's emotions. The person may be looking for answers, or may be wondering 'Why me?' 'Why now?' 'What have I done wrong?' The person may direct their anger at you, your colleagues, their peers and friends or healthcare professionals – this is not meant personally

Support with bargaining – Reassure the person that all that can be done for them has been done and will be done. The person may also need access to pastoral care appropriate to their religious beliefs if they hold such beliefs, and you should ensure this is facilitated

Support with depression – Comfort the person and help them to find peace with their situation. The person may express sadness or regret, and that may be linked to something that you could help them to do or achieve. Explore with the person how any regrets could be resolved

Support with acceptance – The person's physical decline may mean that their ability to socially interact is very limited or non-existent. Helping the person to maintain a calm environment, ensuring their dignity is preserved at all times and they are comfortable will help the person gracefully and peacefully withdraw into themselves.



Change Within a Person

Acknowledging and embracing changes within a person's health can be very difficult for the person themselves, and those closest to them.

If the person is unable to do things or participate in their home life as they once did, this can cause many different emotions, including upset, misunderstanding or anger.

There may also be constant reminders of how the person's health has deteriorated if they require regular support to meet their basic everyday needs, and any invasive medical procedures that may be required can add to the emotional upheaval the person and those closest to them are feeling.

For some people change can represent a 'slow death'.

This is when change signals that the end of the person's life is in sight, but there may still be a lengthy period of time before the person's actual end of life. Finding ways to cope in that intervening period can be challenging for the person, those closest to them, and for you and your colleagues.

Remaining Positive



Remembering that the person is alive and being cared for to the very best of everyone's ability is an important first step in remaining positive.

Making the most of every day, even bad days, can help everyone to feel that they are making a positive contribution to the person's life.

Maximising the chances of achievement. Although the person may not be able to participate in daily life or help themselves in the way they once could, think about what they can be supported to do, however small that achievement might be.

Set realistic expectations, acknowledging any additional support needs that the person has and find ways to meet those needs.

“Just Right Support”

Gauging the right level of support for each person you support is about really understanding the person and being completely person-centred in your approach.

Support needs are likely to fluctuate and increase over time, but they should always be in response to the person's **actual** needs, not the desire to simply do everything for the person because of the assumption that the person cannot do anything anymore.

Remember that every day is different, and the way you respond to the person needs to be about continual assessment, observation and reflection.





Making sense of Loss, Change and Grief

A natural reaction to the feelings and experiences around loss, change and grief is to search for answers.

It is also common to want to find an approach that will work for every person you support, learn that approach and then practice it universally.

However, the nature of these very personal emotions and experiences is that there is no set structure or replicable response.

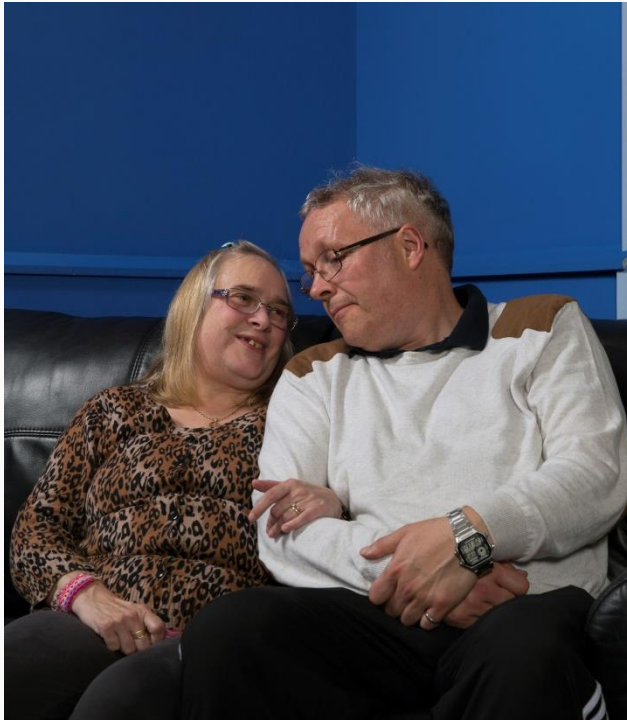
Understanding and accepting this is important in maximising the effectiveness of the support you offer to people with a learning disability, and the professionalism you are able to demonstrate in your role.



The Danger of Bottling up Emotions

- If a person you support is experiencing loss, change or grief, do not attempt to ignore what the person is feeling and experiencing.
- Whilst making a big fuss may not be helpful either, it is important that the person is able to express themselves freely, without risk of reprimand or dismissal.
- If a person does not feel able to express themselves, they are more likely to bottle up how they are feeling, which could impact negatively upon both their physical and mental health.
- An important aspect of supporting a person with a learning disability is to ensure that their residential, learning or working environment is open, welcoming and understanding. It must be a place that the person is at ease and can be themselves at all times, even if they aren't feeling at their best.

There is No Timeframe



Often people experiencing loss and grief will want to know when it will end – when they will ‘feel better’. Unfortunately, however, there is no timeframe.

Never make judgments because a person appears to have reached a point of acceptance quicker than you expect (the assumption being that the person did not feel anything emotionally significant to begin with) or because a person seems unable to reach a point of acceptance (the assumption being that there must be something wrong with the person if they can't find ‘closure’).

Everyone reacts differently to loss, change and grief, and for that reason you will need to ensure your support is very adaptable and individualised. Never make assumptions.



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