



**PalliativeCare**  
AUSTRALIAN CAPITAL TERRITORY

# **LIFE-LIMITING** **ILLNESSES IN THE** **WORKPLACE**



**A TOOLKIT FOR  
EMPLOYEES**



---

## **DISCLAIMER**

The content of this toolkit is intended to provide a summary and overview of the subject matter. It is not intended to be fully comprehensive. Nor does it constitute legal advice. All care is taken to provide current information however currency cannot be guaranteed. You should seek legal or other professional advice before acting or relying on the content.

# TABLE OF CONTENTS

- 04 Foreword
- 05 Working With This Toolkit
- 05 What you will get from this Toolkit

## 06

### **PART 1 - PALLIATIVE CARE AT WORK**

- 06 Understanding Palliative Care
- 06 Your Rights At Work
  - 07 Working While Ill
  - 07 Sick Leave
- 08 Being A Working Carer
  - 08 Leave Entitlements
  - 08 Workplace Assistance
  - 08 Accessing Support
- 09 Workplace Grief

## 10

### **PART 2 - THINGS TO CONSIDER**

- 10 Talking To Your Employer
- 11 Telling Your Colleagues
- 12 Personal Finances
  - 12 Support From Your Insurer
  - 12 Support From Your Superannuation
- 13 End Of Life Planning
  - 13 Advanced Care Planning
  - 14 Legal And Financial Planning

## 16

### **PART 2 - THINGS TO CONSIDER**

- 16 *Appendix A: Taking Care of Me Checklist*
- 16 *Appendix B: Resources for Carers*

# FOREWORD



When faced with the prospect of our own death (or the death of someone we are caring for), most people find it very difficult to articulate their wants and needs – this includes in the workplace.

This practically-oriented toolkit has been written specifically for you as an employee, when you have been given a terminal diagnosis (referred to as a life-limiting illness). The information can also be relevant to employees who have the responsibility of caring for someone with such a diagnosis.

Another toolkit in this series developed by Palliative Care ACT is for Managers and Human Resource professionals focusing on how they can best support employees with a life-limiting illness.

When faced with the prospect of our own death (or the death of someone we are caring for), most people find it very difficult to articulate their wants and needs – this includes in the workplace.

Palliative Care ACT recognises that work can be at the foundations of a person's life and when given a terminal diagnosis this foundation is rocked. We also understand that work continuity is often crucial for maintaining a degree of normality and independence.

The Grattan Institute has recognised that a failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying. There are no procedure manuals or flow diagrams to help navigate the way – everyone's path will be as individual as they are – so how does someone who wants to keep working find their way?

Many workplaces provide positive support to employees through Human Resource Advisors or through access to third party counselling services. However, supporting someone with a life-limiting illness can generate an array of day-to-day challenges that over extend organisational knowledge and

resources. The provision of timely support while you are considering the range of options and decisions that lay ahead, including those relevant to your employment and workplace, will be important.

We hope this toolkit provides key practical advice on subjects including decision making, planning, having productive conversations and how to find suitable support resources and information.

Louise Mayo, AM  
President

# WORKING WITH THIS TOOLKIT

This toolkit is designed for working people who have been diagnosed with a life-limiting illness or an illness where recovery is not certain. It also contains information for working carers of people suffering a life-limiting illness.

The information in this toolkit is not intended to be complete. Rather, it is meant to give you a starting point to discover things you may need to plan for and to explore support options that are right for your situation.

Every experience is different, and your needs will change as time passes. Being well informed and prepared is likely to make your experience less stressful, and provide some peace of mind.

Right now, you may be feeling overwhelmed. Hang onto this guide for when you need it.

## WHAT YOU WILL GET FROM THIS TOOLKIT

This toolkit provides users with resources to:

- make an informed decision on whether, and how long, to keep working
- make plans about your legal and financial situation, and your healthcare preferences
- initiate productive conversations about working with a life-limiting illness
- find other resources to support and advise you throughout your experience
- understand what support you can access if you are caring for someone with a life-limiting illness.



EMPLOYEES ONLY

# PART 1:

# PALLIATIVE CARE AT WORK

We live in a society that doesn't feel comfortable talking about dying, let alone planning for what kind of care you'd like to receive at the end of your life.

Unless people have had direct experience with palliative care, they tend not to know what it means or the kinds of support it can offer. This lack of knowledge is often shared by family and loved ones who can be integral in decision making.

Death is an experience we will all go through and it is important that we think about the end stage of our own lives, talk about it with our loved ones, and plan for it.

## UNDERSTANDING PALLIATIVE CARE

Palliative care is care that is provided for a person with a life-limiting illness where the primary goal is to optimise quality of life over extension of life. It aims to alleviate not only pain but also stress, grief, uncertainty, and other forms of emotional distress by openly talking about and planning for the end of life experience.

It emphasises the needs and wishes of the person being cared for and seeks to help them live as actively and fully as possible until death. It also recognises how involved the person's loved ones and community will be and works to integrate them into systems of support and the person's treatment.

## YOUR RIGHTS AT WORK

When living with a life-limiting illness, a lot of things are uncertain or unknown. Some of the things we do know are your rights in the workplace:

**You do not have to tell your employer you are ill,** though sharing information with them may be helpful in managing your circumstances.

**You do have to tell your employer about anything that will affect your ability to do your job.** You also have to tell them about anything that could reasonably cause a health and safety risk for yourself or other people.

**You do have paid and unpaid sick leave entitlements** (or equivalent entitlements, as a carer). You will have to give your employer notice regarding sick or carer's leave, as soon as is practical. You will also have to provide evidence, such as a medical certificate or a letter from any treating physician that outlines ongoing treatment or care needs.

**You cannot be discriminated against because you have an illness,** or you are a carer.

**You may ask for reasonable adjustments to your work** to accommodate your illness or caring responsibilities. Adjustments will be viewed on a case by case basis and your employer may have reasonable business grounds to not grant some or all of the requested adjustments.

The full extent of your rights will be governed by your employment status, any Enterprise Agreement in place, and the state or territory in which you work.

You should always seek specialised advice relevant to your own circumstances.

## WORKING WHILE ILL

Employers are legally obligated by the *Disability Discrimination Act 1992* to make reasonable adjustments to accommodate employees with serious illness, provided they do not cause an unjustifiable hardship to the business.

Adjustments could be administrative, environmental, or procedural, and they could be temporary or long-term. They might include making minor changes to your work duties, reducing your work hours, approving flexible working arrangements, or providing additional equipment.

Not all jobs can accommodate adjustments. If you are unable to perform the core aspects of your job, then being dismissed is unlikely to be considered discriminatory.

Seek advice about your situation if you are unsure or believe you have been discriminated against.

Go to the Fair Work Ombudsman website for more information on unfair dismissal:

[fairwork.gov.au/ending-employment/unfair-dismissal](http://fairwork.gov.au/ending-employment/unfair-dismissal)

## SICK LEAVE

The minimum provisions for paid sick and carer's leave, as well as information about unpaid sick leave, are covered under the *Fair Work Act 2009*. You can find out about both on the Fair Work Ombudsman website at:

[fairwork.gov.au/leave/sick-and-carers-leave](http://fairwork.gov.au/leave/sick-and-carers-leave)

Your employer must, if asked, provide you with all your leave entitlements, including annual leave, sick / carer's leave and possible long service leave. You can take as much paid sick leave as you have accumulated if you are not fit for work due to illness or injury.

Your employer may provide assistance through health case management in their human resources area. These specialised case managers can assist with workplace adjustments, referral to superannuation advice in relation to invalidity, and any graduated return to work support you may require.

If you are exclusively taking paid leave, then you are protected from dismissal regardless of how long you are on leave. If you are taking a combination of paid and unpaid leave, or just unpaid leave, you are protected if:

- your total time away is less than three consecutive months, or a total of less than three months over a 12-month period
- you provide evidence of illness or injury.

If you wish to work out how much leave you may have, you can use the calculator on the Fair Work Ombudsman website:

[calculate.fairwork.gov.au/leave](http://calculate.fairwork.gov.au/leave)

---

**Unless people have had direct experience with palliative care, they tend not to know what it means or the kinds of support it can offer. This lack of knowledge is often shared by family and loved ones who can be integral in decision making.**

---

# BEING A WORKING CARER

## LEAVE ENTITLEMENTS

**Sick leave** (also known as personal leave) allows you to take paid time off to help you deal with caring responsibilities and family emergencies, not just personal illness. You can take time off to care for immediate family or household members who are sick or injured, or help during a family emergency.

This is known as carer's leave and comes out of your personal sick leave balance.

Under the *Fair Work Act 2009*, carer's leave is available for:

- immediate family members – your spouse, de facto partner, child, parent, grandparent, grandchild, sibling (or the child, parent, grandparent, grandchild or sibling of your spouse or de facto partner)
- household members – any person who lives with you.

You are also entitled to two days of **unpaid carer's leave** for each occasion when a member of your immediate family or household requires care or support because of a personal illness, injury, or an unexpected emergency.

You may take unpaid carer's leave for each occasion as a single continuous period of up to two days, or any separate periods to which you and your employer agree.

You cannot take unpaid carer's leave during a period if you could instead take paid leave. You may also choose to use annual leave or long service leave for the absent days.

You should refer to your employer's leave policy for more detailed advice on leave provisions.

## WORKPLACE ASSISTANCE

You have the right to request reasonable adjustments to your work to accommodate your caring responsibilities, provided the adjustments do not cause an unjustifiable hardship to the business.

In addition to the protections provided by the *Disability Discrimination Act 1992*, under the National Employment Standards employees who have at least 12 months of continuous service have the right to request flexible working arrangements to manage caring responsibilities.

These may include:

- allowing you to work from home or from another worksite
- changing your start, finish or break times
- allowing you to reduce your work hours.

For example, a carer may wish to start work early so they can leave early to take the patient to a medical appointment.

Employers can only refuse such requests on reasonable business grounds.

## ACCESSING SUPPORT

Being a carer is challenging. There is a drain on your time, finances and emotions.

The good news is that there are many organisations providing support in all these areas. The support available will depend on your circumstances and the needs of the person receiving your care.

While being a carer can be a very rewarding experience, there are accompanying impacts. Many carers report severe anxiety, physical and mental exhaustion, and depression. As caring duties take up significant time, you may find yourself socially isolated, with financial pressures from additional expenses or lost income.

The important message here is to seek advice and assistance early and often.

Awareness surrounding carers, who they are and the work they do, has grown significantly along with accompanying resources and funding. Your state or territory will have a representative body for carers to connect you with support (see Appendix B).

In the Australian Capital Territory, this is Carers ACT:

[carersact.org.au](http://carersact.org.au)

and at a national level you can access the Carer Gateway for a range of advice:

[carergateway.gov.au](http://carergateway.gov.au)

A list of further resources can be found under [Appendix B: Resources for Carers](#)

## WORKPLACE GRIEF

*Under the Fair Work Act 2009*, you are entitled to two days of compassionate leave each time an immediate family or household member dies (or suffers a life threatening illness or injury) and some workplaces may provide for more. If you are in a position where you can only take this short amount of leave, you are likely to have to return to work while still in the early stages of mourning.

If you feel comfortable, it may help to discuss the situation with your employer and see if accommodations can be made. Consider discussing your needs and requesting more leave or a temporarily reduced workload, to give yourself time to adjust.

In the short term it is likely that little things may remind you of the person you are grieving and trigger your emotions. It is a good idea to identify a physical space you can go to if you need time alone, and to let your supervisor know this might happen.

Your co-workers are most likely to try and show their support, through words, sending flowers, making donations, or attending the funeral. You may well appreciate this support, or it may make you uncomfortable. Think about what support you would welcome and what would feel comfortable and let your supervisor or your colleagues know ahead of returning to work, as this can really help.

Similarly, preparing what to say in response to awkward conversations, acknowledging the intended support, but also making clear that you don't want to talk about it, may reduce your anxiety in the moment.

Many employers, particularly in larger organisations, offer counselling through employee assistance programs, which provide employees with access to confidential, professional support and other resources. These programs are designed to help deal with personal circumstances, as well as workplace issues.

The issues raised above are likely to also apply if a close work colleague has died.

---

**You can take time off to care for immediate family or household members who are sick or injured, or help during a family emergency.**

---

# PART 2:

## THINGS TO CONSIDER

One of the first big decisions you will have to make when you have a life-limiting illness is when to stop working. How long you plan to stay in the workplace has a huge impact, from qualification periods for insurance policies to the kinds of accommodations you may want to ask for and what you'll tell co-workers.

### TALKING TO YOUR EMPLOYER

There is no law requiring you to tell your employer that you are ill (or are caring for someone who is ill). However, you do have some obligations.

You must tell your employer about anything that will affect your ability to do your job. You must also tell them about anything that could reasonably cause a health and safety risk for yourself or other people. You may wish to seek medical advice about side effects of drugs or treatment to understand the risks.

What you tell your employer, and in how much detail, is entirely up to you. You know your workplace and the relationships you have within it.

Take your time to decide what is best for you and to prepare yourself mentally on how you move forward and plan the conversations you have. Having some notes to take into any conversations with you might be helpful.

Most people do decide to discuss the situation with their employer. If you do, some things to consider include:

- What do you want to tell them? How much information do you want to share about the details of your diagnosis and treatment?
- What do you want your colleagues to know? What information are you happy to have

shared with them, and how do you want that communicated?

- What kind of changes to your working arrangement would you find useful? Where do you need flexibility, and where do you think things can stay as they are?
- When and how often would you like to have further meetings? As things progress, having a regular time to check in and communicate will prove helpful.

Don't feel compelled to agree to everything in the first meeting. Unexpected topics may arise that require further research, or you may just need time to think about things.

If you are the one who is ill, you may also wish to discuss a plan for exiting your workplace. Again, you have a right to privacy and should be able to choose a timeframe that suits you (while normal work function continues). Of course, you may not want any information about your condition divulged at all.

Be mindful that keeping your situation a secret may cause you unnecessary stress. It will also be difficult for your employer to help with flexible work, job changes or other assistance if you choose not to discuss your circumstances to the extent where they can assist. If your employer is not aware of your circumstances they may not provide consideration for any decline in workplace performance.

## TELLING YOUR COLLEAGUES

This is possibly one of the biggest challenges when dealing with your situation early on. There is no perfect, best or right way to let your colleagues know, except the one that suits you.

As with all relationships, it is good to remember that communication is important.

You may wish to ease into telling people or get it out in the open early. When it comes to discussing such a serious and personal topic as having a life-limiting illness, it's understandable that people have different preferences and approaches. Do what feels comfortable for you.

Ultimately, if you are continuing to work, it is possible people will speculate about your condition if your absences increase, you have any changes in appearance or mood, or other changes become evident. Being proactive and sharing as much information as you are comfortable with may be less stressful in the long run than potentially having office rumours and speculation go on around you.

The choice to share whatever information you are comfortable with will provide an opportunity for your colleagues to support you. This may be a few close colleagues, or your entire team.

Be prepared for questions. Deal with what's comfortable for you and be okay with telling people you don't want to talk about it. You may wish to just tell a few close colleagues and give them permission to let the rest of the team know, or to nominate one person to act as your advocate and handle questions. This may suit you as a way to let people know, without having to tell people over and over again.

All of these decisions are completely up to you, so do whatever it takes to feel in control.

It is highly likely colleagues will offer to help. You may like to have a few prepared responses in mind – for you or your advocate – such as:

- “Just keeping things normal would be great”
- “I haven't had time to mow the lawn”
- “I'm finding cooking difficult”
- “The dog hasn't had a walk in weeks”
- “Could I get a lift to work with you, public transport is exhausting me”.

Having thought ahead and identified what kind of support would feel good to you and how much information you are happy to share, and how, will help you maintain your boundaries and deal with your colleagues productively when the time comes to tell them.

---

**Be prepared for questions. Deal with what's comfortable for you and be okay with telling people you don't want to talk about it.**

**All of these decisions are completely up to you, so do whatever it takes to feel in control.**

---

## PERSONAL FINANCES

Before making any decisions about how and when to leave work it may be wise to get some professional financial advice as there are many factors to consider.

Everyone's situation is unique, from their job function and job satisfaction to their finances, debts, insurances and family situation, however common sources of financial support are:

- work leave entitlements
- early access to superannuation funds
- total and permanent disability insurance provided in superannuation benefits
- government agency support.

The government MoneySmart website ([moneysmart.gov.au](http://moneysmart.gov.au)) provides some useful information, both on dealing with illness and being a carer. Centrelink also offers some assistance through its Payment and Service Finder ([servicesaustralia/individuals/centrelink](http://servicesaustralia/individuals/centrelink)).

Medicare ([servicesaustralia.gov.au/individuals/medicare](http://servicesaustralia.gov.au/individuals/medicare)) may provide financial cover for the allied health services that help manage your medical condition. Where you require ongoing care from a multidisciplinary team, your general practitioner will create a GP Management Plan and document the Team Care Arrangements. You will need to have these plans in place to be able to get Medicare rebates, so be sure to talk with your doctor.

These are but a few of the numerous sources of financial advice and assistance, and it is important to think through issues ahead of time if you can.

## SUPPORT FROM YOUR INSURER

Check your insurance policy/policies to see if they cover your bills or replace some of your income.

Types of insurance include:

- Health Insurance - helps you pay medical costs not covered by Medicare
- Total and Permanent Disability Insurance - covers the costs of rehabilitation, debt repayments and the future cost of living
- Trauma Cover - covers you for specified illnesses or injuries
- Income Protection - replaces some of your income if you can't work due to injury or illness.

Be sure to understand the qualifying periods and evidence required to access these funds as there is often a waiting period before an insurance policy pays out.

## SUPPORT FROM YOUR SUPERANNUATION

Superannuation rules now recognise that super benefits can be accessed early under certain circumstances, such as terminal illness.

For the purposes of accessing super benefits, a terminal medical condition is defined as existing if:

*“two registered medical practitioners have certified jointly or separately, that the member suffers from an illness, or has incurred an injury that is likely to result in the member's death within 24 months of the date of certification.”*

When applying to access super benefits early due to terminal illness, both of the medical certificates must still be within their certification period of 24 months from the date of certification. Further, at least one of the registered medical practitioners must be a specialist practicing in an area related to the illness or injury.

You can also apply to access super benefits early on compassionate grounds where the fund member,

or a dependant of the fund member, is dying from a terminal medical condition, and requires money to pay for palliative care.

You can find out more about what is required on this website:

[ato.gov.au/Individuals/Super/In-detail/Withdrawing-and-using-your-super/Early-access-on-compassionate-grounds](https://ato.gov.au/Individuals/Super/In-detail/Withdrawing-and-using-your-super/Early-access-on-compassionate-grounds)

Your superannuation fund can also assist you with the process involved to access your super benefits on the basis of terminal illness.

It is also possible that your superannuation policy may include total and permanent disability cover. Find your policy documents or look them up on line to see firstly, if you do have cover, and secondly, if your circumstances warrant payment. Be aware that qualifying periods may be up to six months.

It is strongly recommended to seek professional advice. Some superannuation funds provide concierge services that are able to give you tailored advice on your account (the Commonwealth Superannuation Corporation provide this).

## END OF LIFE PLANNING

End-of-life planning is about important conversations with your loved ones, doctor(s) and other advisors and caregivers so that your voice is heard and that any objections or concerns can be addressed in advance.

Making plans as soon as possible lets you take control of decisions that will affect you, your care, and your finances when you are incapacitated or have passed.

Clarifying your values and beliefs about ageing, incapacity, dying and death serves as the foundation for all the decisions you will make regarding your own end-of-life process.

Once you know how you want things to be handled, there are legal instruments you can create in preparation for death that will ensure your wishes are carried out.

If you are caring for someone, it is important to encourage them to have these conversations.

## ADVANCED CARE PLANNING

It's important to document your healthcare wishes: how you want things to be handled if you are no longer able to have a say.

If you are very sick, it may fall to your family or close friends to make decisions about your health care. It can be a very stressful time where family members or loved ones may not agree with each other on approaches to your care. If they have a document where you have outlined the type of care you want, this can help them make decisions on your behalf.

Advance care planning can be an informal process, where you write down your wishes on any form or paper. It can also be more formal, including having documents that are legally recognised.

An advance care plan usually has the following parts:

- A list of the names and contact details of who can speak on your behalf with your doctors, if you are unable to. This person is sometimes called your 'substitute decision maker'
- A description of the care outcomes that would, and would not be acceptable to you
- A description of any treatments or services that you do or do not want
- Other wishes, such as wanting to die at home or in a hospital, having your family with you or having your pet with you
- Your signature, a witness signature and the date

The process of formalising your advance care plan, and appointing a legally recognised substitute decision maker, can be different in each state and territory.

The legal document about your health care wishes is called an Advance Care Directive (or other similar term depending on where you live). An advance care directive is often restricted to what treatments you do and do not want, such as restarting your heart if it stops.

Even if you have an advance care directive, your advance care plan may have more information about your goals of care. It will help your family and doctors understand your values and may help in a broader range of situations.

Once you have one, it should be scanned and uploaded onto a shared platform, such as your My Health Records file, kept in a safe place at your residence and/or held by your GP.

The legal document outlining who can make health care decisions for you is usually called an Enduring Power of Attorney (or other similar term depending on where you live). If you want to make sure doctors abide by your decisions, it is very important to have this document.

It is particularly important if the person you want making decisions for you is not your next of kin.

For more information go to:

[advancecareplanning.org.au](http://advancecareplanning.org.au)

## LEGAL AND FINANCIAL PLANNING

Making decisions about your financial and material wealth to provide for your care and comfort through, and after the end of your life, may also require the appointment of a third party to make decisions on your behalf (a decision-maker).

You will need to speak to a solicitor to prepare your document where you can discuss the extent of the powers and when they come into force and any directions you wish to see enacted.

Be aware that without an Enduring Power of Attorney in place, should you be incapacitated no one can deal with your affairs on your behalf.

That means they can't access even information about insurances, superannuation, Centrelink, bank accounts, shares, investments, let alone access money to help with your treatment.

It would also be helpful to give your decision-maker passwords to things like your computer and phone where important information they may need stored. You could perhaps prepare a list of your passwords and PINs in a sealed envelope to be kept by your solicitor for handing over when required.

Depending on which state or territory you live in, the documents used to appoint a substitute decision maker have different names. These can include an enduring power of attorney, enduring power of guardianship or appointment of enduring guardian.

Having a Will is arguably one of the most important things you can do for yourself and your family.

If you don't have a Will:

- you will not have a say about who will benefit from your estate
- you will not have a say about who is charged with the role of administering and making final decisions about your estate
- your estate may take an extended period of time to settle (more than 12 months)
- the cost to settle your estate may be significantly higher than if you had a Will.

No matter the size of your estate, it will need to be administered and settled. The laws surrounding Wills and inheritance vary from state to state so it is best to get local legal advice.

A Will legally protects your spouse / partner, children, and assets, and spells out exactly how you would like things handled after you die.

Your Will is also where you can state your wishes in regard to cremation or burial, honoured with a funeral and/or a memorial service, and whether you are a body, tissue or organ donor.

If you have one, is it up to date and does it reflect your current wishes?

A Will should be updated in the following circumstances:

- after a marriage, divorce or separation
- after the birth of a child or grandchild
- if a spouse or beneficiary of the Will dies
- in the event of a significant change of financial circumstances.

If you don't have one, you should seriously consider getting one.



# APPENDIX A:

## TAKING CARE OF ME

### CHECKLIST

FINANCES	NOTES
My leave entitlements: personal / sick leave	
My leave entitlements: annual leave	
My leave entitlements: long service leave	
Superannuation balance	
Contact a financial planner	
INSURANCES	NOTES
Superannuation – terminal illness / total and permanent disability benefits	
Income protection	
Health insurance	
GOVERNMENT ASSISTANCE	NOTES
Medicare	
Centrelink	
Other	
LEGAL	NOTES
Enduring power of attorney	
Last Will and Testament	
HEALTH CARE	NOTES
Advance Care Plan	
Advance Care Directive	
Counselling / Employee Assistance Program	

# **APPENDIX B:**

# **RESOURCES FOR CARERS**

## **STATE AND TERRITORY ORGANISATIONS**

- Carers ACT: [carersact.org.au](http://carersact.org.au)
- Carers NSW: [carersnsw.org.au](http://carersnsw.org.au)
- Carers NT: [carersnt.asn.au](http://carersnt.asn.au)
- Carers QLD: [carersqld.com.au](http://carersqld.com.au)
- Carers SA: [carers-sa.asn.au](http://carers-sa.asn.au)
- Carers TAS: [carerstas.org](http://carerstas.org)
- Carers VIC: [carersvictoria.org.au](http://carersvictoria.org.au)
- Carers WA: [carerswa.asn.au](http://carerswa.asn.au)

## **PALLIATIVE CARE AUSTRALIA**

[palliativecare.org.au/im-a-carer](http://palliativecare.org.au/im-a-carer)

Palliative Care Australia provides a service provider directory on its website.

## **MY AGED CARE**

[myagedcare.gov.au](http://myagedcare.gov.au)

The Federal Government's My Aged Care website is a good place to start if you are caring for elderly parents or similar.

Ageing parents may be eligible to receive services such as:

- help at home
- personal care, such as help getting dressed
- transport
- modifications to the home, such as hand rails or ramps
- nursing, physiotherapy and other care
- meals and help with cooking
- household jobs such as cleaning or gardening
- social activities.

Short-term help is available:

- when they have had a setback and want to regain independence
- recovery from an accident or illness, including after a hospital stay
- when they or you as the carer needs a break (respite care).

There are also many non-government providers in the aged care space.

Where things can be most difficult is finding help at the time when aged care homes and/or aged care funding, are not available, wanted or required.

Service providers are also very location specific. So, where you live, or the location of the person in need of care, has a big bearing on what is available.

Some places to check for assistance:

- Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services. [carergateway.gov.au](http://carergateway.gov.au)
- Your Local Council
- Meals on Wheels: [mealsonwheels.org.au](http://mealsonwheels.org.au)
- Australian Red Cross – Community Services: [redcross.org.au/get-help/community-services](http://redcross.org.au/get-help/community-services)
- Right At Home: [rightathome.com.au](http://rightathome.com.au)
- Community Options: [communityoptions.com.au](http://communityoptions.com.au)
- Home Care Heroes: [homecareheroes.com.au](http://homecareheroes.com.au)

## NATIONAL DISABILITY INSURANCE SCHEME

[ndis.gov.au](http://ndis.gov.au)

If you are under 65 and eligible for support through the National Disability Insurance Scheme it would be worth making enquiries about support that might be provided through the scheme.

If you are caring for someone suffering a life limiting illness, there are disease specific organisations that provide everything from financial information and referral services to practical and mental health support, such as the examples listed below.

## CANCER COUNCIL

[cancer.org.au](http://cancer.org.au)

- Cancer Council 13 11 20
- Information for Aboriginal and Torres Strait Islanders
- Practical financial assistance
- Cancer Council Online Community
- Cancer Connect
- Cancer and work

## THE LEUKAEMIA FOUNDATION

[leukaemia.org.au](http://leukaemia.org.au)

- Transport program
- Accommodation services
- Support and information programs
- Support and advice
- Child-related assistance
- Financial matters
- Practical matters
- Sexuality and intimacy
- Supporting survivors

## DEMENTIA AUSTRALIA

[dementia.org.au](http://dementia.org.au)

- I am a carer, family member, or friend
- Activities for people with dementia
- Advance care planning
- Caring for someone who lives alone
- Coping with behaviour changes

## MOTOR NEURONE DISEASE AUSTRALIA

[mndaust.asn.au](http://mndaust.asn.au)

- Support and advice
- Practical matters
- State based support for carers
- Symptom management

## ACKNOWLEDGEMENT

Palliative Care ACT would like to acknowledge all who contributed their time, knowledge and skills to the development of this toolkit.

## FOR MORE INFORMATION

---



VISIT  
[www.pallcareact.org.au](http://www.pallcareact.org.au)



EMAIL  
[office@pallcareact.org.au](mailto:office@pallcareact.org.au)



**PalliativeCare**  
AUSTRALIAN CAPITAL TERRITORY

