

Information for family and carers

care at end of life

Providing care for a person with a life-limiting illness





Family members and carers play a crucial role in our community, often without realising it. For many people, looking after someone close to you is ‘just what you do’. They are mums and dads, sons and daughters, brothers, sisters, grandparents, spouses, friends and neighbours.

The Carers (Recognition) Act 2008 (Qld) defines a carer as:

“ *An individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks.* ”



Caring for someone at the end of life

Looking after someone with a life-limiting or terminal illness can be physically and emotionally challenging. As a family member or carer, you may need to learn quickly about:

- 📍 how to care for someone towards the end of life
- 📍 the person's illness and what to expect as it progresses
- 📍 medications and treatments
- 📍 communicating openly and honestly with each other and the healthcare team
- 📍 having a plan for a crisis
- 📍 carrying out advance care planning
- 📍 recording relevant health-related events, questions and information
- 📍 how to look after yourself and where to get help.

What is care at the end of life?

Care at the end of life is a broad term that encompasses all the different types of care and support provided for people with a life-limiting illness.

It helps people to live as well as possible until they die, with a focus on:

- 📍 symptom control
- 📍 independence and autonomy
- 📍 social, emotional, spiritual and cultural wellbeing
- 📍 planning for the future
- 📍 supporting family and carers.

Care focused on quality of life can be provided at any time, from diagnosis of a life-limiting illness through to the last months, weeks and days of life. It is available for everyone regardless of age, culture, background, beliefs or where they live, as well as family and carers.

Support available for family and carers

It can be difficult to ask for help, but there are many organisations and services throughout Queensland that can assist you in your role as a family member or carer.

Practical support at home

If you need help at home, there are services available to provide different types of support.

Sometimes, family members or friends can help. At other times, paid services can assist with activities like bathing, cooking or cleaning.

For healthcare needs, your general practitioner or healthcare team can help with accessing nursing, occupational therapy, physiotherapy and social work. Eligibility, costs and service availability restrictions may apply.

Respite care

Respite care is a form of support for family and carers. It gives you the opportunity to have a break from your caring role, for a few hours, or days, or for longer periods. What you receive depends on your needs, the needs of the person you are caring for, your budget, eligibility and the services available in your local area.

Respite can be provided at a day centre, residential aged care facility or at home. Find out more by speaking with your general practitioner or healthcare team.

Financial support

Caring for someone with a life-limiting illness can have a significant financial impact. There may be a decrease in your household income if you, or the person you are caring for, need to reduce work hours or stop working. There may also be new expenses such as transport, medications, scans, tests and equipment.

Department of Human Services (Centrelink) support

Carer Payment (adult and child): provides financial support to people who are unable to work because they provide full time daily care to someone with a severe disability or medical condition, or to someone who is frail and aged. This payment is income and asset (means) tested.

Carer Allowance (adult and child): a fortnightly income supplement for carers. This allowance is not means-tested and can be paid even if you are working.

Carer Adjustment Payment: a one-off payment to help a family care for a child under 7 years of age who has had a sudden and severe illness. Must also be receiving a Carer Allowance for the child to be eligible.

Carer Supplement: an annual lump sum payment made to people receiving the Carer Allowance and/or Carer Payment.

Queensland Government support

Carer Business Discount Card recognises and supports carers by providing discounts on goods and services at participating businesses throughout Queensland.

Patient Travel Subsidy Scheme provides financial assistance to eligible Queensland patients (and approved escorts/carers) who must travel more than 50 kilometres from their local public hospital to access specialist medical services. Assistance may be provided towards travel and accommodation costs. A different scheme exists for interstate residents receiving treatment in Queensland.

To find out more about financial supports for family members and carers, including eligibility, visit qld.gov.au/careatendoflife.

Family and carer health

It can be easy to put your own needs last, but it is very important to look after yourself. Ways you can do this include:

- 👉 accepting help from others, friends, family or your healthcare team
- 👉 maintaining a healthy diet and exercise
- 👉 getting enough sleep
- 👉 keeping up your usual activities and things you enjoy as much as possible
- 👉 keeping up social contact with friends
- 👉 practising your own spirituality or religion.

Emotional wellbeing

The emotional demands of caring for someone with a life-limiting illness can be significant. It is important to look after your psychological and emotional needs. Many people find counselling helpful. Counselling services may help you to:

- 👉 reduce stress and help you manage feelings of grief and loss
- 👉 manage challenging behaviours and situations
- 👉 manage your relationship with the person you are caring for
- 👉 improve your coping skills
- 👉 continue in your caring role for as long as possible.

Speak to your general practitioner or healthcare team for assistance with accessing a social worker, psychologist, spiritual carers, chaplains or support groups.



Family and carer rights

It is important that you are aware of your rights and options as a family member or carer. These include your rights to:

- 📌 access information to assist you
- 📌 access palliative care support and advice
- 📌 respite and taking a break from your caring role
- 📌 say ‘no’ to things you are not comfortable doing
- 📌 decide that you can’t continue with your caring role
- 📌 make a formal complaint about unsatisfactory services.

Some family members or carers assist with preparing meals, medications and transport to medical and other appointments. Others provide emotional support or help with administering treatment, personal hygiene, bathing, grooming and skin care.

You are not required to take on any of these roles unless you feel comfortable in doing so. If you are not sure, speak to your general practitioner or healthcare team for information and support.

Making decisions on behalf of someone

As a family member or carer, you may be responsible for making decisions on behalf of another person. This may include important decisions about the person's healthcare.

Who is a substitute decision-maker?

A substitute decision-maker is a person legally permitted to make important decisions on behalf of someone who does not have capacity to make the decision required. The decisions can be about personal, health or financial matters. A person can have more than one substitute decision-maker.

Types of substitute decision-makers

A substitute decision-maker can be appointed formally to make differing types of decisions:

1. As an attorney through an Advance Health Directive (under the Powers of Attorney Act 1998 (Qld)). In these circumstances, a health matter can only be dealt with in accordance with the Advance Health Directive, no other way.
2. By an Order of the Queensland Civil and Administrative Tribunal (QCAT) (under the Guardianship and Administration Act 2000 (Qld)), as a guardian, for the person's personal matters; or as an administrator for the person's financial matters.
3. As a Power of Attorney to make decisions other than for personal matters (under the Powers of Attorney Act 1998).
4. As an Enduring Power of Attorney (under the Powers of Attorney Act 1998), for personal matters, or financial matters, or both.

This information can seem complicated but there are a range of people who can help you to understand and provide advice relevant to your personal situation.



Statutory health attorney

If there is no formally appointed substitute decision-maker(s) for health decisions, the Powers of Attorney Act 1988 may enable you to be what is called a ‘statutory health attorney’ for the person you are caring for, if their capacity to make a required health decision is impaired. This gives you automatic authority to make health decisions if the person is unable to make them.

No documentation is required for this role.

By law, a ‘statutory health attorney’ is the first, in listed order, of the following people who is readily available, and culturally appropriate, to make decisions relevant to the health matter:

1. A spouse or de facto partner (if the relationship is close and continuing) of the person with a life-limiting illness.
2. A person who is responsible for the primary care of the person with a life-limiting illness, (but not a paid carer), and who is over the age of 18.
3. A person who is a close friend or relative (but not a paid carer) of the person with a life-limiting illness, and who is over the age of 18.

If there is no one who meets the above criteria, the Public Guardian acts as the ‘statutory health attorney’ for the relevant health matter.

Being paid a Carer Payment or Carer Allowance does not disqualify you from being a ‘statutory health attorney’, because this is not considered as being a ‘paid carer’

Usually, you will know in advance if you are going to be a substitute decision-maker for a person in your care. Remember, you can only act as the person’s substitute decision-maker if they do not have capacity to make the health decision at the time the decision is required. If they do have capacity to make decisions, you will not be a substitute decision-maker.

Is there a difference between a carer and a substitute decision-maker?

In legal terms, there is a difference between a carer and an appointed substitute decision-maker. The difference may depend upon whether you are **formally** or **automatically** appointed as a substitute decision-maker under law, or whether you are caring for a person but not making decisions on their behalf.

If the person in your care has made an Enduring Power of Attorney (for health matters), or an Advance Health Directive appointing you as their attorney, this is considered a formal appointment. In this case you would become the legally-appointed substitute decision-maker, as well as the person’s ‘carer’.

However, it is within the person’s rights to make someone else their substitute decision-maker, but have you as their primary carer. Also, you do not have to agree to be formally appointed as a substitute decision-maker—it is your choice.

Making health decisions for the person in my care

If you need to make decisions about medical treatment for the person in your care, the healthcare team will ask you about how the person would have made the required decision, and what may be important to him/her. They will also discuss options about available treatments.

It is your right as a substitute decision-maker to ask as many questions as you need about the medical treatment being proposed, to help you make an informed decision.

Decision-making at the end of life

Making health decisions for someone important to you at the end of their life can be very difficult. The healthcare team can provide you with support at the time you are required to make any decisions. Don't be worried or anxious about asking for help—that is one of the roles of the healthcare team.

Decisions made on behalf of someone else must align with how that person would have made the decision if they had capacity. In other words, it must be based on their wishes and preferences, and not based upon your preferences. As far as possible, you should take into account any views they have expressed to you previously.

Unless it is an emergency situation and a decision is required immediately, you will be given time by the healthcare team to consider the decision that they want you to make based upon the information they provide. If there are others who also have formal substitute decision-making status, you must also consult with them, to ensure that any decision made truly reflects what the person would want, if they had capacity.


Further advice

The information provided in this booklet is general in nature and is not intended as legal advice. Substitute decision-making arrangements will often be complex. Individual circumstances must be considered and sometimes the level of detail and extra information required will mean you need to seek more support. If you are in any doubt, seek expert advice.





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More information

Every caring situation is different. What you are required to do will depend on the needs of the person you are caring for, and what you are able to do. The level of care you provide may change over time.

You may find it useful to talk with any of the following people. Their contact details can be recorded below:

Doctor / General Practitioner

Nurse

Social Worker

Advance Care Planning Facilitator

Palliative Care Service

Other

To find out more visit qld.gov.au/careatendoflife

Or contact **PalAssist** on **1800 772 273**

PalAssist is a free Queensland 24-hour telephone and online service for palliative care patients, carers, family and friends seeking practical information and emotional support.