

## **Australians encouraged to help people living with a disability better understand death and dying**

### ***Palliative Care Victoria and VALID have created new resources to help talk to people living with a disability about palliative care, death and grief***

More support and resources on death, dying and palliative care are needed for people living with a disability, a new nationwide survey has revealed.

The new research, released today on International Day of People with Disability, shows that an overwhelming majority of people (72 per cent) either agree or strongly agree that people living with a disability need more help and support when it comes to palliative care, death and loss.

The national survey of 1000 Australians between the ages of 18 to 65 years also revealed:

- 61 per cent of Australians believe it's important or very important for people living with a disability to understand the topic of death and dying
- 43 per cent of respondents said they are either comfortable or extremely comfortable talking about death or dying with a person living with a disability

"One of our key missions is to help people live, die and grieve well and part of doing that is to empower them with resources and information in a form and approach that works for them. Our goal is that we move away from the fear of talking about death and dying," said CEO of Palliative Care Victoria, Violet Platt.

"There's a lot of stigma that comes with death and dying and because we don't talk about it, it can often become a hard conversation to have. Death affects us all - we need to talk more openly about it and provide support to all communities, including those that are living with a disability to help them better understand death, loss and palliative care," she said.

The survey also reveals that while respondents believe it's important for people with a disability to understand death and dying, just over half of Australians (51 per cent) also believe that people living with a disability should not be exposed to death and dying.

"I can understand why we've had this result and why Australians would feel this way. It's not uncommon for people to feel like they must protect those with disabilities from life's losses and disappointments. It's done with the best intentions, but it can be detrimental at the same time," Ms Platt said.

"The good news is that you don't have to navigate those challenging discussions on your own. There are health professionals and case workers you can lean on for help and support. We also have easy-to-read and easy-to-digest tools and resources available to help people have those difficult conversations," she said.

The release of the new survey coincides with the launch of Palliative Care Victoria's new resources for people living with a disability, which were created in collaboration with VALID (Victorian Advocacy League for Individuals with a Disability) and the Department of Health and Human Services.

The free-to-download resources, available on the Palliative Care Victoria website, comprise a range of useful booklets including: *Loss of a Loved Pet*, *Loss of a Loved One*, *Let's Talk about Palliative Care*, *When Someone Dies* and *Let's talk about death*.

“There’s not a great deal of resources out there on death and dying for people living with a disability. Many carers, support workers as well as family members require information to support people with a disability going through loss and grief,” said VALID Self Advocacy Project Worker, Anthony Risoli.

“It’s important to talk about death and dying. I know it’s a hard thing to discuss, but for someone living with a disability, it can often be difficult for them to understand why someone in their life has suddenly left. It’s a terribly confusing time and they need to be able to talk to someone they trust,” he said.

Minister for Health, Martin Foley MP, added, “These resources are an important step in promoting access to palliative care for Victorians with an intellectual disability and enhancing their overall health and wellbeing. They will enable providers to work in partnership with people with intellectual disabilities and their carers to deliver safe, high quality palliative care services that are inclusive, appropriate and accessible.”

The resources are available now from Palliative Care Victoria’s website. To download the booklets or for more information, visit <https://www.pallcarevic.asn.au/families-patients/easy-english-resources/>.

## **TOP TIPS BY COUNSELLOR, JANET GALER**

### **HOW TO TALK ABOUT DEATH AND DYING WITH SOMEONE LIVING WITH A DISABILITY**

#### **If there is a trusted relationship, initiate a conversation**

Many people with a disability will not initiate a conversation about death, but that doesn’t mean they don’t want to talk about it. There is a misconception that someone with a disability doesn’t have the same emotions, they don’t experience grief or won’t understand death. To deny someone the right to grieve excludes them further from society.

If there’s a trusted relationship, have a conversation and slowly introduce the topic. Find out what a person understands from what they may have been told. Validate a person’s feelings – it’s OK and normal to feel sad, angry or confused. Don’t overload a person – short sessions work best (follow their lead). Answer any questions honestly.

#### **Use clear and simple words**

When having a conversation about death and dying with someone with a disability, it’s important to use simple terms and beware of euphemisms, so you’re not talking about ‘passing over’ or ‘we’ve lost this person’ or ‘they’ve gone to a better place’. For someone who is living with a disability, this can be confusing so stay away from language that is not clear.

#### **Don’t do it alone**

You don’t have to do it alone. Take advantage of the support and resources available. There are health professionals, counsellors and case workers you can lean on for help and support as well as Palliative Care Victoria’s free-to-use resources to help guide those difficult conversations.

## ENDS

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### **Notes to the Editor:**

#### **About Palliative Care Victoria**

Palliative Care Victoria is the peak body for palliative care and end of life care in Victoria. Established in 1981, we are an incorporated association and charity supported by the Victorian Government, organisation and individual members, other groups and funders. They aim to ensure all people with a life limiting illness and their families are supported to live, die and grieve well.

#### **About VALID**

VALID (Victorian Advocacy League for Individuals with a Disability) is an award-winning organisation that has been at the forefront of advocating for people with a disability in Victoria since 1989. Their mission is to promote, protect and champion the human rights of people with an intellectual disability.