

A guide for carers about end of life and Down syndrome

This guide for carers says why it is important to plan ahead as adults with Down syndrome get older.

The guide explains health problems that can happen with age, such as:

- memory loss
- getting weaker
- sickness that lasts for a long time.

The guide says it is important to treat each person with respect and support them to make their own choices whenever possible. This is called [supported decision making](#).

The guide talks about how to make decisions about what should happen in the future, like:

- writing down wishes for medical care
- learning about brain donation
- knowing who should make decisions if the person can no longer make their own choices.

The guide also talks about helping people and their families through sadness and loss. It explains palliative care, which is health care you get when you are dying.

The guide shares information about community services that can provide support. But the guide is about America. Some of the services it describes are not in Australia.

You can download the guide for free. But you have to fill in a form to get the guide. The form asks for your name and email address. It is your choice whether you want to share this information.

We trust this resource

We trust this resource because it is:

- Made to help, not for profit
- Made by people who know a lot about the topic

We've checked this resource, and you can [follow our guide to know if health information is true and right for you](#).

This resource was made by

National Down Syndrome Society

The National Down Syndrome Society is an American group. The mission of the National Down Syndrome Society is to create a world where people with Down syndrome thrive.

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