Helping Me Understand - Sudden Loss

This Helping Me Understand sheet supports people with Down syndrome or intellectual disability to understand an important topic with support.

Part 1 are for families, carers, and support workers. They give guidance on supporting a person with Down syndrome and explains the topic of the information sheet.

Part 2 uses in clear and easy- to-understand language and can be read together. The language can be adapted to suit different ages, communication styles and support needs.

Supportive Communication Tips

» Use short, clear sentences and talk about one idea at a time.

» Use visual learning supports. Use real life things that relate to the topic, such as phones, apps, forms, letters, photos, calendars, pictures or objects.

» Use real life example to support understanding, avoid general and vague terms.

» Show the person what to do, then practise together.

» Repeat key messages over time. The person may need to hear and the same message many times.

» Give extra time to think and answer.
Do not rush.

» Check understanding by asking the person to show you what they would do, or to choose from clear options.

» Some people may understand more than they can express using words. Give them different ways to communicate, such as choosing between pictures, gestures such as pointing or communication aids if needed.

Part 1:

When someone you know personally dies, suddenly and unexpectedly, the impact can be significant. The connection may be through family, friendship, school, work, sport, or community groups.

Grief after a sudden death can feel intense and confusing. Common and normal reactions include shock, sadness, anger, fear or disbelief.

DOWN SYNDROME NEW SOUTH WALES

Helping Me Understand - Sudden Loss

Supporting a Person with Down syndrome through Sudden Loss

Possible reactions

» Ask repeated questions about what happened.
» Seek detailed explanations about death.
» Worry about their own safety or the safety of others.
» Show changes in sleep, appetite or mood.
» Become more withdrawn or more dependent.
» React strongly to reminders such as photos or social media.
» It is common for people to revisit. the same questions as they process information over time.

Let others know

If the person attends school, TAFE, university, day programs or works, it can be helpful to let staff know what has happened so that they can:

» Provide additional understanding and flexibility.
» Monitor for changes in behaviour or mood.
» Offer extra support if needed.
» Adjust expectations temporarily.

Supporting understanding and grief

» Use clear and honest language about death.
» Avoid phrases such as ‘gone to sleep’ or ‘passed away’.
» Allow space for emotions and different ways of expressing them.
» Acknowledge that strong feelings are normal.
» Maintain routines where possible.
» Prepare in advance for funerals or memorial gatherings.
» Support safe and limited use of social media.
» Talking about the person who died and sharing memories supports healthy grieving.

Social media considerations

Social media may include information, photos or commentary about the death. Algorithms often show more of what has already been viewed.

Repeated exposure can increase distress.

» Encourage breaks from social media.
» View or discuss posts together.
» Use ‘see less of this’ settings.
» Mute or hide upsetting content.

Helping Me Understand - Sudden Loss

Acknowledging your own grief

It is very likely that you, as a parent, carer or support person, are also grieving.

Supporting someone else while managing your own feelings can be exhausting.

It is important to:

» Take time for your own self-care.
» Talk to someone you trust.
» Accept help from others.
» Rest when you can.
» Looking after yourself helps you better support the person in your care.

When to seek additional support

Most grief responses are normal and reduce over time with care and support.

Consider seeking additional support if the person:

» Remains highly distressed for an extended period.
» Is unable to return to usual routines.
» Shows significant changes in sleep, appetite or behaviour.
» Expresses ongoing fear about safety.
» Withdraws from people or activities they usually enjoy.
» Talks about harming themselves or feeling hopeless.
» Early support can make a meaningful difference.

Support services in Australia

Griefline
griefline.org.au
Griefline is a NSW government funded free service offering specialised care for people across NSW.

Intellectual Disability Mental Health Connect
idmhconnect.health

Mental Health Line **1800 011 511**
Lifeline **13 11 14**
Beyond Blue **1300 22 4636**
Black Dog Institute
blackdoginstitute.org.au
If someone is in immediate danger, call **000**



Part 2: Helping Me Understand

Read this together

You can read this together.
You can take your time.

What happened

» Someone I know has died suddenly.
» This is very sad and can feel shocking.
» When a person dies, their body stops working.
» The person does not breathe anymore. The person does not feel anything anymore.
» They cannot come back.

How I might feel

» Feel very sad.
» Feel shocked.
» Feel angry.
» Feel scared.
» Feel worried.
» Think about what happened a lot.
» Have trouble sleeping.
» All of these feelings are normal.
» Grief feels different for everyone.

Talking about the person

» Share memories.
» Look at photos.
» Say what I liked about them.
» Say what I will miss.
» Talking helps us remember them.

Funerals and special gatherings

» There might be a funeral or special gathering.
» People may cry, feel quiet, share stories or listen to music.
» It is okay to feel emotional.
» Ask what will happen.
» Take breaks.
» Sit with someone I trust.
» Choose not to attend if that feels right.

Reminders and special dates

» Sometimes feelings come back on birthdays or anniversaries.
» This is normal.
» I can talk about how I feel.
» I can do something special to remember the person.
» Feelings may come and go. That is part of grief.

Being online

» I might see posts or photos online.
» If I click on them, I may see more of the same information.
» Seeing it again and again can feel over whelming.
» Take breaks.
» Ask for help to hide posts.
» Choose ‘see less of this’.

Things that can help me

» Talking to someone I trust.
» Spending time with family or friends.
» Going for a walk.
» Listening to music.
» Doing something I enjoy.
» Breathing slowly.

A final message

» Someone I care about has died.
» It is okay to feel upset.
» I am not alone.
» There are people who care about me and want to help.

Notes

Support services in Australia

Griefline
griefline.org.au
Griefline is a NSW government funded free service offering specialised care for people across NSW.

Intellectual Disability Mental Health Connect
idmhconnect.health

Mental Health Line **1800 011 511**
Lifeline **13 11 14**
Beyond Blue **1300 22 4636**
Black Dog Institute
blackdoginstitute.org.au
If someone is in immediate danger, call **000**



Published: October 2026