

# How to cope with the **terminal illness** of a loved one



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# Introduction

The news that a loved one has been diagnosed with an illness that will almost certainly progress to death, regardless of treatment, can be almost unbearable. You'll likely feel a range of emotions, from shock to disbelief and sometimes anger.

As you work through your own emotions and pain, you'll also want your loved one to know you're there to support them – whatever they are facing. It's extremely tough, and you'll need a host of tactics, practical strategies and ideas on hand to cope with the coming days, weeks and months as best you can.

How you approach the situation, and what you'll need to do to get through, also depends on the nature of your relationship with the loved one.

Here, we run through some ideas to help you cope and provide support when your child, your sibling or your friend is suffering from a terminal illness.

## End-of-life care in Australia: then and now

It's understandable that many of us want our loved ones to have the support they need at the end of their lives to live comfortably and with dignity. Reach Out Australia points out that people can have differing reactions to death and dying, based on age, cultural background, gender and personal relationships.

Today, a large proportion of end-of-life care happens in hospitals and residential aged care facilities, while in the early 1900s dying at home was common. While up to 70% of Australians would prefer to die at home, the evidence suggests less than 10% of people now do so.<sup>1</sup>

An international study recently ranked quality of death for Australians, judged across a range of palliative care measures, second out of 80 comparison countries, and our health system fourth overall behind the United Kingdom, Switzerland and Sweden.<sup>2</sup>

The changing statistics indicate that attitudes to death and dying have changed over time, and the emotional impact that this can have on families can be marked.

<sup>1</sup> [Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services – Productivity Commission Inquiry Report Overview & Recommendations](#) – Productivity Commission

<sup>2</sup> [Australia's Health 2016](#) – Australian Institute of Health and Welfare





# Caring for your child with a terminal illness

As a parent, it's your worst nightmare to be told your child's life is threatened by an illness that medical treatments just can't cure. If your child has battled for some time, it may be an expected – though still devastating – progression. For others, the news may come as a terrible shock.

Despite the unfairness of the situation and the intense emotions you are dealing with, it's important to remember your role as a parent and that what you do and say is crucial in how your child will handle the challenges ahead.

**To give your child the support they need, focus on these three things:**

## 1 / Educating yourself

To be able to make the best decisions and prepare mentally for the time ahead, find out everything you can about your child's condition from doctors, medical staff and relevant support organisations.

### Ask about:

- ☺ The symptoms that are likely to develop.
- ☺ What to expect in the time ahead.
- ☺ Whether the condition can be treated for some time.
- ☺ The best treatments available.
- ☺ The side effects of treatment.
- ☺ Whether your child will eventually receive palliative care and how it works.
- ☺ Whether your child can be at home during the final stages of his or her illness.
- ☺ How you can handle any medical issues that might come up at home.
- ☺ Any other plans you should be making.



## 2 / Spending time with your child

A study from the Medical Journal of Australia delves into the many complex issues faced by families with children who have a terminal illness, or who may be facing palliative care. The study indicates that parents should aim to spend as much quality time with their child as possible and reassure them that they're not alone in this.<sup>3</sup>

Other recommendations include talking openly with your child about their condition and making time for conversations about the things your child loves and is passionate about. If your family has certain religious or spiritual beliefs, discussions about this may comfort your child.

Also consider whether your child would benefit from being included in conversations with doctors about their end-of-life care.

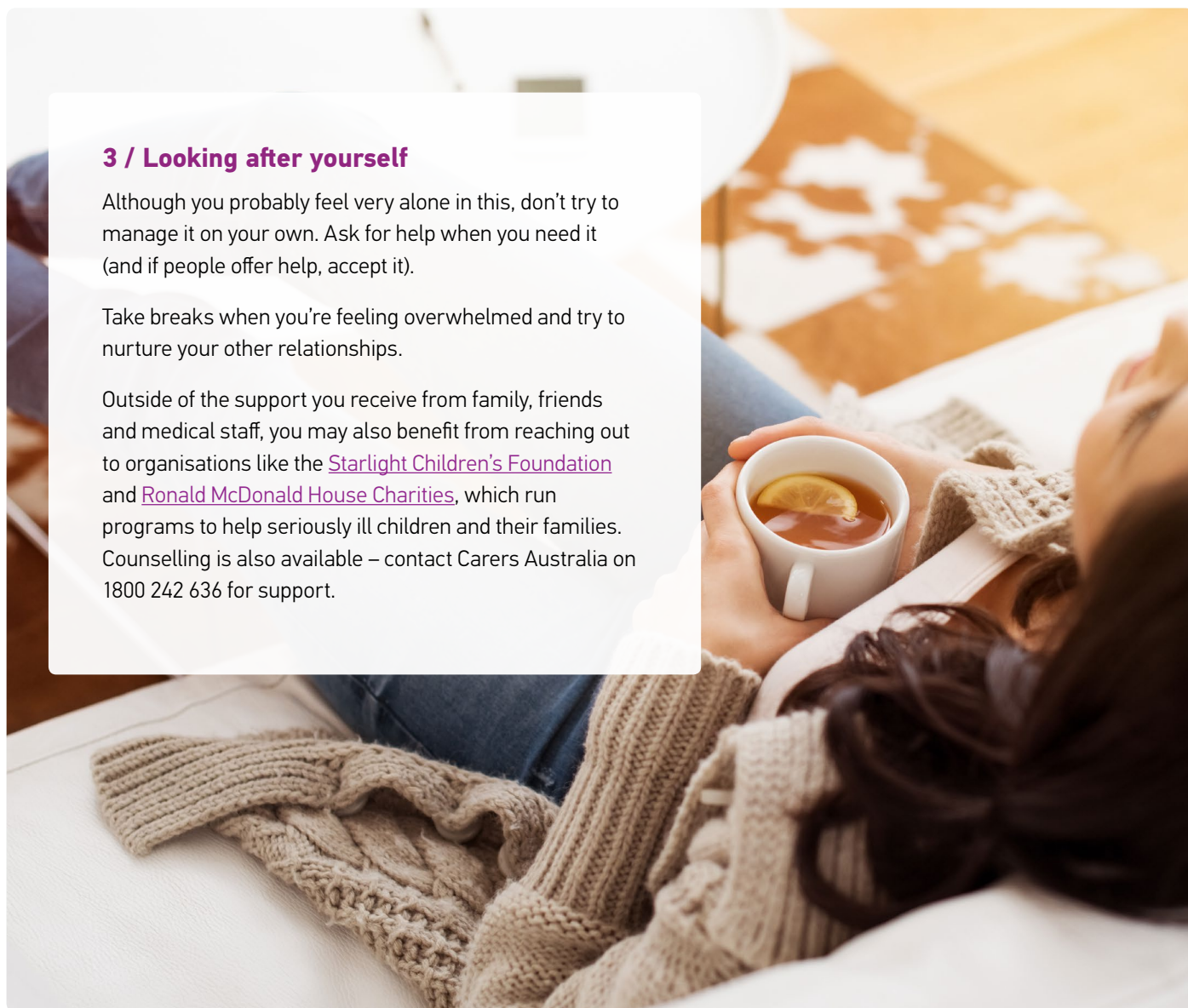
If you have other children, make sure you include them in some of this special time together and look out for signs of depression or stress in all of your children. Talk to hospital staff about support that is available to help your child and his or her siblings cope.

## 3 / Looking after yourself

Although you probably feel very alone in this, don't try to manage it on your own. Ask for help when you need it (and if people offer help, accept it).

Take breaks when you're feeling overwhelmed and try to nurture your other relationships.

Outside of the support you receive from family, friends and medical staff, you may also benefit from reaching out to organisations like the [Starlight Children's Foundation](#) and [Ronald McDonald House Charities](#), which run programs to help seriously ill children and their families. Counselling is also available – contact Carers Australia on 1800 242 636 for support.



<sup>3</sup> [The dying child: how is care different?](#) – Medical Journal of Australia. Jenny L Hynson, Jonathon Gillis, John J Collins, Helen Irving and Susan J Trethewie, Med J Aust 2003; 179 (6): S20.





# Coping with a sibling's terminal illness

When a sibling is terminally ill, you not only have to watch them go through unimaginable challenges, but you may also have to see your parents deal with the enormity of facing life without one of their children.

Siblings often share a special bond, and this may bring your sister or brother enormous comfort in the days, weeks and months ahead. Spend as much time as possible with them, reminiscing about the times you've shared and talking about their fears and concerns as they head into the unknown. They may be more willing to reveal their true feelings to you rather than a parent. Provide reassurance and comfort where you can.

It may help to add some normality to the situation by chatting about what's happening in your life and in the outside world.

Remember that you've been given the opportunity to say goodbye. Tell your sibling what they mean to you. You may also be able to help them create a legacy by documenting their life or writing letters to family and friends.

Although it's confronting, you may be the only person there for them in the final days or hours.

## You can provide comfort and support by:

- ✓ Applying lip balm to dry lips, and keeping their mouth moist with ice cubes.
- ✓ Keeping them warm with a blanket and more comfortable with cushions.
- ✓ Helping them change positions frequently.
- ✓ Asking for soft lighting.
- ✓ Having their favourite music playing.
- ✓ Just sitting with them and holding their hand.
- ✓ Gently massaging their hands or feet with a non-alcohol based lotion.
- ✓ Speaking gently and occasionally reminding them you're there with them.<sup>4</sup>

It's hard to lose a sibling, and you may also believe your own feelings are neglected as your parents focus on your ill sibling. If you need help dealing with grief or depression, contact [Beyond Blue](#) on 1300 22 4636 or [GriefLine](#) on 1300 845 745.

<sup>4</sup> [Providing emotional support](#) – The Cancer Council



## Helping a friend face a terminal illness

When a friend is diagnosed with a terminal illness, it may be hard to find the right words. You may not know what to say. It may be easier to simply say nothing or avoid them or the topic. However, your friend likely feels very alone and it's important to push past your own discomfort and be a true friend in their time of need.

Check in with your friend regularly and ask how they are and what they need. Ask them the best times to call or visit. Be honest if you're not quite sure what to do or how to help – they'll appreciate it.

Offer practical help like driving them to appointments, babysitting or doing the shopping for them if you can. Speak to the person's family where possible and ask if they need help. Tell them how much you value your friendship with their family member and that you're willing to help ease their load.

Also, be prepared to listen and just 'be a friend'. Your friend may reveal their feelings to you like they can't do with their family members or talk about things they don't feel comfortable raising with their family.

Your friend will likely feel like they're missing out on a lot, so try to adapt your usual social activities so they can join in where possible. Always remember the value of friendship and the reasons you have always been good friends. These things don't change just because your friend's health has diminished.



**Friends help shape our lives. The sense of loss and grief you feel as your friend reaches the final stages of their illness is very real. Get help if you are struggling to deal with your grief or start to feel depressed. Contact Beyond Blue on 1300 22 4636 or GriefLine on 1300 845 745.**



## What is an Advance Care Directive?

In most Australian states and territories, adults can make an Advance Care Directive – sometimes known as a living will.<sup>5</sup>

This document allows you to set out what health treatments you would like to have (or refuse) if you're seriously ill and unable to communicate decisions about your care and treatment.

If it's made in a valid way, it must be followed – doctors, nursing staff and family members cannot override your wishes set out in a valid Advance Care Directive. You can also nominate someone you would like to make health decisions for you when you're unable to make them yourself.

Losing a loved one is a difficult but inevitable part of life. While we've provided ideas, tactics and strategies to help you deal with things, remember that every situation is different and you should adapt your approach depending on the situation and how your loved one responds to your attempts to support them.

<sup>5</sup> [Advance care planning in your state or territory](#) – Advance Care Planning Australia





## Coping with the everyday

Dealing with the emotional impact of a loved one with a terminal illness is hard enough – but what about the financial impact on you and your family? If your loved one is the main or sole income earner, how will you manage mortgage or rent repayments, bills and general living expenses without their income?

Products like Real Life Insurance are designed to help you manage the financial gap left behind by a loved one. Real Life Insurance provides a lump sum cash payment directly to you – if you are diagnosed with a terminal illness – or to your family if you were no longer there to provide for them.

When you commence your insurance policy, you, your spouse, partner, or de facto named within the policy are immediately covered for death and terminal illness. Visit [Real Family Life Cover](#) for more information.

