

Gippsland Region

**Palliative Care
Consortium**



GRPCC Specialist Palliative Care Service

Quickguide

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A web version of this Quickguide, along with further information and resources can be found on our website, www.grpcc.com.au

We welcome your feedback on ways we can improve this publication and our website. There is a link to a feedback form on our website's home page, or go directly to: www.grpcc.com.au



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Additional information is available from the Resources section of our website on topics such as:

- Aboriginal and Torres Strait Islander community
- Aged care and palliative care
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- Carer support
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- Community conversations and campaigns
- Advance care planning
- Online training and resources
- Palliative care journals
- Victorian palliative care organisations
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See: <http://grpcc.com.au/resources/>

1. Introduction

For the Gippsland region, this Quickguide answers:

- What are the different types of services that are part of the specialist palliative care service system?
- Where can I access further information and check service details, including referral criteria?

Palliative care partnerships and teamwork across healthcare, human services, social/community sector

Good end of life care outcomes for people and their families often rely on strong cooperation between specialist palliative care services and a range of professionals and volunteers from the healthcare, human services, social and community sectors: GPs and GP teams; medical specialists; other health and allied care professionals; aged, disability and other community service workers and volunteers; and, of course, people with a life-limiting illness themselves and their carers, family and friends.

The key audience for this guide is ...

If you work within the specialist or community palliative care system, you'll already know most of what's in this guide. It wasn't written with you in mind. Likewise, if you are someone living with a life-limiting illness, or caring for someone with a life-limiting illness, while you may find parts of this guide helpful, the guide hasn't been written specifically for you.

Rather, the key audience for this guide is the wide variety of people working in the healthcare, human services, social and community sectors whose everyday work brings them into contact with people who have a life-limiting illness. You might be a nurse at a GP clinic, you might be a GP. You might work in a hospital. You might be part of a Primary Health Network. You might be a medical or allied health specialist. Maybe you work for one of Victoria's chronic illness services. Or perhaps you work for a community aged care provider or an aged care facility, or with people with a disability or in the mental health sector.

The 'why, when and how' of referral to specialist palliative care

The Victorian Government's end of life and palliative care framework (2016) notes that: "Quality end of life and palliative care is everyone's responsibility" (p22) and; "It is no longer possible to leave end of life care to (specialist) palliative care providers." (p1). The framework urges specialist palliative care services and the healthcare, human services, social and community sectors to: "work together to develop innovative new strategies to deliver care." (p1)

A question often posed is: "In what circumstances should we refer to specialist palliative care?" and "How can we work better as partners in care with specialist palliative care services?"

In this guide, we have not attempted to include detailed referral criteria for each service. Rather, you are encouraged to check the websites listed for further information and phone to discuss referral issues. Sometimes picking up the phone and having a conversation with a specialist palliative care service is the best way to get the information you need and begin the sort of high quality, person-centred, care partnership needed by people living with a life-limiting illness and their family and friends.

2. The Gippsland Region

The Gippsland region covers six local government areas (LGAs), and is extremely diverse. It covers an area of 41,375 square kilometres (18.3% of Victoria), from metropolitan Melbourne to the New South Wales border in the east. The distance from Mallacoota in the east to Melbourne CBD is approximately 516km.



In 2011, the resident population in Gippsland was 259,271 persons or 4.6% of Victoria's total population¹ (Table 1). The projected change in population is 1.4% per annum, resulting in an estimated resident population of 342,246 persons in 2031².

The percentage of Gippsland's population aged 65 plus is higher than average. By 2021, persons over 65 years of age are expected to make up 18.2% of Gippsland's population (compared to 14.0% in Victoria as a whole). Gippsland has a higher than average percentage of Indigenous population while the number of immigrants is the lowest for all regions.

Table 1: Selected indicators for Gippsland compared to Victoria, 2011

Indicator	Gippsland	Victoria
Resident Population	259,271	5,534,526
Population aged 65 or above	18.2%	14.0%
Indigenous population	1.5%	0.7%
Birthplace Australia	87.3%	72.3%
Speak language other than English	4.7%	24.2%
20-24 year olds who completed year 10 or less	22.5%	12.0%
Median individual gross weekly income	\$474	\$562
Need assistance with core tasks	6.2%	5.0%
Households on internet	73.1%	79.7%
Dwellings that are rented	23.9%	27.2%

Source: Australian Bureau of Statistics online Table Builder using 2011 Census data

¹ Australian Bureau of Statistics, 2012 - Estimated Resident Population at 30 June 2011

² Department of Planning, Transport and Local Infrastructure, 2014 - Victoria in Future 2014 population projections for Latrobe/Gippsland region

3. Community Palliative Care Services

Palliative Care Services

There are eight funded specialist community palliative care services in the Gippsland region

- Bairnsdale Regional Health Service (BRHS)
- Bass Coast Health (BCH)
- Central Gippsland Health Service (CGHS)
- Gippsland Lakes Community Health (GLCH)
- Gippsland Southern Health Service (GSHS)
- Latrobe Community Health Service (LCHS)
- West Gippsland Healthcare Group (WGHG)
- Yarram and District Health Service (YDHS)

Unfunded generalist palliative care services are also provided by Koo Wee Rup Regional Health Service (KRHS), Omeo and District Health (ODH), Orbost Regional Health (ORH), and South Gippsland Hospital (SGH). There are also a number of smaller bush nursing services in the East Gippsland (Swifts Creek, Ensay, Buchan, Gelantipy, and Cann River).

There are 11 designated palliative care inpatient beds in the region located at:

- BRHS – one bed
- BCH – one bed
- CGHS – two beds
- GSHS – one bed
- Latrobe Regional Hospital (LRH) – four beds
- WGHG – two beds

Specialist Community Palliative Care Service Directory

Bass Coast Shire

Bass Coast Health

Main Towns: Wonthaggi, Inverloch, Phillip Island
 Address: 1 Back Beach Road
 San Remo Vic 3925
 Phone: 03 5671 9219
 Fax: 03 5678 5183
 Website: www.basscoasthealth.org.au

Baw Baw Shire

West Gippsland Healthcare Group

Main towns: Bunyip, Darnum, Drouin, Neerim, Rawson and Warragul
 Address: Landsborough Street
 Warragul Vic 3820
 Phone: 03 5623 0611 (Reception)
 Fax: 03 5623 0896
 Email: info@wghg.com.au
 Website: www.wghg.com.au

Specialist Community Palliative Care Service Directory (Continued)

East Gippsland Shire

Bairnsdale Regional Health Service

Main towns: Bairnsdale,
Address: 122 Day Street
Bairnsdale Vic 3875
Phone: 03 5152 0285
Fax: 03 5152 6683
Email: email@brhs.com.au
Website: www.brhs.com.au

Gippsland Lakes Community Health Service

Main towns: Lakes Entrance, Bruthen, and Metung
Address: 18-28 Jemmeson Street
Lakes Entrance Vic 3909
Phone: 03 5155 8380
Fax: 03 5155 2119
Email: contact@glch.org.au
Website: www.glch.org.au

Latrobe City Council

Latrobe Community Health Service

Main towns: Boolara, Churchill, Moe, Morwell, Traralgon, Tyers and Yinnar
Address: 81-87 Buckley Street
Morwell Vic 3840
Phone: 03 5136 5444
1800 242 696 (General information)
Fax: 03 51365449
Email: AmbulatoryCareAdministration@lchs.com.au
Website: www.lchs.com.au

South Gippsland Shire

South Gippsland Palliative Care - Gippsland Southern Health Service

Main towns: Fish Creek, Korumburra, Leongatha, Meeniyan, Mirboo North and Foster
Address: Koonwarra Road
Leongatha VIC 3953
Phone: 03 5667 5661
Fax: 03 5667 5535
Email: info@gshs.com.au
Website: www.gshs.com.au

Specialist Community Palliative Care Service Directory (Continued)

Wellington Shire

Wellington Palliative Care - Central Gippsland Health Service

Main towns: Dargo, Rosedale, Sale, Seaspray and Stratford
Address: Community Services Building
Guthridge Parade
Sale Vic 3850
Phone: 03 5143 8600 (Reception)
Fax: 03 5143 8890
Email: enquiries@cghs.com.au
Website: www.cghs.com.au

Yarram and District Health Service

Main town: Yarram
Address: Devon Street
Yarram Vic 3971
Phone: 03 5182 0262
Fax: 03 5182 6081
Email: ydhs@ydhs.com.au
Website: www.gha.net.au/ydhs

Unfunded Palliative Care Services

Koo Wee Rup Regional Health Service (KRHS)

Main town: Koo Wee Rup
Address: Rossiter Road
Koo Wee Rup Vic 3981
Phone: 03 5997 9679
Fax: 03 5997 1248
Website: www.kooweeruphospital.net.au

Orbost Regional Health (ORH)

Main town: Orbost
Address: 104-107 Boundary Rd
Orbost Vic 3888
Phone: 03 5154 6684
Fax: 03 5154 6764
Website: www.orbostregionalhealth.com.au

Omeo District Health (ODH)

Main town: Omeo
Address: 12 Easton St,
Omeo Vic 3898
Phone: 03 51590100
Fax: 03 51590194
Website: www.odh.net.au

Unfunded Palliative Care Services (Continued)

South Gippsland Hospital

Main town: Foster
Address: 83-87 Station Road,
Foster Vic 3960
Phone: 03 5683 9777
Fax: 03 5682 2178
Website: www.southgippslandhospital.org.au

Bush Nursing Services

Buchan Bush Nursing Centre

Main town: Buchan
Address: 61 Main Rd
Buchan Vic 3885
Phone: 03 51559222
Fax: 03 51559261
Website: www.buchan.vic.au/buchan-bush-nursing/

Cann Valley Bush Nursing Centre

Main town: Cann Valley
Address: 27 Monaro Highway
Cann River Vic 3890
Phone: 03 5158 6274
Fax: 03 5158 6409
Website: cannvalleybnc.com.au/

Dargo Bush Nursing Centre

Main town: Dargo
Address: 1 Saleyard Road
Gelantipy Vic 3885
Phone: 03 5155 0274
Fax: 03 5140 1236

Gelantipy District Bush Nursing Centre

Main town: Gelantipy
Address: 72 Lind Ave
Dargo Vic 3862
Phone: 03 5140 1246
Fax: 03 5155 0217

Mallacoota District Health and Support Services

Main town: Mallacoota
Address: Mattsson St & Genoa Road
Mallacoota Vic 3892
Phone: 03 5158 0243
Fax: 03 5158 0448
Website: www.mallacoota.org.au/

Bush Nursing Services (Continued)

Swifts Creek Bush Nurse Centre

Main town: Swifts Creek
Address: McMillan Street
Swifts Creek Vic 3896
Phone: 03 5159 4210
Fax: 03 5159 4576

After-Hours Community Palliative Care

Normal 'business hours' of community palliative care services are 8.30am to 5.00pm Monday to Friday. Outside of these hours, existing community palliative care clients and their families/carers have access to an after-hours contact number where a nurse can provide phone advice and, if necessary, initiate an after-hours home visit. Contact your local palliative care service for details of after-hours contacts

4. Gippsland Region Palliative Care Consultancy Service

- The Gippsland Regional Palliative Care Consultancy Service, (GRPCCS) has been established to deliver specialised palliative care across Gippsland. The GRPCCS collaborate with existing local community based and inpatient palliative care services. The GRPCCS aims to provide specialised palliative care to patients and their families according to their preferences and goals.
- The GRPCCS currently visits Bairnsdale, Lakes Entrance, Traralgon, Sale, Warragul, South Gippsland, and the Bass Coast Region. These visits are scheduled throughout the month and work collaboratively with community palliative care providers and health services in those regions.
- The GRPCCS also provide afterhours on call service which can be accessed by all palliative care health care professionals by calling the Latrobe Regional Hospital switch board on **51738000** and asking to be put through to the **Palliative Care on call consultancy service**. This service is provided from 5 pm – 8.30 am on week days and 24 hour cover over the weekend.

Criteria for referral to the GRPCCS

- The client has a progressive life limiting illness requiring specialist input in palliative care symptom management
- The client/caregiver and /or family is aware of the diagnosis and prognosis and the referral has been discussed and agreed with client and family
- The client and family require specialist palliative care input to discuss goals of care to maintain life quality and to maximise function and comfort
- The client and family require specialist palliative care input to discuss End of Life Care and/or Advance Care Planning
- The client/caregiver and family require palliative care input to discuss treatment options on the basis of *burden vs benefit*, which can minimise investigations and procedures that offer no improvement in quality of life³.

Making a referral

Health care professionals can make referral to the GRPCCS include:

- general practitioners;
- consultant physicians;
- palliative care nurse practitioners;
- palliative care community service providers;
- aged care facilities;
- community health settings; inpatient services

Time frames to assist referring sources when making a referral

- Category 1 – 24 hours / urgent (patient is unstable, rapidly deteriorating or in the terminal/dying phase)
- Category 2 – 2 working days (patient is experiencing distressing physical and or psychosocial symptoms not responding to established palliative care management / protocols)
- Category 3 – One week (patient is stable but seeking palliative care information and support)

The GRPCCS is composed of

- Palliative Medicine Physicians;
- Palliative Care Nurse Coordinators; and
- Palliative Care Nurse Practitioner.

4. Gippsland Region Palliative Care Consultancy Service (Continued)

³ Victorian Government Department of Health (June 2016) Victoria's end of life and palliative care framework: a guide for high- quality end of life care for all Victorians

Address: Latrobe Regional Hospital
PO Box 424, Traralgon, Victoria 3844
Phone: (03) 5173 8713
Fax: (03) 5173 8442
Email: PallCareCS@lrh.com.au
Website: www.lrh.com.au

5. Victorian Paediatric Palliative Care Program

Royal Children's Hospital (Victorian Paediatric Palliative Care Program)

Phone: 9345 5374

Fax: 9345 6240

http://www.rch.org.au/rch_palliative/

Very Special Kids

Phone: 9804 6222 or 1800 888 875

Fax: 9822 1252

<http://www.vsk.org.au/>

Basic Symptom Control in Paediatric Palliative Care (Free Download)

The Victorian Paediatric Palliative Care Program section of the Royal Children's Hospital website provides a link to 'Basic Symptom Control in Paediatric Palliative Care', a key clinical tool used by children's palliative care doctors and nurses across the world. It provides comprehensive guidelines for treating a wide range of symptoms experienced by children with life-limiting or complex health conditions. Downloadable from:

http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download

6. Palliative Care Consortium

Gippsland Region Palliative Care Consortium (GRPCC)
c/- West Gippsland Healthcare Group
41 Landsborough Street
Warragul VIC 3820

03 5623 0684

GRPCC.Enquiries@wghg.com.au

www.grpcc.com.au

7. Other Service Contacts

Palliative Care Victoria (PCV) including PCV Service Provider Search

PCV is the statewide peak body for palliative care. The PCV website includes various resources for families, patients and health care service providers, including a service provider search facility.

Phone: 9662 9644

<http://www.pallcarevic.asn.au/> and <http://www.pallcarevic.asn.au/service-provider-search/>

Decision Assist 24hr Palliative Care Phone Advisory Service

For health professionals working with recipients of aged care services (residential or community) including GPs and aged care staff, the Decision Assist Phone Advisory Service provides advice on a palliative approach, including medication, symptom management and psychosocial support.

Phone: 1300 668 908

<http://www.caresearch.com.au/caresearch/tabid/3295/Default.aspx>

Victorian Aboriginal Palliative Care Project of the Victorian Aboriginal Community Controlled Health Organisation (VACCHO)

VACCHO's Victorian Palliative Care Project aims for Aboriginal people to have access to palliative care services and for palliative care services to provide culturally safe services to Aboriginal people. It also aims to develop a long and lasting relationship between palliative care providers and Aboriginal Community Controlled Health Organisations across Victoria.

Phone: 9411 9411

<http://www.vaccho.org.au/wd/vapcp/>

Centre for Palliative Care

The Centre for Palliative Care is part of St Vincent's Hospital and is a Collaborative Centre of The University of Melbourne. The Centre has a statewide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally.

Phone: 9416 0000

<http://www.centreforpallcare.org/>

Department of Health and Human Services (Victorian Government) Palliative Care Program

The Palliative Care Program website of the Victorian Government Department of Health and Human Services provides a range of information about palliative care in Victoria.

Phone: 9096 0509

<https://www2.health.vic.gov.au/palliative-care>

8. Online Clinical Resources and Education

CareSearch

CareSearch is an online resource designed to help those needing information and resources about palliative care. Funded by the Australian Government, the website includes sections designed specifically for health professionals and other sections for people with a life limiting illness and their carers, family and friends.

<http://www.caresearch.com.au/Caresearch/Default.aspx>

Decision Assist

Decision Assist is an Australian Government funded project that aims to enhance the provision of palliative care and advance care planning services to older people. The Clinical Links, Resources, Using Technology, and Education and Training sections of the Decision Assist website (located within the Caresearch site) provides a range of clinical information designed for use by GPs, aged care staff and others.

<http://www.caresearch.com.au/caresearch/tabid/2583/Default.aspx>

Centre for Palliative Care

The Centre for Palliative Care is part of St Vincent's Hospital and is a Collaborative Centre of The University of Melbourne. The Centre's website includes a resources section with links to various clinical practice guidelines documents. The education section of the website provides information on palliative care related professional development and training opportunities.

<http://www.centreforpallcare.org/>

The Palliative Care Bridge

The Palliative Care Bridge is a NSW palliative care education program. The site provides educational videos and resources on palliative care and is designed to equip users with greater confidence and knowledge in the delivery of appropriate palliative care to people in need.

<http://www.palliativecarebridge.com.au/>

Palliative Care Online Training (for health and other professionals working with older people)

The Palliative Care Online Training project provides free online palliative care training for health and other professionals who work with older people. The project is run by the Australian Healthcare and Hospitals Association (AHHA) and Silver Chain Training.

<http://www.palliativecareonline.com.au/>

The Gold Standards Framework (UK)

The National Gold Standards Framework (GSF) Centre in End of Life Care is a UK provider of training in end of life care for generalist frontline staff.

<http://www.goldstandardsframework.org.uk/home>

Appendix A: Specialist Palliative Care Services Overview

The Victorian Government's end of life and palliative care framework summarises specialist palliative care as a designated sector "funded to provide care for those with the most complex end of life and palliative care needs." (p.5). The framework also notes: "Often the most valuable role palliative care specialists play is supporting other healthcare teams and professionals through consultation, advice and support to provide end of life care to their patients." (p.5)

Community palliative care services

Community palliative care services work in partnership with health, aged and community services to support people to stay living at home as long as possible and to die at home if that is their wish. Support is also provided to carers, which can include assistance during their bereavement. Staffing includes home visiting nurses and a variety of allied health professionals, therapists and volunteers. In the Gippsland region, community palliative care services exist within each local government region. GPs, hospitals and other health, aged and community services can make referrals to community palliative care. People can also self-refer.

Palliative care beds in regional hospitals

In Gippsland, regional hospitals are funded to provide palliative care in the inpatient setting. Palliative care beds in regional hospitals do not always specifically refer to a designated bed in a specific ward, although some health services do have a number of allocated palliative care 'beds' that form part of a unit/ward combined with other types of beds, e.g. palliative care beds in general medical wards or in geriatric evaluation and management unit (GEM). This assists clients and carers to have the support of the local hospital if required for symptom management and end of life care.

Regional Palliative Care Consultancy Service

The Gippsland Regional Palliative Care Consultancy Service, (GRPCCS) has been established to deliver specialised palliative care across Gippsland. The GRPCCS collaborates with existing local community based and inpatient palliative care services, and aims to provide specialised palliative care to patients and their families according to their preferences and goals. This service is currently provided in Bairnsdale, Lakes Entrance, Traralgon, Sale, Warragul, South Gippsland, and the Bass Coast Region. Visits are scheduled throughout the month, and the GRPCCS team work collaboratively with community palliative care providers and health services in those regions.

Victorian Paediatric Palliative Care Program (VPPCP)

The Victorian Paediatric Palliative Care Program (VPPCP) is a collaboration of the Royal Children's Hospital (RCH), Very Special Kids (VSK) and Monash Health. Funded by the Victorian Department of Health and Human Services, the VPPCP is a consultation-liaison team responsible for the facilitation of care of children with palliative care needs and their families. The VPPCP team is comprised of specialist doctors, case managers/social workers, occupational therapists and nurses who work closely with each of the member organisations to coordinate care and provide appropriate advice regarding various aspects of patient management. Educational activities for staff from both hospital and community agencies are also offered. The team do not provide direct patient care. Rather, team members facilitate better communication

Appendix A: Specialist Palliative Care Services Overview (continued)

between tertiary institutions and care providers in the community thus allowing more children to be cared for at home by palliative care agencies and other services.

Palliative Care Consortia

Palliative care consortia promote collaborative, coordinated approaches to quality improvement in palliative care across their region. This includes co-operation between specialist palliative care services and general practitioners, medical specialists, health services, the aged care sector, disability services and the broader community services sector. There are eight palliative care consortia in Victoria, including three in metropolitan Melbourne and five in regional and rural Victoria.

Appendix B: Palliative Care Defined

Palliative care language can be very confusing! There are a number of different definitions of palliative care used in Australia and internationally. For example, 'hospice', 'end-of-life care' and 'supportive care' are sometimes used interchangeably with palliative care. A 'palliative approach' is sometimes used to describe palliative care provided by non-specialist palliative care services (e.g. aged care facility staff). Sometimes family carers and friends are specifically included in definitions, but sometimes they are absent from the words used (even though, in practice, all approaches to palliative care include support for family carers and close friends, including with bereavement).

End of life care

Sometimes 'end-of-life care' is used to describe only the very end of life, whereas the Victorian Government's end of life and palliative care framework works with a 12 months' timeframe and defines end of life care as: *"the care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age."* (p5)

Palliative care

Drawing on the widely used World Health Organisation definition of palliative care, the Victorian Government's end of life and palliative care framework defines palliative care as: *"an approach to care that improves the quality of life of people and their families who are facing the problems associated with a progressive illness. It does this by preventing and relieving suffering through early identification and assessment, by treating pain and other physical, psychosocial and spiritual problems and by addressing practical issues."* (p5)

Also noted is that: *"Palliative care is based on people's needs rather than diagnosis or possible time to death and is delivered by a range of health and community providers. Palliative care can be provided at the same time as other treatment intended to reverse or resolve particular conditions."* (p5)

Specialist palliative care

The Victorian Government's end of life and palliative care framework defines specialist palliative care as a designated sector *"funded to provide care for those with the most complex end of life and palliative care needs."* (p5). Also noted is that: *"Often the most valuable role palliative care specialists play is supporting other healthcare teams and professionals through consultation, advice and support to provide end of life care to their patients."* (p5)

Life-limiting/Life-threatening/Terminal/Progressive/Incurable/Advanced

In this Quickguide, amongst the range of terms historically used to describe an illness (or condition) where death as a consequence of that illness can be reasonably expected in the future, we have chosen to use 'life-limiting illness' as a general descriptor. Examples of life-limiting illnesses include many types of cancer and other conditions such as Chronic Obstructive Pulmonary Disease (COPD), Motor Neurone Disease (MND), liver disease, renal disease, heart disease, dementia, and many more.

Appendix C: Principles of a Good Death

The specifics of a 'good death' vary for each individual and defy neat definition.

In a British Medical Journal (BMJ) editorial in January 2000, Richard Smith discussed 'A good death: An important aim for health services and for us all'. Smith's article listed twelve principles of a good death published in a 1999 report on 'The Future of Health and Care of Older People.'

- *To know when death is coming, and to understand what can be expected;*
- *To be able to retain control of what happens;*
- *To be afforded dignity and privacy;*
- *To have control over pain relief and other symptom control;*
- *To have choice and control over where death occurs (at home or elsewhere);*
- *To have access to information and expertise of whatever kind is necessary;*
- *To have access to any spiritual or emotional support required;*
- *To have access to hospice care* in any location, not only in hospital;*
- *To have control over who is present and who shares the end;*
- *To be able to issue advance directives which ensures wishes are respected;*
- *To have time to say goodbye, and control over other aspects of timing;*
- *To be able to leave when it is time to go, and not to have life prolonged pointlessly.*

Source: Debate of the Age Health and Care Study Group (1999) *The future of health and care of older people: the best is yet to come*. London: Age Concern, quoted in Smith, R (2000) 'A good death: An important aim for health services and for us all'. BMJ Volume 320, pp 129-130.

*Hospice care in this context doesn't refer to a specific place of care, rather a concept of care focused on creating a natural and comfortable end-of-life experience for people with a life-limiting illness and their family and friends. For example, in Victoria, community palliative care services are designed to support people to stay living at home as long as possible and to die at home if that is their wish. In some areas, community palliative care style services are known as 'hospice in the home'.

Additional good death principles in line with the WHO definition of palliative care

In line with the World Health Organisation (WHO) definition of palliative care, including the focus on early identification, quality of life and the role of carers and family, additional principles of a good death may include:

- *To have access to a support system to enhance quality of life and live as actively as possible until death;*
- *For family and close friends (primary carers and others involved in providing informal care and/or supporting the primary carer) to have access to a support system to help in their caring role and with their own psychosocial, spiritual and bereavement needs.*

Appendix D: Advance Care Planning

Victorian Government Department of Health and Human Services advance care planning website

The advance care planning section of the Department of Health and Human Services website provides links to a range of information, including the government's 'Advance care planning – have the conversation' strategy for 2014-18 and the 2016 discussion paper 'Simplifying medical treatment decision making and advance care planning: Ensuring Victorians can make decisions about their future medical treatment'.

<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/>

ACP Talk

ACP talk has been designed in collaboration with Australian religious and cultural leaders and organisations. It is intended to provide informational support for health professionals conducting advance care planning with people from different religious and cultural backgrounds

<http://www.acptalk.com.au/>

Advance care planning: resource for doctors and health professionals

This series of nine documents (modules) was developed in partnership with the Australian Medical Association. It is designed to assist doctors and other health professionals to: have the conversation with patients about end-of-life decision making; engage patients in decisions about their care; help them to undertake advance care planning.

<https://www2.health.vic.gov.au/about/publications/researchandreports/acp-doctor-resource>

My Values

Developed by Barwon Health and supported by the Victorian Government, the My Values website is designed to help people identify, consider and communicate their wishes about the medical treatment they would want in the later stages of life. Through the site people can create their own 'values profile' in relation to life, death and medical intervention, with a view that it can be passed on to doctors and family.

<https://www.myvalues.org.au/>

Decision Assist Advance Care Planning Phone Advisory Service

For health professionals working with recipients of aged care services, the Decision Assist Phone Advisory Service can provide information and advice on: advance care planning processes and legislation; specific client/resident scenarios; how to facilitate case conferencing or family meetings to discuss advance care planning; and links to training, evidence based websites and resources.

Ph: 1300 668 908

<http://www.caresearch.com.au/caresearch/tabid/3295/Default.aspx>

Advance Care Planning Australia

Advance Care Planning Australia (ACPA) includes contacts and resources for each state and territory. ACPA initiatives are delivered by Austin Health with the support of the Australian Government Department of Health. ACPA is not a separate organisation, rather a vehicle for identifying and sharing advance care planning activities and resources.

<http://advancecareplanning.org.au/>

Appendix D: Advance Care Planning (continued)

Death Over Dinner (Australia/NZ version)

DOD is an interactive website that encourages conversation to start with family and friends about their choices and thoughts on the end of life and end of life care. DOD provides a range of tools, reading and support materials, as well as tips to get the conversation started.

<http://deathoverdinner.org.au/>

Office of the Public Advocate

The 'Powers of attorney' and 'Medical consent' sections of Victorian Office of the Public Advocate (OPA) website provides include information of direct relevance to advance care planning, including various forms and certificates relating to enduring power of attorney (medical treatment) and refusal of treatment.

<http://www.publicadvocate.vic.gov.au/>

Austin Health Advance Care Planning

In addition to providing advance care planning services for consumers and patients across Austin Health and education and training for Austin Health professionals, Austin Health's Department of Advance Care Planning oversees all Advance Care Planning Australia initiatives.

<http://www.austin.org.au/page/449>

Northern Health Advance Care Planning

Northern Health's website information about advance care planning includes information in Arabic, Chinese, Greek, Italian, Turkish and Vietnamese.

<http://www.nh.org.au/services/advance-care-planning>

Appendix E: Victorian Government End of Life and Palliative Care Framework

The Victorian Government's end of life and palliative care framework was released in July 2016. The vision, guiding principles, goals, and priority areas of the framework are summarised below. For full details of the framework, see the palliative care section of the Department of Human Services and Health website:

<https://www2.health.vic.gov.au/palliative-care>

Vision

All Victorians and their families receive the best possible end of life care that places them at the centre where preferences, values, dignity and comfort are respected and quality of life matters most.

Guiding Principles

1. Dying is part of life: dying is a normal part of life and being human, not just a biological or medical event.
2. The person is central to care: a person's care is tailored and holistic; their rights, values and preferences are respected and they determine their own care whenever possible.
3. Carers are important: carers receive recognition, support and are valued throughout their caring experience and after a person's death.
4. All people have information they discuss openly: people, their carers and families have information they understand about genuine choices that they can discuss authentically with their doctor and service providers.
5. Decision making is legalised and respected: people's decisions that may involve substitute decision-makers, health providers, families and carers are recognised and respected in accordance with relevant legislation.
6. Services are high-quality and coordinated: individuals, their carers and families receive coordinated, integrated care from skilful staff.
7. Care and services are monitored: underpinning end of life care are best practice evidence, effective monitoring, evaluation of patient-centred outcomes and supporting innovation.

Goals

- People experience optimal end of life care.
- People's pain and symptoms are managed using quality interventions.
- People's preferences and values are recognised and respected in their end of life care.
- Better support for carers.
- People are cared for in their place of choice.
- Where possible, people can choose to die in their place of choice.

Priority areas

Priority 1: Person-centred services.

Priority 2: Engaging communities, embracing diversity.

Priority 3: people receive services that are coordinated and integrated.

Priority 4: Quality end of life and palliative care is everyone's responsibility.

Priority 5: Specialist palliative care is strengthened.

Appendix F: Australian Government Palliative Care Initiatives

The Australian Government Department of Health

The Australian Government Department of Health website includes details about the National Palliative Care Strategy and projects funded under the National Palliative Care Program (see listing below).

<http://www.health.gov.au/palliativecare>

Palliative Care Australia

Palliative Care Australia (PCA) is national peak body for palliative care in Australia. The PCA website has a range of information for people living with a life-limiting illness, carers and health professionals.

<http://palliativecare.org.au/>

Carers Australia

Carers Australia, in collaboration with Palliative Care Australia (PCA) have been funded to deliver training to increase the palliative care knowledge and skills of counsellors and other health professionals.

www.carersaustralia.com.au

Program of Experience in the Palliative Approach (PEPA)

Run by Queensland University of Technology, PEPA aims to enhance the capacity of health professionals to deliver a palliative approach. PEPA runs workshops and placements in specialist palliative care services.

<http://www.pepaeducation.com/>

Palliative Care Curriculum for Undergraduates Project (PCC4U)

PCC4U improves the skills of the health workforce by promoting the integration of palliative care training within health training courses, including undergraduate curricula. The project is led by Queensland University of Technology, with Flinders University and Curtin University of Technology.

<http://www.pcc4u.org/>

Palliative Care Outcomes Collaboration (PCOC)

PCOC is run by the Australian Health Services Research Institute (AHSRI) of the University of Wollongong. It utilises standardised clinical assessment tools to measure and benchmark palliative care outcomes.

<http://ahsri.uow.edu.au/pcoc/index.html>

Quality of Care Collaborative Australia for Paediatric Palliative Care (QuoCCA)

QuoCCA aims to improve the quality of palliative care provided to children through research, education and evaluation activities in each state and territory of Australia. The project is led by Children's Health Queensland Hospital and Health Service (CHQ HHS) through the Lady Cilento Children's Hospital.

<https://www.caresearch.com.au/caresearch/tabid/3682/Default.aspx>

Listen, Acknowledge, Respond (co-existing mental illness)

Listen, Acknowledge, Respond is a project of Charles Sturt University, Integrated Living Australia and the Amaranth Foundation focused on people with a life limiting illness and a coexisting mental illness. The project aims to improve the skills and knowledge of the mental health and allied health workforce.

<http://listenacknowledgerespond.com.au/>

Appendix F: Australian Government Palliative Care Initiatives (continued)

Cabrini Health Online Religious and Culturally Sensitive Advance Care Planning

Cabrini Health's Centre for Nursing Research have been funded by the Australian Government to develop an advance care planning resource, with consideration of various religious and cultural communities.

<http://www.cabrini.com.au/research-and-education/research-programs/cabrini-centre-for-nursing-research/>

Caresearch

CareSearch is an online resource run by Flinders University. The website includes sections for health professionals and other sections designed for people with a life limiting illness and carers/family.

<http://www.caresearch.com.au/Caresearch/Default.aspx>

End of Life Essentials: Education for Acute Hospitals

End of Life Essentials, a project of Flinders University, provides e-learning and resources for doctors, nurses and allied health professionals to improve the quality and safety of end of life care in hospitals. The content of End of Life Essentials has been informed by the national consensus statement 'Essential elements for safe and high-quality end-of-life care' of the Australian Commission on Safety and Quality in Health Care.

<http://www.caresearch.com.au/caresearch/tabid/3866/Default.aspx>

The Palliative Care Clinical Studies Collaborative (PaCCSC)

PaCCSC is a national research network run by the Flinders University School of Medicine. PaCCSC aims to generate research evidence to support the use of medicines and other interventions at the end of life; and build capacity within the health workforce in the conduct of clinical research.

<http://www.caresearch.com.au/caresearch/tabid/2476/Default.aspx>

Australian Institute of Health and Welfare (AIHW) Palliative Care Data Analysis

The AIHW's palliative care data includes a range of national and state/territory statistics.

<http://www.aihw.gov.au/palliative-care/>

Palliative Care and Advance Care Planning in General Practice: A training package for Practice Nurses

Hammond Care in NSW has been funded to develop a nationally relevant palliative care and advance care planning in general practice training package for Practice Nurses.

<http://www.hammond.com.au/>

Decision Assist (formerly Respecting Patient Choices)

Decision Assist is a project led by Austin Health that aims to enhance the provision of palliative care and advance care planning services to older people. It includes telephone advice services and resources for GPs.

<https://www.caresearch.com.au/caresearch/tabid/2583/Default.aspx>

Palliative Care Online Training (for health and other professionals working with older people)

This project of the Australian Healthcare and Hospitals Association (AHHA) and Silver Chain Training provides free online palliative care training for health and other workers working with older people.

<http://www.palliativecareonline.com.au/>

Appendix G: Primary Health Networks

Australian Government funding for Primary Health Networks (PHNs)

On 1 July 2015, the Australian Government established 31 Primary Health Networks (PHNs) across Australia. At the same time 61 Australian Government funded organisations known as 'Medicare Locals' ceased to exist. PHNs were established to increase the efficiency and effectiveness of medical services for people, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure people receive what is described as 'the right care in the right place at the right time'. PHNs work with general practitioners, other primary health care providers, secondary care providers and hospitals. The six key priorities for targeted work by PHNs are: mental health, Aboriginal and Torres Strait Islander health, population health, health workforce, eHealth, and aged care. Palliative care is an area of interest for all PHNs. For example, the HealthPathways initiative for GPs, including the palliative care pathway, is a PHN initiative. Also, some PHNs have been active in Advance Care Planning initiatives. The catchment area for our Consortium's north and west metropolitan region overlaps with two PHNs.

<http://www.health.gov.au/PHN>

Appendix H: Carer Websites and Information

Palliative Care Australia

The carer section of the Palliative Care Australia website includes a range of information, including tip sheets on topics such as: 'talking about palliative care' and 'how can I support my friend/family member?'

<http://palliativecare.org.au/im-a-carer/>

Palliative Care Victoria

The families and patients section of the Palliative Care Victoria website includes links to helpful websites and documents for carers, along with links to personal stories.

<http://www.pallcarevic.asn.au/families-patients/about-palliative-care-2/guide-for-carers/>

Caresearch

The Australian Government funded Caresearch website of Flinders University includes a section for carers and families, with information on topics such as: 'how to care' and 'bereavement, grief, loss.'

<http://www.caresearch.com.au/caresearch/tabid/64/Default.aspx>

Supporting a person who needs palliative care: a guide for family and friends (booklet)

This booklet published by Palliative Care Victoria provides a range of information, tips and strategies for family carers of people diagnosed with a life-limiting illness who require palliative care.

<http://www.pallcarevic.asn.au/library/for-families-patients/fp-carer-support/>

Gippsland Region Palliative Care Consortium Carers Kit

This kit is focused on instructions to help carers on how to perform some basic tasks safely, such as how to use shower and bath chairs and how to help a person in and out of a car.

<http://www.grpcc.com.au/health-professionals/health-professional-resources/palliative-care-patients-and-carers/>

Carer Gateway (Australian Government site for all types of caring situations)

The Australian Government Carer Gateway website contains information on the experience of carers and assistance available, including links to further information about Australian Government payments for carers through Centrelink. Carer Gateway also includes some disease-specific information, along with sections on health and wellbeing and connecting with other carers.

<https://www.carergateway.gov.au/>

Carers Victoria

Carers Victoria is the statewide body for family carers, representing and providing support to carers in Victoria. Their website includes a range of information for carers.

<http://www.carersvictoria.org.au/>

National Carer Counselling Program (accessed via Carers Victoria)

The National Carer Counselling Program provides free of charge short-term counselling (up to six sessions) on issues related to a person's caring role, including all palliative care situations and bereavement. In Victoria the program is organised by Carers Victoria.

<https://www.carersvictoria.org.au/how-we-help/counselling/about-counselling>

Appendix I: Grief and Bereavement Support

Understanding Grief (Palliative Care Australia booklet)

The Understanding Grief booklet published by Palliative Care Australia explains what grief is, the thoughts, feelings and sometimes physical reactions a person can experience and where to find further help.

<http://palliativecare.org.au/understanding-grief/>

Community palliative care services

All community palliative care services provide access to grief and bereavement support for carers and family members. For specific details of the grief and bereavement support provided by community palliative care services in our region, contact directly: Banksia Palliative Care Service; Melbourne City Mission Palliative Care; and Mercy Palliative Care.

Hospital based specialist palliative care services

Unlike community palliative care services, access to long term bereavement support for people who need it is not part of the service model for hospital based specialist palliative care services. The grief and bereavement support available through hospitals will vary from service to service and will depend on availability of staff from the hospital's allied care team.

The Australian Centre for Grief and Bereavement (Bereavement Counselling and Support Service)

The Australian Centre for Grief and Bereavement (ACGB) operates a statewide bereavement counselling and support service for Victoria. The program is funded by the Victorian Government Department of Health and Human Services and provides support for people experiencing grief and bereavement as well as bereavement advice and consultation for workers from other settings to assist their work with people experiencing grief and bereavement. Services include: counselling; support groups; written resources; remembrance events; practitioner consultation and support. Bereavement counselling is available for anyone in the community, including children and adolescents, who need support following the death of someone close to them. ACGB charges fees in accordance with a schedule dependent on income and personal circumstances.

Phone: 9265 2100.

<http://www.grief.org.au/>

National Carer Counselling Program (accessed via Carers Victoria)

The National Carer Counselling Program provides free of charge short-term counselling (up to six sessions) on issues related to a person's caring role, including all palliative care situations and bereavement. In Victoria the program is organised by Carers Victoria.

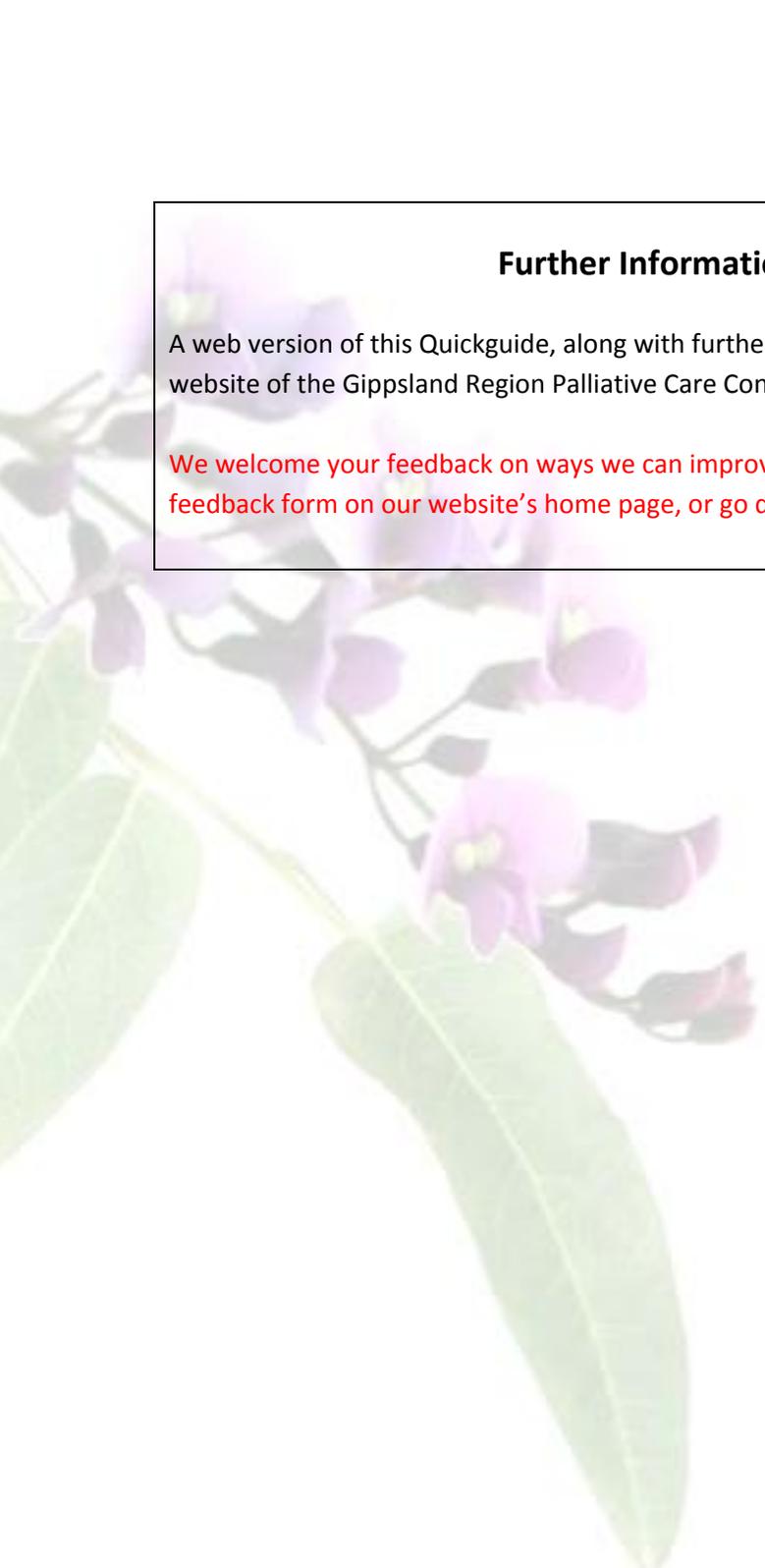
<https://www.carersvictoria.org.au/how-we-help/counselling/about-counselling>

GriefLine

GriefLine provides counselling support services free of charge to individuals and families, including: telephone support; online counselling; and in-house one on one counselling.

Melbourne metro phone: 9935 7444

<http://griefline.org.au/>



Further Information and Your Feedback

A web version of this Quickguide, along with further information and resources can be found on the website of the Gippsland Region Palliative Care Consortium (GRPCC) www.grpcc.com.au

We welcome your feedback on ways we can improve this publication and our website. There is a link to a feedback form on our website's home page, or go directly to: www.grpcc.com.au/feedback/