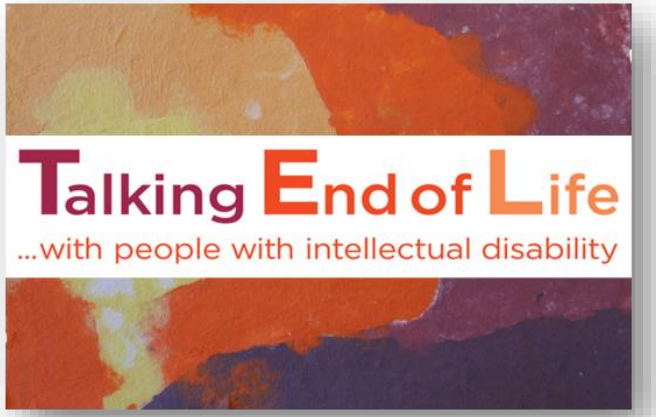
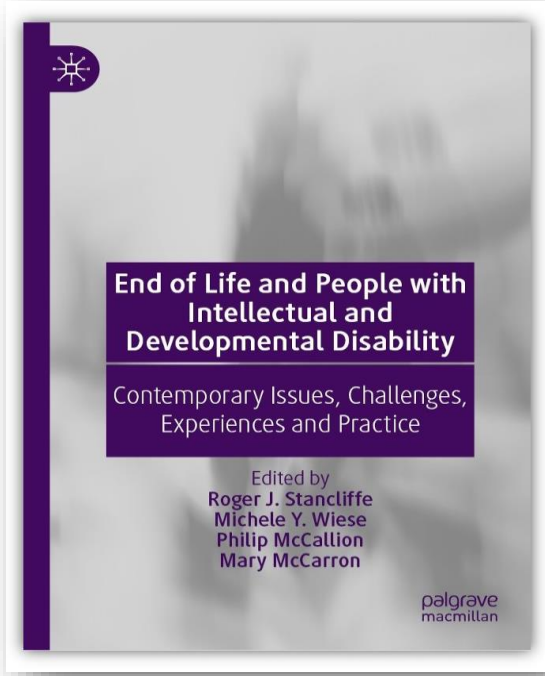
"Into the light" by Derek Coyle (1960-2014). Unisson Community Access Program Art Studio (now Blue Apple Art Studios)

ASID 2025 Conference
12th November Sydney NSW

Talking about the end of life with people with intellectual disability





Michele Wiese
Adjunct Fellow
School of Psychology
Western Sydney University

Roger Stancliffe
Professor Emeritus
Faculty of Medicine & Health
University of Sydney

THE UNIVERSITY OF SYDNEY

WESTERN SYDNEY UNIVERSITY

Aims

1. What happens for people with intellectual disability if nobody talks about dying and death?

2. What are the advantages if we talk about it?

3. Introducing our end-of-life resources

4. How can we help people with intellectual disability understand the end of life and make decisions if they wish?

5. An example of successful intervention

6. Introducing end-of-life assessment instruments specifically for people with intellectual disability

Aim 1

What happens for people with intellectual disability if nobody talks about dying and death?

Let's discuss

Why is it hard to talk about?

It's a sensitive topic

Avoidance common when person has an intellectual disability

For all parties (family, disability staff, health providers) challenges include:

- How to share something we understand only in the abstract?
- Learning difficulties can translate to compromised ability to understand
- Own fears, loss, superstition
- Own lack of experience or confidence
- Natural to wish to protect self and others
- Fear of doing harm
- Don't know what to say
- Feels uncomfortable

Bruun et al., 2024b; Foo et al., 2021; Kuchenbecker & Bevan, 2024; Stancliffe et al., 2016; Wiese & Stancliffe, 2025

This translates to...

- Seemingly widespread acceptance 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)*

- End-of-life decisions are made by others, and person is routinely excluded from participation, including not being made aware of their own terminal diagnosis

- May not be invited to funerals/ rituals

- Decreased opportunities to understand or plan for end of life

Forrester-Jones et al., 2022, Kirkendall et al., 2017;

The research tells us...

Up to one third of bereaved not told about impending death of loved one, even if have reasonable communication skills

People with intellectual disability do have at least some understanding of end of life

Almost unanimously, have had direct experience with dying and death

If we don't talk about it, then risk:

- **Incomplete or incorrect understanding**
- **Unnecessary fear?**
- **Complicated grief (prolonged grief disorder)**

Fernández-Ávalosm et al., 2023; O'Riordan et al., 2022, 2024; Parchomiuk et al., 2025; Persechino et al., 2024; Stancliffe et al., 2016; Tuffrey-Wijne et al., 2020; Wiese & Stancliffe, 2025

What about one's own impending death?

Over one half of those with terminal illness told they were ill, but most were not told they were going to die

Findings held irrespective of communication skills of individual

Tuffrey-Wijne et al., 2020

Consequences for dying person? Can't do:

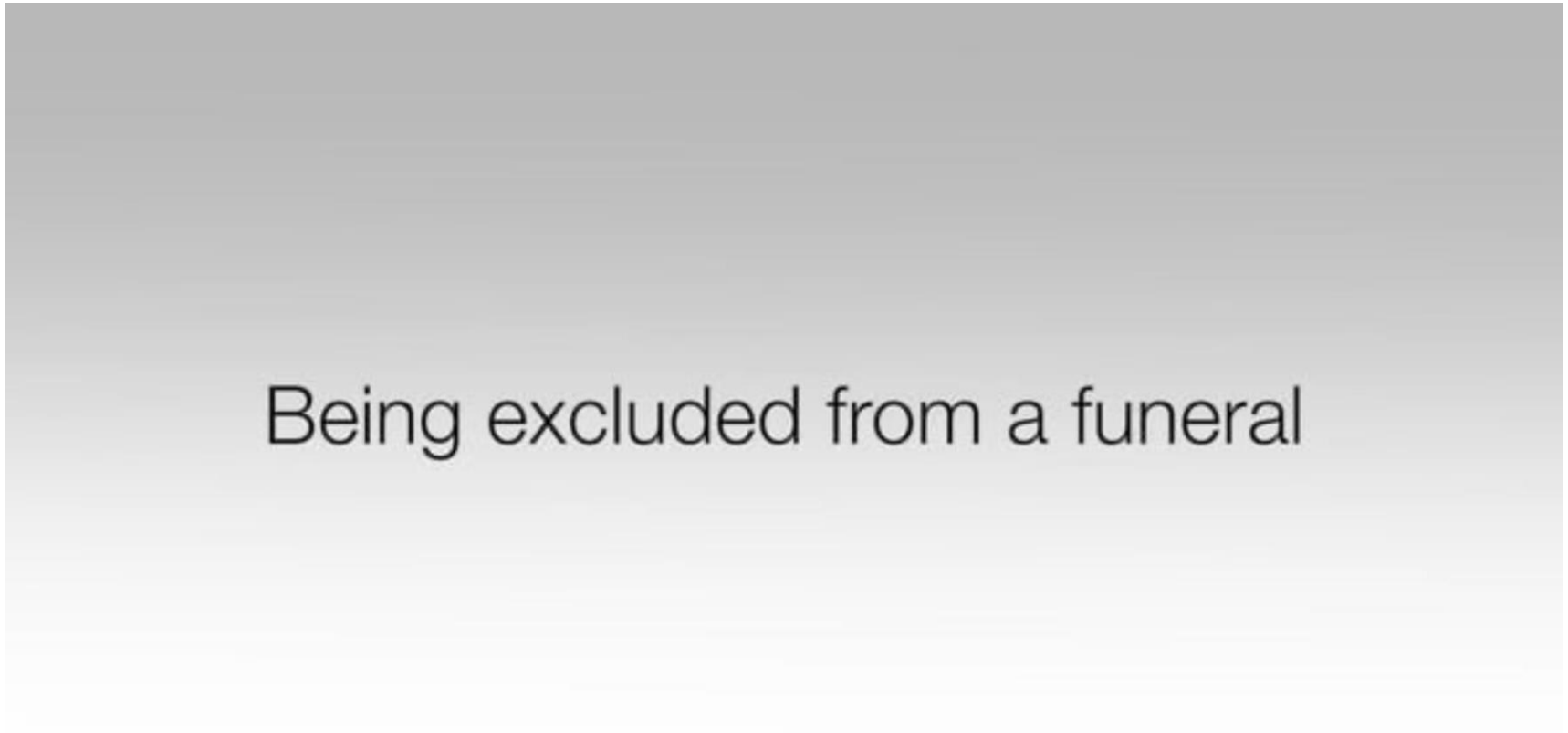
- Unfinished business
- Final goodbyes
- Advance care planning: organ donation, preferred place of care, funeral wishes

Consequences for others? Can't do or compromised:

- Health practitioner treatment
- Palliative care
- Faith, spiritual leaders, grief counsellors, death doulas

Adam et al, 2021; Ellison, 2022; Foo et al., 2021; Read & Morris, 2008

The impact of being excluded from a funeral (1):
From TEL Module "Funeral wishes"



The impact of being excluded from a funeral (2)

Discussion:

1. What is the most important take-away message from this video?

2. What effect do you think being excluded may have had on Kathie?

- Kathie can talk about this difficult subject

- She initiated repeated opportunities to do so with her support staff

Aim 2

What are the advantages if we talk about the end of life?

The advantages of knowing are?

Write your responses to the following question? Think widely...

I know what dying and death is.

What are the advantages of that knowledge for me?

The advantages of knowing for people with intellectual disability

- Increased comfort with conversations
- Reduced anxiety about death
- Better understanding of concept of death
- Advanced care planning supported
- Healthier attitudes to death
- Assists problem solving and coping
- Supports grief
- Better health
- Early intervention palliative care
- Collaboration: family, professionals

Bruun et al., 2024b; De Veer et al., 2024; Deliens, 2022; Fernández-Ávalosm et al., 2023; McKenzie et al., 2024; Noorlandt et al., 2024; Stancliffe et al., 2021

The research tells us...

People with intellectual disability want to talk about end of life, and feel comfortable:

Initiate conversations

- Deaths of famous people
- Past personal death experiences
- Pet deaths
- Questions about loved ones with current terminal illness

It is normal to have a continuing relationship with the dead

Disability support staff strongly support the right of person to know but don't know how to do it

Consider the conversation partner/s. BUT this does not mean "*I'll let someone else worry about that*".

*Bruun et al., 2024b; Dusart, 2008; Hunt et al., 2020; Stancliffe et al., 2021;*Tuffrey-Wijne et al., 2025; Parchomiuk et al., 2025

What needs to be known?

Discussion:

Knowing about the end of life includes what topics?

- *Someone is going to, or has died*
- *What a funeral is*
- *Organ and tissue donation*
- *Where care happens, and what might be preferred*
- *Funeral wishes*
- *Making a will*
- *Preferred carers*
- *Advance care planning*
- …

Wiese & Stancliffe, 2025

Aim 3

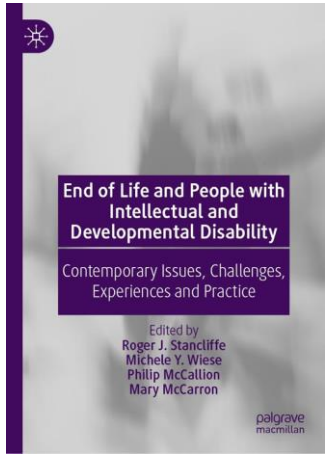
Introducing our end-of-life resources

End of life resources

Many end-of-life resources like the *Books Beyond Words* book used in the video, **designed specifically for people with intellectual and developmental disabilities,** are available. You can find resource lists in:

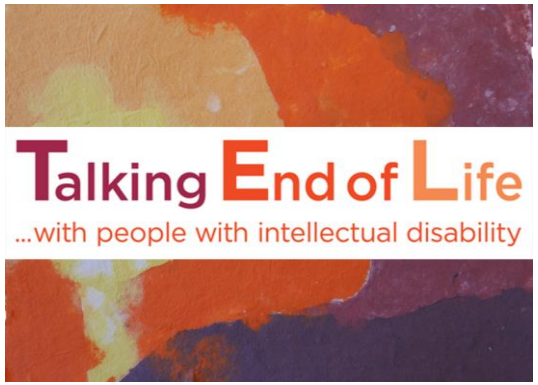
- **2022 book: *End of life and people with intellectual and developmental disability***

(at the end of most chapters & in Ch.17 *End of Life Resources*)



- ***Talking End of Life (TEL) website***
  www.caresearch.com.au/TEL

Talking end of life with people with intellectual disability (TEL)



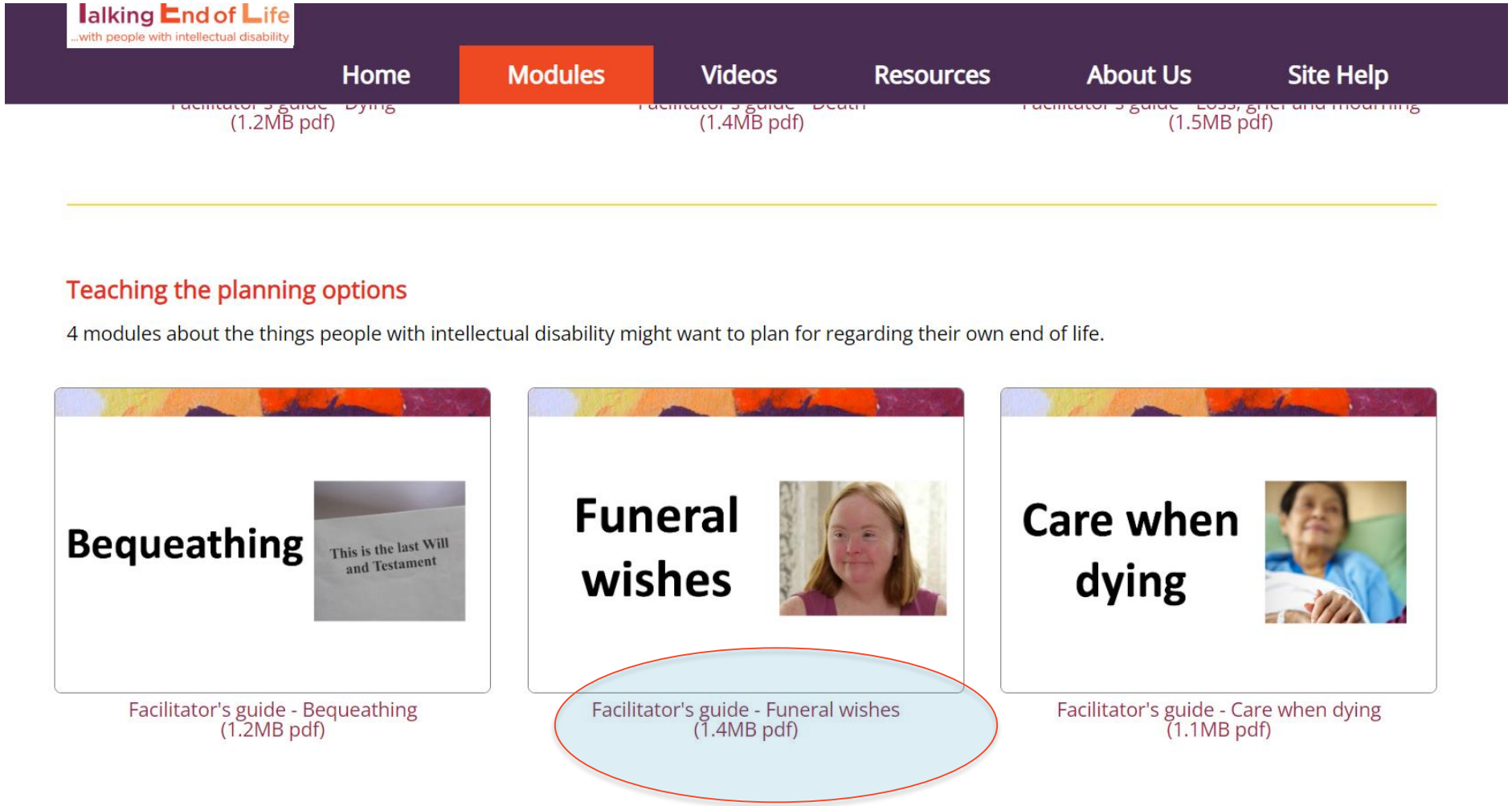
TEL can be found at:

www.caresearch.com.au/TEL

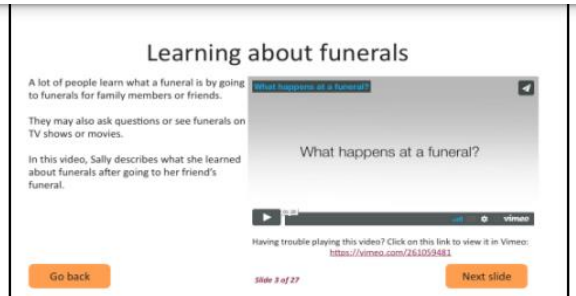
- FREE online resource, with 12 modules, 17 case studies, 38 short videos
- Designed for disability support professionals (DSPs)
- Videos feature *real people* with intellectual disability and DSPs

Wiese et al.(2018, revised 2020, 2024)

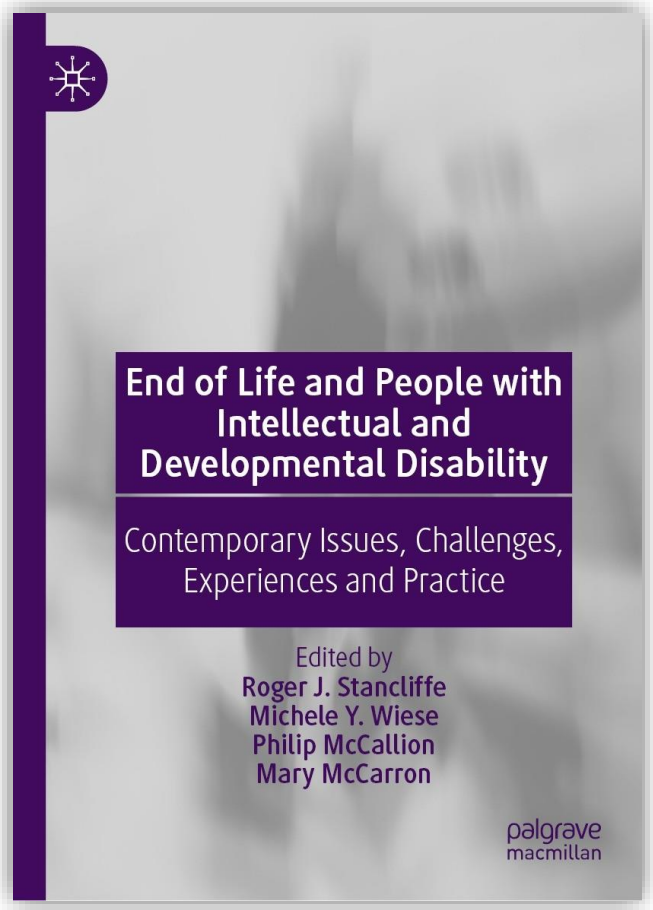
12 modules – each has key messages, videos and/or animations, case studies, reflection questions, links to resources, tips, related research, and a *facilitator's guide*



Facilitator's guide includes slide-by-slide guidance to help you focus the discussion

	The key point for discussion from this video clip is listed below: Sally shows us that people with intellectual disability can understand what happens at a funeral.
	The key point for discussion from this video clip is listed below: Although Richard said going to the funeral was "upsetting", he also said it "was good". These are common responses. People with intellectual disability should be able to go to funerals, say goodbye, and feel proud that they attended, just as Richard did.

2022 publication...



- 17 chapters and 37 authors from 10 countries in Australia, Europe, North America.
- Focus on challenging and new topics, including **suicide, do not resuscitate orders, children, people with profound/multiple disabilities, death doulas, accessible funerals, COVID-19**
- Chapters include **real-world personal stories**, and **realistic scenarios** with **reflection questions to support translation into practice**
- **Lists of resources**, many designed specifically for people with IDD, are provided to support practical implementation

For more information:

https://link.springer.com/book/10.1007/978-3-030-98697-1

Aim 4

How can we help people with intellectual disability understand the end of life and make decisions if they wish?

Dying to Talk

- Our *Dying to Talk* project, provides the ***first direct empirical evidence*** on the long-term psychological effects of talking about end of life. We evaluated change over time in:
  - **Depression**
  - **Anxiety**
  - **Fear of death**

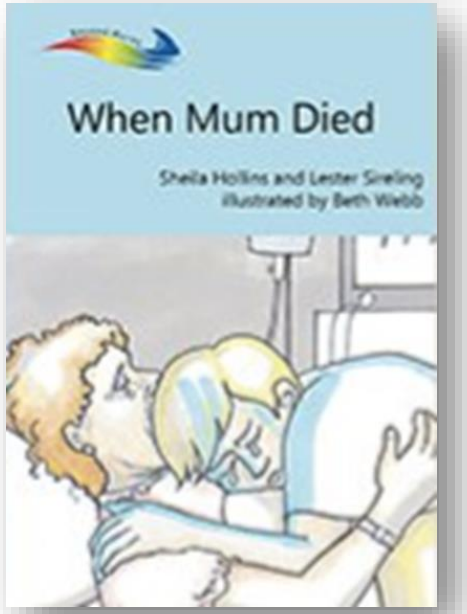
- We also measured "*Encounters*" (conversations or activities related to end of life) during the pre-test and throughout the **6-month intervention**

Stancliffe et al., 2021

Our intervention: Everyday conversations (and activities) about end of life

We advocate:

- 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



Wiese et al., 2015

Examples of encounters

Trained disability staff encouraged participants to talk about end of life (usually for no more than a few minutes)

Encounters can be prompted by, for example:

- **News item** (e.g., 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** (looking at a photo of the dead person, attending funeral, picking up person's ashes) – **arose rarely**

Stancliffe et al., 2021

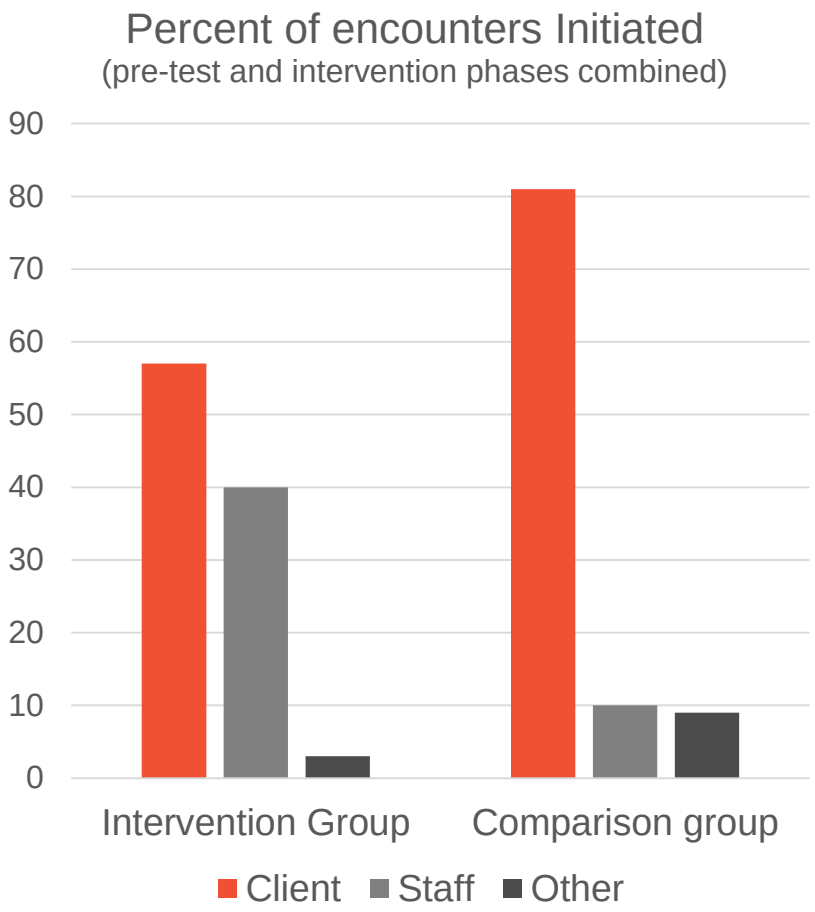
Client-initiated "encounters"

- 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

Stancliffe et al., 2021



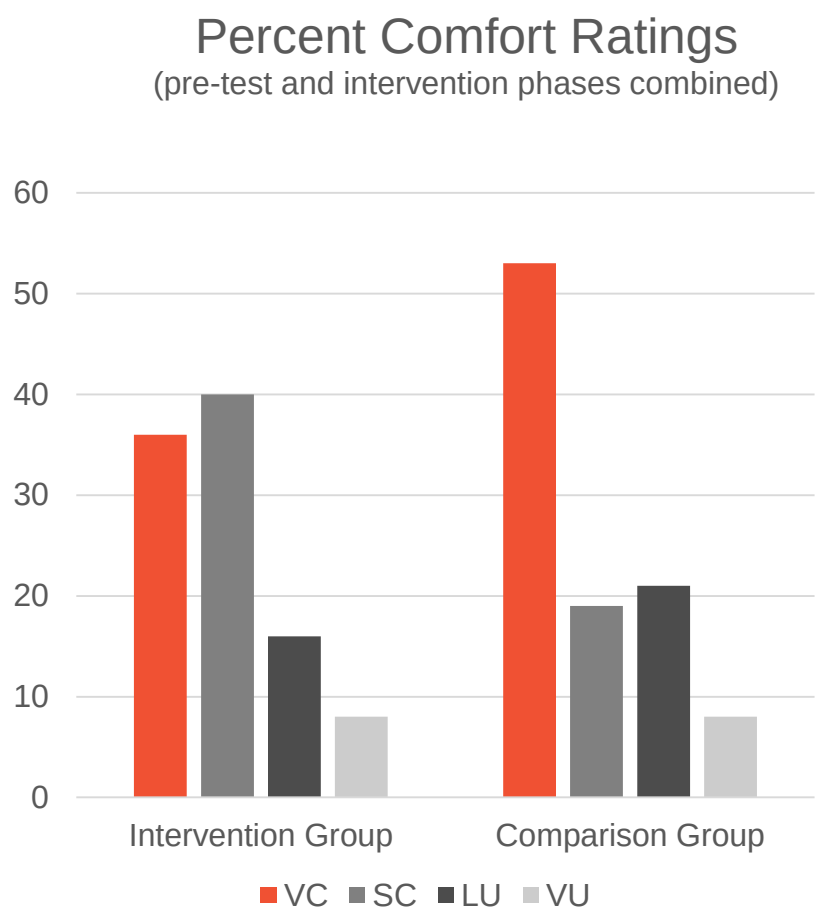
Staff-rated client comfort with encounters

- 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

Stancliffe et al., 2021



Following a 6-month intervention that involved talking/learning about end of life

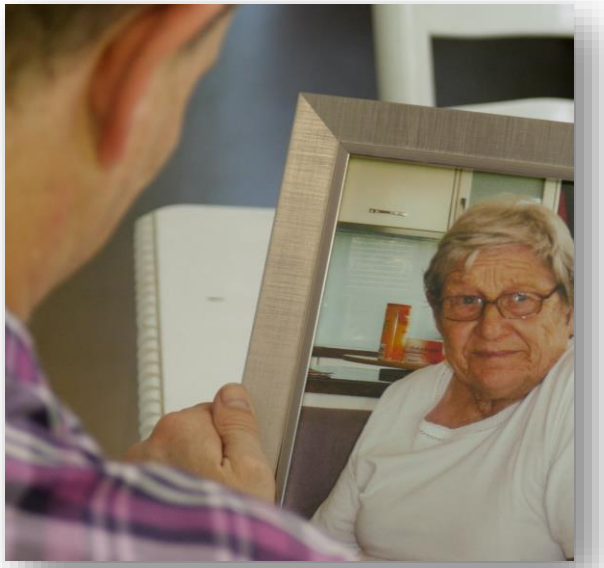
- There was no significant pre–post change in assessed
  - Depression
  - Fear of death

- Anxiety improved significantly

Stancliffe et al., 2021

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 than their pre-test scores on any psychological measure. The same was true for the comparison group

- There were **no adverse events** (serious negative outcomes)

Stancliffe et al., 2021

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

Stancliffe et al., 2021

Accessible funerals

- Many people with IDD are **not invited to the funerals of loved ones**

- Little information available about **adaptations to the funeral proceedings** to accommodate the needs of people with IDD and, where desired, to enable *active participation* in the service itself

- Resources available to **help people understand and prepare to go to a funeral,** but no research known about the effectiveness of these efforts

Forrester-Jones, 2013 ; Forrester-Jones et al., 2022

Benefits of being included in a funeral

From TEL Module “Funeral wishes”. Richard talks about going to his mother’s funeral.

Remember Kathie's video? If she were your client...

- Write down what you would do to help her say goodbye to her mother, even though she was not able to go to her funeral

Was your answer perhaps like this?

Kathie saying goodbye: From TEL Module “Funeral wishes”

How a person can understand funeral wishes, and make a choice

(From TEL Module “Funeral wishes”)

Telling others is not enough…recording wishes

In the preceding video Carolyn* talks about the music she would like, and cremation or burial

But telling someone is not enough….Carolyn* records her choices

– From **TEL** Module "Funeral wishes"

A helpful resource to complete with clients: When I Die booklet Booklet

See also on the **TEL** Resources tab: "My end-of-life choices book"

**pseudonym*

Carolyn* records her choices (From TEL Module "Funeral wishes")

Helping people understand what dying and death is

- Some people with intellectual disability have a limited understanding of dying and death

- How would you help a person better understand the five biological components of death?
  - ***Causality*** (biological or external causes of death)
  - ***Finality*** (the dead cannot come back to life)
  - ***Non-functionality/Cessation*** (all life functions stop after death)
  - ***Universality*** (all living things die)
  - ***Inevitability*** (one's own death is inevitable)

Ask questions to check for understanding

From **TEL** Module "Handy Teaching Skills"

In this video Eric asks Holly questions to check her understanding of death.

Repeat ideas and activities often

From **TEL** Module “Handy Teaching Skills”

One conversation is not enough for a person to understand the whole of end of life.

Aim 5

An example of successful intervention

Fernández-Ávalos, M. I., Fernández-Alcántara, M., Cruz-Quintana, F., Turnbull, O. H., Ferrer-Cascales, R., & Pérez-Marfil, M. N. (2023). Coping with death and bereavement: A proactive intervention program for adults with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, *16*(4), 339–362. https://doi.org/10.1080/19315864.2023.2169420

Study overview: Fernández-Ávalos et al. (2023):

- Evaluated the effectiveness of a brief intervention program among 38 Spanish adults with mild or moderate intellectual disability to improve understanding of the concept of death, grief processes, and adaptive attitudes toward death

- **Randomly assigned** to an intervention (*n*=20, mean age 43.0) or control (*n*=18, mean age 45.3) group - RCT

- Found **half** of the intervention participants had experienced a **recent loss** (withing the last 16 months on average for the control group) of a parent, grandparent or other relative. For 4 of these 10, **the person did not know that the loved one was sick and could die at any time**

Fernández-Ávalos et al. (2023)

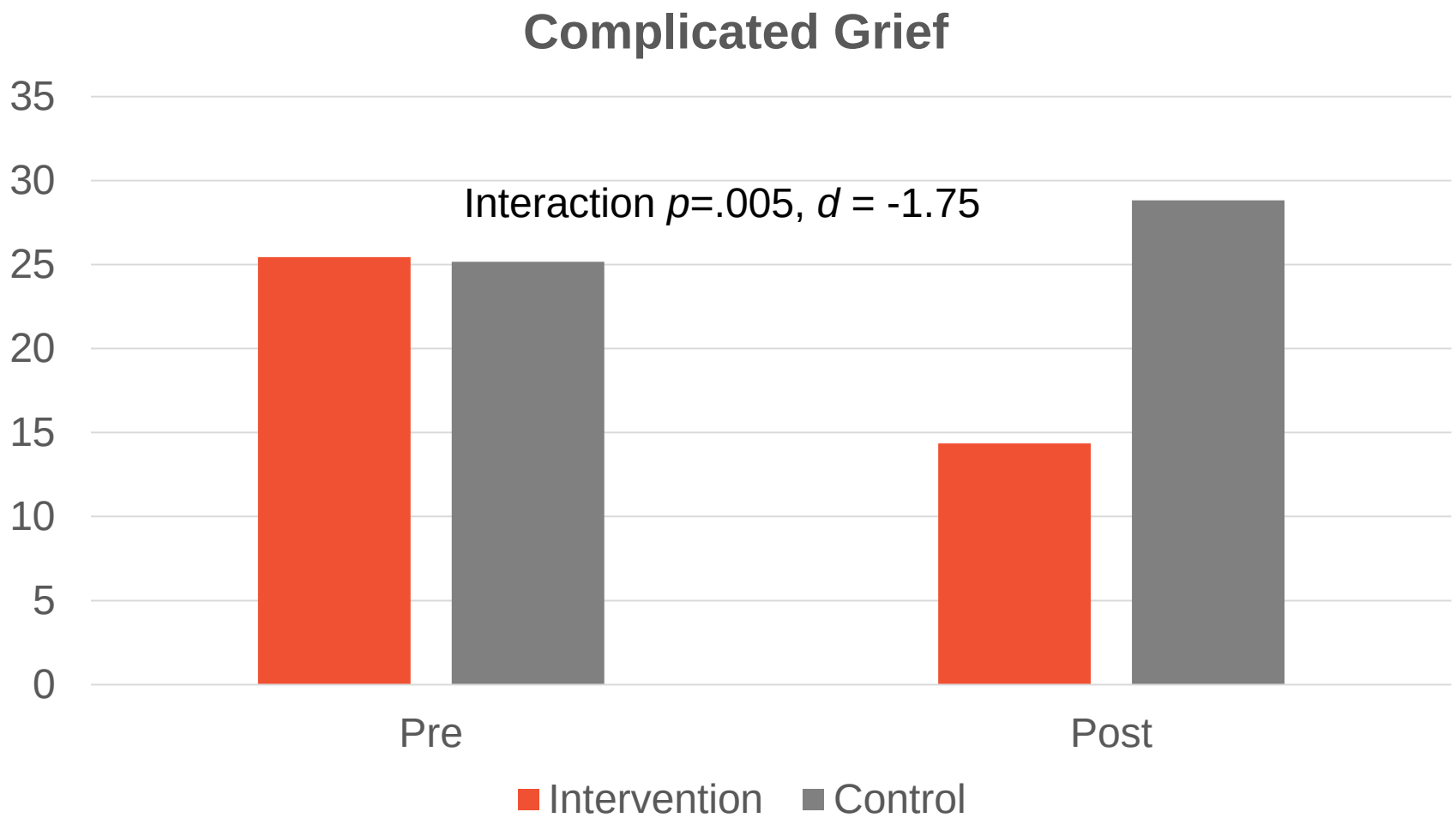
Intervention

- A four-session intervention program called "*Education in death and prevention of complicated grief in adults with intellectual disabilities*" was developed. There were 4 weekly one-hour sessions, in four groups of five people

- Participants learnt skills and strategies to help them to solve problems and to actively cope with the feelings of loss and grief, instead of using avoidance or denial-based strategies

Fernández-Ávalos et al. (2023)

Results: *Complicated Grief Questionnaire for People with Intellectual Disabilities* (CGQID; Guerin et al., 2009)



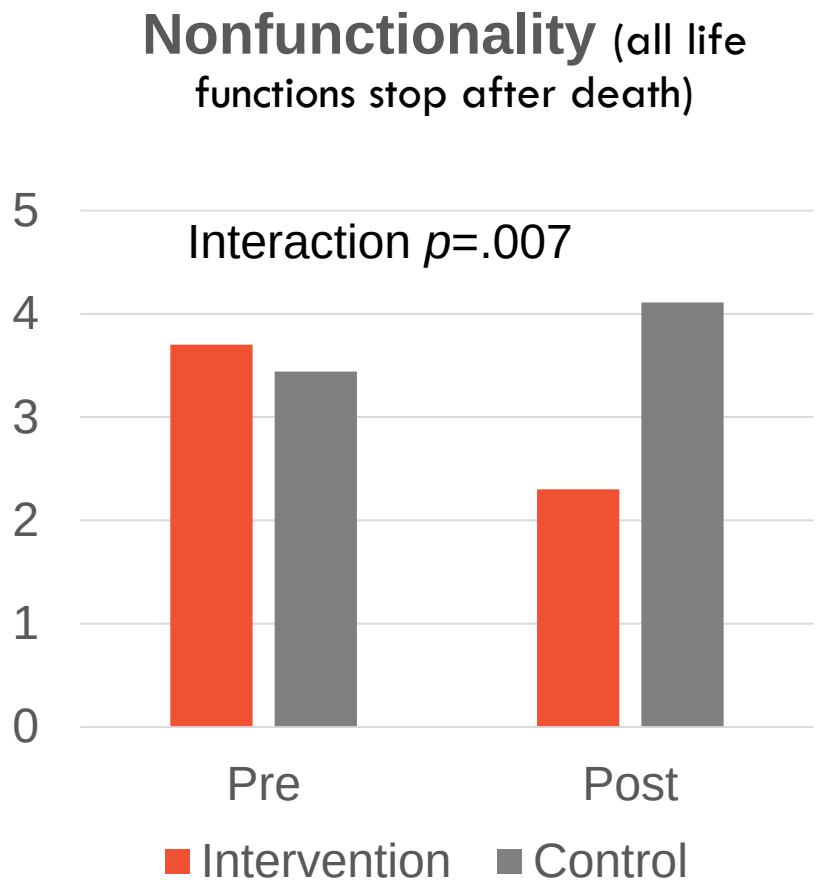
Lower scores = less complicated grief

Results: Understanding biological concepts about death

Biological Concept of Death (Ramos et al., 2010) scale. Four dimensions:

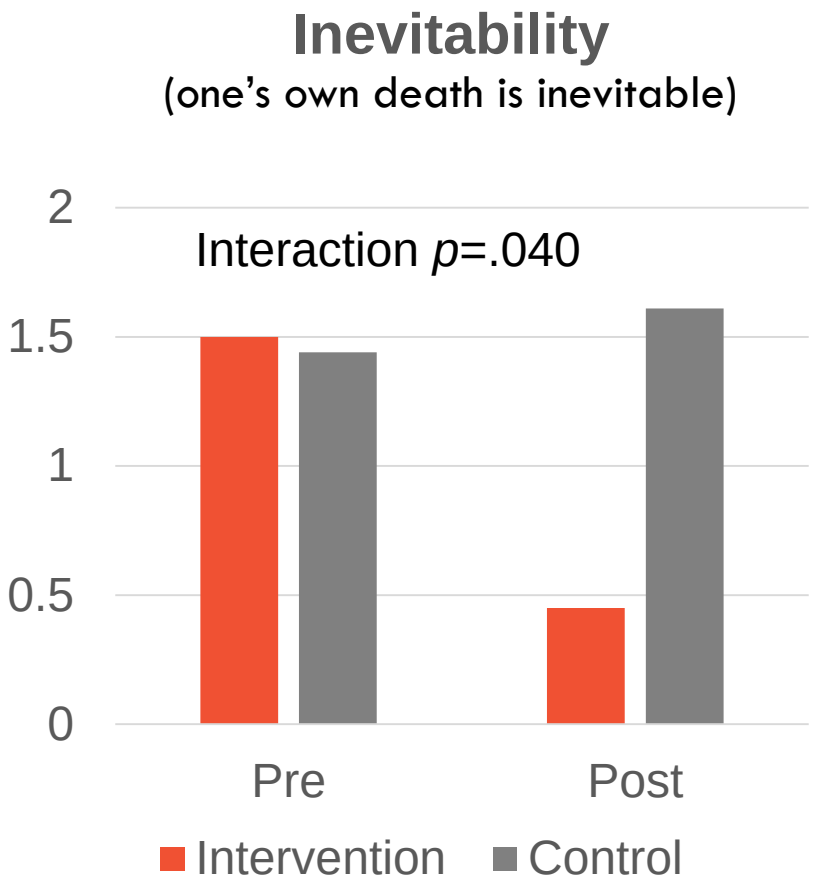
- *Nonfunctionality* and *Inevitability* each showed significant pre-post improvement for intervention group

- *Irreversibility* and *Universality* showed larger mean improvement for controls but not significant



Lower scores = better understanding

Results: Inevitability



Lower scores = better understanding

Conclusions

Intervention group showed:

- **Reduced intensity of complicated grief**
- **Improved understanding** of biological concepts of death
- **Healthier attitudes** to death, grief, and talking about death

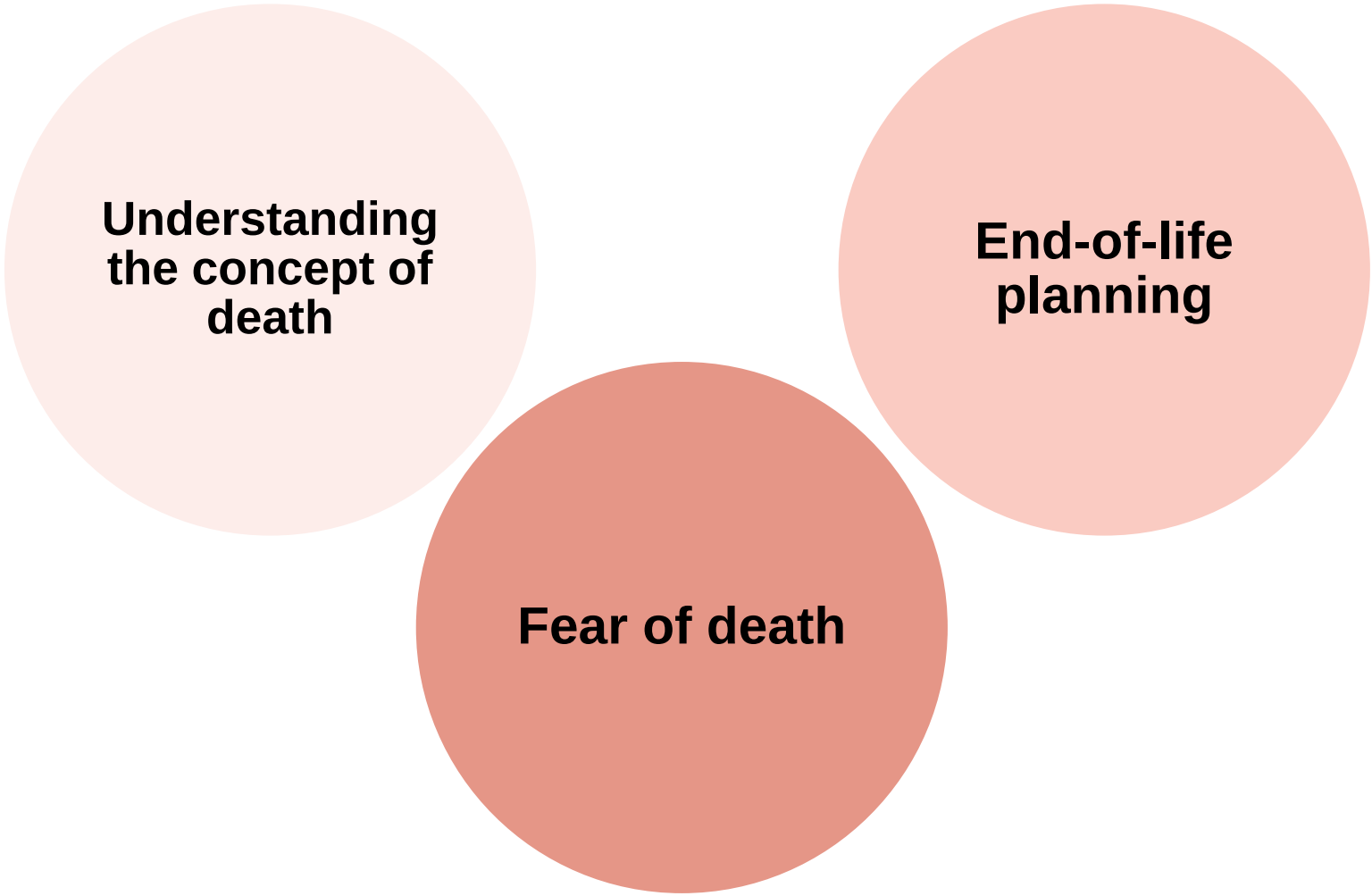
- "the findings show, as Stancliffe et al. (2021) suggested, that **most adults with ID can deal with issues related to the end of life,** and thus promote an adaptive change in their conceptions toward death, **without this generating emotional discomfort or psychological distress.**"

(Fernández-Ávalos et al., 2023, p. 356)

Aim 6

Introducing end-of-life assessment instruments specifically for people with intellectual disability

End-of-life domains assessed using ID-specific instruments

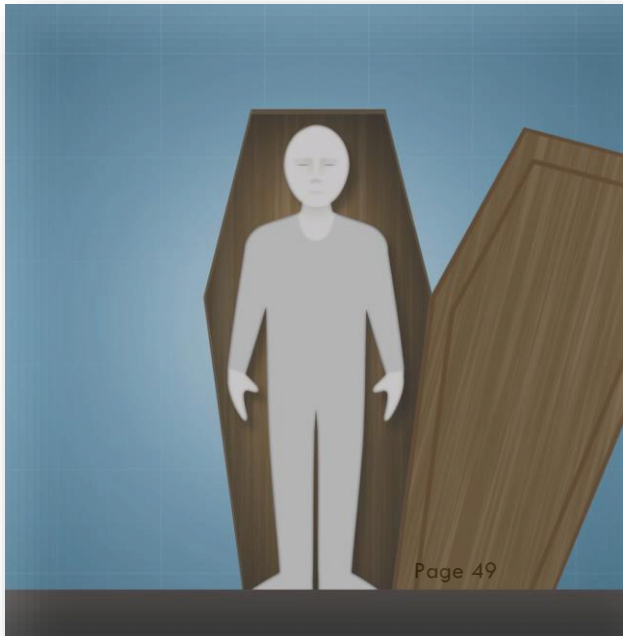


Stancliffe et al. (2016, 2017)

Concept of Death Questionnaire (CODQ)

- Evaluates understanding of the five components of death:
  - ***Causality*** (biological or external causes of death)
  - ***Finality*** (the dead cannot come back to life)
  - ***Non-functionality/Cessation*** (all life functions stop after death)
  - ***Universality*** (all living things die)
  - ***Inevitability*** (one's own death is inevitable)

McEvoy et al., 2012



CODQ Vignette: Patrick's brother is eighteen. Patrick's brother was killed in a car crash.

1a. Will Patrick's brother ever be alive again? **[Finality]**

1b. Why do you think that?

2a. What can Patrick's brother do now that he is not living anymore? **[Non-functionality/Cessation]**

2b. Why do you think that?

3a. Could this ever happen to someone else? **[Universality]**

3b. Why do you think that?

4a. Could this happen to you? **[Inevitability]**

4b. Why do you think that?

End-of-Life Planning Scale (EOLPS)

A new scale developed for our research.

EOLPS assesses **knowledge** of, and **self-determination** about:

(1) Bequeathing
(2) Preferred place of care
(3) Funeral wishes
(4) Preferred carers
(5) Advance care planning
(6) Things to take with me
(7) Organ donation

Wiese et al., 2014

Each topic is illustrated in a vignette (with 1 or 2 photos)

3 questions for each topic vignette:

1. "Who decides if …?"
2. "C*ould* the person decide if …?
3. "What can the person do *now* to ensure their wish is known about?"

– The EOLPS total score ranges from **0-42**

End-of-Life Planning Scale (EOLPS) – Sample item

Things to take with me vignette:

"All his adult life David has loved to build things. His dad gave him a hammer and he loves it more than anything he owns. David thinks that when he dies he would like the hammer put in the coffin with his dead body."

Wiese et al., 2014

Fear of Death Scale: FODS3.0-Intellectual Disability (FOD3.0-ID)

- Based on the *Collett-Lester Fear of Death Scale*, version 3.0 (FODS3.0)
- Modified to meet the needs of adults with intellectual disability by creating the **FODS3.0-ID**

Retained the same structure with four 7-item factors to evaluate fear of:

a) others' dying

b) others' death

c) your own dying

d) your own death

Lester & Abdel-Khalek, 2003

Fear of Death Scale – Sample item

How frightened are you about ….

(a) Others' dying

"Being with a person who is dying"

(b) Others' death

"Seeing the person's dead body"

(c) Your own dying

"Dying in hospital away from family and friends"

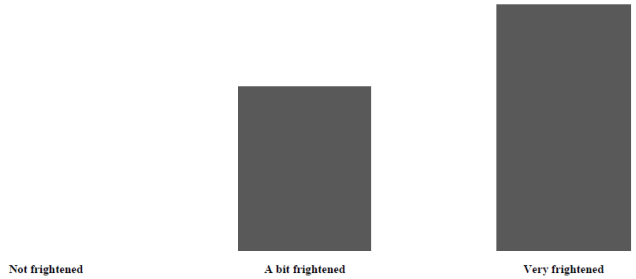
(d) Your own death

"Dying young"

Responses and scoring*

- Not frightened (1)
- A bit frightened (2)
- Very frightened (3)

Pictorial concrete-referent scale (allows pointing)



28 items

FOD3.0-ID total score ranges from **28-84**

Other excellent resources (1)

Advance Care Planning. *A website from New Zealand comprising resources to help make advance care planning easier for people with learning disabilities. It includes easy-read templates, guidebooks for supporters, a training workshop, and policy development guidance.* *https://www.understandable.org.nz/advance-care-planning*

Beyond Words. A website aimed at making information accessible. It comprises picture-only books (i.e., no text) that can be used to assist the individual to understand a range of topics about dying including funerals, others' deaths and one's own dying, (e.g., "*Let's Talk about Funerals*", "*When Somebody Dies*" and "*Am I Going to Die?*"). https://booksbeyondwords.co.uk

- End of Life book set (8 books) https://www.booksbeyondwords.co.uk/book-sets/p/end-of-life-set

Other excellent resources (2)

Palliative Care and People with Learning Disabilities (PCPLD) Network. A network of people, including those with intellectual disability, professionals and families with the aim of ensuring quality palliative care. This website includes webinars, podcasts and resources on a range of palliative care topics. https://pcpld.com/

Talking End of Life...with People with Intellectual Disability [TEL]. An Australian website with 12 modules on end of life and people with intellectual and developmental disability. Designed for disability support workers but also helpful for families, health professionals, and educators. TEL includes a suite of topics on 1) Teaching how to understand the end of life, and 2) Teaching the planning options.
https://www.caresearch.com.au/TEL/

Other excellent resources (3)

The Victoria & Stuart Project: End of Life Care Planning with People with Learning Disabilities. A UK toolkit created together with people with intellectual disability, families, disability staff and healthcare professionals to support end of life care planning. https://www.victoriaandstuart.com/

The team

- **Professor Roger Stancliffe** *University of Sydney*
- **Dr Michele Wiese** *Western Sydney University*
- **Professor Josephine Clayton** *HammondCare; University of Sydney*
- **Professor Sue Read** *Keele University, United Kingdom*
- **Ms Gail Jeltes** *Unisson Disability,*
- **Dr Rebecca Barton** *University of Sydney*
- **Mr Lewis Kidson** *CDRP, University of Sydney*
- **Ms Hayley Brooks** *CDRP, University of Sydney*
- **Dr Bronwyn Newman** *CDRP, University of Sydney*
- **Professor Jennifer Tieman**, *Flinders University, CareSearch*
- **Ms Sarah Wagstaff** *CDRP, University of Sydney*
- **Professor Nathan Wilson** *Western Sydney University*
- **Dr Daniel Piepers** *Western Sydney University*
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- **Ms Baby Foo** *University of Sydney*

Acknowledgements

Email

m.wiese@westernsydney.edu.au

roger.stancliffe@sydney.edu.au

WESTERN SYDNEY UNIVERSITY

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Centre for Disability Research and Policy

In conclusion

Words of wisdom from disability support workers:

It's okay to talk about death…talking about it won't make it happen any sooner

AND

You do only get one chance…

SO….

Give it a go

Questions and comments

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