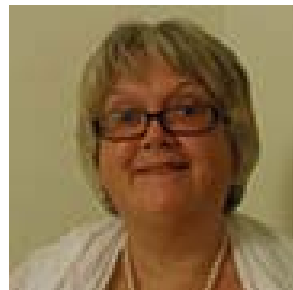**Webinar: American Association on Intellectual and Developmental Disabilities (AAIDD)**
20th April 2020

End of Life and Loss

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Acknowledgements

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Webinar aims

1. **Research findings** about understanding and planning for end of life by people with intellectual disability

2. Introducing free online resource **Talking End of Life (TEL) …with people with intellectual disability**

3. Describing effective approaches to help people with intellectual disability deal with **loss and grief.**

4. Providing a **list of useful resources** about loss and end of life, designed specifically for people with intellectual and developmental disabilities.

5. **Q and A** at the end

Aim 1

Research findings about understanding and planning for end of life by people with intellectual disability

Experience with, and understanding about death and planning for end of life

Adults with intellectual disability:

— Have experienced the death of others

— Have varied or incomplete understanding of death, especially the inevitability of their **own death**

— Have limited understanding of end-of-life **planning**

Stancliffe et al., 2016

Disability staff:

— Have varied experience with end-of-life issues **in their workplace**

— Have **little to no training** in the topic

— Strongly support the **right** of people with ID to know about end of life but didn't know how to tell them

Wiese et al., 2012, 2013, 2015

Limited opportunity to participate, learn, and make decisions

People with intellectual disability (ID) have few opportunities to understand or plan for end of life, because carers and clinicians **protect** them (and also protect themselves) from issues of dying and death

- End-of-life decisions are **made by others** and people with ID are routinely excluded from participation, including not being made aware of their own terminal diagnosis *(Kirkendall et al., 2017)*

- Seemingly widespread acceptance of the notion that **"people with intellectual disabilities are unable to make decisions related to end of life and need to be protected"** *(Kirkendall et al., 2017, p. 985)*

- Not consistently invited to funerals *(Forrester-Jones, 2013)*

Worries about causing harm

Harm?

Studies asking adults with intellectual disability to talk about end of life all reported that they were willing and able to talk, **with no serious negative outcomes** (but *anecdotal* evidence only):

- UK *(Forrester-Jones, 2013)*
- Ireland *(McEvoy, MacHale, & Tierney, 2012)*
- Australia *(Stancliffe et al., 2016, 2017)*

Help?

- Less confusion and fear when death comes

- Can participate in rituals and remembrance of loved ones who have died

- Opportunity to make plans and decisions about your own end of life if you choose to

   Wiese et al.., 2015

Our intervention: Talking (and doing things) about end of life

— Instead of avoidance and protection, **repeated opportunities to learn and talk about dying and death** need to be provided **as part of everyday life**

— These opportunities should be provided **across the lifespan when the person is well**

— Needs to be done sensitively, at the person's own pace, with emotional support as needed

Stancliffe et al., 2016; Wiese et al.., 2015
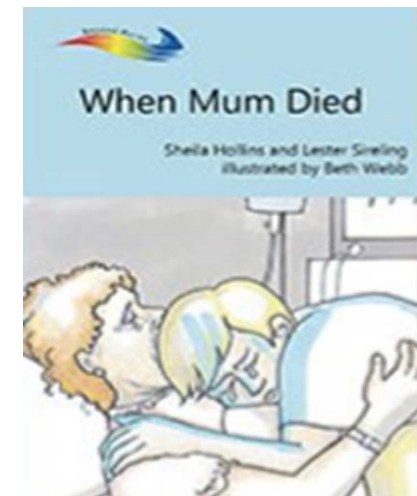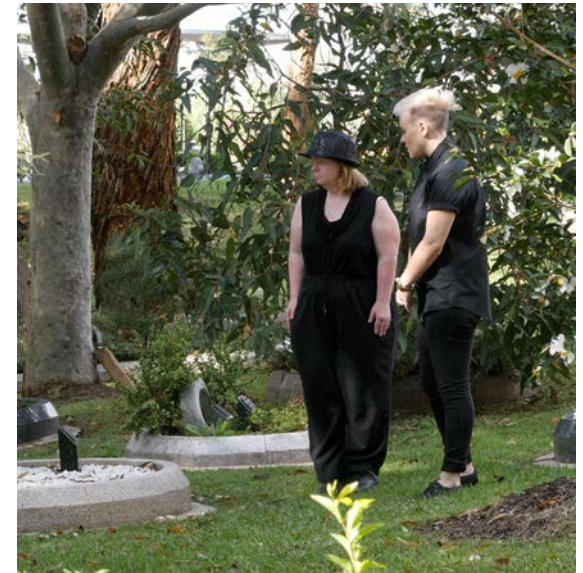
The *Dying to Talk* project

At pre-test and 6 months later, we measured:

- Anxiety
- Depression
- Fear of Death

We also measured "**Encounters**" (conversations or activities related to end of life) during the pre-test and throughout the **6-month intervention**

Provides the **first direct empirical evidence** on the long-term

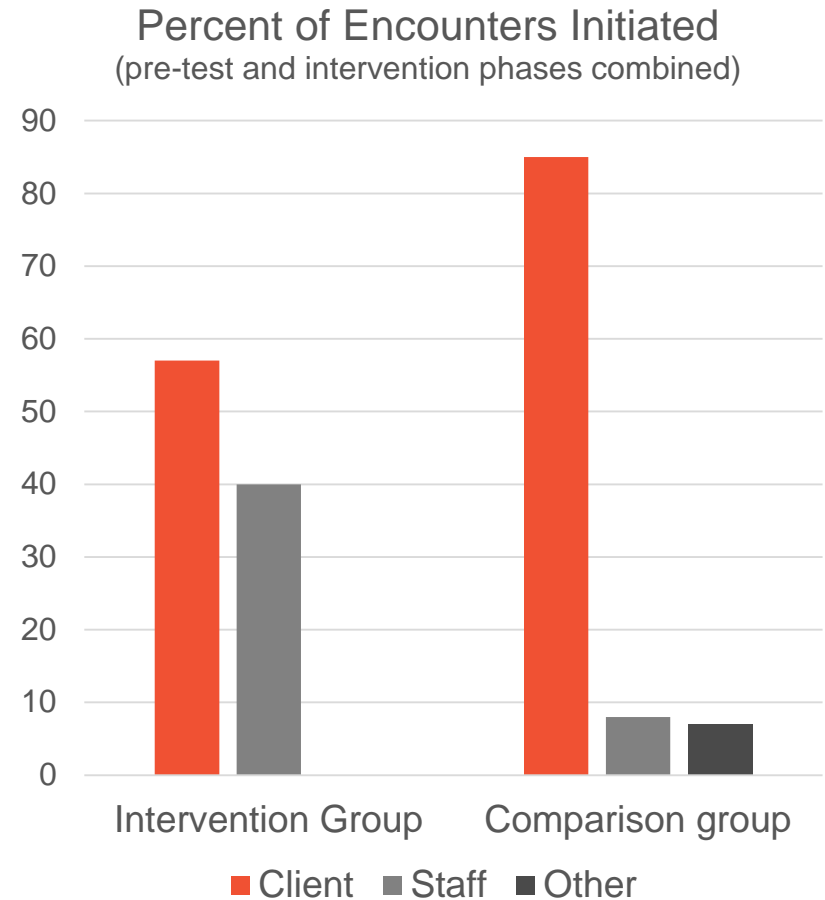psychological effects of talking about end of life.

Encounters examples

Talking about end of life (usually for no more than a few minutes)

Prompted by:

— Death of a family member, friend, or pet (not necessarily recent)
  — Looking at a photo of the dead person

— News item (e.g., COVID-19, bushfire, terrorism, death of a celebrity) involving death or risk of death

— TV program with some content related to end of life

— Seeing something in the community (cemetery, funeral director's, church)

— Specific issue related to a dead person (attending funeral, picking up person's ashes) – arose rarely

Client-initiated "Encounters" (preliminary data)

– For each encounter we collected data from participating staff on:
  – *Who* initiated the encounter
  – How *comfortable* the client was during the encounter

– **Most encounters were initiated by the adult with intellectual disability**

– This finding strongly suggests that adults with intellectual disability
  – Want to know about dying and death
  – Feel comfortable enough with the topic to raise the issue themselves

Percent of Encounters Initiated
(pre-test and intervention phases combined)

Legend: ■ Client ■ Staff ■ Other

Staff-rated client comfort with Encounters (preliminary data)

- Ratings could range from
  - Very comfortable
  - Somewhat comfortable
  - A little uncomfortable
  - Very uncomfortable

- *Very/somewhat comfortable* were the most common ratings

- *Very uncomfortable* was the least common rating but still occurred occasionally

Percent Comfort Ratings
(pre-test and intervention phases combined)
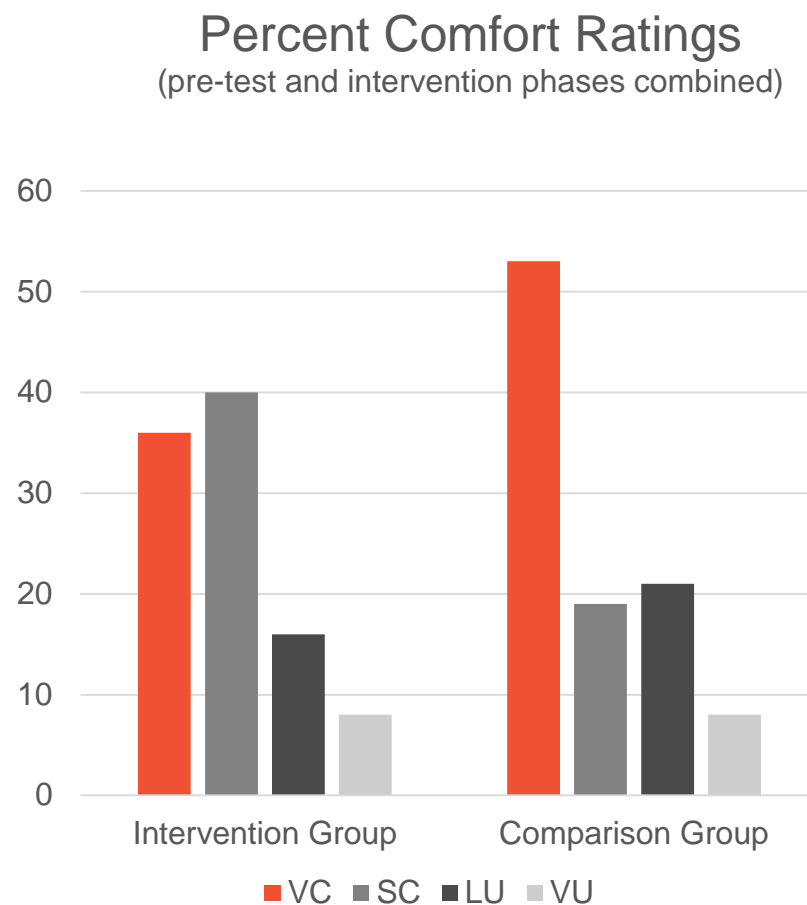
Results

**Talking about dying and death does not make people more fearful, anxious, or depressed**

– At 6 months, intervention participants did not did not fare significantly worse from their pre-test scores on any psychological measure. The same was true for the comparison group. There were no **adverse events** (serious negative outcomes)

Conclusions

- Most people with intellectual disability could participate in end-of-life discussions and activities without obvious discomfort
  - A few experienced *transient discomfort* at times when discussing end of life. Most managed their discomfort themselves. A small number asked to stop. Prompts about stopping were offered if the person appeared uncomfortable

- **Concerns about doing long-term harm are unfounded**

- Families, service providers and researchers can have end-of-life conversations and support people to engage with the topic, without fear of negative psychological consequences

- Some individuals were quite fearful, so sensitive judgements are needed

Aim 2
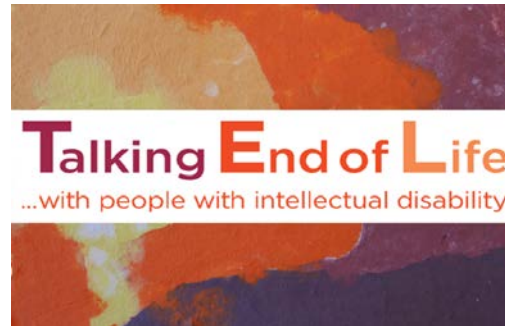
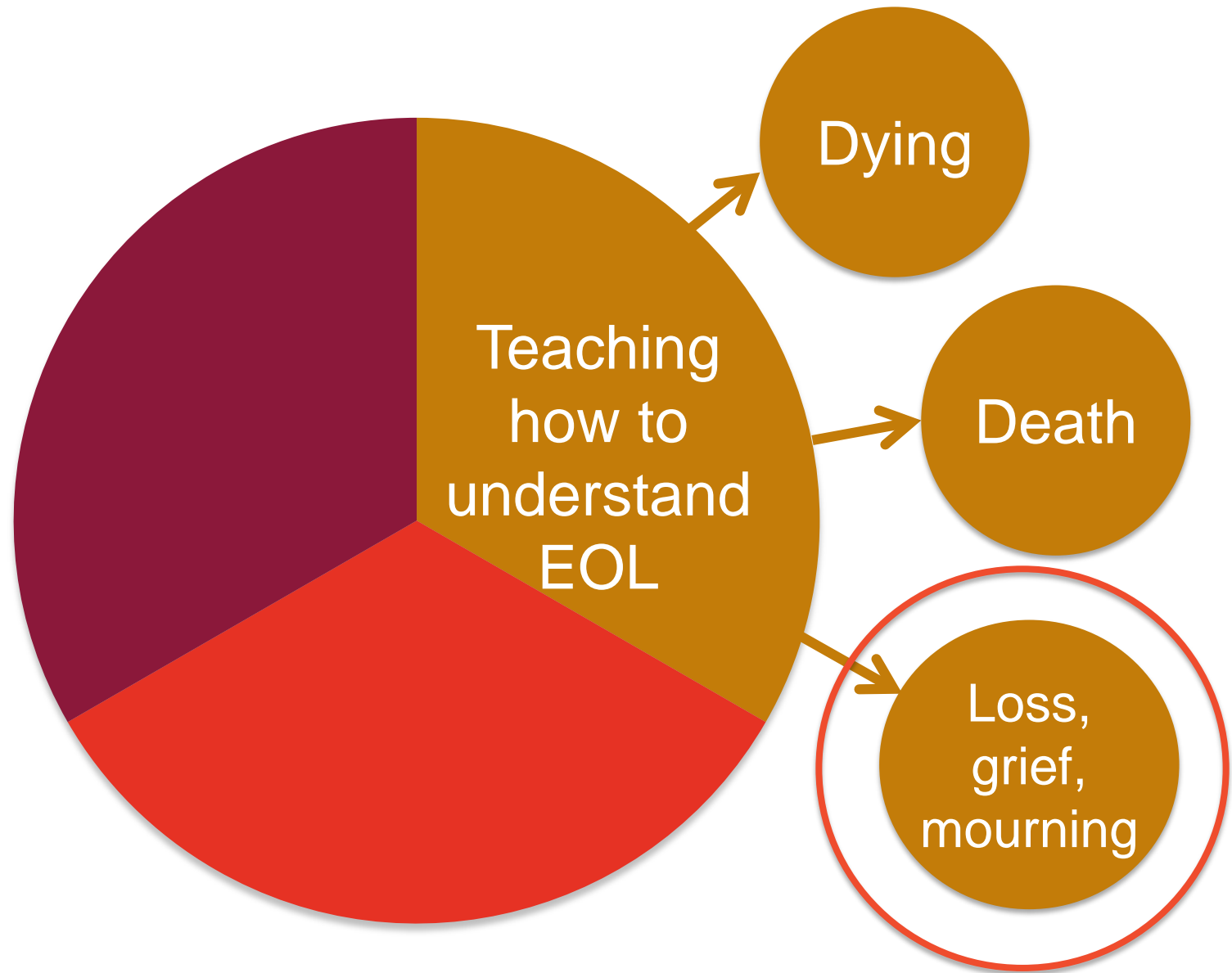Introducing free online resource **Talking End of Life (TEL) …with people with intellectual disability**

The **TEL** project is supported by funding from the Australian Government under the Public Health and Chronic Disease Grant Program
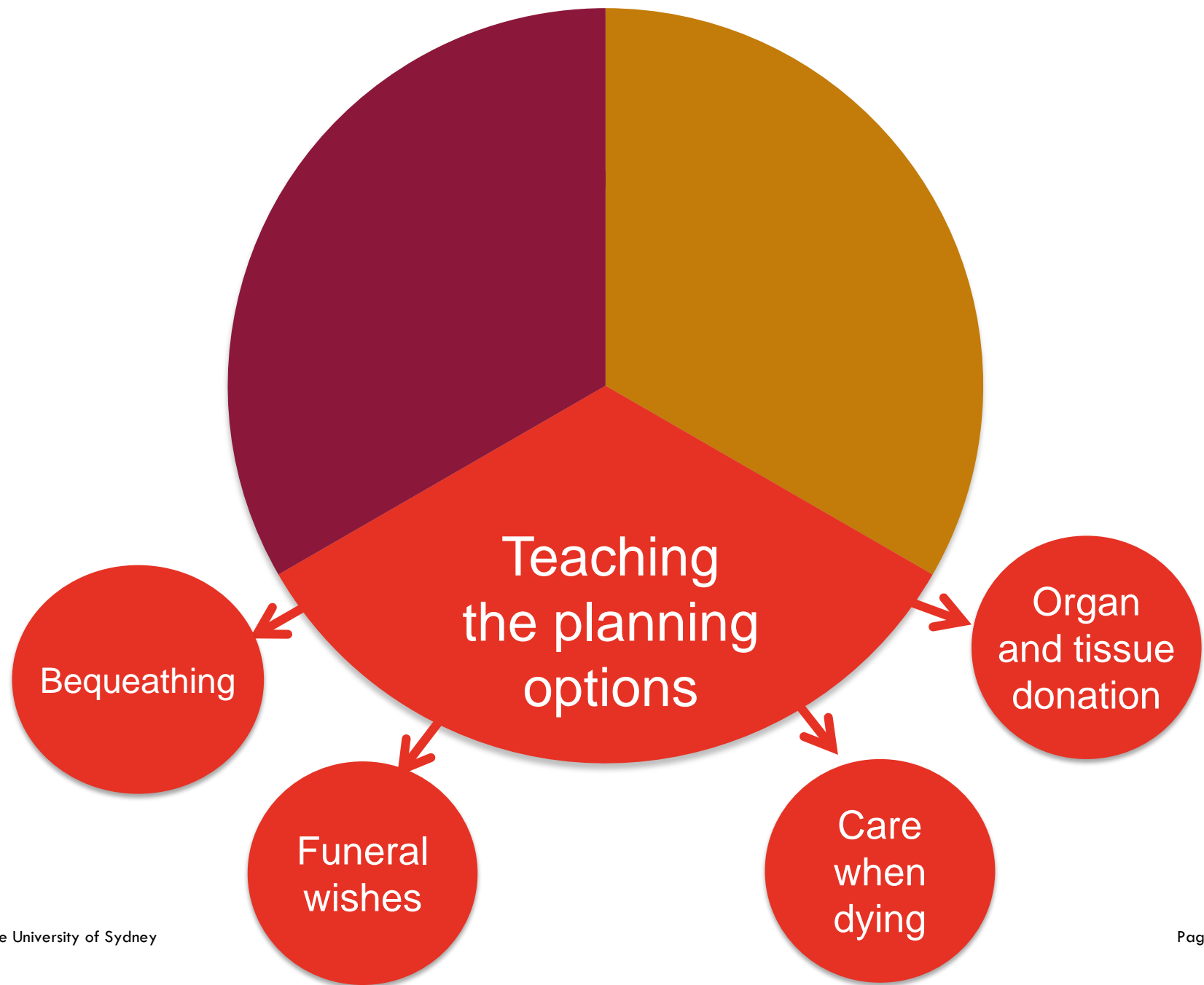
TEL in summary

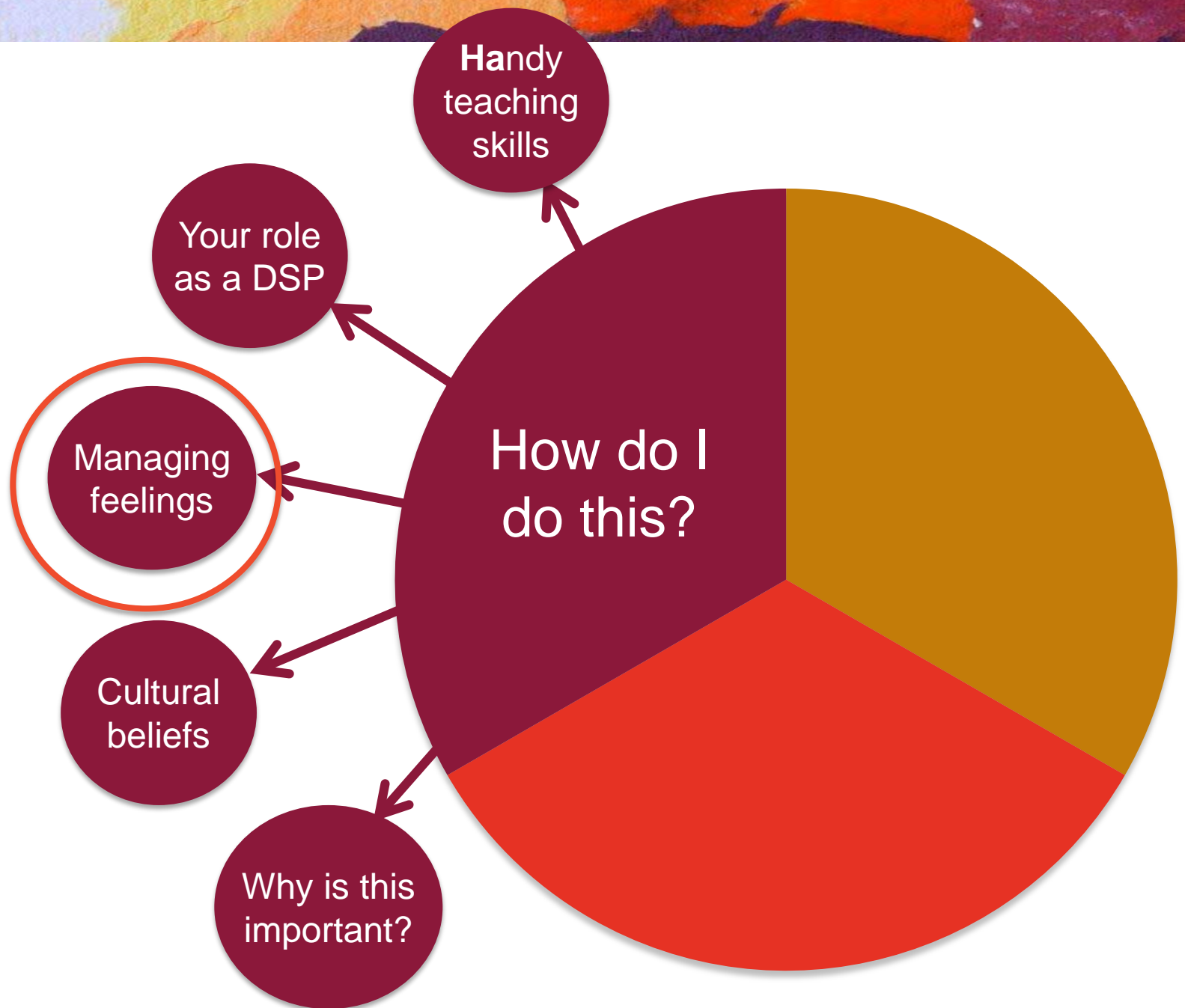**TEL** comprises 12 learning modules around a suite
of 3 topics:

    1) Teaching how to understand end of life

    2) Teaching the planning options

    3) How do I do this?

Teaching the planning options

Bequeathing

Funeral wishes

Organ and tissue donation

Care when dying

Handy teaching skills

Your role as a DSP

Managing feelings

Cultural beliefs

How do I do this?

Why is this important?

TEL: Suite of 3 topics and 12 learning modules

TEL features

- Aimed at disability support professionals, people with intellectual disability, families and health professionals

- No paid actors. Real people with intellectual disability and disability staff

- Each module can be done as a standalone, or you can complete any number of modules in any order

- You can do each **TEL** module on your own, or you can run it as a facilitated group session. For the latter, there are facilitator's guides.

- **TEL** modules include case studies, video examples, teaching tips, problem solving exercises, and reflection questions

- **TEL** uses simple language, so it is easy to understand for many different people

TEL is available at
https://www.caresearch.com.au/TEL/

Jurisdictional considerations…

TEL is based on Australian state/ territory jurisdictions

Important to check your own jurisdiction's requirements. For example:

— Advance care planning (see the **TEL Care when dying** module): e.g., USA: POLST (Physician Orders for Life- Sustaining Treatment) or MOLST (Medical Orders for Life- Sustaining Treatment) *(McGinley, Waldrop & Clemency, 2017)*

— Guardianship law (see the **TEL Care when dying** module): may be different in your jurisdiction

Aim 3

Describing effective approaches to help people with intellectual disability deal with loss and grief.

People with intellectual disabilities have more **similarities** *to us* than differences *from us*.

(Krishef, 1983: cited in McDaniel, 1989)

Particularly when it comes to loss, dying, death, and bereavement (Read, 2005; 2015).

Similarities

— When we are **born**

— When **old age** approaches

— When **death** approaches

"Death is not the enemy, Doctor. Inhumanity is."

(Bertman, 1991)

Listening to the voices of others

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

- Prone to multiple and successive losses (Oswin 1991; Elliott, 2003; Read 2015)

- Cultural differences in bereavement support (Dodd et al, 2005)

Vulnerable from a death and dying perspective:

- Actively excluded from death and dying (Read & Elliott, 2003; Read 2015)
- More complex the needs, the less likely hood of being involved (Read & Elliott, 2003)
- People usually experience sudden as opposed to anticipatory grief (O'Nians, 1993)
- Have an external locus of control (reliant on so many for so much).
- Prone to complicated grief (Dodd & Blackman, 2015)

Why hearing the words is difficult

–   Cultural and societal taboos generally

–   Combination of cognitive ability, attention span and limited emotional vocabulary (Conboy-Hill, 1982)

–   Low expectations, stereotyping and stigma (Kitching, 1987)

–   Emotional needs often remain neglected (Arthur, 2003)

- Perceptions of ability to grieve (McLoughlin, 1986; Elliot, 1995; Read, 1996)

- Cultural and societal taboos: death and disability (Oswin, 1991)

- Over protectiveness (Deutsch, 1985)

- Carers feelings of fear, inadequacy and uncertainty (Emerson, 1976; Thurm, 1989; Oswin, 1991; Parks, 2015)

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'
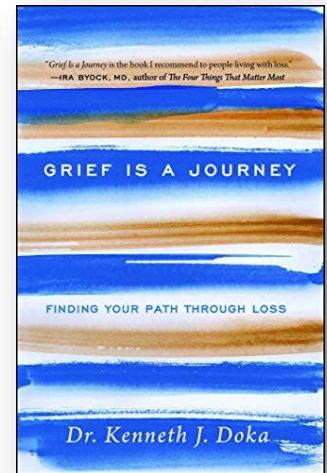
- Results in disenfranchised grief...

Disenfranchised
Grief

New Directions,
Challenges, and
Strategies for Practice

Kenneth J. Doka / Editor
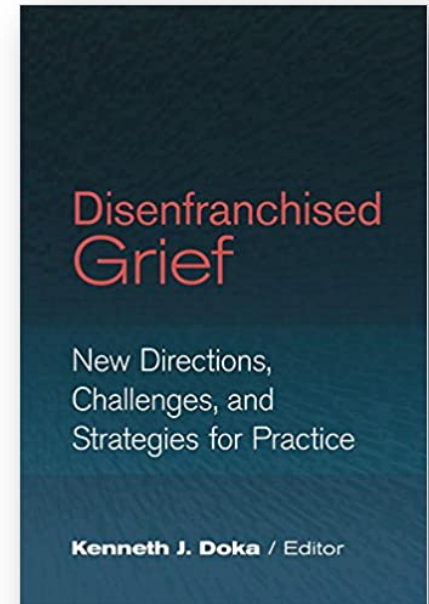
Disenfranchised Grief

(Doka 1989; 2002; 2016)

"*…the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported…*"

1. The **relationship** is not recognised

2. The **loss** is not recognised

3. The **griever** not recognised (1989)

4. The **circumstances** surrounding the death

5. The **ways** that individuals grieve (2002)

Responding to disenfranchised grief (Doka, 2002; 2016)

- 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).

- Constructive use of ritual (powerful therapeutic tool):
  - Funerals
  - Rituals of continuity, transition, reconciliation, affirmation
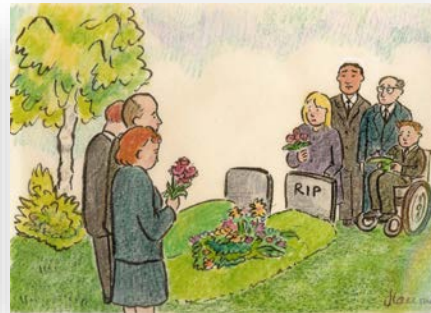
Responding to loss: Continuum of support model

(Read, 2007)

Intervention

Facilitation

Participation

Education
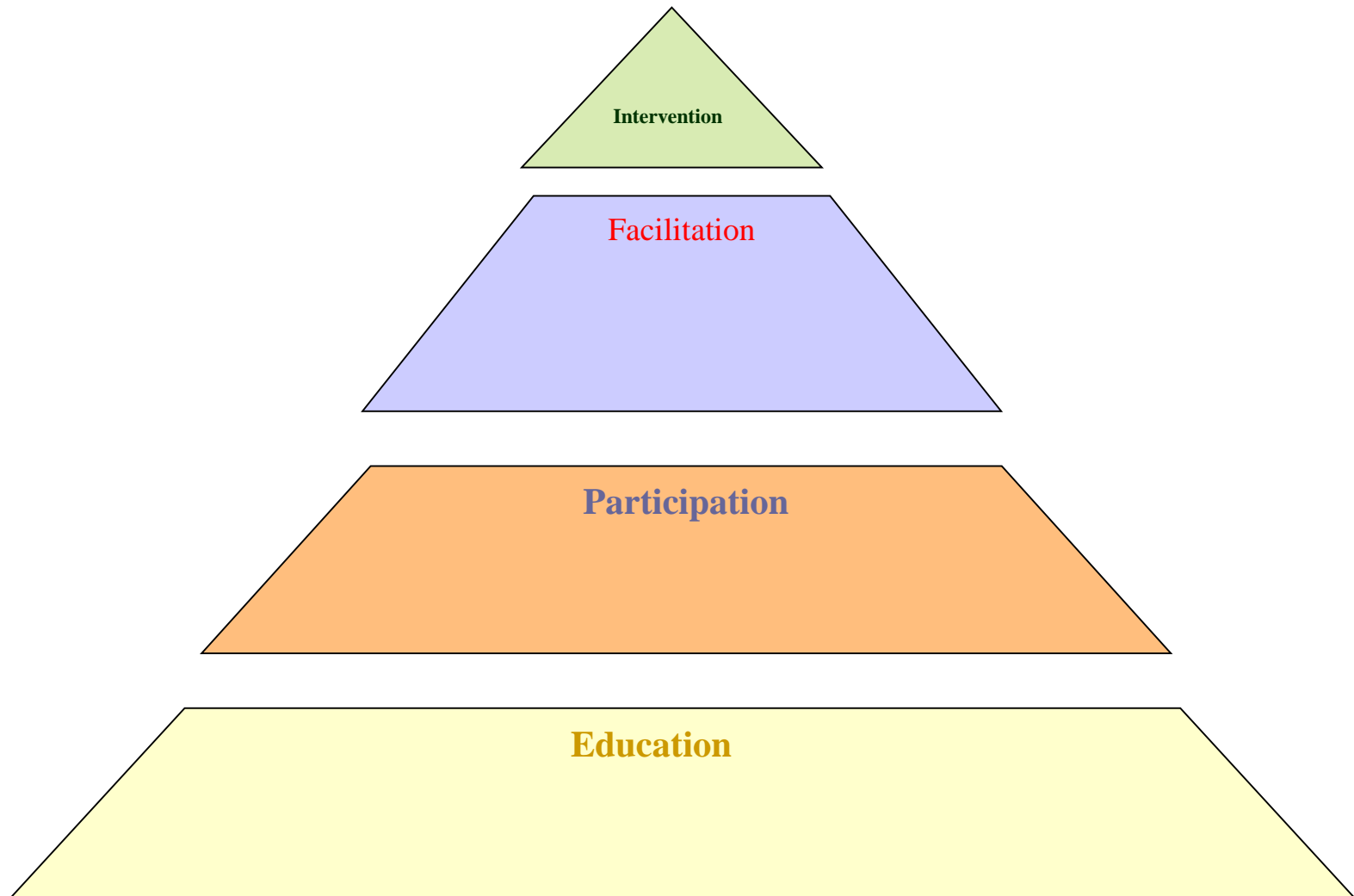
Covid-19: Unprecedented Global Impact and Loss

- Physically, emotionally, practically.

- Culturally

- Socially

- Economically

- Environmentally

....

- How do we begin to explain the uncertainty around what's happening?

- How do we adapt the social consequences of associated losses:

  - Closures of services

  - Illness / death of staff/ friends/ families

  - Reactions to loss (emotional, behavioural)

- How do we manage the multiple losses people are exposed to?

- How do we support the disenfranchised grief of others, when we ourselves feel disenfranchised?

- How do we prepare carers in supporting people in the aftermath?

'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.'

George A. Bonanno (2009: 3)
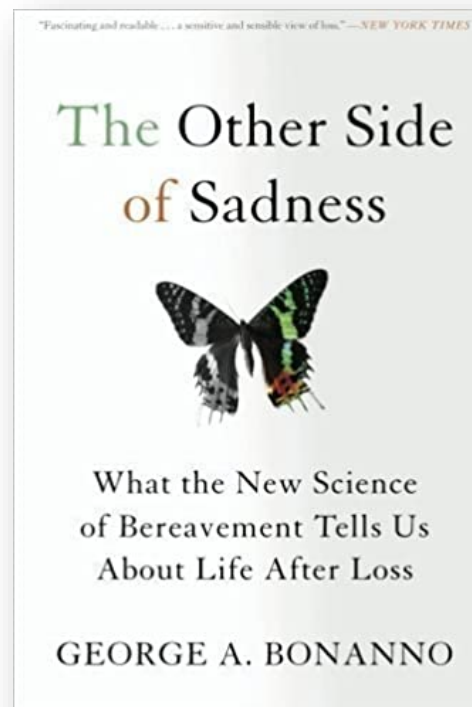
Aim 4

– Providing a list of useful resources about loss and end of life (including some specific to COVID-19)
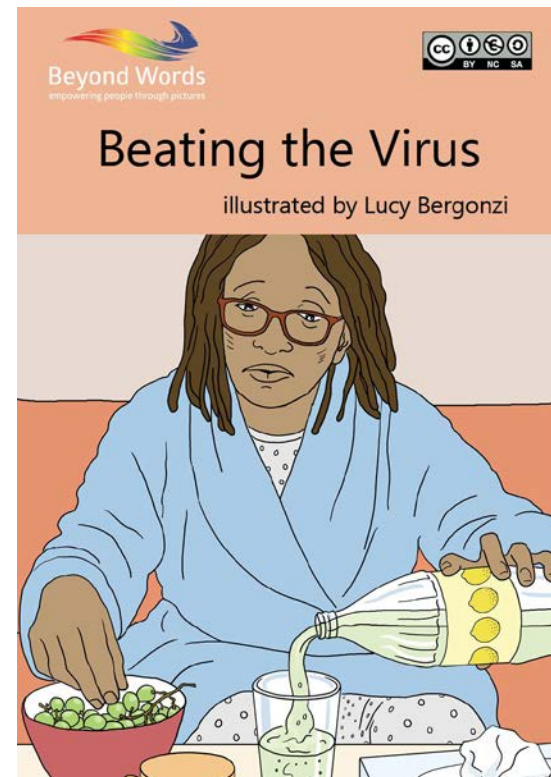
Books Beyond Words: *Beating the Virus*

Features

– 26 pages of pictures (no words, so the story can be tailored to the person's individual situation and communication style)

– A 1-page suggested story, plus page-by-page suggested storyline points.

– Guidelines about how to use the book.

– List of UK COVID-19 resources for people with IDD.

– From the UK, so some details differ in other countries (e.g., dialling 111 for the emergency [health] number)

– Another book, *When someone dies from coronavirus: a guide for families and carers,* is also available for free download.

Available for free download at https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus

Beyond Words
empowering people through pictures

Beating the Virus

illustrated by Lucy Bergonzi

Useful Resources

Resources List

— We have provided a 2-page list of end-of-life resources and some COVID-19 resources.

— All of the resources in this list have been **designed specifically for people with IDD** and the people who support them. **Most are available online for free download**.

— The resources are intended to assist people with IDD to understand, plan and stay safe.

Where to find the list

— The resources list,

— a pdf of the PowerPoint slides

— a recording of the webinar

will all be available in the coming days at AAIDD Education Archive https://www.aaidd.org/education/education-archive

References

Arthur, A.R. (2003).The emotional lives of people with learning disability. *British Journal of Learning Disabilities, 31,* 25–30.

Bonanno, G. (2009). *The other side of sadness: What the new science of bereavement tells us about life after loss.* New York: Basic Books.

Bonell-Pascual, E. Huline-Dickens, S. Hollins, S. et al. (1999) Bereavement and grief in adults with learning disabilities. *Br. J. Psychiatry, 175,* 348–350

Conboy-Hill, S. (1992). Grief, loss and people with learning disabilities. In A. Waitman, S. Conboy-Hill, Ed. *Psychotherapy and mental handicap* (pp.150–170). Sage: London.

Dodd, P. & Blackman, N. (2014). Complicated grief. In S. Read (Ed.) *Supporting people with intellectual disabilities experiencing loss and bereavement: Theory and compassionate practice* (pp. 59-70). London: Jessica Kingsley Publishers.

Doka, K.J. (1989). *Disenfranchised grief: recognising hidden sorrow.* Lexington Books: Toronto

Doka, K. (2002). *Disenfranchised grief: new directions, challenges and strategies for practice.* Research Press: Illinois.

Emerson, P. (1976). Covert grief reactions in mentally retarded clients. *Mental Retardation, 15*(6), 27–29.

Esbensen, A. J. & Benson, B. A. (2006). A prospective analysis of life events, problem behaviours and depression in adults with intellectual disability. *Journal of Intellectual Disability Research, 50,* 248–258.

Forrester-Jones R. (2013). The road barely taken: funerals, and people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 26,* 243-256. doi: 10.1111/jar.12022

Kirkendall, A., Linton, K., & Farris, S. (2017). Intellectual disabilities and decision making at end of life: A literature review. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 982-994. doi: 10.1111/jar.12270

McEvoy, J., MacHale, R. & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 56,* 191–203.

McGinley, J., Waldrop, D. P., & Clemency, B. (2017). Emergency medical services providers' perspective of end- of- life decision making for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 30,* 1057–1064. doi.org/10.1111/jar.12363

McLoughlin, I.J. (1986). Care of the dying: bereavement in the mentally handicapped. *Br. J. Hosp. Med.* 256–260Octo. ber.

O'Nians, R. (1993). Support in grief. *Nursing Times, 89,* 50:62-64.

References

Oswin, M. (2000). *Am I allowed to cry?* (second ed). London: Souvenir Press

Parkes, M. (2014). Living with shattered dreams: A parent's perspective. In S. Read (Ed.) *Supporting people with intellectual disabilities experiencing loss and bereavement: Theory and compassionate practice* (pp. 206-216). London : Jessica Kingsley Publishers:.

Read, S. (2005). Loss, bereavement and learning disability: providing a continuum of support. *Learning Disability Practice, 8* (1), 31–37.

Read, S. & Elliot, D. (2003). Death and learning disability: a vulnerability perspective. *Journal of Adult Protection, 5* (1), 5–14.

Read, S. & Elliott, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities. *Journal of Intellectual Disability, 11* (2), 167–182.

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

Stancliffe, R. J., Wiese, M. Y. & Read, S. (Eds.). (2017). End of life and people with intellectual disability. [Special issue]. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 977-1164.

Stancliffe, R. J., Wiese, M. Y., & Read, S. (2017). End of life and people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 977-981. doi: https://doi.org/10.1111/jar.12383

Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltes, G. & Clayton, J. M. (2016). Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ? *Research in Developmental Disabilities*, 49-50, 47-59. doi: 10.1016/j.ridd.2015.11.016

Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltes, G. & Clayton, J. M. (2017). Assessing knowledge and attitudes about end of life: Evaluation of three instruments designed for adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 1076-1088. doi: 10.1111/jar.12358

Thurm, A. (1989). I've lost a good friend. *Nurs. Times, 85* (32), 66–68.

Wiese, M., Dew, A., Stancliffe, R. J., Howarth, G., & Balandin, S. (2013). "If and when?": Experiences of community living staff engaging older people with intellectual disability to know about dying. *Journal of Intellectual Disability Research, 57*(10), 980-992.

Wiese, M., Stancliffe, R. J., Balandin, S., Howarth, G., & Dew, A. (2012). End-of-life care and dying: Issues raised by staff supporting older people with intellectual disability in community living services. *Journal of Applied Research in Intellectual Disabilities, 25*(6), 571-583. doi:10.1111/jar.12000

Wiese, M., Stancliffe, R. J., Read, S., Jeltes, G. & Clayton, J. (2015). Learning about dying, death and end-of-life planning: Current issues informing future actions. *Journal of Intellectual & Developmental Disability, 40*(2), 230-235. doi 10.3109/13668250.2014.998183

Aim 5

Q and A

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