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

End of Life and Loss

Professor Emeritus
Roger Stancliffe

Professor Emerita
Sue Read
The team

- **Prof Roger Stancliffe** CDRP, University of Sydney
- **Dr Michele Wiese** Western Sydney University
- **Prof Josephine Clayton** HammondCare; University of Sydney
- **Prof Sue Read** Keele University, United Kingdom
- **Ms Gail Jeltes** Unisson Disability, Australia
- **Dr Rebecca Barton** University of Sydney
- **Mr Lewis Kidson** CDRP, University of Sydney
- **Ms Hayley Brooks** CDRP, University of Sydney
- **Ms Bronwyn Newman** CDRP, University of Sydney
- **Prof Jennifer Tieman**, Flinders University, CareSearch
- **Ms Sarah Wagstaff** CDRP, University of Sydney
- **Dr Nathan Wilson** Western Sydney University
- **Dr Daniel Piepers** Western Sydney University
- **Dr Seeta Durvasula** Centre for Disability Studies, University of Sydney
- **Ms Bernadette Curryer** Western Sydney University
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)](chart)
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
Results

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

- At 6 months, intervention participants 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?
Dying
Teaching how to understand EOL
Death
Loss, grief, mourning
How do I do this?

Your role as a DSP

Managing feelings

Cultural beliefs

Handy teaching skills

Why is this important?
TEL: Suite of 3 topics and 12 learning modules

- Teaching how to understand EOL
- Teaching the planning options
- Why is this important?
- Cultural beliefs
- Managing feelings
- Your role as a DSP
- Handy teaching skills
- Dying
- Death
- Loss, grief, mourning
- Organ and tissue donation
- Care when dying
- Funeral wishes
- Bequeathing
**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**

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.

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

(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 likelihood 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
(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)
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)
- 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](https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus)
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


References


Aim 5

Q and A
Centre for Disability Research and Policy

www.sydney.edu.au/health_sciences/cdrp/

Email: roger.stancliffe@sydney.edu.au
s.c.read@keele.ac.uk