

AAIDD Webinar on *End of Life and Loss*, April 20, 2020

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Resources

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

Talking End of Life (TEL) ...with people with intellectual disability Free online Australian resource with 12 modules <https://www.caresearch.com.au/TEL/>

End of Life and Loss Resources

Resources listed in the *Loss, grief and mourning* module of TEL

- [Grief and loss \(751kb pdf\)](#)
An easy read document about grief and loss developed by New South Wales Health. (Australia) The full resource, which includes the pages on grief and loss, is also available in Arabic, Chinese, Dinka, Korean and Vietnamese [here](#).
- [Making a difference toolkit- End of life healthcare](#)
A collection of resources from the UK designed for people with intellectual disability and caregivers.
- [Grief and bereavement](#)
Resources from Connectability Canada to support a client who is grieving, such as creating a book of memories and planning for the anniversary of a death.
- [Helping people with intellectual disabilities cope with loss \(341kb pdf\)](#)
Tips and resources for caregivers to assist people with intellectual disability cope with loss. From the Vanderbilt Kennedy Centre, Nashville, USA
- [PicTTalk: Keele University](#)
PC compatible software from Keele University, UK, designed by and for people with intellectual disability that can be used to facilitate conversations about illness, life, the impacts of illness, and the future.

Resources about dying, death, end of life planning and funeral wishes listed in various TEL modules

- [Living well: Using person centred thinking tools with people who have a life limiting illness \(598kb pdf\)](#)
A demonstration of how person-centred planning tools can be applied to end of life.
- [When I die \(634kb pdf\)](#)
An example of a completed end of life book from the UK.
- [My end of life choices book \(116kb word\)](#)
A template document to write down end of life choices from Australia.
- [Breaking bad news](#)
This UK website contains information and guidelines for caregivers of people with intellectual disability about how to break bad news.
- [The Books Beyond Words series](#)
Books from the UK designed for people with intellectual disability that include only pictures. This allows you to make the story relevant to the client. Topics include 'Am I Going to Die' and 'When I Die', 'Getting on with Cancer' and 'Anne has Dementia'. (Note: these excellent books are available for purchase via the website).

Wills and bequeathing

- [Wills for people with intellectual disability](#)
A fact sheet about making a will, published by the Intellectual Disability Rights Service in Australia.
- [An easy to read guide to making a will \(320kb pdf\)](#)
An example from Ireland about will making, designed for people with intellectual disability.

COVID-19 Resources

- The Self Advocacy Resource and Technical Assistance Center (SARTAC) has a number of plain language COVID-19 resources available for free download on its website (USA) <https://selfadvocacyinfo.org/>
- The *International Association for the Scientific Study of Intellectual and Developmental Disabilities* (IASSIDD) has drawn together a number of free online resources at <https://www.iasidd.org/covid-19-resources/> These include social stories, plain language explainers, tips on staying healthy and safe. These resources are designed specifically for people with ID or ASD and use pictures and plain language/Easy English.
- There is a free downloadable *Books Beyond Words* publication called *Beating the Virus* available at <https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus> There

are related books (also free) *Good Days and Bad Days During Lockdown* and *When someone dies from coronavirus: a guide for families and carers*. (from the UK)

- AAIDD webinar *COVID-19 and People with IDD: Taking Action to Mitigate Risk* is available at <https://www.aaid.org/education/education-archive>
- The US National Down Syndrome Society (NDSS) has online resources on COVID-19 and Down syndrome <https://www.ndss.org/covid-19-fact-sheet/>
- Easy read resources and videos about COVID-19 and staying healthy for people with intellectual disability - from Australia <https://cid.org.au/covid-19/>