



Consider the Carer

2024



A resource to help palliative care professionals:

- understand the impact of the caring role on carers
- reduce the impact of the caring role on carers.

Thank you to Robyn Reid, former Motor Neurone Disease Project Worker at Southern Metropolitan Region Palliative Care Consortium (SMRPCC), for compiling the first 3 editions of this document.

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DISCLAIMER

The information contained herein may be subject to change and those affected should always seek advice from the appropriately qualified professional or agency. Consult with solicitors or allied health workers or the agency that is relevant to the information required.



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INTRODUCTION

At the last census in 2021, there were almost 2.5 million unpaid carers in Australia. A report commissioned by Carers Australia in 2022 estimated that the total cost to replace all informal care in Australia in 2022 was \$77.9 billion — almost \$1.5 billion each week — an increase of 29% since similar research in 2015.

According to the most recent survey of Disability and Carers in Australia (ABS 2018):

- 10.8% of Australians provided unpaid care
- around 1 in 11 carers (235,300 people) were under the age of 25
- women were more likely to be carers than men with 12.3% of all females providing care in 2018, and 9.3% of all males.

Carers' contributions have been acknowledged in the development of the *Victorian Charter Supporting People in Care Relationships*, which reflects and supports the *Carers Recognition Act* (2012). For specialist community palliative care agencies, carers are essential to achieving the client's goal of 'place of care' if they wish to remain at home.

Caring for a loved one can be meaningful and rewarding but research indicates that the burden of caring can be costly for wellbeing and health. Carers are at risk of physical injury, anxiety, depression, and a reduction in social connectedness. Caring for someone with a life-limiting illness can jeopardise financial security and emotional, mental and physical wellbeing. The decision to care for someone, made in the early stages of the disease, may have unforeseen and far-reaching consequences.

The quality of life of the person in palliative care depends on the wellbeing and capacity of their carers. To prevent poor health and burnout in carers, it is important that palliative care staff are aware of carer needs so that appropriate assessment, adequate monitoring and relevant referrals are undertaken. Service models need to include carer assessment and referral throughout the journey of care, including post-bereavement.

This resource has been developed to help palliative care specialists understand the problems that carers face. It outlines areas of decision-making and discussion that may be relevant to carers and loved ones, as they negotiate the impact of a life-threatening disease.

Please note: this resource is for health care workers, not carers.

Some useful resources for carers are:

- [A Palliative Care Victoria booklet: *Supporting a person who needs palliative care: A guide for family and friends*](#)
- [Australian Family Carer Toolkit Project](#)



BECOMING A CARER

Many people willingly take on the role of carer and find the experience rewarding and deeply meaningful. However, at times, carers agree to provide care at home without having considered the impact that caring can have on their life. They also might not be aware of alternative options.

Making an informed choice

To help carers make an informed choice, it is necessary to ensure they understand the situation they are in, what is demanded of them and potential consequences.



The needs and expectations of the client and their carer can differ, and this might not be recognised or openly discussed. The dynamics of the relationship and the congruence, or otherwise, of those needs can greatly influence bereavement and carer outcomes.

To pre-empt any crises or disruption to care, it is important that there is an adequate assessment of both the carer and the cared-for. This requires good communication skills and appropriate allocation of time and resources.

Separate counselling support

Carers are under considerable strain at times. It is essential they have an opportunity to talk to a health professional about what might happen with the illness and the dying process.

This discussion is difficult while in the presence of the cared-for person, especially if there is conflict, or if there are differences in understanding the trajectory of the illness. It may be beneficial for carers to have their own, separate counselling support.

Alternative caring options

It may be helpful to outline alternative caring options at the outset of the caring role. This can introduce the idea that changes can occur to care arrangements and that options are available. Alternatives include:

- respite options
- inpatient palliative care service
- residential aged care



IMPACT OF THE CARING ROLE

Financial

Carers may need to reduce or give up employment due to the demands of caring. This may adversely affect their financial capacity in both the short and long term. There are also the added costs of medical care, equipment, transport and medication. Carers may have differing levels of financial literacy and may need help to organise their finances. Carers may need an advocate when dealing with government departments. A lack of experience, knowledge or assertiveness can lead to disadvantage.

Failing to consider financial matters can have serious consequences for the financial viability of the carer's family. If the person they are caring for becomes unable to communicate or make decisions, vital information may not be available. Obtaining the legal right to administer the dying person's affairs can be a lengthy, stressful, and financially draining process, if the person has not made an [enduring power of attorney](#).

Financial counselling at no charge or at a low cost is offered by some community agencies, community legal services and government agencies.

Ambulance cover

It is essential that palliative care clients have [ambulance cover from Ambulance Victoria](#). Some clients, especially migrants and refugees, might not be aware that calling the ambulance without cover will incur costs. Even for Health Care Card holders, or those with Private Health Cover, it is advisable to have ambulance cover as some transports may not be covered.



Changes to income

If the carer needs to stop work, it is important to determine how the family can meet their expenses.

Carer payment / Carer allowance

There are two types of payments that carers may be able to access:

- Carer Payment
- Carer Allowance



The [Carer Payment](#) provides an income support payment (like the pension) for people who are unable to participate in the paid workforce because they're caring for a loved one. It is permissible to work up to 25 hours per week including travel time while receiving these benefits. For more information, go to [Services Australia: Carer Payment](#).

The [Carer Allowance](#) provides an income supplement payment for people who provide daily care. It can be paid even if working and on top of pensions. It is not means tested. For more information, go to [Services Australia: Carer Allowance](#).

Superannuation and insurance

Total and Permanent Disability Insurance is available to people with a diagnosis of terminal illness or ongoing disability. This is separate to the money people put into superannuation over their working life and is part of their superannuation policy. People with a diagnosis of a terminal illness may withdraw the total amount of their superannuation plus the Total and Permanent Disability insurance payment tax free.

It might be possible to make a claim for financial support by contacting the superannuation or insurance company. [MoneySmart.gov.au](#) has information about making a claim.

Services Australia

Services Australia <https://www.servicesaustralia.gov.au/> can also give information about:

- [rent assistance](#)
- [age pension](#)
- [concession cards](#)
- [financial information service](#)

Department of Families, Fairness and Housing

The Department of Families, Fairness and Housing (DFFH) [concessions and benefits web page](#) has information about assistance, including:

- hardship assistance
- health and medical expenses benefits
- energy and water concessions and benefits

Mortgage or rent

If there is a mortgage, and income is reduced, the carer and cared-for may need to consider:

- accessing the Total Permanent Disability Insurance on a superannuation policy



- accessing income protection, if available (check the policy for conditions of payment)
- discussing the situation with the bank to organise an interest-only loan for a period of time
- using the equity in a home for short-term measures (increase the mortgage)
- accessing mortgage insurance or income protection insurance

If renting, the carer may need to consider:

- applying for rent assistance

Bills

Account holder and privacy

Due to privacy regulations, most providers will discuss an account only with the account holder. If the account holder is the palliative care client, both the carer and client will need to take part in discussions with the provider. The provider might allow the client to authorise the carer to act on their behalf. If appropriate, change the bills into the carer's name so the carer can manage accounts.



Centrepay deductions

For people who receive Centrelink payments, it is possible to set up fortnightly deductions through Centrepay, to reduce the stress of large monthly, quarterly or yearly bills. You can find more information about [Centrepay on Services Australia's website](#).

Community Information Centres

Community Information Centres provide vouchers for food and telephone calls in times of financial hardship. Community Information & Support Victoria (CISVic) is the peak body representing local community information and support services (formerly Citizens Advice Bureaus). To find local community information centres, go to the [CISVic website](#).

Energy and water bill payments

The Utility Relief Grant Scheme (URGS), from DFFH, helps low-income Victorians who are experiencing unexpected hardship to pay electricity, gas and water bills. The grant can be used to help pay mains or non-mains energy or water bills. Account holders can receive a maximum of \$650 on each utility type in a 2-year period (or a maximum of \$1,300 for households with a single source of energy, such as electricity only).



Eligibility for the Utility Relief Grant Scheme:

- An account holder who has a Pensioner Concession Card, Health Care Card or Veteran's Affairs Gold Card, can apply for the grant.
- Some account holders who do not have one of these cards but are on low incomes or experiencing financial hardship, may also be able to apply. For more information about eligibility, go to the DFFH page about the [utility relief grant scheme](#).
- To apply, contact the energy or water provider for an application form.

Banking

The following issues are essential to organise:

House title

- The house title should be in joint names — not Tenants in Common — as this impacts on the house being left to the surviving partner.
 - **Joint Tenants** — joint tenants have equal ownership of the property. The right of survivorship applies and on the death of one owner, that person's share of the property automatically transfers to the surviving owner/joint tenant.
 - **Tenants in Common** — two or more people co-own a property and have defined shares. On the death of one owner, that owner's shares will be distributed in accordance with their will. The surviving owner does not automatically become the owner of the property.

Bank accounts

- Any bank accounts must be accessible with a signature by *either* person so that two signatures are not required to access funds.

Enduring Financial Power of Attorney

- There needs to be an Enduring Financial Power of Attorney so that finances can be attended to on behalf of the person who is sick if they are unable to do so.

Superannuation

Current binding nomination

Be sure that there is a current binding nomination with the superannuation company stating the division of the benefits. Superannuation is not administered according to a will and others may make a claim if they have had a co-dependent relationship with the deceased.



Children of a prior marriage may also have a claim if they have been supported by the deceased.

Financial issues after death

This is a very difficult personal time, made more challenging by the fact that changes in finances occur rapidly after death. Ideally, the financial circumstances of the family have been adequately assessed prior to this time.

General help and advocacy

It is critical that carers, if necessary, have access to allied health professionals who can take the time to advocate on the carer's behalf. Social workers, welfare workers or trained volunteers can help by writing letters to creditors, schools, etc.

Help with funeral expenses

When a person cannot afford a funeral for a loved one, there are options available to assist with expenses.

A funeral director may be able to ask the [State Trustees](#) for up to \$2,500 to support a bereaved family that is unable to pay for a burial or cremation.

The carer may be eligible for bereavement assistance through Services Australia, which can help with funeral expenses. Refer to [Services Australia – Death of a loved one](#).

DFFH has some information on their website about not-for-profit funeral homes: [Bereavement assistance - DFFH Services](#).

[The Greater Metropolitan Cemeteries Trust's website](#) includes some useful information about financial help and support options for funerals.

Income for the carer

There is no longer a widow's pension for people born after 1955. This means that following 12 weeks of bereavement, if the person does not have a source of income and needs to go onto a benefit, they will start on the [JobSeeker Payment](#) from Centrelink and must look for work. This can be difficult if the carer has not previously been in the workforce, lacks skills, or finds it challenging to manage their grief while looking for work.

The carer may be eligible for bereavement assistance through Services Australia. See: [What help is available when a loved one dies - Death of a loved one - Services Australia](#)

Carers who are employed should consider taking leave while being a carer, rather than resigning, so that post-bereavement they have the option to return to work.



RESOURCES

- [Money Smart](#) has some information about financial counselling.
- The [Cancer Council](#) helps some families with financial matters and support.
- The [Council for the Ageing \(COTA\) has developed a resource called Death of a Partner](#), which explains what you need to do after the death of a partner.
- Services Australia has information about financial assistance following the [death of a loved one](#).
- [See Appendix 3](#) for a detailed list of resources.

Medical Treatment Decisions

The [Medical Treatment Planning and Decisions Act 2016](#) creates clear obligations for health practitioners caring for people who do not have decision-making capacity.

Health practitioner obligations

Health practitioners need their patient's consent before providing medical treatment. Anyone can experience an injury or illness that means they are unable to make decisions, either temporarily or permanently.

If a patient does not have capacity to make a decision about the treatment, the health practitioner must first check if the patient has consented to or refused the intended treatment in an instructional directive in a valid advance care directive.

If not, the health practitioner will ask the patient's medical treatment decision-maker to consent for the patient.

Medical treatment decision-maker

If people don't have capacity to make their own medical decisions, someone else has to make these decisions for them. This can be someone who has been appointed as a medical decision-maker as part of Advance Care Planning, or a spouse, partner or other close family member.

For more information: <https://www.publicadvocate.vic.gov.au/your-rights/your-healthcare/appointing-a-medical-treatment-decision-maker>



RESOURCES

- Both [Office of the Public Advocate \(OPA\)](#) and the [Department of Health](#) have developed resources to inform health professionals and patients of their rights and responsibilities.
- See [Appendix 3](#) for a detailed list of resources.

Note: Before the *Medical Treatment Planning and Decisions Act 2016* began (in 2018), the patient may have appointed someone to make medical treatment decisions on their behalf. This could have been a Medical Enduring Power of Attorney, an Enduring Power of Attorney or an Enduring Power of Guardianship. These appointments are still valid.

Legal

The following legal documents are important to consider, depending on the circumstances of the family. These documents can be prepared without assistance, but some people may benefit from consulting a solicitor (or community legal centre if appropriate). [State Trustees](#) can be engaged to manage affairs.



- **A will** is very important. If a person dies without a legal will, they are deemed to have died intestate. This means that a surviving partner will not automatically inherit the estate. This could jeopardise the family's security.
- **Enduring Power of Attorney** for capacity to manage financial affairs on behalf of their loved one should they no longer be able to do so themselves. This ceases after death and the Executor will take over.
- **Guardianship arrangements** for people who cannot manage their affairs competently (including children who may be left without a parent or relative to care for them).
- **House title must be in joint names**, not tenants in common, as this impacts on the house being left to the surviving partner.

Legal issues after death

After death, there are legal issues to be considered, including:

- **Probate** is a document issued by the court, if the estate is over a certain amount, certifying the will's validity and confirming the appointment of an Executor to administer the deceased estate. The court requires proof that the Executor



appointed in the will is alive, willing and competent to undertake the tasks involved. Also, it is important to verify that the document is the *last* will made by the deceased and that there are no objections to that will. Without probate assets cannot be distributed.

- **If the will is invalid** an application for Letters of Administration will need to be made and advertised in the paper for 6 weeks. Letters of Administration is the court's approval to administer the estate of a person who dies without a Will. In most instances Letters of Administration will be granted to the next of kin of the deceased: e.g. a spouse, domestic partner or a child of the deceased.

RESOURCES

- [State Trustees](#) provide legal and financial services, including wills, powers of attorney & executor services.
- [Office of the Public Advocate - OPA](#) – provides financial, legal and lifestyle assistance where individuals need help or are unable to manage their affairs themselves.
- See [Appendix 3](#) for a detailed list of resources.

Immigration and the impact on carers

People who have arrived in Australia as migrants or refugees and do not have permanent residency may have issues accessing and using the health system.

Prior to arrival in Australia, some may have experienced psychological and physical trauma, deprivation, unhealthy environmental conditions and disrupted access to health care. These experiences might reduce their ability to trust service providers and negotiate the health system. In addition, there might be language, cultural and financial barriers that reduce their ability to receive effective health care.

Language and interpreters

People who do not speak English fluently might have difficulty negotiating the health system. It is best to use professional interpreters, not family or friends, to ensure information is received and understood and to allow people to communicate specific cultural needs.



Additional health care costs

People without permanent residency can become a health care user while not eligible for Medicare. They might be required to pay for all associated costs of medical treatment. However, public health services in Victoria will provide services without charge for asylum seekers.

Seeking work and benefit payments

Following the death of a spouse, some carers may have to seek work which they may never have done before in Australia. They may lack language, computer and work-related skills and reduced social support. There are also restrictions on access to welfare payments for immigrants.

Helping carers who are migrants or refugees

Health professionals should be aware that carers who are migrants or refugees can have complex needs and issues. Care must be taken to ensure cultural competency as well as understanding issues within communities when attempting to liaise with ethno-specific support services.

Visa applications

Some carers may not be permanent residents. If there is a visa application in process it is important to seek advice about any status change of the application if the visa is linked to the person who is likely to die. A Migrant Resource Centre, or an immigration agent, may provide advice and support.

RESOURCES — INCLUDING MIGRANT RESOURCE CENTRES

- Migrant Resource Centres offer intensive settlement services for refugees and migrants for the first five years after their arrival.
- [Southern Migrant & Refugee Centre \(SMRC\)](#) provides services to migrants and refugees living in the southern region of Melbourne, including the local government areas of City of Greater Dandenong, City of Casey, Shire of Cardinia, and surrounding suburbs.
- For a detailed list of resources, see [Appendix 3](#).



Children *OF* carers

Many carers are looking after children while dealing with a palliative care situation. Children's need for age-appropriate information and support might be overlooked due to the parents' fatigue, exhaustion, lack of understanding or time.

Talking to children

Children are often aware of parents' burdens, and in trying to be helpful, might not talk about problems or ask questions. Parents might wait for children to raise issues, instead of initiating discussion. Parents and grandparents may require assistance with talking about the person's illness, death and dying.



RESOURCES

- [The Cancer Council](#) has a resource called [Talking to Kids About Cancer](#). You can read the information online, download a PDF or order a free booklet. It contains helpful hints for talking to children about terminal illnesses.

Finding support for parents, grandparents and guardians

Practical support for parenting can come from family, friends and the community. Schools have their own social workers and psychologists.

It is important to inform welfare staff in the school about the home situation to ensure optimal support of the child. This support is offered in school hours, which reduces the need to travel to yet more appointments. Liaison with welfare staff in schools can reduce the workload for welfare staff in palliative care agencies.



Supporting teachers to support children

Teachers also need support to best assist the child — both before and after bereavement.

The impact of the child's situation may lead to cognitive, emotional and behavioural challenges, so it is very helpful for teachers to know what their students are experiencing. Teachers can alter expectations and study requirements and provide ongoing support.



Post-bereavement, classmates benefit from discussion about how best to support the child or young person. Normal routines can provide great benefit for children in difficult situations.

RESOURCES

- [The Cancer Council](#) has a resource called [Cancer in the school community](#), which is a guide for school staff to help them support students, families and colleagues affected by cancer.

Children AS carers

Many children and young people are also carers, either by themselves or in conjunction with their family. These young carers might do physical work at home, such as housework, cleaning, and cooking, while attempting to complete schoolwork and leisure activities.

Impact of the caring role on children

Young carers may become isolated and unable to participate in age-appropriate activities, either due to the demands of their caring role or because of transport or financial constraints.



They may be required to sometimes stay at home and miss school which, over time, could significantly reduce their educational outcomes. There may be pressure from family or cultural expectations that mean the young carer might finish school early and not complete education. It is critical that young carers are identified and that they have access to extra resources and support.

RESOURCES

- [Canteen](#) is a charity that provides resources and support for young people from 12 to 25 years old who have been affected by cancer, including young carers.
- For a detailed list of resources, see [Appendix 3](#).

Voluntary Assisted Dying

The state of Victoria passed legislation in 2019 to allow those with a life-limiting illness to choose Voluntary Assisted Dying (VAD). There are strict criteria for accessing this option.



Health professionals working in palliative care need to know their organisation's decision regarding participation in VAD and the subsequent implications for practice. Any client choosing to access this option will still be eligible to receive palliative care.

The availability of VAD, combined with the complexity of eligibility and access, may pose a strain for the family. In particular, if the view of the carer differs from the view of the patient, the carer may need additional support and counselling.

RESOURCES

- To find out more about VAD please go to the website listed in [Appendix 3 - Resources](#).

REDUCING THE IMPACT

Carer's health

Given the lengthy and difficult nature of caring it is important that the carer receives appropriate support.



Community support

Much of the practical support can be provided by friends and family, although the carer may be reluctant to take up offers of help. Other community connections such as religious groups, clubs, schools and networks may be able to offer assistance.

The [Lotsa Helping Hands](#) website is an example of how help can be organised. Please also see the resource [My Collaborative Care Plan](#). Developed by LaTrobe University, it is a document that can be downloaded, printed and used to help plan and coordinate assistance.

Social media

Social media and email can provide information for, and connection to, friends and family, minimising intrusion through constant requests for updates. The carer can tell a small group of people about the daily status of the person who is ill and then those people can circulate the information, ensuring it is accurate and up to date. A number of Apps have been developed to assist with community support. The [Healthy End of Life](#) App is specific to palliative care.



Physical activity, hobbies and self-care

Physical activity is important to maintain the carer's wellbeing. This may include a social game of sport, time at the gym or a walk around the neighbourhood. Physical activity can assist with the processing of emotions and provide a healthy outlet for frustration and sadness.

Participating in hobbies and pastimes can be vital. Maintaining social connections is also an important protective factor for grief post-bereavement. Participating in specific interests reinforces the sense of self and separateness. This increases the capacity to cope with the demands of caring.

Many carers are reluctant to do something for themselves, but it is very important that the carer takes a break from caring and maintains social connectedness.

It is important for carers to remember that accepting some form of respite can help them maintain their ability to care.



Fatigue

Sleep deprivation and interrupted sleep may cause health issues in the carer. They may also become fatigued and irritable, which will impact on capacity to care. The carer may also feel guilty for being less able to tolerate the caring role due to fatigue.

All of this impacts on the one being cared for and also the extended family members. Fatigue increases the risk of accident and injury as well as comprehension of instructions and the ability to carry out tasks (driving, handling medications, etc).

Respite for the carer

It is difficult for carers to discuss their situation and feelings while in the presence of the person they are caring for as they may feel disloyal or guilty.

Time away from the role of caring rejuvenates the carer and provides a rest from the demands of being on call. Time out enables the person to share their issues with trusted friends and loved ones and gain support.

Volunteers in palliative care agencies can be an invaluable source of support to enable carers to have a break or continue their desired activities. Respite provides a break from caring and is an important factor in making sure the carer role has some longevity.



Educating the carer

Carers may have limited medical and nursing knowledge. It is important to discuss the tasks and issues of providing palliative care in the home. This is best discussed at the time of the referral.

Carers may need education about nursing tasks, equipment, disease progression, medications, after hours care, the process of dying, emotional and psychological impacts on them and their loved ones, resources and services, financial and legal issues as well as funerals and care of the deceased.



There are a number of resources available that can help reinforce carer education. Some palliative care agencies also run carer education groups. It is important to carry out an assessment of carer capacity to ensure their safety and that of their loved ones.

Subcutaneous injections and other at-home care

Caring at Home packages are available to support symptom management by carers. These packages include the following and can be ordered from the [Caring at Home project website](#):

- fridge charts
- standardised teaching materials
- a practice kit to learn how to do subcutaneous injections
- phone applications for carers to assist with managing medications
- information about the most commonly used prescriptions.

RESOURCES

- [The Loddon Mallee Carers Kit](#) includes a collection of documents about different aspects of care.
- [Palliative Care Victoria](#) has some useful resources in its [‘Patients & Families’ tab](#), including: [Supporting a Person Who Needs Palliative Care: A Guide for Families & Friends](#).
- For a detailed list of resources, see [Appendix 3](#).



Community support

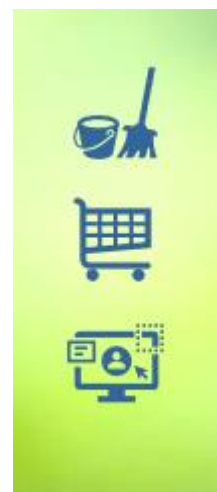
During extended periods of illness or caring, many carers refuse help, even when they need it. Friends, family or community groups may want to help, but are unsure how to help the carer.

[My Collaborative Care Plan](#), developed by LaTrobe University, is a document that can be downloaded, printed and used to help plan and coordinate assistance.

Respite

Respite can be targeted to the needs of an individual carer and range from a few hours to days or weeks. It can provide relief for both the carer and the person being cared for. The person being cared for may take comfort in being able to 'help' the carer and may welcome interaction with new people.

- Palliative care services may offer respite through volunteers. Volunteers can allow carers to shop, participate in social activities, attend medical appointments or just have some time alone.
- Palliative care services may also arrange for overnight or day respite with a nurse so that the carer can take a break from caring.
- Local government — councils — can offer respite services, transport, home help and other sources of support. Some of these are means tested or need referral from a GP.
- Private agencies may offer respite on an ongoing basis according to income and needs.
- The Commonwealth funds services on a regional basis to provide support including respite for carers. The Southern Metropolitan service is called [Alfred Health Carer Services](#).
- People over 65 may be eligible for a home care package or a short term or long term stay in an aged care facility. For further information contact the [My Aged Care](#) website.
- Family and friends can be a great source of help with meals, comfort and assistance.



Carers should be assessed for support systems and encouraged to obtain help from others so they can continue to care for their loved one at home. Family and friends often feel helpless in the face of a life-threatening illness and allowing them to help can alleviate that feeling. It also ensures that carers and loved ones remain engaged and do not become isolated.



The NDIS

The National Disability Insurance Scheme (NDIS) provides Australians under 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life.

People with a terminal illness under 65 may be eligible if they have a permanent and significant disability caused by their illness (for example people with Motor Neurone Disease or a person who has suffered a permanent disability as a result of their cancer treatment).

The NDIS funds reasonable and necessary supports that are necessary for the person to communicate, interact socially, learn, be mobile, care for or manage themselves.

Since October 2019 the NDIS will fund some health supports if they are a regular part of the participant's life and a result of their disability. This may include:

- dysphagia supports
- diabetic management supports
- continence supports
- wound and pressure care supports
- respiratory supports
- nutrition supports.

How to access the NDIS

Anyone who believes they may be eligible for the NDIS should refer to the NDIS website to check eligibility and apply:

- Find more information on the NDIS website: <https://www.ndis.gov.au/>

Palliative care and the NDIS

- Most of the clients in palliative care are aged over 65 so will not be eligible for the NDIS. They may be eligible for an aged care package instead.
- For people who may be eligible for the NDIS, it can be difficult to ascertain if an impairment caused by an illness is temporary or if it can be defined as a disability. The people making these assessments at NDIS may not be health professionals, so it is possible that they may need guidance about the particular disability and the needs of the client. It is important to write the application appropriately for the NDIS.
- [MyCareSpace](#) has an extensive resources page that includes several best practice guides for writing reports for the NDIS, including:

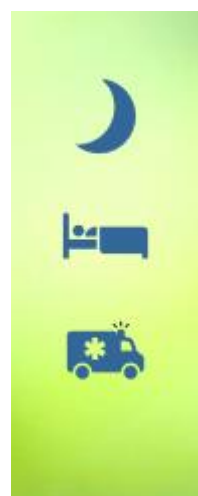


- Making NDIS Applications and Report Writing Easier – A guide to NDIS for individuals, practitioners and families.
- [Refer to MyCareSpace's resource page.](#)
- Clients and carers might need assistance with the NDIS application as it can be a lengthy process. It is advantageous for expert attendance at care planning meetings when planning goals and funding to provide best outcomes and advocacy.
- If circumstances change rapidly, timelines are lengthy, or funding is delayed you can intervene by emailing the following address to alert the NDIS that the needs are urgent. Send your email with the subject heading: '*Urgent action required*' followed by the relevant subject details to: AT.VICEAST@ndis.gov.au

Caring after hours

Caring at home after hours, especially at night, can be more difficult especially when the carer is not well prepared. Adequate care planning prior to any after-hours emergency is essential to minimise trauma or unnecessary admission to hospital emergency. This includes:

- assessment of the carer's skill
- the ability to manage symptoms
- information about who to call (consider interpreting services)
- the availability and knowledge of administering emergency medications
- the availability of any relevant documentation, such as an Advance Care Plan and Refusal of Medical Treatment documents.



It could also be beneficial to consider if there is someone (a neighbour or friend) who could assist the carer in an unplanned event after hours.

Preparing for the death

It is important to prepare the family for what happens during and after the dying process. Hopefully this can be a gentle and extended process within the context of a respectful relationship between client, carer and palliative care staff.

The degree of information and education needed will depend on the carer and client's willingness to be open about the prognosis. Where the issue of death and dying cannot be broached, care and discretion are required to meet the carer and client's needs tactfully while continuing to provide support.



Carers need to be aware of their options around care in case they are unable to continue caring at this time or in case of symptoms which can't be managed at home. This may require ongoing contact, reassessment, and support from palliative care staff.

Information about the stages of dying and the likely cause of the death should be discussed along with how to manage the point of death and the supports available at the time.

Carers should have information about care of the body and permission to attend to their personal emotional, psychological, spiritual and cultural needs. They should know what happens after death, for example:

- who to call
- how to obtain the death certificate, if appropriate
- how to commence funeral proceedings.

Bereavement

Best practice for caring for carers in palliative care currently includes a bereavement risk assessment¹. This is usually carried out and monitored by the palliative care team to ensure that the carer is provided with appropriate post-bereavement support.

The carer's emotional, physical and financial health

The carer might be of poor health, exhausted and overrun by the many demands before the bereavement occurs, adding to the burden of grief. The financial state of the carer may dictate a radical change in lifestyle — they might need to acquire new skills and do tasks they have never done before. They might experience changes, not only to their outer world but also their inner one, as they adjust to life without their loved one.

All this takes place at a time of least clarity and confidence for the carer, when they are also experiencing problems with concentration, sleep, social and family concerns.

The carer's post-bereavement life

When the carer gives up their caring role, post-bereavement, they might need to readjust to having time on their hands. They might have become



¹ Hall C, Hudson P, Boughey A, 2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne.



disconnected from their social groups. Their lifestyle and needs might have completely changed.

Carers might feel guilty about how they carried out their role or about possible feelings of relief on the death of the loved one. They might be unsure how to navigate life as a single person after many years as a spouse or partner. They might find the needs of their children hard to meet while experiencing their own grief. They may need information and education about how to support themselves and grieving family members. They may need to take on new roles at a time when grief is affecting their ability to learn new things.

Caring for the carers is a vital part of quality care

Caring for the carers is a vital part of quality care and ensures that the impact of the caring role is mitigated as much as possible. It is necessary for post-bereavement carer circumstances to be taken into account in order to cater for lifestyle changes after the death of the loved one.

Early carer assessment with adequate time and allocation of resources is required to ensure that the outcomes for carers, particularly around poor mental and physical health, are improved wherever possible.

Impact on palliative care staff

Palliative care staff who have been part of the care team also need to consider the impact of the death of the client and their relationships with the carers. They may need to take time to reflect on or ritualise the end of these relationships in a way that optimises their wellbeing and reduces burn out.

The [Australian Centre for Grief and Bereavement](#) can provide more information and training.

CARER ASSESSMENT

Health professionals may not be fully aware of carers' issues. A comprehensive assessment will highlight any gaps in knowledge and skills. Experience in the health care system does not necessarily equip a carer with an understanding on how the system works. Often the client and the carer are viewed as one unit. Without formal assessment tools, there is the possibility that the health practitioner will lead the conversation about when and which areas to discuss.

It is important to note that assessment is not a one-off event but an ongoing process of monitoring that encourages carers to identify and communicate their needs.



If needs are identified that cannot be met by the palliative care agency, community resources and interagency collaboration should take place.

Carer Assessment Tool

In 2012, the Department of Health commissioned a report to assess clinical tools and endorsed the [Carer Support Needs Assessment Tool Intervention \(CSNAT-I\)](#). An evidence-based tool, it is designed for carers supporting someone at home towards the end of life. It was developed by Dr Gail Ewing, senior researcher at the Centre for Family Research, University of Cambridge, and Professor Gunn Grande, University of Manchester. Both have long experience of palliative and end of life care research, particularly with carers.

The tool has been designed to be short and simple to use for both carers and practitioners. It comprises 14 broad support domains in which carers commonly say they require support.

The CSNAT-I differs from other carer assessment tools in that the process is facilitated by the practitioner but led by the carer. This ensures that the response to the support needs identified by the carer is tailored to their individual needs. It uses a simple question and answer format to ask carers in which areas they need more support. The 'visibility' of common areas of support provided by the tool has been found to be helpful for carers. A carer can indicate whether or not they need more support in relation to each domain.

The CSNAT-I is copyright but available free of charge for use by practitioners supporting carers. The team behind its development also provide training and support for services wishing to implement the CSNAT-I.

RESOURCES:

- For further information visit the website: [CSNAT Intervention](#).

Positive impact of carer assessment tools

Carer assessment tools can:

- open up conversations that otherwise may not have happened
- help the carer talk about the impact of caring
- make the carer's needs transparent
- cover the range of carer's issues quickly and thoroughly
- flag issues and so reduce the need for crisis calls to the agency and reduce contact time overall.



In addition, because of the format, different health professionals can help the carer fill out the form. This can be done at a convenient time and the information can be used to refer the carer to the appropriate person or agency.

Challenges and barriers of carer assessment tools

At times it can be difficult to introduce a new clinical tool into the palliative care service model. Some barriers that may impact on the successful implementation of a carer assessment tool are:

- staff may feel that they already provide appropriate informal assessment
- staff may anticipate an increase in workload
- assessing carers may take up time from agency resources
- staff may fear not being able to address issues raised
- carers may be reluctant to receive their own assessment
- carers may not want to talk about certain areas of their lives.

While most health professionals believe they cover the areas in the tool, a more formal assessment means all areas are covered at once and systematically. (G. Emery University of Cambridge).

Some research suggests that carers may not be fully aware of the impact of caring themselves and a tool may raise new issues (some carers find this unhelpful, while others are very grateful to see their issues addressed).

Referral

It is critical that palliative care staff are familiar with the need to provide appropriate, proactive and informed responses to the needs of carers. This includes providing access to practical support across a range of areas, some of which may be outside their area of expertise.

[Infoxchange Service Seeker](#), an initiative by the Victorian Government, can help staff find the right type of assistance for the carer.

The website lists services by topic and location. Because searches bring up a variety of results — some not appropriate — it is important to help the carer with the search, facilitate access if necessary, and follow up if the intervention has led to anticipated results.



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APPENDICES

Appendix 1: Checklist — Commencing caring conversations

This checklist helps staff have conversations about commencing caring. The aim is to:

- Provide a baseline assessment of the carer and their capacity
- Give the carer and the cared-for person clear and understandable information about their choices so they can make fully informed decisions (give informed consent) around the challenges and difficulties of caring and the possible outcomes
- Outline potential important tasks
- Validate the needs of the carer as separate from the client
- Ensure the carer is introduced to the idea that care can be intermittent — there are options for care, and they are encouraged to use these options
- Ensure the carer achieves the client’s goals with as few poor outcomes as possible for the carer and their own situation and wellbeing

Carer role

<i>Topic</i>	<i>Covered?</i>	<i>Needs follow-up or referral?</i>
Who is able to carry out the main caring role?		
What is this person’s current health status?		
How much support can the family and friends provide?		
Do they know that they will be the main carer 24 hours a day with only some visits from health professionals?		
How will this impact on their family?		
Do they need to continue working and caring for dependants?		
What are the challenges for them in continuing their caring role?		



Are there issues of mental health coexisting with the carer or client currently?		
What do they understand about the diagnosis and prognosis?		

Place of care

<i>Topic</i>	<i>Covered?</i>	<i>Needs follow-up or referral?</i>
At home:		
<ul style="list-style-type: none"> • What are the implications for the carer? 		
<ul style="list-style-type: none"> • What services can be provided by Local Government? 		
<ul style="list-style-type: none"> • Community palliative care referrals explained. 		
Hospice:		
<ul style="list-style-type: none"> • What is a hospice and what services can be expected. 		
<ul style="list-style-type: none"> • Hospital 		
<ul style="list-style-type: none"> • Under what circumstances would the client be admitted to hospital? 		
Respite:		
<ul style="list-style-type: none"> • Options explained and contacts made for future uptake of respite. 		



Appendix 2: Checklist — Practical Considerations

This checklist helps palliative care staff have conversations about practical and emotional issues for carers. Clinical tools that can also assist are the carer assessment tools, such as CSNAT and Bereavement Risk Index.

See [Appendix 3](#) for a detailed list of resources.

Legal

<i>Topic</i>	<i>Covered?</i>	<i>Needs follow-up or referral?</i>
Is there a will?		
Enduring Medical Power of Attorney		
Enduring Financial Power of Attorney		
Have they nominated the beneficiaries of their Superannuation?		
Advance Care Plan		
Refusal of Treatment certificate		
If they own their home, is it in joint names?		

Financial

<i>Topic</i>	<i>Covered?</i>	<i>Needs follow-up or referral?</i>
Has the family got ambulance cover?		
If applicable: mortgage insurance / disability insurance		
How will their financial situation be affected by current and future circumstances?		
Do they need financial counselling or assistance?		
Are there any grants or funding that they are eligible for?		
How will they manage day to day with income and expenditure?		



Emotional / psychological / spiritual / social

<i>Topic</i>	<i>Covered?</i>	<i>Needs follow-up or referral?</i>
How is the carer coping?		
What questions do they have about the diagnosis/ prognosis or assistance required?		
Have they been referred to relevant support agencies? E.g., local government, allied health, respite agencies, counselling services, interpreter services, disease specific support agencies like MND Victoria, Alzheimer's Australia?		
How will they maintain their links with their spiritual supports?		
How will they maintain their links with their community supports?		
Have younger family members been offered support via their school communities?		



Appendix 3: Resources

General

<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
Ambulance Victoria Membership	https://www.ambulance.vic.gov.au/membership/	Ambulance Victoria membership — protects against the high cost of transport and treatment
Cancer Council – How we can help you	https://www.cancervic.org.au/support	Resources for family carer support
CarerHelp	www.carerhelp.com.au/	CarerHelp brings together a range of tools, videos, and information to support carers.
Carer Support Needs Assessment Tool Intervention	https://csnat.org/	Information about CSNAT-I and how to use it
Carers Victoria	https://www.carersvictoria.org.au/	Multiple resources and support services for carers
Caring at Home	https://www.caringathomeproject.com.au/	Practical resources to help carers, including a kit to teach carers about subcutaneous injections
Centre for Palliative Care	https://www.centreforpallcare.org/	Resources, education and research about palliative care and carer resources.



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
	https://www.centreforpallcare.org/page/145/carers-resources	
COTA Victoria	https://cotavic.org.au/publication/death-of-a-partner/	A guide to dealing with practical issues after death.
Grief Australia	https://www.grief.org.au/	Bereavement support, resources and information
Healthy End of Life Project - La Trobe University	https://healthyendoflifeprogram.org/wp-content/uploads/2022/09/HELP-2022-Individuals-and-Families.pdf	A printable document that can help carers plan how to involve their community — family, friends, neighbours, other groups — in caring.
Infoxchange Service Seeker	https://www.serviceseeker.com.au	Directory of community support services.
Lotsa Helping Hands	https://lotsahelpinghands.com/ https://lotsahelpinghands.com/how-it-works/	Carers can easily set up an online community to get help with care, such as: meals for the family, rides to medical appointments, or stopping by to visit.
Medical Treatment Planning and Decisions Act 2016 — Department of Health	https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/medical-treatment-planning-decisions-act	Information about the <i>Medical Treatment Planning and Decisions Act 2016</i>
Office of the Public Advocate - OPA	https://www.publicadvocate.vic.gov.au/	Resources on medical treatment decisions and consent.



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
	https://www.publicadvocate.vic.gov.au/medical-treatment	
Palliative Care Victoria	www.pallcarevic.asn.au	Resources, education and research about palliative care. Includes 'find a palliative care service provider' in Victoria.
Services Australia - Death of a loved one	https://www.servicesaustralia.gov.au/death-loved-one	Information on payments, counselling and financial services to help people adjust to life after a loved one has died.
Young Carers Network	https://youngcarersnetwork.com.au/	Information to help young carers.

Legal

<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
OPA - Office of the Public Advocate	www.publicadvocate.vic.gov.au/	Financial, legal and lifestyle assistance where individuals need help or are unable to manage their affairs themselves.



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
<u>OPA - Guardianship</u>	<u>https://www.publicadvocate.vic.gov.au/guardianship-and-administration</u>	Guardianship may be needed if a person is no longer able to make reasonable judgements.
<u>OPA - Take Control</u>	<u>Search: 'Take Control' on the OPA website to find OPA's Take Control 2022 Information Kit</u>	Kit of information produced by the Office of the Public Advocate for making enduring powers of attorney and guardianship.
<u>State Trustees</u>	<u>https://www.statetrustees.com.au/</u>	Legal and financial services for security and peace of mind, including wills, powers of attorney & executor services

Financial

<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
<u>Cancer Council</u>	<u>https://www.cancer.org.au/about-cancer/patient-support/practical-and-financial-assistance.html</u>	Practical and financial assistance for cancer patients.
<u>Cancer Council Victoria - Get support - Financial and legal</u>	<u>https://www.cancervic.org.au/get-support/legal-and-financial/finance/finances-overview.html</u>	Information on getting help with bills, including rent, medical costs and utility bills.
<u>Carers Victoria</u>	<u>www.carersvictoria.org.au/</u>	Resources and advice for carers who provide unpaid care and support to family members or friends who have a disability, mental illness,



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
		chronic condition, terminal illness or who are frail aged.
<u>Moneysmart - Financial Counselling</u>	<u>https://www.moneysmart.gov.au/managing-your-money/managing-debts/financial-counselling</u>	Information about free financial counselling and how to find a free financial counsellor
<u>Services Australia - Bereavement Allowance</u>	<u>https://www.servicesaustralia.gov.au/what-help-available-when-loved-one-dies?</u>	Information about financial services to help people adjust to life after a loved one has died.
<u>Services Australia – Death of a loved one – What help is available</u>	<u>https://www.servicesaustralia.gov.au/what-help-available-when-loved-one-dies?</u>	Information about payments and services that may be available when a loved one dies.
<u>Services Australia - Carer Allowance</u>	<u>https://www.servicesaustralia.gov.au/carers-allowance</u>	Information about an income supplement for carers who provide additional daily care for someone with a disability or medical condition, or who is frail aged.
<u>Services Australia - Carer Payment</u>	<u>https://www.servicesaustralia.gov.au/carers-payment</u>	Information about a payment for people who provide constant care, in the home, to someone with a severe disability, illness, or who is frail aged.
<u>Services Australia - Centrelink</u>	<u>https://www.servicesaustralia.gov.au/centrelink</u>	Financial assistance when income is reduced such as disability, carer, unemployment benefits and health care cards for those on limited incomes.



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
<u>Services Australia - Centrepay</u>	<u>https://www.servicesaustralia.gov.au/centrepay</u>	A free and voluntary service to pay bills and expenses as regular deductions from Centrelink payments.
<u>Services Australia - Concession and health care cards</u>	<u>https://www.servicesaustralia.gov.au/concession-and-health-care-cards</u>	Information on eligibility and how concession and health care cards can help access cheaper health care services and medicines.
<u>Services Australia - Financial Information Service</u>	<u>https://www.servicesaustralia.gov.au/financial-information-service</u>	Free service that provides education and information on financial issues.
<u>Services Australia - JobSeeker Payment</u>	<u>https://www.servicesaustralia.gov.au/jobseeker-payment</u>	Financial help for people between 22 and Age Pension age who are looking for work, or if sick or injured and can't do their usual work or study for a short time.
<u>Services Australia - Rent Assistance</u>	<u>https://www.servicesaustralia.gov.au/rent-assistance</u>	Financial help for people who pay rent and receive a Centrelink payment.
<u>Services Australia - Age Pension</u>	<u>https://www.servicesaustralia.gov.au/age-pension</u>	Income support and access to a range of concessions for eligible older Australians.
<u>Victoria State Government - Energy and water concessions and benefits</u>	<u>https://services.dffh.vic.gov.au/energy</u>	Concessions and benefits to help pay energy and water bills.



Emotional and Psychological Support

<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
Cancer Council Victoria	https://www.cancervic.org.au/	Resources for Family Carer Support.
Cancer Council Victoria - Talking to Kids About Cancer	https://www.cancervic.org.au/cancer-information/children-teens-and-young-adults/talking-to-kids-about-cancer/overview.html	Resources for talking to children, teens and young adults about cancer.
Canteen	https://www.canteen.org.au	Information and resources for 12 –who either have cancer or know someone 24-year-olds with cancer.
CareSearch	www.caresearch.com.au	Online service information for carers.
MND Australia - MND Connect	https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers	Information and resources for health professionals and disability and aged care providers who support and care for people living with MND.
New Hope Community Care	https://newhopecare.net.au/asylum-seekers/	Assistance for Asylum Seekers and Refugees.
Palliative Care Victoria - Booklet - Supporting a Person Who Needs Palliative Care: A Guide for Families & Friends	<p>Order a free copy: https://www.pallcarevic.asn.au/store/products/16/booklet-supporting-a-person-who-needs-palliative-care-a-guide-for-families-friends</p> <p>Or read online at: https://www.pallcarevic.asn.au/page/107/useful-information</p>	A comprehensive and practical resource for family carers of a person with a life-limiting illness who needs palliative care.



<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
Southern Migrant & Refugee Centre	http://www.smrc.org.au/	Community-based agency providing services to migrants and refugees living in the southern region of Melbourne, including the local government areas of City of Greater Dandenong, City of Casey, Shire of Cardinia, and surrounding suburbs.
Violet - Support for the last stage of life	https://www.violet.org.au/	A national not-for-profit organisation, providing information and support to help everyone in Australia navigate the last stages of life and the grief and loss that accompanies it.

Respite Services

<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
Alfred Health - Carer Services	https://www.alfredhealthcarers.org.au/	Carer support programs Southern Metro Region – information, urgent respite.
Carer Gateway – What is respite	https://www.carergateway.gov.au/what-respite	Information about respite care for carers in need of a break.
My Aged Care - Find a provider	https://www.myagedcare.gov.au/find-a-provider	Information to find aged care provider or respite care.



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<i>Organisation or program</i>	<i>Website URL</i>	<i>Description</i>
My Aged Care - Home Care Packages	https://www.myagedcare.gov.au/help-at-home/home-care-packages	Information regarding access and services provided by Home Care Packages.
MyCareSpace	https://mycarespace.com.au/	Resources to help navigate NDIS. Use the Resources pages to search for information and guides, including about how to write an NDIS application.

