

Help for
**Families
& Carers**



PalliativeCare
VICTORIA

Living, dying & grieving well

About Palliative Care Victoria

Palliative Care Victoria is an incorporated association and charity established in 1981.

Our vision is that all people with a life limiting illness and their families are supported to live, die and grieve well.

We value the collaboration and support of people with a life limiting illness, carers, our members and partners, the Victorian Government and many others to achieve this vision.



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Palliative Care Victoria
Suite 3C, Level 2
182 Victoria Parade
East Melbourne Victoria 3002

Reg. Inc. No. A0022429M
ABN 88 819 011 622

Free call	1800 660 055
Call	+61 03 9662 9644
Web	pallcarevic.asn.au
Email	info@pallcarevic.asn.au
Facebook	facebook.com/PalliativeCareVictoria/
Twitter	@pallcarevic

Introduction

About this leaflet

This leaflet provides information about care and support available for people with a life limiting illness and their families living in Victoria. Some information will be helpful for all carers.

You can find the information you want easily by:

- clicking on the section titles below
- clicking on web links
- clicking on the topics in the index at the end.

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About carers

Carers give their time, effort and love to care for a family member, partner or friend who needs extra care and support due to special needs. They improve the quality of life of the person they care for.

Caring can be very satisfying. It is also hard work. It is important to recognise, value and support carers.

There is no greater gift than caring.



People with a life limiting illness

A life limiting illness has no cure. The person may live for years, months or weeks. This depends on the nature of the illness and each person is different. Life limiting illnesses include some advanced cancers, organ failure, dementia, and other conditions.

Each person with a life limiting illness has unique physical, practical, emotional, psychological, social, cultural and spiritual needs.

Palliative care

Palliative care helps people with a life limiting illness to live well until they die. It improves quality of life, relieves pain and symptoms, supports family and friends providing care, and helps with grief and loss.

Palliative care can be provided by doctors, health professionals, aged and disability services caring for people with a life limiting illness. Community support is also very important.

Specialist palliative care services provide extra layers of specialist expertise to improve the quality of life of people with complex needs. They work with the person and the family and their usual GP and other health and care providers. Palliative care can be provided at home, in a care facility and in hospital. If the person receiving care is living at home, additional assistance from aged, disability or other care services may be needed.

Start points to get help

Help is available for the person receiving care and for the person who is giving care.

Here are some useful start points to find help - for the person needing care and for the caregiver.



Don't hesitate to ask for help at any time!

Carers

Carer Gateway

This free national service helps carers to find the right information, advice, services and support.

For help in caring for someone, it covers financial help, health conditions, legal rights, finding a service and practical advice.

To help carers, it includes information on speaking up, self-care, taking a break, and making a complaint. It also includes advice on what to do when the care situation changes.

Call 1800 422 737
Monday to Friday, 8am to 6pm

Web carergateway.gov.au

Better Health Channel, Victoria

This website allows you to search by topics to find services in your area.

The section on carers, caring and respite care services is here:

Web betterhealth.vic.gov.au/servicesandsupport/carers-caring-and-respite-care-services

Carers Victoria

Carers Victoria assists carers with free information, referral, support groups and education for carers. It also provides up to six free counselling sessions for carers.

Call 1800 242 636 for the Carer Advisory Line

Web carersvictoria.org.au

Email reception@carersvictoria.org.au



Health care

Primary health care

Local doctors (GPs), community health centres, pharmacists and allied health professionals contribute to the ongoing care of people with a life limiting illness and their families.

It helps to let them know about your role as a carer and to discuss any support you may need.

Healthdirect

Healthdirect is a free service supported by the governments of Australia. It provides safe, practical health information and advice. You can use the service finder on their website to find specific health care practitioners and health services in your area.

Call 1800 022 222 - 24 hours, every day

Web healthdirect.gov.au

Nurse-on-Call

Nurse-on-Call provides immediate expert health advice from a registered nurse. It also provides information about local health services. An interpreting service is available.

Call 1300 60 60 24
available 24 hours, every day.

Web betterhealth.vic.gov.au/health/ServiceProfiles/nurse-on-call-service

In an emergency, call 000 for an Ambulance or go to the nearest emergency department.



Palliative care

Palliative care helps people with a life limiting illness to live well until they die. It supports families and friends providing care, improves quality of life, relieves pain and symptoms, and helps with grief and loss.

Specially trained palliative care staff assists people with complex conditions and needs, which may be physical, emotional, social, cultural and spiritual. They work with the person and their family and their other health and care providers.

Palliative Care Victoria

Palliative Care Victoria provides free information and help to access needed palliative care and other services. It also undertakes advocacy, community engagement, and capacity building (including work with diverse communities and volunteers).

Call 1800 660 055 or (03) 9662 9644

Web pallcarevic.asn.au

Search for a palliative care service in Victoria by postcode or suburb on the Home Page.

The [Families and Patients section](#) has helpful information about physical care, quality of life, support for families and carers and grief.

Palliative Care Australia

Palliative Care Australia advocates for high quality palliative care at the end of life for all Australians. Its website includes information and links to the Palliative Care Association in each state and territory.

Web palliativecare.org.au/contact

Older people

Aged care services can help with care and support needed by people aged 65 years or more.

Myagedcare

This Australian Government service provides a free assessment of needs and information about services that can help care for the person and support carers. You may need to contribute to the cost of some services.

The **Aged Care Assessment Service** provides a free assessment of the person needing care and also considers support for their carers. This is needed before you can get financial help for care and support.

Call 1800 200 422
Monday to Friday 8am to 8pm
Saturday 10am to 2pm

Web myagedcare.gov.au

Dementia Australia

Dementia Australia provides information, support, counselling and education. This includes education and support groups for carers of people with dementia.

Call 1800 100 500

Web dementia.org.au

People with a disability

Disability services provide care and support to people aged under 65 years with a disability.

Better Health Channel, Victoria

This provides helpful information about disability services, how to get help, planning for the future, rights of people with a disability, and support for their carers. It includes some information in 20 community languages.

Web betterhealth.vic.gov.au/servicesandsupport/disability-services

The National Disability Insurance Scheme (NDIS)

This national program provides funding for the care and support of people with a permanent and significant disability. It assists with information and referrals, support to access services and activities, personal plans and funded supports.

The NDIS is available in some regions and will be available across Victoria by 30 June 2019.

Web ndis.gov.au

Call 1800 800 110





People with complex health conditions

Many organisations exist to provide information and support services for people with specific complex health issues and their carers. For example:

- Cancer - specific services support people with brain, breast, ovarian, prostate and other cancers
- Organ failure - specific services support people with kidney, lung and heart failure
- Neurological conditions - specific services support people with dementia, Motor Neurone Disease (MND) and Parkinson's Disease
- Other complex conditions - such as diabetes, stroke.

It is not possible to name all the organisations and services available. However, you can search for them by key word and location.

Search for services

Infoexchange Service Seeker

This national website enables you to search using key words for specific services in your area. It includes brief information about the service, including contact details and opening hours.

Web serviceseeker.com.au

To care for others well, it helps to receive the support you need.

Specific groups

Aboriginal people

VACCHO

The Victorian Aboriginal Community Controlled Health Organisation has information about health and other support services available to Aboriginal people in Victoria and their contact details.

Web vaccho.org.au/om/our-membership/members

Helpful resources for Aboriginal people on the journey to the dreaming and their families produced by VACCHO and Palliative Care Victoria are available here:

Web pallcarevic.asn.au/families-patients/aboriginal-australians

Children and young people

Better Health Channel, Victoria

This provides guidance for families and carers of children and young people with a life limiting illness.

Web betterhealth.vic.gov.au/health/ServicesAndSupport/End-of-life-and-palliative-care-for-children-teenagers-and-young-adults

Palliative Care Australia

This website includes resources for families and carers of children and young people with a life limiting illness.

Web palliativecare.org.au/children

Very Special Kids, Victoria

Very Special Kids assists Victorian families with a child with a life limiting condition. Their free services include: counselling and emotional support, sibling support, respite, networking and peer activities and sibling support. Their children's hospice provides specialist respite and end of life care.

Call 1800 888 875

Web vsk.org.au



Children of carers

Resources are available to assist carers to discuss illness, dying, death and grief with their children.

Cancer Council Victoria

Cancer Council Victoria has this free guide on talking to kids about cancer.

Web cancervic.org.au/cancer-information/children-teens-and-young-adults/talking-to-kids-about-cancer

Caresearch

Caresearch provides links to websites with helpful advice for parents.

Web caresearch.com.au/caresearch/tabid/1139/Default.aspx

Little Dreamers

Little Dreamers sells over 15 activities books about chronic illnesses and disabilities.

Web littledreamersonline.com/resources/happy-kids-publishing

People from diverse cultural and language backgrounds

Many ethnic community organisations provide a range of care and other services that meet the specific cultural and linguistic needs of their communities.

Better Health Channel, Victoria

Provides information about support available for carers from diverse backgrounds.

Web www.betterhealth.vic.gov.au/health/ServicesAndSupport/carers-from-culturally-and-linguistically-diverse-backgrounds

Centre for Cultural Diversity in Ageing

The Centre has an online directory of aged care services with bilingual staff.

Web culturaldiversity.com.au/consumers-and-carers/aged-care-services-with-bilingual-staff

Health Translations, Victoria

This website has health information in community languages. It has an A-Z list of topics and you can search by key word and language.

Web healthtranslations.vic.gov.au/

Palliative Care Victoria

Information about palliative care is available in 17 community languages. Palliative care services respect diversity and provide culturally safe care.

Call 1800 660 055
Ask for an interpreter, if needed

Web pallcarevic.asn.au/families-patients/community-languages/

Victorian Multicultural Commission Community Service Directory

You can search this online directory to find ethno-specific organisations providing care and other services relevant to specific culture, faith and language needs.

Web multicultural.vic.gov.au/resources/community-directory

People with diverse gender identity, sex and sexuality

QLife

QLife provides a national counselling and referral service for Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people of all ages experiencing poor mental health, social isolation, discrimination, or other concerns that affect their health and wellbeing.

Call 1800 184 527
3pm to midnight, every day

Web qlife.org.au

Thorne Harbour Health, Victoria

The Positive Living Centre run by Thorne Harbour Health provides care and support services for people living with HIV.

Call 1800 134 840

Web thorneharbour.org

Queer Space, Victoria

Provided by Victorian organisation Drummond Street, Queer Space is staffed by queer identified practitioners. They provide information, counselling and support to access health and wellbeing services for LGBTI people.

Call (03) 9663 6733

Web ds.org.au/our-services/queerspace

People with mental health needs

Better Health Channel, Victoria

This includes information for carers of a person with a mental health illness.

Web betterhealth.vic.gov.au/health/ServicesAndSupport/caring-for-someone-with-mental-illness

beyondblue

This national service provides a helpline, resources, and assistance to find professional services for people with anxiety, depression, suicidal feelings and other mental health issues. The website has a section *supporting someone* for families and carers.

Call 1300 22 4636
available 24 hours, every day.

Web beyondblue.org.au

Lifeline

Lifeline is a national service providing crisis support and suicide prevention.

Call 13 11 14 - available 24 hours, every day
Call EMERGENCY 000 if a life is in immediate danger.

Web lifeline.org.au

Sane

This national organisation provides a helpline and resources for people with a mental illness and their carers. Their website has a section for families and carers.

Call 1800 187 263 – to talk to a mental health professional (weekdays 10am to 10pm AEST).

Web sane.org

Young carers

Little Dreamers

Little Dreamers provides practical support, mentorship, and education to support young carers. They also provide events and access to support networks for young carers.

Reach out via an online message, they will get back to you shortly.

Web littledreamersonline.com

Young Carers Network

A website for young carers to share their stories and opinions, attend live webinars and learn new skills. It is produced by Carers Australia.

Web youngcarersnetwork.com.au

It is important to recognise and support the valuable contributions of carers.



Specific information

Aids and equipment

Carer Gateway

The Australian Government supports the provision of some aids and equipment free or at a reduced cost. This includes essential medical equipment, continence aids, hearing services, and other aids to support activities of daily living.

Links to the specific programs are available here:

Web carergateway.gov.au/financial-support-for-aids-and-equipment

Victorian Aids & Equipment Program

This Victorian program helps fund aids and equipment for older people and people with a permanent disability. This includes help with speaking, moving, sitting, sleeping, bathing, and some changes to the home.

A health professional must assess the person's needs and complete a form with the application. Equipment or funding may be provided.

Call 1300 747 937

Web swep.bhs.org.au/aids-and-equipment

Email swep@bhs.org.au



Advance care preferences

Every person in Victoria has the right to make decisions about their future medical treatment and care. Helpful information about what this involves is available on these websites:

Advance Care Planning Australia

Web advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory

Better Health Channel, Victoria

Web betterhealth.vic.gov.au/health/servicesandsupport/advance-care-plans

Office of the Public Advocate, Victoria

Provides advice about:

- guardianship and administration
- medical treatment decision making
- enduring powers of attorney.

Its booklet, [Take Control](#), has more information and forms and is on their website.

Call 1300 309 337

Web publicadvocate.vic.gov.au

Communication assistance

Non-English speakers

Some health services are required to provide free interpreting services. Ask for an interpreter if this would assist you.

Translating and Interpreting Service

This service is available 24 hours, every day. Calls are charged at the cost of a local or mobile call.

Call 131 450 - for immediate phone interpreting, 24 hours every day

Web tisonline.gov.au

Hearing or speech problems

The National Relay Service

This Australia-wide service helps people with speech and hearing problems at no extra cost all day, every day.

Call 1300 555 727 - Speak & listen service

Call 1800 555 677 - TTY / Voice service

Call 1800 555 660 - Helpdesk available 8am to 6pm Monday to Friday

Web relayservice.gov.au

Concerns & complaints

Discuss a concern or complaint about a service with the person of concern or the person in charge of the service. If your concern is not resolved, government funded services can help.

Aged Care Complaints Commissioner

This is a free service. You can raise concerns about aged care services that are subsidised by the Australian Government.

Call 1800 550 552 - 9am to 5pm weekdays or leave a phone message.

Web agedcarecomplaints.gov.au

Australian Human Rights Commission

Its National Information Service provides free information and referrals about human rights and discrimination issues under Australian law and how to make a complaint. You can submit a complaint to the Commission for investigation and resolution.

Call 1300 656 419
10am to 4pm weekdays

Web humanrights.gov.au/complaint-information

Disability Services Commissioner, Victoria

This free service provides information and coaching on how to raise a concern with a disability service provider in Victoria. It will also provide assistance to resolve complaints.

Call 1800 677 342

Web odsc.vic.gov.au



Health Complaints Commissioner, Victoria

You can make a complaint about any health service in Victoria. Complaints may cover any issue including: access, safety, quality, privacy, dignity, decision-making, and costs.

Call 1300 582 113

Web hcc.vic.gov.au

Financial help for carers

Better Health Channel, Victoria

This website includes a summary and links to financial support for carers provided by the Australian Government and the Victorian Government.

Web betterhealth.vic.gov.au/health/ServicesAndSupport/financial-support-for-carers

Department of Human Services

Carer Payment, Carer Allowance, Carer Supplement

These forms of financial assistance are for people who care for a person who is either frail aged, has a severe disability or has a severe medical condition.

Carer Payment is for carers who provide full-time care and therefore cannot work in substantial paid employment.

Carer Allowance is an income supplement for carers providing extra daily care. There is an annual income test to qualify. It is paid in addition to wages and any other income support.

Carer Supplement is an annual lump sum payment to help with the costs of caring. This is paid to recipients of the Carer Payment and Carer Allowance.

Further details and how to apply are on the website.

Call 132 717

Web humanservices.gov.au/individuals/subjects/payments-carers

Bereavement Allowance, Bereavement Payment

Bereavement Allowance may be available to a person not receiving any other income support and whose partner has died within the last 4 weeks (a claim can be made up to 14 weeks). There is an income, asset and residency test to qualify.

Bereavement Payment is a lump sum or short term payment to a carer following the death of the person they were caring for. A bereaved carer may qualify for this payment if they were receiving income support, including a *Carer Payment* or *Carer Allowance*. The amount of bereavement payment depends on individual circumstances and when you tell the Department about the person's death.

Call 132 300

Web humanservices.gov.au/individuals/services/centrelink/bereavement-payment

Victorian Carer Card

This Victorian Carer Card is available to the main unpaid carer of another person who requires significant care due to advanced age, severe disability or significant illness. It provides a wide range of discounts and other benefits from businesses, local government and community organisations. You can apply online.

Call 1800 901 958

Web carercard.vic.gov.au

Health Care and Pensioner Concession Cards

These concession cards make some essential goods and services more affordable. For example, medical expenses, energy and water bills, public transport. These concession cards are automatically provided to people receiving Government income support, such as the age pension, carer payment, bereavement allowance and disability support pension. Some people over 60 years who have been receiving other income support payments for more than 9 months may also be eligible.

Call 132 300

Web humanservices.gov.au/individuals/services/centrelink/pensioner-concession-card

Web humanservices.gov.au/individuals/services/centrelink/health-care-card

Financial help for companions of a person with a disability

The Victorian **Companion Card** is available to people with a significant permanent disability who require an attendant carer to support them to attend events and venues. The Companion Card entitles the companion to a free ticket or admission so they can provide the required support.

The organisations that accept the Companion Card are listed on the website.

Call 1800 650 611

Web companioncard.org.au

Email companioncarddhhs.vic.gov.au

Financial help for people living with an illness, injury or disability

The Australian Government Department of Human Services provides income support for eligible people living with an illness, injury or disability. Payments may also be available to cover telephone costs and continence aids.

Call 132 300 (Older people)
132 717 (People with a disability)

Web humanservices.gov.au/individuals/subjects/payments-people-living-illness-injury-or-disability



Funerals

Better Health Channel, Victoria

The website includes a helpful summary of what you need to know about funerals and where to get help.

Web betterhealth.vic.gov.au/health/servicesandsupport/funerals

Help with funeral costs

Bereavement Assistance is a not for profit funeral service that assists people in financial hardship to give the person who has died an inexpensive and dignified funeral.

Call (03) 9564 7778
Available 24 hours, every day

Web bereavementassistance.org.au

Email info@bereavementassistance.org.au

State Trustees

Their booklet, *Needing help after someone has died*, covers the practical things that must be done after a death. It is available on their website.

Call (03) 9667 6444 or 1300 138 672

Web statetrustees.com.au/wp-content/uploads/2015/03/whats-next.pdf

Immigration and visas

People with a life limiting illness or their carers who do not have a permanent resident visa may need to seek advice about their visa. Migrant and refugee resource centres can assist with information, advice and referral. Search for the one nearest you at:

Victorian Multicultural Commission Community Service Directory

Web multicultural.vic.gov.au/resources/community-directory

Respite

Respite may be available on a planned or emergency basis. It may be provided at home or at a centre.

Commonwealth Respite and Carelink Centres

These centres provide respite care and other support to meet the needs of carers and the people they are caring for. They can help with short term, planned respite and emergency respite.

To reach the centre nearest to where you live, call **1800 052 222** during business hours or call **1800 059 059** for emergency support outside business hours.

Home Support Program, My Aged Care

Carers can request a free assessment to find out if they are eligible for planned respite.

Call My Aged Care 1800 200 422

Web myagedcare.gov.au

Sadness, grief and loss

Feelings of sadness, grief and loss can arise when dealing with changes such as illness, disability, caring responsibilities, loss of employment, future uncertainty and death. It can help to talk about your feelings with family, friends or trained counsellors.

Better Health Channel, Victoria

This website includes information about grief, how people respond, and the help available.

Web betterhealth.vic.gov.au/health/ServicesAndSupport/grief

Australian Centre for Grief and Bereavement

Provides a specialist bereavement counselling and support service to individuals and families following the death of someone close to them. This is not a crisis service. A fee based on income is charged. Their website includes grief information sheets you can download.

Call 1800 642 066

Web grief.org.au

GriefLine Community and Family Services

This grief helpline provides counselling support free of charge to people who need help dealing with loss and grief.

Call 1300 845 745 for phone counselling, 12 noon to 3 am, every day.

Web griefline.org.au/phone-counselling/ for free online counselling 24 hours, every day.

Spiritual care and wellbeing

Spiritual wellbeing is about having a sense of purpose, meaning and connection. It may or may not include faith and religious practices. The need for spiritual wellbeing may increase for some people facing serious illness, dying, death, grief and loss.

Spiritual Health Victoria

Spiritual and pastoral care by qualified spiritual care practitioners and volunteers is available in hospitals, aged care and mental health facilities throughout Victoria. Spiritual Health Victoria provides a contact list of these practitioners on their website.

Web spiritualhealthvictoria.org.au/spiritual-care-providers

Transport Assistance

Ambulance

Victorians with a Health Care Card or Pensioner Concession Card are not charged for emergency ambulance travel to the nearest medical facility necessary for their care. Ambulance fees apply in all other situations, unless covered by an Ambulance Victoria membership or health insurance. Non-emergency ambulance travel can be organised by a doctor, clinic or health service.

Call 000 ONLY IN AN EMERGENCY

Multi-Purpose Taxi Program

This provides reduced taxi fares for people with severe and permanent disabilities. Conditions apply.

Call 1800 638 802 or 03 8327 7700
Select option 3 (community programs)
then option 1 (patient transport)

Web taxi.vic.gov.au/passengers/mptp/how-to-apply

Red Cross Transport Services

This is a door-to-door transport service for elderly or disabled people in regional and rural areas to attend non-urgent medical appointments, if they have no other means of transport. Volunteers provide the service. The person must be able to get in and out of the car without assistance. A doctor's referral is required.

Call (03) 8327 7700 8 am to 3.30 pm
weekdays to make a booking

Web redcross.org.au/get-help/community-services/patient-transport

Travellers Aid

Provides services for people travelling in Victoria. Medical companion, buggy or personal guide services must be booked in advance. Meal assistance, personal care, communication assistance and accessible facilities are available at Flinders St and Southern Cross stations 7 days a week.

Call (03) 9654 2600 Head Office

Call (03) 9670 2072 Southern Cross Station

Call (03) 9068 8187 Flinders Street Station

Web travellersaid.org.au

Victorian Patient Transport Assistance Scheme

This scheme contributes to travel and accommodation costs for rural Victorians who travel to receive approved specialist medical and dental treatment. The person and any approved escorts must travel more than 100 kilometres one way, or an average of 500 kilometres a week for one or more weeks, to receive the subsidy.

Call 1300 737 073

Web health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply

Email vptas@dhhs.vic.gov.au

Allow people to help you - it's part of friendship and community.

Tips & tools for safe care

Helpful guidance

Supporting a person who needs palliative care

This helpful guide includes sections on: caring for your relative, caring for yourself, practical care and care as death approaches.

Web pallcarevic.asn.au/families-patients/about-palliative-care-2/guide-for-carers/helpful-documents-for-families-carers/

Call (03) 9662 9644 – Victorian carers can receive a free copy by post.

Accepting help supports your wellbeing as a carer.

Practical tips on providing safe care

These websites provide illustrated step-by-step guidance on how to use equipment and to provide care safely, for the person receiving care and the caregiver.

Web lmrpcc.org.au/health-care-workers/carers-kit/

Web grpcc.com.au/clients-carers/resources/

Helpful tools

CanDo App

The CanDo app is free and can help to coordinate social and practical support by family and friends. This can help both the person who is ill and their main carer. The app is available free and has been developed by the Garvan Institute of Medical Research.

Web www.candoapp.com.au



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