

Webinar: Wednesday 19th July 2017

**Supporting bereaved people with special
educational needs:**

Bereavement support for people with a learning disability





Supporting bereaved people with special educational needs:

Bereavement support for people with a learning disability

Sue Read,

Professor of Learning Disability Nursing,
School of Nursing and Midwifery,
Keele University



s.c.read@keele.ac.uk

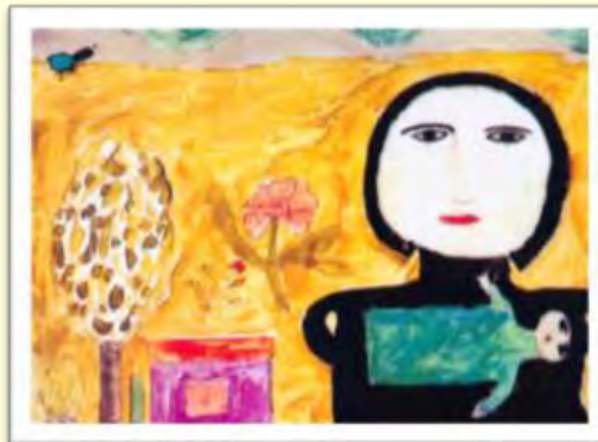


Aims

- provide an introduction, background and rationale to the bereavement world of people with a learning disability
- identify and catalogue the challenges when supporting people with learning disabilities, particularly with disenfranchised grief and death
- critically explore the concept, nature and meaning of support associated with loss and death
- consider ways of overcoming the recognised barriers.

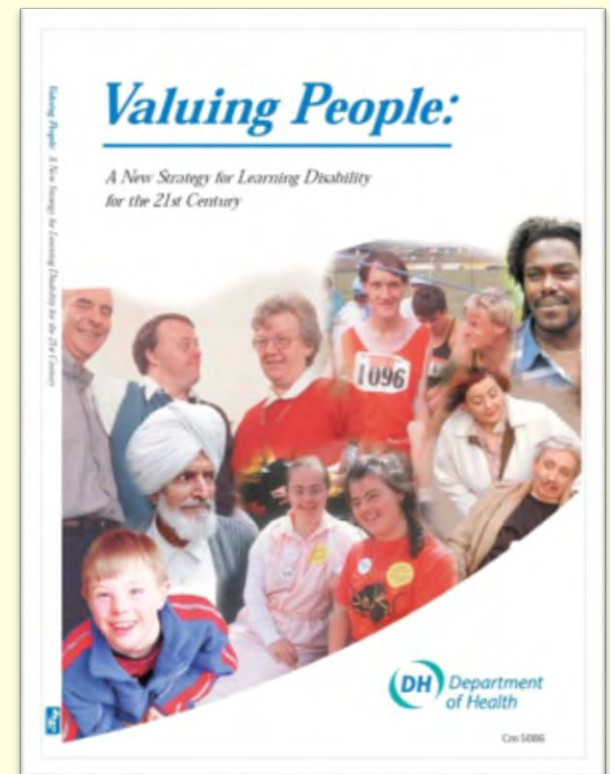
Aims

Ultimately, to demonstrate that people with a learning disability can indeed teach us so much about death and dying.



Defining learning disability

DH (2001) describe people with learning disabilities as having a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood and with a lasting effect on development.



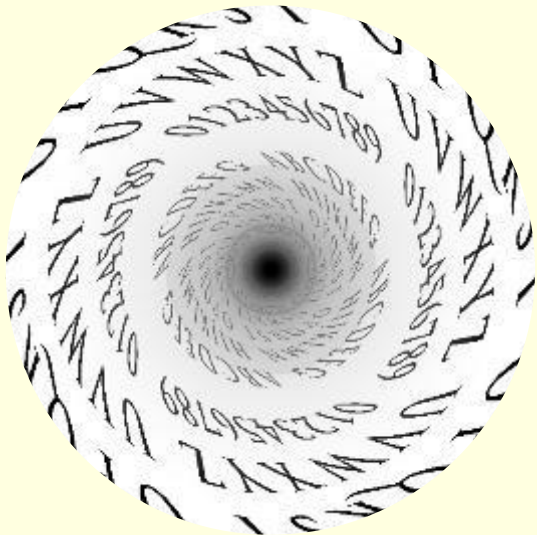
Defining learning disability



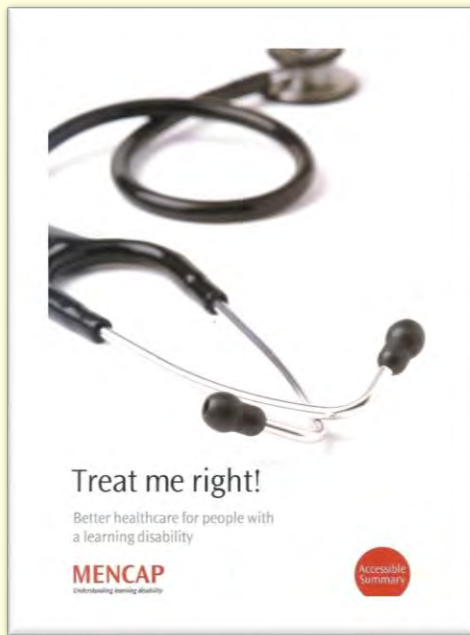
In real life a learning disability is when someone learns to do things slower.

Someone may find it difficult to understand complicated words or to concentrate for a long time.

But they can still do what other people can do.



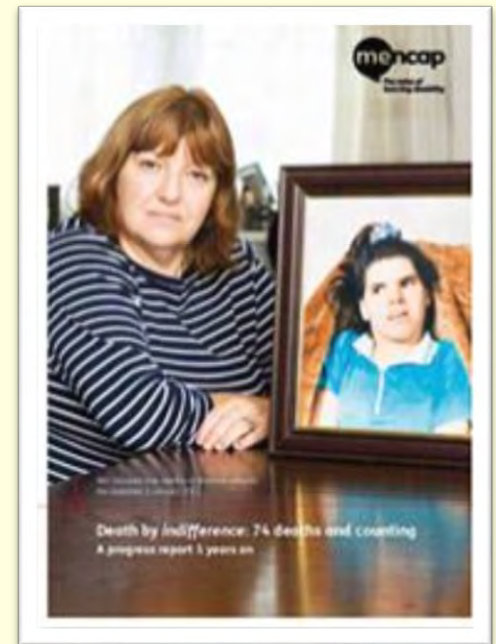
People with a learning disability are more likely to “...function on a developmental level that is inconsistent with their chronological age” (Lavin, 2002:314), and carry a history of marginalisation, devaluation and stigma.



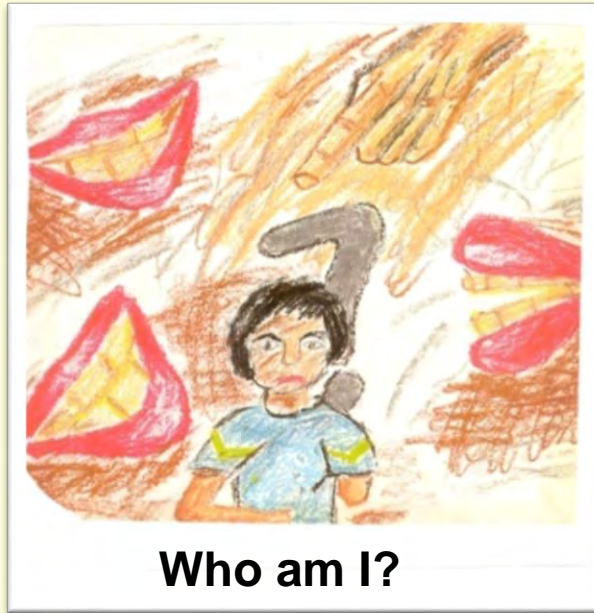
2004



2007



2012



Who am I?

*People with a learning disability
have more **similarities** to us than
differences from us, particularly from
within the loss, death and bereavement
context.*

(Read, 2005; Cartlidge & Read, 2010)

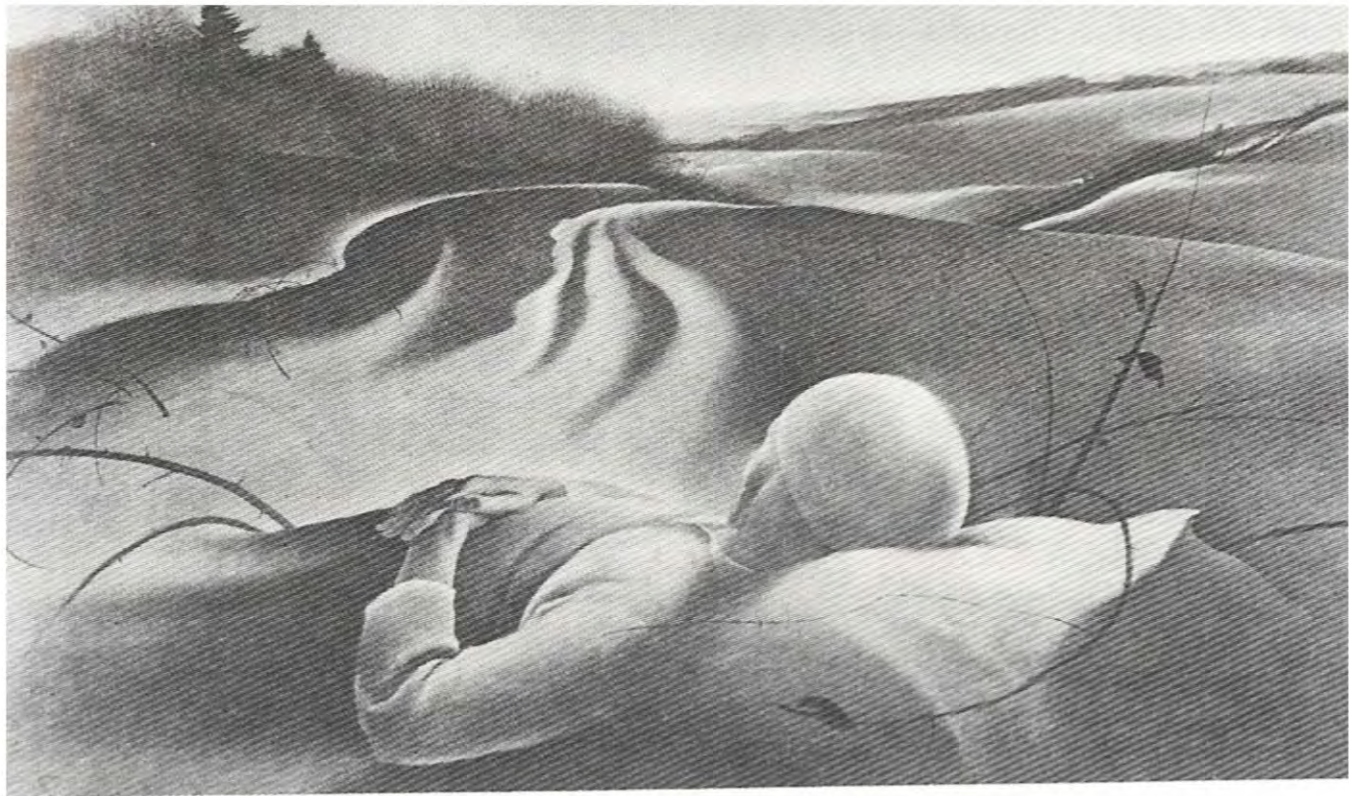
Key times of similarity

At birth





As old age approaches



“Death is not the enemy, Doctor. Inhumanity is.”

(Bertman, 1991)

Living with loss

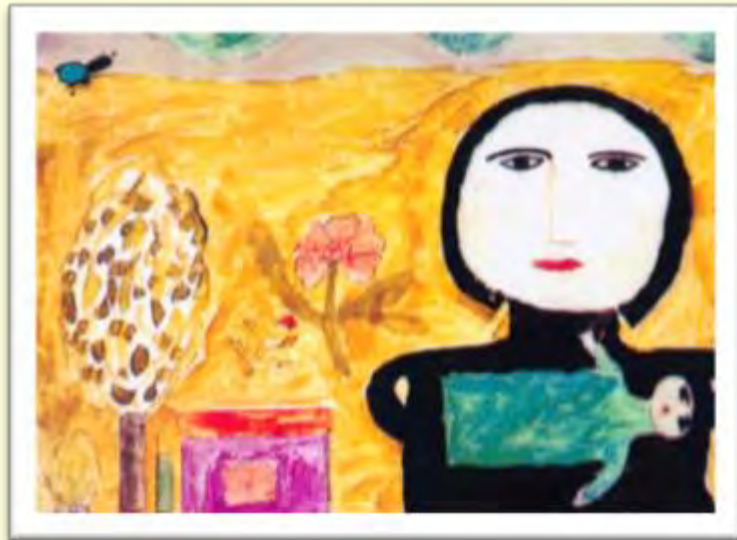


Life is characterised by movement, change and development, therefore by transitions, losses and grief.

(Thompson, 2002)

Defining loss

Loss can be described as a sense of being deprived or being without, and as such can be expected or unexpected.



- Developmental loss
- Circumstantial loss
- Invisible grief
(Machin, 2010)

LOSS (Read, 2014)

For the **majority** of people, loss is dealt with within the bereaved individual's immediate **social** context, with help and support sought and found from friends, family and work colleagues (Worden, 2001).

Some people may be described as having complicated or prolonged grief, where they **struggle** to (unsuccessfully) re-establish their lives without the dead person (Shear *et al*, 2011).

For a small percentage of people, there is the need for more specific **professional** help and support in the form of psychological support from psychotherapists or counsellors.

For some groups of people, such help may be **difficult** to access and grief work can be left unsupported and unresolved.



Death

The dead and dying have much in **COMMON** with people with a learning disability in terms of social responses to them; a response that has been based upon exclusion and broken bonds.

(Read, 2012)



“our major challenge is the acceptance of death as a natural part of life, by ourselves, by our patients, by families, and by our culture” (Smith, 1994).



Death of any individual can only count if the individual counted in life. *“Longevity is unimportant. The contribution one makes to life is”* (Greenwell, 2003: 97).

The contributions that people with a learning disability make can be huge, if only society looked for, recognised and appreciated, them.

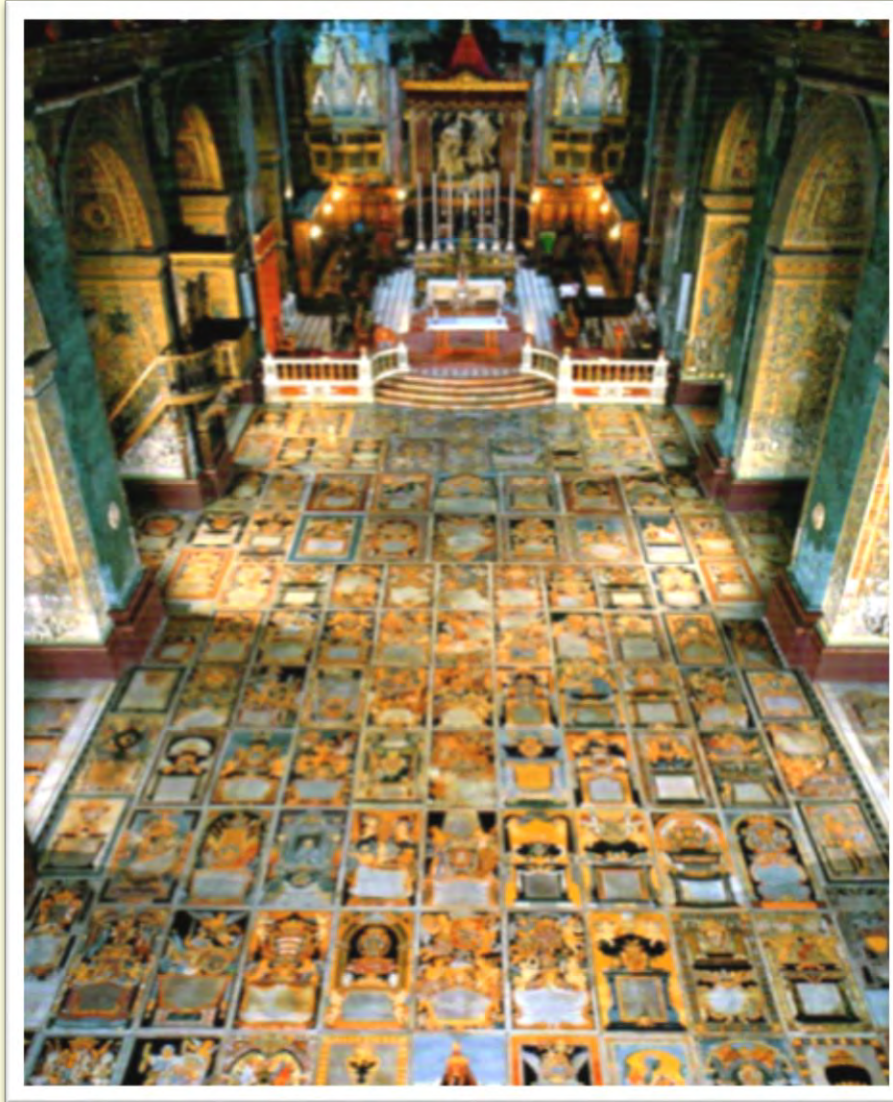


Death never occurs in a vacuum but within a **social context** and the nature of that context can influence greatly how the person faces the end of their life and how others accommodate the death of their friend/ family member (Read 2008).



Kissane, D. & Bloch, S. (2002). Family focused grief therapy. Buckingham: Open University Press.

Faces of death (Read, 2011)



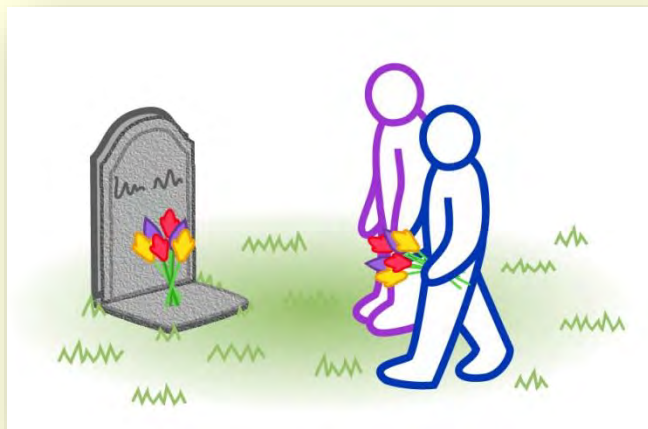
The nave of St John's co-Cathedral, Malta, with some of the 375 memorial tombstones.

Death is often perceived as the ultimate **LOSS** and the only certainty within life itself. Death can be :

- a regular **companion** as, for example, people with life-limiting conditions live with the prospect of an untimely death for many months or even years
- a sudden and **unexpected** visitor, when it arrives without warning or time to prepare, and is often perceived as untimely



- a welcomed friend, after times of enduring pain with no expectation of release
- a stranger, when, for example, death and loss are shrouded in secrecy and individuals are not allowed to know about death and loss until absolutely necessary, for example when the bereaved person has a learning disability.





'If we understand the different ways people react to loss, we understand something about what it means to be human...'

...something about the way we experience life and death, love and meaning, sadness and joy.'

(Bonanno, 2009:3)



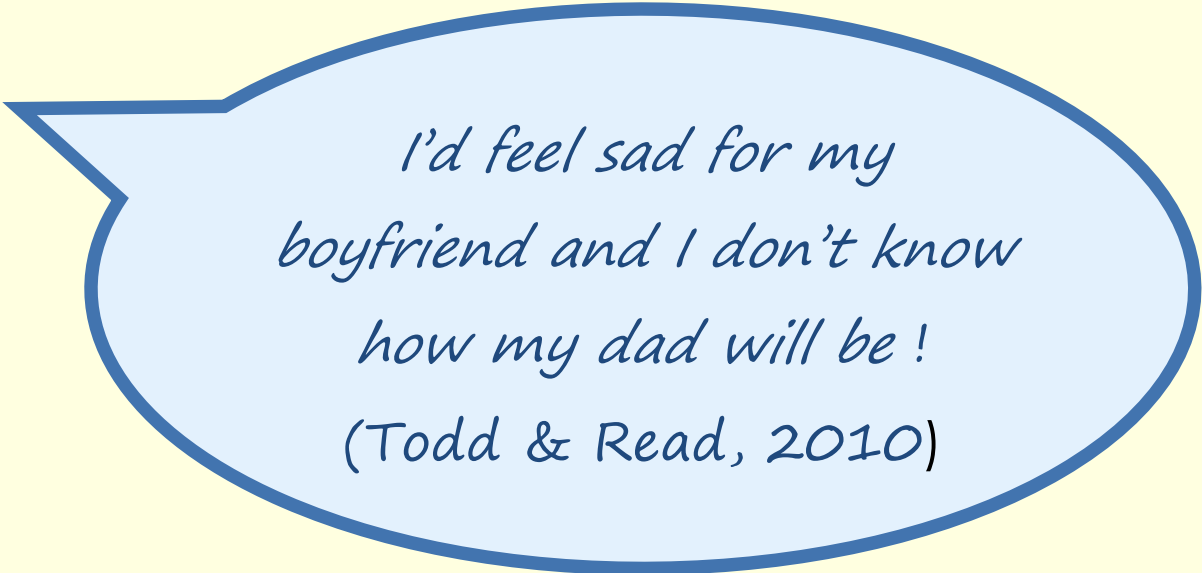
Listening to previous voices

- Do **experience** grief (Oswin, 1990; 2000; Hollins & Esterhyzen, 1997).
- Impact of grief is **varied** and often complex (Conboy-Hill, 1992; Hollins & Esterhyzen, 1997; Sheldon, 1998; MacHale & Carey, 2002).



Listening to previous voices

“...response to bereavement by adults is *similar* in type, though not in expression, to that of the general population” (Bonell-Pascual et al, 1999).



*I'd feel sad for my
boyfriend and I don't know
how my dad will be !
(Todd & Read, 2010)*

Prone to multiple and successive losses (Oswin 1991; Elliott, 2003).

Listening to previous voices

- People with a learning disability have a significantly poorer understanding of the concept of death
- Less self-determination about end of life planning
- Have a greater fear of death (Stancliffe, Weise, Read, Jeltres & Clayton, 2016)





Listening to previous voices

Vulnerable from a death and dying perspective:

- Actively excluded from death and dying (Read & Elliott, 2003).
- Need more thoughts and practical interventions when participating in funerals and others rites of passage (Forrester –Jones 2013)
- More complex the needs, the less likely hood of being involved (Read & Elliott, 2003).



Disenfranchised grief

(Doka 1989; 2002)

“...the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported...”

- The relationship is not recognised
- The loss is not recognised
- The griever not recognised (1989)
- The ways that individuals grieve
- The circumstances surrounding the death (2002)





Todd & Read (2010)

- Struck by the **number** of loss and death experiences encountered; fundamental feature of everyday life
- **Normality** of loss and grief
- Importance of **pets**; animals play a huge part in many people's lives
- Not afraid to contemplate their **OWN** death
- Support staff were **surprised** at the extent which death had coloured and touched the lives of people they knew well

Todd & Read (2010)

- Eager to talk
- Worrying about other people, and about dying
- Sharing it
- Less contact with dying people-the hidden face of dying
- Wanting to be informed



Why hearing the words is difficult

Communication (Kerr *et al*, 1996)

- Often the individual lacks an appropriate verbal repertoire
- Support person may not know how to communicate effectively
- Uncertainty around what has been absorbed / understood
- Counselling is perceived as a 'talking therapy'

Why hearing the words is difficult

- Emphatically bad attitudes {double taboo of death and disability} (Oswin, 1991; 2001).
- How death is conceptualised.
- Parents and carers tending to focus upon the symptoms rather than addressing the cause (Crick, 1988).
- Lack of appropriate specialist education, training and supervision (Read, 1996).

Why hearing the words is difficult

- Record keeping (accessible & meaningful)
- Lack of heritage and history
- Appropriate assessment formats
- Lack of empirical research
- Grief may go unnoticed
- Grief may be ignored
- Results in disenfranchised grief



What can help...



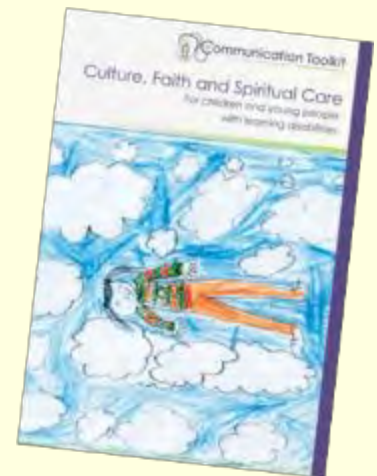
Responding to disenfranchised grief (Doka, 2002)

- Acknowledging the loss/ legitimise the emotional pain
- Active listening
- Empathy (making sense of life experiences by interacting with others, sharing and supporting)
- Meaning making (finding benefits).



Responding to disenfranchised grief (Doka, 2002)

- Sharing of fears and anxieties
- Spiritual support
- Support groups
- Counselling

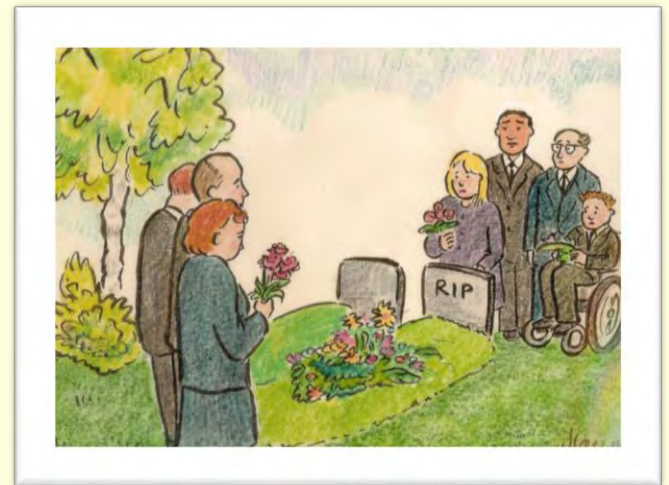




Responding to disenfranchised grief (Doka, 2002)

Constructive use of ritual (powerful therapeutic tool):

- Funerals
- Rituals of continuity (lighting candles on
• certain days)
- Rituals of transition
(mark the change or
transition stage)



Responding to disenfranchised grief (Doka, 2002)

Constructive use of ritual (powerful therapeutic tool):

- Rituals of reconciliation (allow person to offer or accept forgiveness or to complete some degree of unfinished business)
- Rituals of affirmation (allow individuals to affirm the loss and recognise any good things that have come out of the loss experience).

Access to bereavement counselling

“Access to ordinary counselling services would be ideal, but as yet, the practitioners within these services are not geared to our clients’ needs and the services themselves are not free”.

(Conboy –Hill, 1992: 168)



Bereavement counselling

“ ...the skilled facilitation of the individual’s response to loss through purposeful communication within a caring relationship forged upon trust and mutual regard.

The core conditions are seen as central to this reciprocal relationship.”

(Read, 2007)

Bereavement counselling

“Such skilled facilitation may involved a range of activities in addition to the spoken word (such as the development of memory books; art; photographs)...

...through which the counsellor can access the individual's thoughts, feelings and inner dynamic world in an effort to engage with their sadness, understand their pain and help the person to explore their feelings.” (Read, 2007)



Current Perspectives

*“Grief support is at best inconsistent,
and at worse, non existent”*

(Read & Elliott, 2007)

In conclusion...

Death and dying remain sensitive issues for everyone, but can be more challenging for some people.



In conclusion...

Collaborative working is the key to effective support.



In conclusion...

People with a learning disability are likely to experience profound and multiple losses across the lifespan, many of which are *invisible*, and therefore go unnoticed, unrecognised and unsupported.

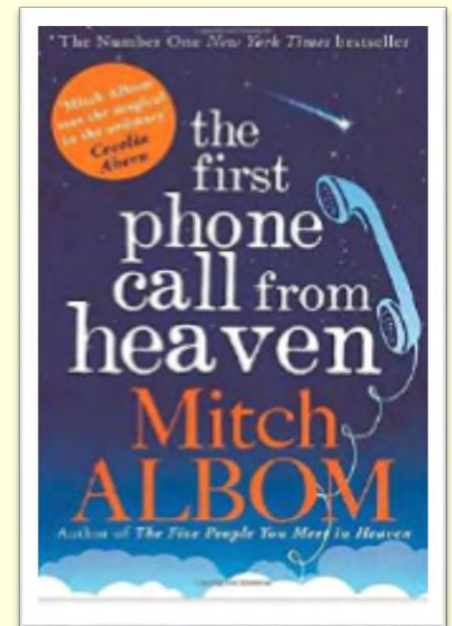


What have I learned on my journey ...

- To be humble
- To not be afraid to ask for help
- That people with a learning disability are largely like everyone else
- That people with a learning disability have stories to tell and can teach us so much.

‘...no soul remembered is ever really gone’.

(Albom, 2013: 308)







Supporting bereaved people with special educational needs:

Bereavement support for people with a learning disability

Sue Read,

Professor of Learning Disability Nursing,
School of Nursing and Midwifery,
Keele University



s.c.read@keele.ac.uk