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The Program Framework describes systems of care and planning processes for people with a progressive, life limiting illness. It is a general guide to practice, to be followed subject to the clinician’s judgement and the patient’s preference in each individual case. For clinical guidance, GPs should refer to the Therapeutic Guidelines: Palliative Care and other relevant guidelines (see Appendix 1). Participating GPs will receive ongoing education and CPD in palliative care as a part of the GP Palliative Shared Care program and may also contact the Specialist Palliative Care Service for advice and support at any time.

The Framework was initially developed (in 2015) by GP partners Australia in collaboration with the SA Palliative Care Clinical Network and the GP Palliative Shared Care Clinical Governance Committee. This current edition has developed and reviewed by the GP Palliative Shared Care Operations Consultative Committee, GP Palliative Shared Care Clinical Governance Committee and ratified by the SA Health Palliative Care Clinical Working Group. The Program Framework will be reviewed and updated in accordance with best practice and relevant guidelines, at a minimum of every two years. Any changes to the Framework will be endorsed by the SA Health Palliative Care Clinical Working Group, or its equivalent group.

The following members of the GP Palliative Shared Care Operations Consultative Committee and Clinical Governance Committee participated in the development of the GP Palliative Shared Care Program Framework (2017).

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## Acronyms

<table>
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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACD</td>
<td>Advance Care Directive</td>
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<td>ACP</td>
<td>Advance Care Planning</td>
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<td>ACRRM</td>
<td>Australian College of Rural and Remote Medicine</td>
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<td>AFP</td>
<td>Australian Family Physician</td>
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<td>AKPS</td>
<td>Australia-modified Karnofsky Performance Status</td>
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<td>AMA</td>
<td>Australian Medical Association</td>
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<tr>
<td>BDM</td>
<td>Births, Deaths and Marriages</td>
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<td>BRAT</td>
<td>Bereavement Risk Assessment Tool</td>
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<tr>
<td>BRI</td>
<td>Bereavement Risk Index</td>
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<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<td>CPD</td>
<td>Continuing Professional Development</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>GPMP</td>
<td>General Practitioner Management Plan</td>
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<td>MBS</td>
<td>Medicare Benefits Schedule</td>
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<td>MRU</td>
<td>Metropolitan Referral Unit</td>
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<td>NAT:C</td>
<td>Needs Assessment Tool: Carers</td>
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<td>NAT:PD</td>
<td>Needs Assessment Tool: Progressive Disease</td>
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<td>OT</td>
<td>Occupational Therapist</td>
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<td>PA</td>
<td>Palliative Approach</td>
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<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
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<td>PCPSS</td>
<td>Palliative Care Problem Severity Score</td>
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<td>PEPA</td>
<td>Program of Experience in the Palliative Approach</td>
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<td>PIP</td>
<td>Practice Incentive Payments</td>
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<td>PSC</td>
<td>Palliative Shared Care</td>
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<tr>
<td>QI&amp;CPD</td>
<td>Quality Improvement and Continuing Professional Development</td>
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<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<td>RACGP</td>
<td>Royal Australian College of General Practice</td>
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<tr>
<td>RUG-ADL</td>
<td>Resource Utilisation Groups – Activities of Daily Living</td>
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<td>SA</td>
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<td>SAAS</td>
<td>South Australian Ambulance Service</td>
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<td>SAS</td>
<td>Symptom Assessment Scale</td>
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<td>SC</td>
<td>Subcutaneous</td>
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<td>TCA</td>
<td>Team Care Arrangement</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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1. Introduction

1.1 Definition of Palliative Care

Palliative care is defined by the World Health Organisation (WHO) as ‘... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten or postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life, and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'

The Palliative Care Australia, Standards for Providing Quality Palliative Care for All Australians, provides a set of philosophical standards that articulate and promote a vision for compassionate and appropriate end of life care. The standards are available at http://palliativecare.org.au/policy-and-publications/the-national-standards.

1.2 Palliative Care Providers

General Practitioners

General practitioners have a vital role in assisting the community to deal with the reality of death and its consequences (Medical Board of Australia, 2014, p. 7). The general practitioner (GP) is the key person in the community who can implement palliative care for all those who require it. A range of healthcare providers can support the GP, including palliative medicine specialists who may provide advice and support but do not usually assume primary responsibility for care of patients in the community (Palliative Care Expert Group, 2016).

In caring for patients towards the end of their life, good medical practice involves (Medical Board of Australia, 2014):

• Taking steps to manage a patient’s symptoms and concerns in a manner consistent with their values and wishes.
• Providing or arranging appropriate palliative care.
• Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient. Understanding that there is not a duty to try to prolong life at all cost. However, there is a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that patients receive appropriate relief from distress.
• Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.
• Respecting different cultural practices related to death and dying.
• Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.
• Facilitating advance care planning.
• Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they desire.
• Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.
• When a patient dies, being willing to explain the circumstances of the death to appropriate members of the patient’s family and carers, unless the patient would have objected.

The GP may be responsible for (Palliative Care Expert Group, 2016):
• Coordinating care to ensure that healthcare, other services and equipment are available to meet a patient’s needs
• Medication management, including prescribing and deprescribing when applicable
• Helping the patient to decide which ongoing hospital or specialist appointments are needed for their care
• Deciding whether to refer the patient to a specialist palliative care service
• Ensuring that family and carers and appropriate support and advising carers on what to do and who to call when help is required.

GPs should aim to meet the care needs of every individual patient, including palliative care needs, using evidence-based practice, as well as consider the needs of the patient’s family and carers (RACGP, 2016). Support for a family is best provided with the consent of the patient to share their personal information; however, in the absence of patient consent, support of a general nature can be given, while being mindful of patient confidentiality (Palliative Care Expert Group, 2016). Conducting a family meeting can be useful to provide information and address the family’s questions and concerns (Palliative Care Expert Group, 2016). For guidance on conducting a family meeting in palliative care refer to the Therapeutic Guidelines: Palliative Care (p 64).

Specialist Palliative Care Services

‘All patients who are dying can benefit from a palliative approach to care, but not all patients for whom death is expected will need specialist palliative care’ (Palliative Care Expert Group, 2016). Referral to (or a phone discussion with) specialist palliative care services is ‘appropriate at any time in the disease trajectory when a patient with a life-limiting illness, or significant others associated with the patient, have identified needs that are not being adequately addressed, whether these needs are physical, psychological, social or spiritual’ (Girgis, et al., 2006).

Specialist Palliative Care Services have a vital role in providing expert clinical advice – particularly for those with complex symptoms requiring palliation. They also provide direct care for a small number of patients and more broadly provide capacity building and support services to the health and human services sectors.

The three adult SA Public Specialist Palliative Care Services in metropolitan Adelaide are:
• Northern Adelaide Palliative Service (based at Modbury Hospital)
• Central Adelaide Palliative Care Service (based at The Queen Elizabeth Hospital)
• Southern Adelaide Palliative Services (based at Flinders Medical Centre)
Further details of each of the adult Specialist Palliative Care Services in metropolitan Adelaide including a map of their service delivery areas, is provided in Appendix 2.

The Broader Palliative Care Team

The expertise of a team of providers from different disciplines may be required in order to adequately assess and address the complex needs of patients and their families. Additional members of the palliative care team may include Specialist Medical Practitioners E.g. Oncologists, Nurses, Social Workers, Counsellors or Psychologists, Pastoral Carers, Allied Health Providers E.g. Occupational Therapist, Community Pharmacy or Pharmacist, Volunteers, and Community Groups e.g. Palliative Care Australia, Cancer Council.

Further information on each of these providers and their role is included in Appendix 3.

2. GP Palliative Shared Care Program

2.1 GP Palliative Shared Care Overview

The GP Palliative Shared Care (GP PSC) Program was established in 2015 because of an initiative by SA Health and GP partners Australia and supported by the SA Palliative Care Clinical Network.

The GP Palliative Shared Care Program plays an important role in building the capacity and skills of general practitioners to support patients with a life limiting illness within the community setting.

Program Aims

The GP Palliative Shared Care Program aims to:

- **Promote and support the role of general practitioners** in providing continuity of care and end of life support in the community for people experiencing a progressive, life limiting illness.

- **Strengthen the relationships between general practitioners and public Specialist Palliative Care Services** providing care to people with a life limiting illness.

- **Provide a best practice framework** for the provision of palliative shared care, involving adult South Australian Public Specialist Palliative Care Services and GPs in metropolitan Adelaide.

- **Build the capacity and skills of general practitioners** in providing palliative care to people with a life limiting illness through the provision of Continuing Professional Development (CPD) activities and clinical support.

What is the GP Palliative Shared Care Program?

The GP Palliative Shared Care Program provides adults who have a life limiting illness and have been referred to a SA Health public, metropolitan Specialist Palliative Care Service with the option to obtain shared palliative care with a participating GP. This ‘sharing’ of the provision of palliative care between general practitioners and the Specialist Palliative Care Service is termed ‘GP Palliative Shared Care’.

GPs participating the program will receive CPD activities, clinical support and guidelines to assist them in meeting the needs of their patients with a life limiting illness. The general practitioner will have the GP Palliative Shared Care Program Framework to guide them in the process of completing a needs assessment, engaging in a case conference with the Specialist Palliative Care Service to establish the goals of care, and developing a care plan with the patient.
Patients of GPs participating in the program, will be supported by the provision of a Patient Held Record which will store essential clinical information including a medication list, advance care plans and a ‘who to call’ list for assistance at any time.

**How the Program Works for GPs**

For general practitioners, there are three key components to the GP Palliative Shared Care Program – the Program Framework, Orientation and Ongoing Education, and the Provision of GP Palliative Shared Care. All participating GPs will receive a hard copy of the Framework at the Orientation Seminar. Participating GPs will also receive ongoing support from the GP Advisors to the GP Palliative Shared Care Program and Specialist Palliative Care Services.

For details of how to participate refer to Section 3: GP Participation, of the Framework.

**Who can be provided with GP Palliative Shared Care?**

The GP Palliative Shared Care program is available to adults who are patients of a metropolitan Adelaide Specialist Palliative Care Service and being cared for in a community setting. This includes people living at home, being discharged into the community from hospital and living in residential aged care facilities.

**Definition of Metropolitan Adelaide**

For the purposes of the GP Palliative Shared Care program, metropolitan Adelaide refers to the areas of Adelaide serviced by the Southern Adelaide Palliative Services, Central Adelaide Palliative Care Service and Northern Adelaide Palliative Service. A guide to the postcodes that fall within the boundary for these services may be accessed on the GP partners Australia website at [www.gppaustralia.org.au/psc](http://www.gppaustralia.org.au/psc), and a map of the service areas is included in Appendix 2.

For further information on how a patient may access GP Palliative Shared Care, refer to Section 5 of the Framework.

**2.2 GP Palliative Shared Care Information Line: 1300 303 409**

GP Partners Australia provide a GP Palliative Shared Care Information Line on 1300 303 409, available during normal business hours of 9am to 5pm, Monday to Friday. The aim of the GP Palliative Shared Care Information Line is to provide general practitioners and Specialist Palliative Care Services with a direct point of contact for all enquiries related to the operation and processes of the GP Palliative Shared Care Program, the Program Framework, GP participation and education.

**Note:** The GP Palliative Shared Care Information Line is not a clinical information or support service. All clinical enquiries are to be directed to a patient’s GP or Specialist Palliative Care Service, as appropriate.
3. GP Participation

GP Partners Australia manages the orientation and education for general practitioners participating in the GP Palliative Shared Care Program, in collaboration with SA Health.

3.1 Orientation to the Program

**GP Registration**

Registrations to participate in the GP Palliative Shared Care Program can be made by general practitioners using the GP Palliative Shared Care Program – Registration Form (see Appendix 4) available at [www.gppaustralia.org.au/psc](http://www.gppaustralia.org.au/psc). All general practitioners registered as a Medical Practitioner with the Australian Health Practitioner Regulation Authority (AHPRA) may register to participate in the program.

**Orientation Seminar**

All GPs participating in the GP Palliative Shared Care Program will complete a GP Palliative Shared Care Orientation Seminar. The Orientation Seminar will familiarise GPs with the GP Palliative Shared Care Program Framework and provide professional development in palliative care. GPs completing the Orientation Seminar will receive:

- a copy of the GP Palliative Shared Care Program Framework;
- a hard-copy of the current edition of the Therapeutic Guidelines: Palliative Care; and
- 40 (category 1) QI&CPD points

For details of the next GP Palliative Shared Care Orientation Seminar phone the GP Palliative Shared Care Information Line on 1300 303 409.

3.2 Ongoing Education & Professional Development

**Ongoing Education**

The ongoing education of GPs for the GP Palliative Shared Care Program is managed within a 3-year cycle, which is conducted in parallel with the Continuing Professional Development (CPD) triennium as defined by RACGP and ACRRM. To maintain participation in the GP Palliative Shared Care Program a GP needs to demonstrate over the 3 year period that they have completed one of the following:

a) a GP Palliative Shared Care Refresher Seminar; or

b) a minimum of two (2) RACGP or ACRRM accredited CPD activities relevant to Palliative Care.

**Available CPD Activities**

GP partners Australia provides regular CPD events for participating GPs to further develop their skills and knowledge in caring for people with a life limiting illness. The details of RACGP and/or ACRRM accredited palliative care CPD activities delivered by GP partners Australia and other education providers are available at [www.gppaustralia.org.au/events](http://www.gppaustralia.org.au/events).
Peer Support

GPs participating in the GP Palliative Shared Care Program are expected to remain current with the GP Palliative Shared Care Program Framework. GP Advisors to the GP Palliative Shared Care Program are available to offer support to participating GPs.

3.3 Database of Participating GPs

GP partners Australia maintains a GP Palliative Shared Care Database of GPs participating in the GP Palliative Shared Care Program. The database has searching and sorting functionality and is accessible to GP partners Australia, Specialist Palliative Care Services and GP Advisors to the GP Palliative Shared Care Program.

If a patient of a Specialist Palliative Care Service does not have a usual or identifiable GP, the Specialist Palliative Care Service may use the GP PSC Database to identify a participating GP. With the patient’s consent, the Specialist Palliative Care Service may contact the participating GP to discuss if they are able to care for the patient. The acceptance of new patients is optional for participating GPs.

It is essential that participating GPs ensure that GP partners Australia have their current contact details and that they inform GP partners Australia of any changes.
4. Shared Care Arrangements

In GP Palliative Shared Care, a collaborative relationship is negotiated between the GP and the Specialist Palliative Care Service. A patient centred care plan is established including roles, responsibilities and communication pathways for all key persons involved in care. The Case Conference between the GP and Specialist Palliative Care Service provides the opportunity for the shared care arrangements to be discussed and agreed. However, the level of involvement of the GP and Specialist Palliative Care Service may fluctuate and will require regular discussion.

4.1 Level of Need Model

Palliative Care Australia describes a hierarchy of needs for people with life limiting illnesses (see image below):

- **Sub-group (A)** refers to patients who do not require access to specialist care, and who are supported by their own resources or primary care providers to meet their needs.
- Some patients with a life limiting illness fall into **sub-group (B)** and will have sporadic exacerbations of symptoms or may experience social or emotional distress. These patients may require access to Specialist Palliative Care Services for advice and support, consultation or care coordination.
- Palliative care patients who have the greatest needs, with complex physical, social, psychological and/or spiritual needs, will fall into **sub-group (C)**. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers. The services most often required for this sub-group are care coordination or episodes of specialist led care.

Within the GP Palliative Shared Care program, patients are likely to have intermediate (sub-group B) or complex (sub-group C) care needs. Within both of these patient groups the general practitioner will remain the primary care provider and the level of support from the Specialist Palliative Care Service with be based on the needs of the patient, carer and family members. The only exception to this is if the patient requires admission to an acute care (in patient) setting, where the Specialist Palliative Care Service may lead the care.

![Conceptual model of level of need within the population of patients with a life limiting illness](image)

(Source: Palliative Care Australia, 2005, A Guide to Palliative Care Service Development: A population based approach, Deakin West, ACT)

**GP and Specialist Palliative Care Service Roles**

**General Practitioner**

As described above, GPs participating in the GP Palliative Shared Care Program are considered the primary care provider and have an ongoing role in facilitating the provision of good quality patient-centred care that emphasises continuous,
open, informed communication and collaboration between the patient, the health care team, and, where appropriate, the patient’s carer, family members and/or substitute decision-maker. The GP role in providing palliative care is described in the Introduction section of the Framework. Specific GP responsibilities related to key components of the GP Shared Care Program are discussed in the GP Care Planning section of the Framework.

**Specialist Palliative Care Service**

The Specialist Palliative Care Service will work collaboratively with the GP to determine the level of input and services required to support each individual patient, and their carer and family members, being cared for in the GP Palliative Shared Care Program. It is anticipated that the level of input may vary throughout the patient’s disease trajectory, particularly as they approach end of life (terminal phase). Approaches to service delivery and the types of services offered by Specialist Palliative Care Services are described in further detail in Appendix 2.

### 4.2 Communication in Shared Care

A shared care arrangement requires effective communication between all parties involved in the shared care arrangement, including the GP, Specialist Palliative Care Service and the patient.

**GPs and Specialist Palliative Care Communication Arrangements**

Agreed methods and expectations in relation to communication, should be discussed between the GP and Specialist Palliative Care Service on patient entry to the program. A tool that may be used by the Specialist Palliative Care Service to initiate these discussions is the GP/Referrer Faxback Form (see Appendix). The key purpose of the faxback form is to establish the preferred communication methods e.g. fax, phone, email, the GPs availability and preferences. The multidisciplinary case conference will provide the opportunity to clarify and confirm communication arrangements.

**Sharing of Clinical Information**

Sharing up-to-date clinical information is essential for patients who are receiving GP Palliative Shared Care and dealing with different parts of the health system. This may occur via a healthcare record kept in the home, a shared electronic patient record, or by electronic transfer of information between relevant healthcare providers.

It is recognised that a patient-held record can be a useful tool which healthcare providers, patients and carers can use (Palliative Care Expert Group, 2016). GP Palliative Shared Care Patient Held Records are specifically available to order and use for patients receiving GP Palliative Shared Care. For further information refer to Section 6.2 of the Program Framework.

**Common Language in Palliative Care Assessments**

Metropolitan Specialist Palliative Care Services use specific palliative care assessment tools as a part of the Palliative Care Outcomes Collaboration (PCOC) to provide a consistent, formal approach to the documentation of assessments, that drive the focus of care. The knowledge and use of these tools by GPs in the assessment of patients with a progressive, life limiting illness enables the establishment of a common language across primary care and Specialist Palliative Care.

The clinical assessment tools used consistently across Specialist Palliative Care Services assess key domains of palliative care. These are the phase of illness, the patient’s functioning and performance status, pain and other common physical symptoms, the patient’s psychological/spiritual problems and family/carer problems associated with the patient’s illness.

The five clinical assessment tools used in PCOC are:

- Palliative Care Phase, Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)
- Palliative Care Problem Severity Score (PCPSS)
- Australia-modified Karnofsky Performance Status (AKPS)
- Symptom Assessment Scale (SAS)
GPs participating in the GP Palliative Shared Care Program will receive training in the use of the assessment tools at the GP Palliative Shared Care Orientation Seminar, as well as a PCOC lanyard that provides a quick reference guide to the assessments. For further details of each of the assessment tools, refer to Appendix 6.

### 4.3 Home Visits & After Hours Care

#### Home Visits

GPs need to consider how to provide continuity of care to patients who can no longer attend the practice. According to the RACGP *Standards for General Practices*, home and other visits (e.g. to residential care facilities) need to be available to regular patients of the practice where such visits are safe and reasonable and are clinically necessary. Visits may be performed by, or on behalf of, the general practitioner.

What is ‘safe and reasonable’ is a decision that each practice needs to make in their local context. Information that may assist includes the Australian Medical Association (AMA) Position Statement, *Personal Safety and Privacy for Doctors* (available at http://ama.com.au/node/2182) and the RACGP publications *Keeping the doctor alive: A self-care guidebook for medical practitioners* and *General practice – a safe place*. Refer also to the RACGP *Standards for General Practices* for guidelines to enhance the safety of health professionals undertaking home and other visits on behalf of the practice. In individual circumstances where home or other visits will be neither safe nor reasonable, the GP needs to arrange an alternative system of care that these patients can access.

#### Visits on behalf of the General Practitioner

There needs to be a direct continuing relationship between the GP and those doctors who perform the home and other visits on their behalf, including services that provide care outside normal opening hours. This includes arrangements to exchange clinical details about patient care and any concerns the practice may have about the safety of a visiting GP.

#### After Hours Care

Patients with a progressive terminal illness can become unstable or change quickly. Therefore, it is prudent to consider after hours arrangements as soon as possible to avoid distressing uncertainty for patients and carers when problems arise out of hours. The general practitioner needs to communicate to the patient whether they are able or prepared to visit the patient at home, and what arrangements they have made for afterhours emergency care. The details should be clearly documented and available where the patient is. The GP Palliative Shared Care Patient Held Record includes a Contact List template (inside the front pocket) for the General Practitioner to complete.

‘Many after-hours issues involve carer anxiety about changes in symptoms and can be easily resolved over the phone. Lack of ready access to medical advice can be a reason for admission of a patient to hospital’ (Palliative Care Expert Group, 2016, p. 52).

After hours care to patients may be provided by the patient’s general practitioner, or via other arrangements for example:
- another general practitioner within the practice
- an afterhours cooperative with other general practices
- engaging an accredited Medical Deputising Services.

If after-hours care will be provided by another healthcare provider, the GPs should ensure that there is appropriate written information at the patient’s home, including the patient’s medical history and an up-to-date medication list. This may be kept in the patient’s GP Palliative Shared Care Patient Held Record (see Section 6.2).

A guide to the MBS Items for After Hours GP services is included in Appendix 7.
*An afterhours cooperative can be defined as general practices working together to provide care to patients outside the normal opening hours of their practices. Cooperative arrangements should make sure notes of consultations and information about the care provided are sent back to the practice. This must occur in a timely manner that is suitable to both parties, where patient consent has been obtained.

The Practice Incentive Program (PIP) - After Hours Incentive aims to support general practices to provide their patients with appropriate access to afterhours care. For the purposes of the PIP, the complete after-hours period is defined as outside 8am to 6pm weekdays, outside 8 am to 12 noon on Saturdays, and all day on Sundays and public holidays. For details of the After-Hours Incentive, including requirements and payments, visit www.humanservices.gov.au.

Specialist Palliative Care Service – After Hours Telephone Advice
Specialist Palliative Care Services provide a **seven day a week out-of-hours** telephone advice service for health professionals and patients. For advice in relation to a patient who is registered with a Specialist Palliative Care Service, it is recommended that the participating GP contacts the Service involved in the patient’s care and asks to speak with the ‘Palliative Care Doctor On-Call’. General practitioners may also ring any of the major public hospitals in metropolitan Adelaide and request to speak with the ‘Palliative Care Doctor On-Call’ for advice at any time.

SA Ambulance Service (SAAS)
SA Ambulance Service clinicians work collaboratively with Specialist Palliative Care Services to respond to and minimise acute symptom issues, with the aim of keeping patients at their place of residence. Access is via triple zero (000) or following discussion with a member of the Specialist Palliative Care team. A triage is completed by SAAS at the time of the call, to determine the most appropriate response.

4.4 Inpatient Care

Dedicated palliative care beds play a critical role in meeting the needs of people at end of life who require periods of intensive inpatient care. Admission to acute palliative care beds assist people who require optimal control over complex or difficult symptoms, therapeutic investigations, interventions or care focused on rehabilitation and restoration of functional independence, or terminal care in instances where this is the patient or family’s choice or cannot be provided elsewhere.

Ideally patients should be able to move freely between institutions and home, in response to their needs and the needs of the carers. Adequate transfer of information between the GP, Specialist Palliative Care Service, the patient/carer and agencies is essential to provide continuity of care. For further information, refer to the Communication in Shared Care section of the Framework.

Palliative Care/Hospice Beds
Palliative care beds are currently available under the bed card of Palliative Medicine Specialists at Modbury Hospital, The Queen Elizabeth Hospital, Royal Adelaide Hospital and Repatriation General Hospital (Daw House). These are the dedicated bed card options in Northern, Central and Southern Local Health Networks. Mary Potter Hospice at Calvary Hospital, North Adelaide, provides both public and private inpatient hospice care and this is coordinated by the Central Adelaide Palliative Care Service. Specialist Palliative Care Services provide a large workforce as consultation liaison in all public hospitals of Adelaide. If one of your patients is admitted to hospital and requires palliative care input you can ask the treating team to facilitate a palliative care assessment or alternatively speak to the office of your local Specialist Palliative Care Service to see how to best facilitate their assistance.
4.5 Support for Carers

Identifying and supporting carers is crucial in order for care at home to be achievable and sustainable. It is important to note that identified carers are not always family members or that family members may have shared or differing roles with respect to care of the patient. Hence it is important to establish the nature of the care provider/patient relationship and what impact the loss or impending loss of the patient may have on the carer. Carers often immerse themselves in their role, may be loath to consider their own needs and may struggle with the unceasing demands of the role.

‘The difficulties faced by a carer may be acknowledged by healthcare providers, but they may not be properly addressed. This can result in increasing distress for the carer and negative consequences for the patient; for example, carer exhaustion is often a reason for a patient to be admitted to an inpatient facility’ (Palliative Care Expert Group, 2016, p. 68).

‘Distress can be reduced if needs are assessed early and community supports are introduced when they are required’ (Palliative Care Expert Group, 2016, p. 68).

All members of the palliative care team should be aware of the need to support carers and as a key component of the palliative care team, the GP is well placed to engage in discussion regarding carers’ needs. The patient’s carer(s) should be offered needs assessments and access to relevant psychosocial support. The needs assessment should include a discussion of bereavement issues and associated risk assessment (refer to the Bereavement section of the Framework). This may be conducted by the carer’s own GP or this may be provided through services and support offered by the patient’s Specialist Palliative Care Service. Contact the Specialist Palliative Care Service for advice and support. Additional strategies for GPs to support carers are discussed in the ‘Caring for the Caregivers’ section of the Therapeutic Guidelines: Palliative Care.

The patient’s carer(s) should be offered needs assessments and access to relevant psychosocial support. The needs assessment should include a discussion of bereavement issues and subsequent risk assessment (refer to the Bereavement section of the Framework). The carer’s own GP may be well suited for the role of assessing and managing carers’ needs or this may be met through services and support offered by the patient’s Specialist Palliative Care Service. Contact the Specialist Palliative Care Service for advice and support.

**Respite**

Having regular breaks from the care giving role and/or awareness of respite care that is available if needed may help carers continue to provide care at home. Respite care can take place:

- in the person’s home with care ranging from a few hours each week to overnight care (in-home respite)
- in a day care centre which provides full or half-day care
- in a residential aged care facility for two or three weeks.

Respite care is provided by community care services, such as the National Respite for Carers Program (NRCP), the Home and Community Care Program (HACC) or by residential care homes. All carers should be encouraged to register with their local Carer Respite Centre.

For details of the type of respite services available locally, as well as government funding that may be available call the Commonwealth Respite and Carelink Centre on 1800 052 222.

Carers SA also provide professional counselling, specialist advice and information for carers. For more information go to [http://carers-sa.asn.au](http://carers-sa.asn.au), or phone 1800 242 636.

**Resources**

**Supporting a Person Who Needs Palliative Care: A Guide for Family & Friends**

This practical and comprehensive guide, produced by the Centre for Palliative Care, helps carers to care for their loved ones and also to care for themselves. It is informed by the latest research and includes input from carers who share their
firsthand experiences of caring for a person who needs palliative care. The publication is available at http://centreforpallcare.org.

**Needs Assessment Tool: Carers (NAT:C)**
The NAT:C is a form that carers can use to help them pinpoint their particular needs. It was developed by a group of researchers who looked at the most common issues that affect carers supporting someone with cancer. The tool and further information is available on the CareSearch website at www.caresearch.com.au > Patients, Carers and Families > How to Care > Carer Needs Tool.

### 4.6 Self-Care for GPs

‘Caring for a patient who is dying can be personally and professionally demanding (Palliative Care Expert Group, 2016, p. 71).’ Advice on emotional care and self-care principles for palliative care providers, including GPs, is available in the ‘Caring for dying patients: impact on healthcare providers’ section of the *Therapeutic Guidelines: Palliative Care*. GPs who have personal difficulties or who are concerned about stress, burnout or their emotional needs should consult their own medical practitioner, a trusted colleague or a professional support program.
5. Patient Access to GP Palliative Shared Care

5.1. Process for Patient Access

There are three key steps in the process of a patient accessing GP Palliative Shared Care, as illustrated below. All patients will need to be referred to their local Specialist Palliative Care Service to receive GP Palliative Shared Care. For details of each of the three-metropolitan adult Palliative Care Services, refer to Appendix 2.

Specialist Palliative Care Services will provide an assessment of the patient and contact the patient’s usual/preferred GP to discuss shared care arrangements. For GPs participating in the GP Palliative Shared Care program the shared care will be provided according to the GP Palliative Shared Care Program Framework, where appropriate.

**Patient Referral to Specialist Palliative Care Service**

**Referral Criteria**

Criteria for eligibility and a guide for referral to a palliative care service:

a) Patient has a progressive, life limiting illness
b) Patient or their decision maker is aware of, understands and has agreed to palliative care referral
c) Primary goals of patient care are to control symptoms, maximise function, maintain quality of life and provide comfort.

If a patient does not meet the three criteria above, the individual case should be discussed with the local Specialist Palliative Care Service.

**Who can refer to a Specialist Palliative Care Service?**

Referrals to the metropolitan adult Specialist Palliative Care Services may be initiated by anyone. Examples of referral sources include:

- Acute care setting or hospital
- Specialist Medical Practitioner E.g. Oncologist
- General Practitioner
- Community nursing staff
- Allied health
- The patient (self-referral)
- Family member, carer, advocate or friend
- Residential Aged Care Facilities
- Other palliative care services

**General Practitioner Referrals**

Referral to (or a phone discussion with) specialist palliative care services may be appropriate at any stage of patient care.

‘In general, GPs should consider involving a specialist palliative care service early when:

- Future need for palliative inpatient or home-based care at the end of life is anticipated
- Symptom control is expected to be difficult, e.g. head and neck cancers
- Complex psychosocial or care issues exist
The family or carers are feeling overwhelmed or distressed.’ (Palliative Care Expert Group, 2016).

A more urgent consultation should be considered when:

• Symptoms are not well controlled  
• A palliative care emergency is imminent.’ (Palliative Care Expert Group, 2016, p. 51)  
• The patient’s carer is distressed or overwhelmed (CareSearch, 2015).

Reasons for referral may include:

• The patient requires a palliative care assessment and provision of service information  
• Symptoms and/or concerns that exceed the capacity, resources, knowledge or skills of the primary care provider,  
• Difficulty maintaining care at place of residence  
• Terminal care (patient in the last few weeks of life).

To assist GPs in identifying patients that may require a referral to a Specialist Palliative Care Service, the Needs Assessment Tool: Progressive Disease (NAT:PD) may be used (see Appendix 8).

**Palliative Care Referral Form**

Referrals to a Specialist Palliative Care Service can be made by general practitioners (and others) using the state-wide SA Health Palliative Care Referral Form (see Appendix 5).

General practitioners can tick the ‘Shared Care’ option on the Referral Form under ‘Referrer and/or GP details’ to indicate that their preferred response to the referral is the provision of shared care. There is also a field on the referral form to indicate if the GP participates in the GP Palliative Shared Care Program (see below).

New referrals will be processed by the Specialist Palliative Care Service during office hours Monday to Friday 9.00 am to 4.00 pm. If the matter is urgent, please phone the local Specialist Palliative Care Service.

**Specialist Palliative Care Assessment**

Patients referred to a Specialist Palliative Care Service receive a Palliative Care Assessment, which starts with an initial triage by a designated triage officer (usually an advanced practice nurse) to assess appropriateness of referral, complexity and urgency of response. A comprehensive assessment process, using standardised systematic multidisciplinary assessment tools is then initiated to ensure early identification of physical, social, spiritual and emotional needs, and tailor service responses to meet need. The assessment completed by the Palliative Care Service on receipt of a referral will include an assessment of suitability for GP Palliative Shared Care.

The level of urgency dictates the time-frame for response to both triage and the initiation of the palliative care assessment process. The referrer will be contacted by the Specialist Palliative Care Service, informed of the outcome of the assessment and provided with advice where required.
**Shared Care with a General Practitioner**

For all patients referred to Specialist Palliative Care Services, the service will seek to work with the patient’s usual/preferred general practitioner as appropriate. If the patient’s usual or preferred GP is participating in the GP Palliative Shared Care program, care will be provided in the format of the GP Palliative Shared Care Framework. If the patient’s usual/preferred GP is not participating in the program, care will be provided as negotiated between the GP and Palliative Care Service outside of the GP Palliative Shared Care program.

If the patient does not have a usual or preferred GP, the Specialist Palliative Care Service may use the GP Database to identify a suitable GP (of the patient’s choice) who is participating in the GP Palliative Shared Care Program and refer the patient (with their consent) to that GP to receive GP Palliative Shared Care.
Components of Care Planning in GP Palliative Shared Care

For patients with a life-limiting illness, careful planning and good communication between all members of the healthcare team is crucial to optimise their care. The key components of care planning that are provided to all people with a life-limiting illness being supported in the GP Palliative Shared Care program are outlined in the table below. Each care planning component is discussed in further detail throughout this section.

Care Planning Components and GP Responsibilities

<table>
<thead>
<tr>
<th>Component</th>
<th>GP Responsibilities</th>
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| Patient Held Record                           | • Provision of the Patient Held Record and Explanation of Intended Use  
• Completion of Contact List  
• Ongoing Review and Updating in collaboration with Specialist Palliative Care |
| Needs Assessments                              | • Completion of Initial Needs Assessment.  
• Ongoing, Regular Review of Needs |
| Case Conference                                | • Arrange and Participate in the Case Conference  
  > Obtain patient consent  
  > Book a time with the Specialist Palliative Care Service  
  > Prepare for the case conference  
  > Phone (or accept the phone call from) the Specialist Palliative Care Service and participate in the Case Conference at the agreed time  
  > Document the case conference  
  > Offer a summary to the patient and provide to other team members (optional)  
  > Discuss outcomes with the patient (optional) |
| Care Plan Documentation and Ongoing Review    | • Develop a Care Plan in collaboration with the patient  
• Sharing of the Care Plan with the Specialist Palliative Care Service  
• Regular Reviews of the Care Plan |
| Advance Care Directives and Clinical Planning for End of Life | • Discuss and support patients in the completion of Advance Care Directives  
• Offer the Completion of a Resuscitation Plan - 7 Step Pathway  
• Communication of Advance Care Directives and Resuscitation Plan - 7 Step Pathway Forms  
• Ongoing Review of Advance Care Plans |

Talking to patients about death and dying & planning care

The Palliative Care SA booklet - *Talking to patients about death and dying*, available at [www.pallcare.asn.au](http://www.pallcare.asn.au), provides advice for health professionals in discussing patient concerns and advance care directives.
Summary points include:

- Talking about death and dying and planning care is a time-consuming process and will require more than one prolonged consultation.
- Active listening and empathic communication are two vital elements in the discussion of death and dying.
- Open-ended questions are better to explore these issues. Don’t be afraid to ask the patient what they mean by their answers.
- The family will need to be involved in discussions at some point and the doctor’s knowledge of the patient and their family is likely to be the most important factor in deciding when this should be.
- Families and individual family members will vary in their coping styles including their willingness to discuss issues around death and dying. If possible, each family and patient should be allowed to move forward at their own pace.
- The medical practitioner and family should never assume that they know what the patient’s wishes are in relation to the time around their death, as research has shown this to be consistently inaccurate.
- Attention to spiritual, religious and existential issues is vital in palliative care, and the medical practitioner will need to encourage the patient to explore these with the most appropriate person for that patient.
- Be aware of the spectrum from sadness to clinical depression, and that it may be appropriate to explore the diagnosis of depression in more depth.
- It is extremely important to remember that patient and family understanding of certain terms may be different from the medical practitioners and so definitions of all terms around end of life care should be clearly discussed.
- The skills required around these discussions are rarely natural – they are learned through experience and training.


Cultural Considerations

‘The perspectives and experiences that each [patient] brings to a consultation impacts on communication. Every individual is different and the level they adhere to specific cultural traditions and values will vary. It is important never to make assumptions about people’s cultural backgrounds or religions.’ The AFP article, End of Life Care: The importance of culture and ethnicity, available at www.racgp.org.au, discusses how cultural diversity may impact care and provides some strategies for the general practitioner when considering the provision of end of life care. Refer also to the ‘Communicating with the patient’ section of the Therapeutic Guidelines: Palliative Care for further guidance.

6.2 Patient Held Record

Purpose

In palliative care, the following information should be readily available to healthcare providers involved with the patient: (Palliative Care Expert Group, 2016, p. 50)

- a diagnosis and problem list, including extent of disease and active co-morbidities
- an up-to-date medication list including dosage regimen and purpose of each medication
- agreed instructions on how to handle anticipated emergencies
- key contacts (e.g. community nursing service and general practitioner phone numbers)
- advance care planning documents.

The Patient Held Record assists in having this information readily available to all clinicians caring for a patient. It provides the patient and/or carer with a central place to keep essential information, and key documents associated with his or her
The record is recognised across settings, alerting new care providers that the patient is in the GP Palliative Shared Care Program and of their care plan(s). Through the sharing of important documentation, the Patient Held Record aims to improve the quality and safety of care and reduce unwanted and unnecessary interventions which may result from poor communication.

Confusion for patients and their carer, particularly about who to contact in an emergency, can lead to inappropriate and unwanted treatment. The Patient Held Record provides a Contacts List for the patient and their carers to know who to call for assistance at any time of the day or night.

**Format**

The GP Palliative Shared Care Patient Held Record consists of a bright purple plastic folder (for easy recognition). The folder should be kept in a place that is easy to locate by the patient, carer(s) and care providers including the GP, Specialist Palliative Care Service, and SA Ambulance Service. For patients in the home setting, it is recommended that the Patient Held Record is kept with their medications.

The essential information to be stored in the Patient Held Record includes:

- Contact List – a list of ‘who to call’ for assistance at any time of the day or night
- Copy of any ACD and 7 Step Pathway (if completed)
- Copy of the Care Plan
- Printed up-to-date Medication List

All Patient Held Records include a blank Contact List template and patient and/or carer information and support brochures.

**GP Responsibilities**

**Provision of the Patient Held Record and Explanation of Intended Use**

The Patient Held Record is to be provided by the GP to each patient receiving GP Palliative Shared Care. It should be issued by the participating GP at the time of their first contact, following entry of the patient into the program.

When initially providing a copy to a patient it is recommended that the GP:

- Advise the patient to **keep it in a place that is easy to locate** (for patients living at home it is recommended that the Patient Held Record is kept with their medications)
- Advise the patient to **present the record at each contact** with their GP, Specialist Palliative Care Service and other relevant care providers (e.g. SA Ambulance Service, any specialists they are seeing), as well as when moving across settings (e.g. if admitted to hospital or hospice).
- Complete the **Contact List** form inside the front cover of the Record – a list of ‘who to call’ for assistance at any time (see below).
- Add a printed **Medical Summary** to the folder, including an up to date medication list, as well as a copy of any other important documents such as an Advance Care Directive

A copy of the following documents should be added to the Patient Held Record when completed:

- **Advance Care Directive**
- **Resuscitation Alert 7 Step Pathway**
- **Care Plan** (e.g. GP Management Plan and Team Care Arrangements)
**Completion of Contact List**

When providing the Patient Held Record the GP needs to complete the Contact List details inside the front cover of the record including:

- patient name & date of birth
- general practitioner details
- available hours for the GP and who to contact out-of-hours
- the patient’s local Specialist Palliative Care Service

**Ongoing Review and Updating in collaboration with Specialist Palliative Care**

GPs and Specialist Palliative Care Service providers should review and update (if required) the Patient Held Record, at each contact with the patient.

### 6.3 Needs Assessments

#### Purpose

The completion of needs assessments of patients, family and carers, assists the GP and other care providers to identify and address any problems a patient has with:

- the health system and information (e.g. information, access to services, resources, treatment centre environment)
- patient care and support (e.g. choices, reassurance, prompt attention to needs).

- identify and address issues as they arise to enhance the management of physical and daily living needs and quality of life for the patient.

The assessment of a patient's needs prior to the case conference helps to define what is discussed in meeting to assist in the development of a care plan. It is also important that patient needs are re-assessed on a regular basis to ensure the correct level and types of care are being accessed.

#### Format

'Individuals and their family members living with a life-limiting illness have a range of care needs - physical, emotional, social and spiritual. Palliative care is holistic in approach, acknowledging the importance of attending to needs and experiences in each of these domains.' The Needs Assessment Tool: Progressive Disease (see Resources) and the Therapeutic Guidelines: Palliative Care provide an optional format and guidance to assist GPs in completing an assessment of patient and carer needs.

Needs assessments may also be completed in collaboration with the Specialist Palliative Care Service and broader palliative care team. For example, the results of the initial patient assessment completed by the Specialist Palliative Care Service may be shared with the general practitioner and contribute to their initial needs assessment, where appropriate.

#### GP Responsibilities

**Completion of Initial Needs Assessment**

Each patient of the GP PSC program is to have an initial needs assessment completed by their GP, prior to the Case Conference. The results of the needs assessment should be documented as per normal medical practice and used to prepare a list of discussion points for the Case Conference with the Specialist Palliative Care Service.
Ongoing, Regular reviews of Needs

A patient’s needs, goals and wishes at the end of life may change over time. Ongoing, regular reviews will be required throughout the course of care, with the frequency determined by the patient’s care needs, assessment scores and phase. The ongoing monitoring of needs is the responsibility of the GP with Specialist Palliative Care support as negotiated. The frequency of these assessments should be discussed within the case conference and documented in the care plan.

Resources

Needs Assessment Tool: Progressive Disease

Used in both generalist and specialist settings, the Needs Assessment Tool: Progressive Disease (NAT: PD) can assist in matching the types and levels of need experienced by people with progressive chronic diseases (e.g. cancer, heart failure, COPD) and their carers with the most appropriate people or services to address those needs. In generalist settings, including general practice, the NAT: PD can be used to determine which needs may be met in that setting and which needs are be more complex and may be better managed by specialists. The NAT: PD is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

A copy of the NAT:PD, is shown in Appendix 8 and is available to download on the CareSearch website at www.CareSearch.com.au.

6.4 Case Conference

A key feature of the GP Palliative Shared Care Program is the provision of a multidisciplinary case conference between the GP and Specialist Palliative Care Service providers. The case conference provides the opportunity for issues and questions about end of life care to be raised and appropriate strategies agreed upon. Having everyone with a stake in a patient’s care ‘on the same page’ is vital to achieve the best outcomes for the patient. A single case conference for patients receiving specialised community-based palliative care has been shown to reduce hospitalisations and better maintain a patient’s performance status (AKPS).

Purpose

The purpose of the palliative care case conference is to:

- negotiate shared care arrangements
- identify clear goals of care in accordance with the patient’s wishes and values
- determine GP and Specialist Palliative Care roles and responsibilities including who has responsibility for:
  - maintaining prescriptions for palliative medications
  - regularly reviewing patient’s symptoms and assessing their care arrangements
  - either being available or ensuring availability of home visiting for patients who are no longer able to attend a GP clinic
  - being available to write a death certificate for patients who wish to die at home
- confirm communication arrangements
- determine after hours arrangements
- assist in the development of a palliative care plan for the patient
- review any advance care plans
- discuss the needs of the carer(s) and family, and who is looking after them.
Timing of a Case Conference

The best instances for a Palliative Care Case Conference between Specialist Palliative Care Units and GPs have been shown to be at the time of patient referral, time of discharge to the community, or where the case was complex.21

A further trigger to consider a case conference may be when a patients' functional status declining to AKPS 60 or less. The benefit of a case conference has been shown to be significantly greater for people at or below AKPS 60. This threshold is where people require some help with the activities of daily living. (Abernethy, et al., 2013)

Within the GP Palliative Shared Care program, it is recommended that the Case Conference be completed early in a patient’s entry to the program, as routine care planning rather than crisis management. Further case conferences may also be appropriate as patient and carer needs change.

Format - Teleconference

Each of the Specialist Palliative Care Services offer case conferences with GPs via teleconference to plan for the care of patients who are receiving GP Palliative Shared Care. The participants from the Specialist Palliative Care Service in the case conference will include at a minimum a Palliative Medicine Specialist or Registrar, and a Specialist Palliative Care Nurse (or allied health provider, as appropriate).

The patient or their representative may be invited to participate in the case conference, to enable their perspectives to be included in the discussion, and other additional health or care providers may also be invited where appropriate and with patient consent e.g. community nursing.

To arrange the case conference, GPs should contact the patient’s Specialist Palliative Care Service to book a time for the teleconference to occur. Further instructions will be provided to the GP at that time including how to join the teleconference (e.g. if the Specialist Palliative Care Service will phone the GP or if the GP is required to phone the Service at the agreed time). It is anticipated that over time, Specialist Palliative Care Services will provide regular, allocated times during which Palliative Medicine Specialists, Palliative Care Nurses and/or other clinicians are available to participate in case conferences.

Note: The Specialist Palliative Care Service may also be contacted by the GP for clinical advice and support, as required, at any time outside of the case conference.

Other Format Options

If another format for the case conference is preferred such as face-to-face (e.g. at the patient’s home, residential aged care facility or GP practice) or a family meeting, this may be negotiated. Contact the patient’s Specialist Palliative Care Service for options and advice.

Family Meetings

‘A family meeting is a discussion with involved family members and the caring team to exchange information and improve communications. The patient can be included. These meetings provide an opportunity for family members to express and share their feelings within a safe and structured context. Family meetings are not a platform for clinical debate about a patient’s condition and should not be a tool saved for crisis situations only.’21 The Centre for Palliative Care Education and Research, Family meetings in palliative care: multidisciplinary clinical practice guidelines offer a framework for preparing, conducting and evaluating family meetings, to help health care professionals to conduct effective meetings. The guidelines are available at http://centreforpallcare.org.
GP Responsibilities

Arrange and Participate in the Case Conference

Key steps for the GP to arrange and participate in the Case Conference are:

1. Explain to the patient the nature of a multidisciplinary case conference, ask the patient for their agreement to the conference taking place, and record the patient’s agreement;

2. Contact the local Specialist Palliative Care Service, book an available time for the Case Conference and confirm instructions for how to participate. Schedule the booking in your appointment schedule.

3. Prepare a summary of issues, or key points, to be discussed in the case conference (with consideration of the results of the needs assessment)

4. Ensure availability at the scheduled time for the case conference (booking the case conference in the morning, if possible, may help avoid unexpected delays). Phone or accept the phone call from the Specialist Palliative Care Service at the booked time for the Case Conference to be held. During the case conference, participants:
   a. discuss the patient’s history;
   b. identify the patient’s multidisciplinary care needs;
   c. identify outcomes to be achieved by each team member;
   d. identify tasks that need to be undertaken to achieve these outcomes, and allocate those tasks to members of the case conference team;
   e. assess whether previously identified outcomes (if any) have been achieved.

5. Document the Case Conference:
   a. record the day is held, and the times at which the conference started and ended;
   b. record the names of participants
   c. record all matters discussed and identified by the case conferencing team and put a copy of that record in the patient’s medical records.

6. Following the Case Conference: *
   a. Offer the patient and the patient’s carer (if appropriate, and the patient agrees) a summary of the conference and provide this summary to other team members;
   b. Discuss the outcomes of the conference with the patient and the patient’s carer (if appropriate and the patient agrees)

*Note: The requirements above under step 6 ‘Following the Case Conference’ are only a requirement for the MBS Items for Organising & Coordinating a Multidisciplinary Case Conference (Items 735, 739 and 743). They are not a requirement of the MBS Items for GP Participation in a multidisciplinary case conference (Items 747, 750 and 758).

Phone the GP Palliative Shared Care Information Line on 1300 303 409, for administrative assistance and support in arranging and completing the components of the case conference.

MBS Multidisciplinary Case Conference Items

The MBS Multidisciplinary Case Conference Items are for GPs to organise and coordinate, or to participate in, a meeting or discussion held to ensure that their patient’s multidisciplinary care needs are met through a planned and coordinated approach. There are six case conferencing items based on the duration of the service and the GP role in the case conference. The case conference can occur face-to-face, by phone or by video conference, or through a combination of these. A minimum of three care providers (including the GP) must be in communication with each other throughout the conference.
## Checklist for MBS Case Conferencing Items

<table>
<thead>
<tr>
<th>Component</th>
<th>Requirements</th>
<th>Met</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MBS Items 747, 750 and 758 – Participate in a Multidisciplinary Case Conference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Eligibility</strong></td>
<td>Patient has a chronic or terminal medical condition</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>The patient has complex care needs requiring care or services from their usual GP and at least two other health or care providers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient is in the community, being discharged into the community from hospital or living in a residential aged care facility.</td>
<td></td>
</tr>
<tr>
<td><strong>Case Conferencing Team</strong></td>
<td>Case Conferencing Team includes a GP and at least two other health or community care providers (one of whom can be another medical practitioner)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Each team member provides different kind of care or service to the patient.</td>
<td></td>
</tr>
<tr>
<td><strong>Patient Consent</strong></td>
<td>Explain to the patient the nature of the multidisciplinary case conference and ask the patient whether they agree to the GP’s participation in the conference.</td>
<td></td>
</tr>
<tr>
<td><strong>Documentation</strong></td>
<td>Record the patient’s agreement to the GP’s participation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Record the day on which the conference was held, and the times at which the conference started and ended</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Record the names of the participants</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Record all matters discussed and identified by the case conferencing team and put a copy of that record in the patient’s medical records.</td>
<td></td>
</tr>
<tr>
<td><strong>MBS Items 735, 739 and 743 – Organise, Coordinate &amp; Participate in a Multidisciplinary Case Conference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td>All requirements to Participate in a Multidisciplinary Case Conference (above) are met</td>
<td></td>
</tr>
<tr>
<td><strong>Following the Case Conference</strong></td>
<td>Offer the patient and the patient’s carer (if appropriate, and the patient agrees) a summary of the conference and provide this summary to other team members</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discuss the outcomes of the conference with the patient and the patient’s carer (if appropriate and the patient agrees)</td>
<td></td>
</tr>
</tbody>
</table>

## Resources

### Case Conference Template

An optional GP Palliative Shared Care Case Conference Record template is available at [www.gppaustralia.org.au/psc](http://www.gppaustralia.org.au/psc), as shown in Appendix 9.
6.5 Care Plan Documentation & Ongoing Review

**Purpose**

The purpose of the care plan is to translate the case conference notes and outcomes to an agreed plan of care, in collaboration with the patient. The care plan forms a record that can be placed in the Patient Held Record as a reference for the patient and/or carer and for review by care providers. It is important that the care plan is regularly reviewed and updated as the patients’ needs change.

**Format**

A written care plan document must be prepared. The development and review of care plans, in collaboration with the patient, is well suited to the format of the MBS Care Planning e.g. GP Management Plans (GPMP) and Team Care Arrangements (TCAs). Refer to Appendix 7 for further details of the MBS Care Planning Items.

**GP Responsibilities**

**Develop a Care Plan in collaboration with the patient**

The GP is responsible for developing a care plan in collaboration with the patient (with their consent), recording the agreed care plan as a written document and adding a copy of the plan to the patient’s medical records. The GP should offer a copy of the plan to the patient and the patient’s carer (if any, and the patient agrees) and place a copy in the Patient Held Record (where appropriate).

**Sharing of the Care Plan with the Specialist Palliative Care Service**

A copy of the Care Plan should be shared (e.g. via fax) with the patient’s Specialist Palliative Care Service on completion.

**Regular Reviews of the Care Plan**

The general practitioner is responsible for ongoing, regular reviews of the care plan, in collaboration with the Specialist Palliative Care Service, and ensuring any changes are communicated with the patient and other care providers (as appropriate). The management plan needs to be flexible and responsive to a patient’s changing needs and priorities as their life-limiting illness progresses. ‘A proactive approach with frequent review, reassessment and modification is essential to achieve holistic patient-centred symptom management.’ (Palliative Care Expert Group, 2016, p. 143)

**Resources**

**GP PSC Care Plan Template**

An optional GP PSC Care Plan template (in the format of a GPMP and TCAs) is available that provides a guide for GPs regarding the common areas that need to be considered for patients with a progressive, life limiting illness. The GP PSC Care Plan template is available at [www.gppaustralia.org.au/psc](http://www.gppaustralia.org.au/psc).
6.6 Advance Care Directives and Clinical Planning for End of Life: The Resuscitation Plan – 7 Step Pathway

Purpose

Patients often lose decision-making capacity in the period before they die. In these circumstances, care is improved if the patient has been able to document wishes and instructions in advance, and/or if they have been able to appoint a Substitute Decision-Maker. Care can be further improved if clear instructions regarding resuscitation and end of life are developed and documented by the doctor responsible for the patient’s care, consistent with the patient’s wishes but also in line with good medical practice.

Format

Advance Care Directive (ACD)

An Advance Care Directive is a legal form on which a competent adult can document the following for a time in the future when they lose the capacity to decide:

- the appointment of one or more Substitute Decision-Makers
- wishes and instructions for health care
- specific refusals of health care (including medical treatment/life sustaining treatment) (binding provisions)
- wishes regarding residential and personal matters
- personal values

From 1 July 2014, the Advance Care Directives Act 2013 came into effect in South Australia with the introduction of a single new legal form called the Advance Care Directive. This form replaced the previously existing legal forms: The Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction forms (although it is important to note that if individuals completed these documents prior to 1 July 2014, and they have not completed a new Advance Care Directive form, these pre-existing documents continue to have legal effect).

An Advance Care Directive takes effect during any period of impaired decision-making capacity, which may be temporary or permanent. At these times, Substitute Decision-Makers and health professionals responsible for the care of the individual must apply substituted judgement decision making - that is, they should attempt to make decisions that the individual would have wanted and decide as if in the "patient’s shoes”.

Note that alongside the Advance Care Directives Act 2013, changes to the Consent to Medical Treatment and Palliative Care Act 1995 also came into effect 1 July 2014. These include the requirement to obtain consent before providing medical treatment from a category of individual termed a Person Responsible, if an individual does not have an available Substitute Decisions-Maker or relevant wishes documented on an Advance Care Directive. In addition, the changes include protections for health practitioners acting in good faith in emergencies, and a clarification that there is no requirement to provide treatment that is of no medical benefit if a patient is in the terminal phase of a terminal illness.

For more information regarding the Advance Care Directives Act 2013 and changes to the Consent to Medical Treatment and Palliative Care Act 1995 visit www.sahealth.sa.gov.au.

Resuscitation Plan - 7 Step Pathway

SA Health have introduced a standardised model of practice for resuscitation and care planning decisions, called the Resuscitation Plan-7 Step Pathway.

The Resuscitation Plan -7 Step Pathway:

- Provides a best practice step by step process for clinical decision-making and documentation of decisions regarding resuscitation and care for patients near the end of their lives
• Supports safe and high-quality resuscitation planning and end-of-life care that is patient centred and, wherever possible, is aligned with the values, needs and wishes of the individual either expressed directly, via Substitute Decision-Maker/s or Person/s Responsible, or documented on a patient’s Advance Care Directive
• Describes the process for clinicians to follow to reach sound decisions with their patients about curative treatments ranging through to a palliative approach to care.

The Resuscitation Plan - 7 Step Pathway form is used to document decisions (and the decision-making process used) about resuscitation and end-of-life clinical treatment and care. This form is being phased in by SA Health from 1 July 2014, including the development of community versions of the form.

The Resuscitation Plan - 7 Step Pathway form is not a legal document but should be considered as a formalised extension of the medical notes which allows the medical practitioner responsible for the patient to document instructions regarding resuscitation and end of life discussions for implementation by other health practitioners treating the patient.

GP Responsibilities

Discuss and support patients in the completion of Advance Care Directives
It is a responsibility of a GP in the Shared Care Program to encourage and support patients, who remain competent, to document their values, wishes instructions, as well as the appointment of Substitute Decision-Maker/s, in an Advance Care Directive. In particular, in the context of discussions about diagnosis, prognosis and treatment options, GPs should assist patients if they wish to write specific medical instructions, including specific refusals of treatment such as resuscitation. Note, however, that it is the patient's choice whether or not they wish to complete an Advance Care Directive. Some patients may have existing Advance Care Directives. GPs can assist the patient in the reviewing these and ensuring they reflect the patient's current values and wishes for future health care.

Completion of a Resuscitation Plan - 7 Step Pathway
It is also a responsibility of a GP in the Shared Care Program to offer and to complete a Resuscitation Plan - 7 Step Pathway for the patient to facilitate early and improved clinical decision-making and documentation of decisions regarding resuscitation and end of life care. The process of completion of a Resuscitation Plan - 7 Step Pathway encourages the GP to work with the patient, Substitute Decision-Maker/s, Person/s Responsible and family and to be "on the same page" regarding these decisions. In addition, clear documentation of specific medical instructions and goals of care inform and assist other members of the treating team regarding how to act, particularly in emergencies.
Note that the need to consider the completion of a Resuscitation Plan - 7 Step Pathway early in the process needs to be balanced with sensitivity to the readiness of the patient and family to discuss these issues, and that it is the choice of the patient, Substitute Decision-Maker/s or Person/s Responsible whether to allow the completion of a Resuscitation Plan - 7 Step Pathway.

Communication of Advance Care Directives and Resuscitation Plan - 7 Step Pathway forms
A copy of the patient’s Advance Care Directive and/or Resuscitation Plan - 7 Step Pathway, should be included in medical files and be available to accompany patients across healthcare settings22 - this is supported by placing a copy of these documents in the Patient Held Record. It is important that Specialist Palliative Care Services, are provided with a copy of the current Advance Care Directive and Resuscitation Plan - 7 Step Pathway. If an Advance Care Directive or Resuscitation Plan - 7 Step Pathway is revoked and/or a new version developed, this must be communicated with Specialist Palliative Care as a priority and with confirmation that they have received the information.

Ongoing Review of Advance Care Plans
Over the course of the patient’s illness their values and wishes for future health care may change. It is suggested that the Advance Care Directive is reviewed with the patient and, if appropriate, and any changes to their values or wishes documented in a new Advance Care Directive and/or Resuscitation Plan - 7 Step Pathway and shared with Specialist Palliative Care.
Resources

Advance Care Directives - Form & DIY Kit
The Advance Care Directive website at www.advancecaredirectives.sa.gov.au, provides information for health professionals and the public. The Advance Care Directive form is available to download and/or order from the website as well as an online version of the form and an Advance Care Directive Do-It-Yourself Kit including step-by-step guide.

Resuscitation Plan/Alert 7 Step Pathway Form – Community Version
A copy of the community version of the Resuscitation Alert 7 Step Pathway is included in Appendix 10.

Further Information, Resources and Training
Information, fact sheets and a poster on the 7 Step Pathway is available on the SA Health website at www.sahealth.sa.gov.au.
7. End of Life (Terminal Phase)

7.1 Care at End of Life

‘Good end-of-life care is based on the understanding that death is inevitable, and a natural part of life. As the final stage in a person’s life it is a uniquely important time for the dying person and their family and close friends.’ Recognising dying is the first step in terminal care management. The Therapeutic Guidelines: Palliative Care provide guidance in recognising that death is approaching.

The clinical priorities in the Terminal Phase are to:

- Talk to the patient and/or family
- Address symptoms
- Ensure needed medications are available
- Plan end-of-life care according to the setting
- Advise other health professionals

Clinical guidelines for the terminal phase are provided in the Terminal Care section of the Therapeutic Guidelines: Palliative Care and advice is available 24 hours, 7 days a week, by contacting the Specialist Palliative Care Service.

7.2 Site of Care

Patient care should be provided, where possible, in the setting of the patient’s choice. It is important that the person’s wish to die at home (or elsewhere) is identified and discussed well before the terminal phase. However, this may need to be reviewed as death draws closer because the patients’ care preferences or needs may change. Discuss the place of care with the patient and family as the situation unfolds. Moving to inpatient care such as hospital or palliative care unit should not be seen as a failure; it may be required if carers are becoming exhausted, or patient needs are overwhelming. (Palliative Care Expert Group, 2016, p. 362)

End of Life Care at Home

Many palliative care patients wish for a home death. The benefits of palliative care at home include a sense of normality, choice, and comfort. Home death is commonly viewed as a more dignified and comfortable experience than death in hospital. Whilst significant barriers to home deaths exist, some of these can be overcome by active planning and timely practical support. The GP’s involvement in supporting families in this phase is crucial. When a patient does not have access to a GP who will do home visits, assess, prescribe appropriate medications, and write a death certificate, then a home death may not be achievable.

GP Checklist – Planning for an expected home death

A checklist of issues for the GP to consider when helping a patient and their carers plan for a home death, produced by CareSearch and available at www.caresearch.com.au, is presented in Appendix 9.

Brochure for Carers – The dying process

This brochure, by Palliative Care Australia, provides advice for carers, including changes they may notice and what they can do to help, how they will know if death has occurred and what they should do. Online and PDF versions are available at http://palliativecare.org.au/the-dying-process.
End of Life Care in Residential Aged Care

‘Residents who are dying commonly experience distressing symptoms in the last days and hours of life. High quality end of life (terminal) care requires ongoing assessment of the resident and timely use of pharmacological and non-pharmacological strategies to address emerging symptoms. Failure to do so can result in poor resident/family outcomes as well as poor health system outcomes if dying residents are inappropriately transferred to emergency departments/hospital wards.’

‘As the dying resident may be clinical unstable, proactive management is necessary.

- Talk to the patient, family and carers about plans for their care
- Review anticipatory prescribing
- Ensure medicines are immediately available
- Doses should be regularly reviewed based on frequent reassessment of symptoms
- For persistent problems chart regular medications
- Always chart ‘as needed’ doses of required medications to cover “breakthrough” symptoms. These include pain, nausea, delirium, agitation, shortness of breath
- Administer medications by the most reliable route. In the dying patient, this is generally subcutaneous (SC)

Caring for a dying patient can be a trigger to review processes in working with residential aged care staff.’

Residential Aged Care Palliative Approach Toolkit

### 7.3 Prescribing Guidelines

All patients at the end of life are entitled to treatment at optimising their comfort and dignity. The treating team – doctors, nurses and other clinicians - responsible for the care of a dying patient must work together with the patient and their nominated carers/family members to ensure that the patient receives appropriate, timely and adequate treatment to prevent and relieve distress. This will usually include the prescribing of medications for symptom management.

**Anticipatory Prescribing**

Anticipatory prescribing is prescribing done in advance of the development of the occurrence of symptoms. It is designed to enable prompt symptom relief at whatever time the patient develops distressing symptoms and is based on the premise that although each patient has individual needs, many symptoms at the end of life are predictable, meaning management measures can be prepared in advance. (Government of South Australia, 2015)

The SA Health *Prescribing Guidelines for the Pharmacological Management of Symptoms for Adults in the Last Days of Life* outline recommended initial medications, doses and administration regimens for the management of common symptoms in the last days of life. The guidelines can be used:

- in response to a patient suffering from distressing symptoms, and/or
- in anticipation of distressing symptoms developing.

The guidelines are available on the SA Health website at [www.sahealth.sa.gov.au](http://www.sahealth.sa.gov.au) and included in Appendix 10 of this Framework. Refer also to the Therapeutic Guidelines: Palliative Care.

### Medication Cessation for Adults at the End of Life

Many maintenance or preventative medications prescribed for a patient may no longer be appropriate in the last days of life. Therefore, a thorough medication review should occur. This review becomes urgent as patients lose the ability to safely and effectively swallow oral medications and medication uptake by the gastrointestinal tract becomes unreliable.

The SA Health *Fact Sheet: Medication Cessation for Adults in the Last Days of Life* is available at [www.sahealth.sa.gov.au](http://www.sahealth.sa.gov.au) as shown in Appendix 11.

### 7.4 After Patient Death

#### Determination of Life Extinct and Certification of Cause of Death

There is a very distinct difference between the **assessment that life is extinct** and the **certification of the cause of death**.

**Assessment that Life is Extinct**

Assessment that life is extinct is a clinical assessment process which is undertaken to establish that the person is dead. Life extinct may be declared following this assessment. Where there is a **medical practitioner** available, the medical practitioner would determine that life is extinct (this may be performed at the same time as certifying cause of death).

SA Health have produced a policy guideline for the assessment and declaration of life extinct by registered nurses and midwives in the absence of a medical practitioner where patients die in a hospital, health centre, nursing home, hostel or at home. The guideline is used by public sector hospitals and health centres (incorporated under the South Australian Health Care Act 2008) and does not negate the need for certification of cause of death to be undertaken by a medical practitioner.
practitioner. Nurses and midwives are not to declare life extinct when it is reasonable for a medical practitioner to attend and perform the function.\textsuperscript{33}

Deaths that are Notifiable to the Coroner

‘The Coroners Act 2003 requires that a person immediately after becoming aware of a death that is, or may be, a reportable death, notify the State Coroner or SA Police.’\textsuperscript{29} A list of deaths that must be reported to the State Coroner in South Australia, and further information, is available at [www.courts.sa.gov.au/OurCourts/CoronersCourt/Pages/The-Coronal-Process.aspx](http://www.courts.sa.gov.au/OurCourts/CoronersCourt/Pages/The-Coronal-Process.aspx).

Notification and Certification of Death

For all deaths which are not required to be referred to the Coroner

The certification of cause of death is the process by which the time, specific details and causes of death are reported by a medical practitioner. A doctor who:

- was responsible for a person’s medical care immediately before death, or
- who examines the body of a deceased person after death?

must, within 48 hours after the death, give written notice of the death to the Registrar of Births, Deaths and Marriages (BDM), including the particulars required by regulation. When notice of a death is given, the doctor must also give a certificate (in a form approved by the Registrar of BDM), certifying the cause of death, (a) to the Registrar of BDM and (b) the funeral director or other person who will be arranging for the disposal of the human remains.\textsuperscript{30}


Burial and Cremation Forms


Further Information

Coronial officers and the Registrar of Births, Deaths and Marriages are happy to discuss concerns of medical practitioners about individual cases and questions of interpretation. Please see contact details below.

- **South Australia – State Coroner’s Office** Phone: (08) 8204 0600
- **Registrar of Births, Deaths and Marriages** Phone: 131 882

Planning & Communication

It is important that the GP and Specialist Palliative Care Service plan in advance for the tasks that need to be completed after the patient’s death. At the case conference, an initial discussion regarding who will be available and responsible for the assessment and declaration of life extinct, and for the completion of cause of death certificates, should occur and be documented. Further discussion and confirmation of any plans may be required as the terminal phase approaches.

The GP and Specialist Palliative Care Service need to determine who is responsible for planning conversations with the patient’s family and carer and ensuring that they are aware of what to do if death occurs in the community setting.
If a patient is expected to die at home, the family and carers need clear instructions (written down if necessary) on what to do when this happens, including (Palliative Care Expert Group, 2016, p. 362)

- How to recognise that the patient has died
- Who to call after the death?
- The GP’s wishes in relation to being called out at time of death (particularly if this occurs at night), or alternative arrangements if GP is not available
- That it is usually not necessary to call the police or an ambulance when an expected death occurs at home
- The need to contact a funeral director.

**Communication with ‘Shared Care’ team following death**

It is the responsibility of either GP or Specialist Palliative Care Service (depending on who is notified first) to inform the other members of the ‘shared care’ team that the patient has died.

**Practical Matters**

Practical matters for the GP to consider include (Palliative Care Expert Group, 2016, p. 385):

- completing legal requirements
- contacting the funeral director (often done by the family or carer)
- offering to contact a minister of religion or funeral celebrant
- contacting the Specialist Palliative Care and/or community nursing team; they can help with practical matters including organising support for the family
- communicating the death to relevant healthcare providers or health services (including the Specialist Palliative Care Service).

**Information for Family and Carers**

The Department of Human Services provide information for family and carers on *What to do following a death*, including practical matters, who to notify, funeral plans and government & community supports to help people adjust to life after someone close to them has died. Visit [www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death](http://www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death) for further information.

### 7.4 Bereavement

Grief and bereavement are a natural part of the dying process and the experience for the patient, family members and the health care team will be influenced by many factors. Whilst there are likely to be shared and commonalities of experience, the course is unique to each individual. The health care team can play a vital role in reducing the impact of bereavement on family members and carers. Counselling should be available to the patient throughout their end of life care and to their family members and carers, as well as the health care team, before and after the patient’s death.9

Bereavement is known to have a significant impact on the health of surviving family members and is associated with increases in mortality. In the first months of bereavement, mortality appears to be mostly due to accidental and violent deaths including suicide, alcohol related deaths, and an increase in deaths from ischaemic heart disease. Consequently follow up of family members and carers early within the bereavement phase is an important component of comprehensive palliative care and affords the opportunity to provide information/debriefing with respect to the death of a loved one, in addition to screening for both physical and emotional/mental health and well-being.
Assessment of Bereavement Risk

Within the GP PSC Program, there are no prescribed tools for the participating GP to use when assessing patient and carer bereavement risk. However, two commonly used assessment tools within specialist palliative care include the Bereavement Risk Index (BRI) (see Appendix 10) and Bereavement Risk Assessment Tool (BRAT). The Bereavement Risk Assessment Tool, or BRAT, is a psychosocial assessment tool used by care team members to communicate personal, interpersonal and situational factors that may place a caregiver or family member at greater risk for a significantly negative bereavement experience. Further information on the BRAT is available on the Victoria Hospice website at www.victorhospice.org/health-professionals/clinical-tools.

Post-death screening and assessment using the BRI and/or BRAT distinguishes between three risk categories and targets services at people who are most in need and where interventions are most effective. If the family member or carer has been identified with moderate to severe risk factors, the GP should consider referring them for specialist bereavement support in the community or the specialist palliative care bereavement team.

In a mental health emergency, contact the Mental Health Triage Service / Assessment and Crisis Intervention Service. Available 24 hours, seven days a week. Phone: 13 14 65.

Bereavement Follow-up after Death

Bereavement follow-up for the patient’s family and carer can be initiated by the GP or a member of the Specialist Palliative Care Service. The level of service will depend on the nature of the relationship between the deceased and bereaved, in addition to their anticipated needs.

Considerations for GPs in following up with the bereaved and possible strategies are provided in the CareSearch GP HUB: Bereavement available online at www.caresearch.com.au, and the ‘Grief, Loss and Bereavement’ section of the Therapeutic Guidelines: Palliative Care. GPs may also phone the Specialist Palliative Care Service for advice at any time. The GP Mental Health Treatment Items and programs including Better Access to Mental Health or Access to Allied Psychological Services (ATAPS) are available to support the bereaved, where appropriate.

(a) If the bereaved person is a patient of the GP who also provided the care to the deceased, the GP should offer an extended appointment to review the bereaved person’s overall health/mental health status and active medical conditions. This interaction provides opportunity to discuss grief and bereavement generally in addition to any issues of concern for the bereaved, assessment of their coping skills and the support networks available to the carer.

(b) If the bereaved person is not a patient of the GP, then depending on the individual circumstances, it may be appropriate for the GP to arrange for follow-up to occur with the bereaved person’s own GP.

Services & Support

Specialist Palliative Care Service – Bereavement Service

A person is eligible for a Specialist Palliative Care Bereavement Service if he/she:

- is a family member or carer of a patient who was registered with a Specialist Palliative Care Service (SPCS) at the time of death;
- has been identified as being at significant risk of poor outcomes; and
- understands and has consented to bereavement services.

A referral can be made by the general practitioner or directly by the individual family member/carer by contacting the Specialist Palliative Care Service which was responsible for the care of the patient. (N.B It is recommended that persons
with known mental health disorders who are experiencing exacerbations or deterioration of a previously stable condition be referred for further assessment and management to mental health services or specialist mental health providers). On receipt of the referral, a member of the psychosocial team may complete a BRI or BRAT with the family member or carer, if not previously completed by the GP. Further assessments to explore the complexity of grief may be conducted by psychosocial team members if required. The level of bereavement support and urgency of response will correspond with the need and risk identified through screening and assessment process.

**Community Support**

Individuals who are not eligible for specialist palliative care bereavement services or who have indicated a preference for other options may be able to access support from the following community groups and organisations -

- **Anglicare Grief and Loss Counselling** – Anglicare offer a specialised loss and grief counselling service for people of all ages who are bereaved or experiencing other types of loss. A fee for service applies with fees structured to ensure everyone is able to access counselling support. Anglicare SA Loss & Grief services also offer support groups and grief counselling for children and young people. Individuals can self-refer or they may be referred by their doctor or someone in the community. Visit [http://anglicaresa.com.au](http://anglicaresa.com.au) or phone: (08) 8131 3400

- **Compassionate Friends SA** – Compassionate Friends SA offer friendship and understanding to families following the death of a son or daughter, brother or sister, and support in the grief and trauma which follows the death of a child at any age and from any cause. Services include Support Group Meetings held at various locations in Adelaide, and Grief Telephone Support. Phone: (08) 8351 0344 or visit [www.compassionatefriendssa.org.au](http://www.compassionatefriendssa.org.au).

- **Grief Line** Community and Family Services Inc, provides free, confidential telephone (or online) counselling service to anyone in the community who is experiencing loss and grief. The volunteer counsellors are trained to listen, care and support. People who want to access support can call between 12.00 noon and 3.00 a.m. seven days a week, 365 day a year. Phone: 1300 845 745 or visit [www.grieflink.asn.au](http://www.grieflink.asn.au).

- **Lifeline** - The national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services. Phone: 1800 800 768 or visit [www.lifeline.org.au](http://www.lifeline.org.au).

- **Solace** – grief support for widows, widowers and partners provided by trained volunteers. Telephone and group support available. Phone: 8272 4334 or visit [www.solace.org.au](http://www.solace.org.au).
Appendix 1: GP Resources and Further Reading

**GP partners Australia**

Further information and resources to support GPs participating in the GP Palliative Shared Care program are available on the GP partners Australia website at [www.gppaustralia.org.au/psc](http://www.gppaustralia.org.au/psc).

**Therapeutic Guidelines: Palliative Care**

The Therapeutic Guidelines: Palliative Care provide concise information about common palliative care problems encountered by healthcare workers involved in the care of patients with a life-limiting illness. Further information on the Therapeutic Guidelines is available at [www.tg.org.au](http://www.tg.org.au).

**CareSearch – Palliative Care Knowledge Network**

CareSearch acknowledges GPs’ contribution to ensuring quality care at the end of life for all by linking them to palliative care tools, information, and resources in a GP Hub available at [www.caresearch.com.au](http://www.caresearch.com.au). The CareSearch GP Hub consolidates evidence and facilitates access to practical resources and Australian guidance.

**Palliative Care South Australia**

Palliative Care South Australia is the peak body for palliative care in South Australia. For information, resources and details of education & training opportunities, including Program of Experience in the Palliative Approach (PEPA), visit the Palliative Care South Australia website at [www.pallcare.asn.au](http://www.pallcare.asn.au).

**Decision Assist**

The Decision Assist project aims to enhance the provision of palliative care and advance care planning services to the aged nationally. The project includes the provision of clinical guidelines and resources, including a PalliAGED Smartphone App for GPs to enable quick access to clinical guidelines and medication advice. For further information visit [www.caresearch.com.au/caresearch/tabid/2583/Default.aspx](http://www.caresearch.com.au/caresearch/tabid/2583/Default.aspx).

**Residential Aged Care Palliative Approach (PA) Toolkit**

The Palliative Approach Toolkit includes a set of resources which, when used in combination, are designed to assist residential aged care providers to implement a comprehensive and evidence-based approach to care for residents, available at [www.caresearch.com.au](http://www.caresearch.com.au), including a Guide to the pharmacological management of end of life (terminal) symptoms in residential aged care residents – A resource for GPs.

**Advance Care Directives**

The Advance Care Directive website at [www.advancecaredirectives.sa.gov.au](http://www.advancecaredirectives.sa.gov.au), provides information for health professionals and the public. An Advance Care Directive form is available to download and/or ordered, an online version of the form can be completed and a Do-It-Yourself Kit including step-by-step guide is available on the website.

**Centre for Palliative Care**

The Centre for Palliative Care is part of St. Vincent’s Hospital Melbourne and is a Collaborative Centre of The University of Melbourne. The website at [www.centreforpallcare.org](http://www.centreforpallcare.org) provides clinical practice guidelines including *Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients, Family Meetings in Palliative Care.*

**Australian & New Zealand Society of Palliative Medicine (ANZSPM)**

ANZSPM) is a specialty medical society that facilitates professional development and support for its members and promotes the practice of palliative medicine. Visit [www.anzspm.org.au](http://www.anzspm.org.au).
Appendix 2: Metropolitan Adult Specialist Palliative Care Services

SA Health recognises specialist palliative care as a *specialised* health field which aims to meet the needs of people with a life limiting illness, drawing upon multidisciplinary practice across a range of health care settings; hospitals, hospices, outpatient clinics and community settings (e.g. home or residential aged care facilities).

Within metropolitan Adelaide, there are three regionalised, adult specialist palliative care services:

- **Northern Adelaide Palliative Service** (based at Modbury Hospital)
- **Central Adelaide Palliative Care Service** (based at The Queen Elizabeth Hospital)
- **Southern Adelaide Palliative Services** (based at Repatriation General Hospital)

For an illustrative guide to the service delivery areas covered by each of these services, refer to the Adelaide Metropolitan Hospital and Local health Network map.

Specialist Palliative Care Services & Support

| Eligibility Criteria | Specialist palliative care teams work in a consultative way with general practitioners and other health care providers, when symptoms and/or concerns exceed the capacity, resources, knowledge or skills of the treating health professional/s. A person is eligible for referral to a specialist palliative care services if:
| a) he or she have a progressive, life limiting illness 
| b) his or her, or his or her decision maker, is aware of, understands and has agreed to a palliative care referral; and 
| c) the primary goals of patient care are to control symptoms, maximise function, maintain quality of life and provide comfort. |

| Team Members | The composition of specialist palliative care teams differs across the three metropolitan sites and is dependent on local resourcing and demographic needs. Individual teams may comprise of:
| Administration staff 
| Allied health 
| Bereavement counsellors 
| Carer network facilitator (supports family carers) 
| Complementary care staff (e.g. massage therapist, music therapist) 
| Palliative Medicine Specialists and registrars 
| Nurse practitioners 
| Nurses (clinical practice consultants and/or clinical nurses) 
| Pastoral care services 
| Pharmacists 
| Psychiatrists and psychologists 
| Social workers and 
| Volunteer coordinator & volunteers |

SPCS support education and training of health professionals through clinical placements, and regularly have students as members of the multidisciplinary team.

| Specialist Skills & Knowledge | Palliative care clinicians build on a base of generalist skills and knowledge, to develop specialised expertise in providing care for patients with a life-limiting illness. Specialist palliative care clinicians:
| have knowledge of disease progression, and the anticipated interventions required during the dying process |
• have high level communication skills which include the ability to engage in:
  > advocacy for patient wishes including dignity, autonomy, quality of life and cultural and spiritual preferences, in line with legal documentation
  > collaborative practice
  > complex supportive care
  > conflict resolution including aggression management
  > deliver sensitive information and break bad news
  > therapeutic relationships
• can identify and respond to psychosocial distress, including bereavement needs
• can engage in contemplative, yet timely decision making
• have trans-disciplinary skills, with an awareness of when to refer to other members of the multidisciplinary team
• have an awareness and understanding of different cultural death practices
• have a personal resilience to death and awareness of self-care strategies

Individual team members may also have specialised skills and knowledge, recognised by an accrediting body.

### Supports & Services
For people with a life limiting illness who are being supported within the community (home or residential aged care facility), Specialist Palliative Care Services provide:
- specialist multi-disciplinary assessment
- care planning, including referral to and coordination of other additional services and equipment
- support to document end of life values and wishes
- treatment of complex symptoms
- psychosocial support
- pre and post bereavement support

### Approaches to Service Delivery
Specialist palliative care clinicians provide services using the following four approaches:
- **Advice and support** are provided to the treating health professional, based on patient information relayed to the specialist palliative care clinician. Clinical decision making remains the responsibility of the treating health professional.
- **Consult liaison** is provided to the patient through direct face-to-face contact, with or without the treating health professional present. Outcomes of the assessment and recommendations are discussed with the treating health professional. Clinical decision making remains the responsibility of treating health professional requesting the consultation.
  
  Note: the specialist palliative care clinician may recommend a follow-up consult to review the treatment plan.
- **Care coordination** is provided by a designated specialist palliative care clinician. It involves facilitating the appropriate delivery of health care services, sharing of information and ensuring referrals and supports are in place. Clinical decision making is shared and agreed between key persons involved in the patient’s care.
- **Specialist led care** is provided when the patient is admitted as an inpatient under the care of a Palliative Medicine Specialist. Clinical decision making is the direct responsibility of the SPCS.

### Service Hours
SPCS office hours vary across the metropolitan sites, and can range between 8am to 5pm, Monday to Friday. Specialist palliative care clinicians are routinely available between 9am to 4pm, Monday to Friday. **Note: All new referrals are triaged within office hours.**

Out-of-hours services, including telephone support and SA Ambulance Service support, are described under ‘After Hours Care’ in Section 4.3: Shared Care Arrangement of this Framework.
Specialist Palliative Care Service Referral Form

Palliative care referral form

An assessment by the palliative care team will aim to develop a management plan involving services that are appropriate to the patient's circumstance. Incomplete forms or absence of additional documentation will delay the process.

If the matter is URGENT, please telephone your local palliative care service.

Criteria for eligibility and a guide for referral to a palliative care service

If patient does not meet the three criteria below, please discuss your case with your local palliative care service.

☐ Patient has a progressive, life limiting illness
☐ Patient or their decision maker is aware of, understands and has agreed to a palliative care referral
☐ Primary goals of patient care are to control symptoms, maximise function, maintain quality of life and provide comfort

Patient information

Name ____________________________ DOB ____________________________
Address ____________________________ Sex ☐ Female ☐ Male
Suburb ____________________________ Postcode ____________________________ Medicare no. ____________________________
Phone ____________________________ Hospital/UR number (if relevant) ____________________________
☐ Lives alone ☐ Interpreter required/Language
☐ Patient's current location Planned discharge date (if relevant)

Indigenous status  ☐ Aboriginal  ☐ Torres Strait Islander  ☐ Both  ☐ Unknown  ☐ Neither

Essential contact - Substitute Decision Maker/Person Responsible (cross out which one does not apply)  

Name ____________________________ Phone ____________________________
Address ____________________________ Relationship ____________________________
Suburb ____________________________ Postcode ____________________________ ☐ To be present at assessment

Primary contact - (leave blank if this is the Substitute Decision Maker or Person Responsible)

Name ____________________________ Phone ____________________________
Address ____________________________ Relationship ____________________________
Suburb ____________________________ Postcode ____________________________ ☐ To be present at assessment

Life limiting illness

Primary diagnosis ____________________________ Comorbidities ____________________________

Date of diagnosis ____________________________

Reasons for referral - (please tick boxes to indicate your main reasons for referral)

☐ The patient requires a palliative care assessment and provision of service information
☐ Symptoms and/or concerns that exceed the capacity, resources, knowledge or skills of the primary care provider
  ☐ Nausea  ☐ Gastrointestinal  ☐ Psychosocial  ☐ Counselling  ☐ Spiritual  ☐ Functional
  ☐ Pain  ☐ Neurological  ☐ Dyspnoea  ☐ Services/Support  ☐ Other ____________________________
☐ Difficulty maintaining care at place of residence
☐ Terminal care (patient is in the last few weeks of life)
☐ Other ____________________________

1 Substitute Decision Maker - appointed under an Advance Care Directive and includes medical agent/enduring guardian.
Person Responsible - usually a close family member or friend.

Information contained in this referral form may be private and also may be the subject of legal professional privilege or public interest. If you are not the intended recipient, any use, disclosure or copying of this document is unauthorised under the Health Care Act 2008 and may attract a fine of up to $10,000. If you have received this document in error, please inform the appropriate Palliative Care Service.
# Palliative care referral form

**Additional information and documentation (including safety alerts)**

Please ensure relevant detailed medical letters and results accompany this form. Indicate attachments accompanying referral:

- [ ] Medical correspondence
- [ ] Pathology results
- [ ] Current medication list
- [ ] Radiology results

- [ ] Advance Care Directive
- [ ] Advance Care Plan
- [ ] Resuscitation Plan - 7 Step Pathway

Alert:

- [ ] Patient is receiving cytotoxic therapy

## Referrer and/or GP details

<table>
<thead>
<tr>
<th>Date of referral</th>
<th>☐ GP same as referrer</th>
<th>Referrers preferred response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrer name</td>
<td>GP name</td>
<td>☐ Consultation</td>
</tr>
<tr>
<td>Referrer phone</td>
<td>GP phone</td>
<td>☐ Shared care</td>
</tr>
<tr>
<td>Referrer address</td>
<td>GP address</td>
<td>☐ Other</td>
</tr>
<tr>
<td>Referrer signature</td>
<td>Provider no.</td>
<td></td>
</tr>
</tbody>
</table>

GP participates in the GP Palliative Shared Care Program: [ ] Yes [ ] No

## Refer to

**Metropolitan Services**

- [ ] Northern Adelaide Palliative Care  
  Phone: 8161 2499  
  Fax: 8161 2469
- [ ] Central Adelaide Palliative Care  
  Phone: 8222 0825  
  Fax: 8222 6955
- [ ] Southern Adelaide Palliative Care  
  Phone: 8275 1732  
  Fax: 8277 4957
- [ ] Paediatric Palliative Care  
  Phone: 8161 7994  
  Fax: 8161 6631

**Statewide Services**

- [ ] Lower North Palliative Care (Clare)  
  Phone: 8842 6559 / 8842 6500  
  Fax: 8842 6590
- [ ] Murray Mallee Palliative Care (Murray Bridge)  
  Phone: 8535 6800  
  Fax: 8535 6808
- [ ] Naracoorte Palliative Care  
  Phone: 8762 8160  
  Fax: 8762 8164
- [ ] Port Augusta Palliative Care  
  Phone: 1300 760 177  
  Direct phone (urgent): 8668 7706  
  Fax: 8668 7801
- [ ] Port Lincoln Palliative Care  
  Mob: 0427 006 983  
  Fax: 8682 5831
- [ ] Port Pirie Palliative Care  
  Phone: 8638 1100  
  Fax: 8115 5734
- [ ] Riverland Palliative Care (Barmera)  
  Phone: 8588 0435  
  Fax: 8588 0499
- [ ] South Coast Palliative Care (Victor Harbor)  
  Phone: 8552 0649  
  Fax: 8551 0424
- [ ] South East Palliative Care (Mt Gambier)  
  Phone: 8721 1460  
  Fax: 8721 1461
- [ ] Whyalla Hospital Palliative Care  
  Phone: 8648 8393  
  Fax: 8648 8479
- [ ] Yorke Peninsula Palliative Care (Wallaroo)  
  Phone: 8823 0289 / 8823 0270  
  Fax: 8823 2902

## Country Services

For metropolitan referrals to country, please direct to the Country Referral Unit.

For local referrals within country, please direct to the Country Referral Unit (preferred) or the relevant specialist palliative care service.

- [ ] Country Referral Unit  
  Phone: 1800 003 307  
  Fax: 1800 771 211
- [ ] Kadina Palliative Care  
  Phone: 8822 3030  
  Fax: 8822 3029
- [ ] Port Lincoln Palliative Care  
  Phone: 8638 1100  
  Fax: 8115 5734

## Instructions:

Once you have filled out the form, print and fax (do not email) to the relevant palliative care service with additional information attached.

Information contained in this referral form may be private and also may be the subject of legal professional privilege or public interest. If you are not the intended recipient, any use, disclosure or copying of this document is unauthorised under the Health Care Act 2008 and may attract a fine of up to $10,000. If you have received this document in error, please inform the appropriate Palliative Care Service.
# Appendix 3: The Broader Palliative Care Team

## Palliative Care Team Members in addition to GPs and Specialist Palliative Care

| Other Medical Specialists | The palliative team may include specialists in other fields for expert advice and management of patients with specific needs in these areas e.g. surgeons, oncologists, radiotherapists.

| Community Nurses | Nursing is a vital component of palliative care of patients living in the community. The nursing needs of palliative care patients range from basic hands-on care to complex and specialist problem solving. Any nurse may be required to provide palliative care on occasion. Specialist palliative care nurses and nurse practitioners are vital to the successful care of patients with complex problems, and in some settings may be the key healthcare providers. (Palliative Care Expert Group, 2016)

| Social Workers | Social workers help to organise a wide variety of practical supports, from arranging accommodation and social security benefits to facilitating legal matters such as making a will. Their role frequently merges into practical counselling. (Palliative Care Expert Group, 2016)

| Counsellor or Psychologist | Counsellors may support patients to address complex life issues, such as managing conflict between a patient and their family, between family members, or between a patient, family and care providers. Counsellors also follow up bereaved families and carers after the patient has died. (Palliative Care Expert Group, 2016)

| Pastoral Carer | The role of pastoral care staff is often not religious and involves providing help to patients dealing with issues such as inner conflict, the search for meaning and unresolved spiritual or religious issues. (Palliative Care Expert Group, 2016)

| Allied Health | A range of allied health providers provide essential skills that can be directed to help with the wide range of problems that can arise for patients and to optimise function, particularly for home based care. Providers include physiotherapists, occupational therapists, speech pathologists, dietitians, psychologists.

| Community Pharmacy / Pharmacist | Timely access to medicines within the community is important for palliative patients where their preferred place of care is the home environment. ‘Health practitioners should identify the patient’s usual community pharmacy and involve the pharmacist in discussions about care planning related to medicines for community-based palliative patients in advance.’ Pharmacists can also contribute expertise in the therapeutic use of medications, particularly as many palliative care patients have complex medication regimens with increased risk for drug-related problems.

| Volunteers | Volunteers often expand the range of services that can be offered to the patient and can give support to the family in the form of time and a helpful presence. They carry out a range of activities such as helping directly with care, transport, giving carers a break, minding children, doing basic jobs around the house, or providing companionship. Volunteers can usually be accessed through local palliative care services, community nursing services, church and community groups.

| Community Groups | Palliative Care South Australia and organisations devoted to specific diseases (e.g. cystic fibrosis, motor neurone disease) offer support to their members and/or to disadvantaged members to the community. A list of support groups and disease-based organisation is available on the CareSearch website at [www.caresearch.com.au](http://www.caresearch.com.au).
Appendix 4: GP Registration Form

GP Palliative Shared Care Program – Registration Form

PERSONAL DETAILS (as shown on AHPRA Registration)

Title: ________ Given Name(s): __________________________ Surname: __________________________

Preferred Name: __________________________ Gender: □ Male □ Female

Phone: __________________________ Email: __________________________

Languages spoken (other than English): __________________________

☐ General Practitioner ☐ Registrar (Completion date: ____________)

AHPRA Registration Number: __________________________ RACGP QI&CPD Number: __________________________

PRACTICE DETAILS

1. Practice Name: __________________________

   Address: __________________________

   Phone: __________________________ Fax: __________________________

2. Practice Name: __________________________

   Address: __________________________

   Phone: __________________________ Fax: __________________________

PARTICIPATION

• As a participant in the GP Palliative Shared Care Program:
  □ I would consider caring for new patients with a progressive, life limiting illness
  OR
  □ I am unable to accept new patients with a progressive, life limiting illness

• I consent to my name and practice details being included on the GP Palliative Shared Care Database, accessible to Specialist Palliative Care Services, GP Advisors and GP partners Australia.

Signature: __________________________ Date: __________________________

Please return the completed form to: GP partners Australia
Post: PO Box 7293, Hutt Street SA 5000
Phone: (08) 8112 1100 Fax: (08) 8227 2220
Email: info@gppaustralia.org.au
Appendix 5: GP/Referrer Faxback Form

To:
Fax:
Date:

Specialist Palliative Care: GP/Referrer Faxback Form
To ensure that we can liaise with you effectively, please assist us by completing this form and returning via the fax details above.

| Patient’s name: | | |
|-----------------|------|
| DOB: | |

| Referrer name: | Service/practice: | |
|----------------|-------------------|
| GP name: | Provider no.: |
| Phone number: | Fax number: |

<table>
<thead>
<tr>
<th>E-mail address:</th>
<th>Preferred method of contact:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant in the GP Palliative Care Program</td>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>In regards to this patient:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you available to provide home visits?</td>
<td>In hours:</td>
</tr>
<tr>
<td>Afterhours:</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Do you wish to be contacted after hours?</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Would you be willing to participate in a case conference?</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Do you prefer to:</td>
<td></td>
</tr>
<tr>
<td>4.1. be the primary decision maker for this patient, with the Specialist Palliative Care Service providing consultation when requested?</td>
<td>Yes or</td>
</tr>
<tr>
<td>4.2. work with the Specialist Palliative Care Service in a collaborative shared care model, inclusive of care coordination for community supports?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Please indicate your usual hours of work:

<table>
<thead>
<tr>
<th></th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td>AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

☐ My work hours vary each week

If I am not available, the following supports may be accessible to this patient eg name of another GP within the practice: ____________________________

Information contained in this facsimile message may be private and also may be the subject of legal professional privilege or public interest immunity. If you are not the intended recipient, any use, disclosure or copying of this document is unauthorized. If you receive this document in error, please call the sender.
Appendix 6: Palliative Care Assessment Tools

Palliative Care Phase

The palliative care phase identifies a clinically meaningful period in a patient’s condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patient, their family and carers. There are five phases in the palliative care phase assessment: Stable, Unstable, Deteriorating, Terminal, Bereaved (post death support). The phases provide a framework for referrals, triage and care planning as well as communication between teams. Phases are based on the principles that in palliative care, the focus is on patient needs, goals and priorities rather than the disease, the patient and their carers are the unit of care and that palliative care patients have episodes of care that include acute exacerbations. To document the phase - use the phase definitions and the algorithm. The PCOC recommend it is assessed routinely and whenever there is a change in the patient’s needs or a change in the family or carer needs impacting on the patient’s care. Note: Palliative Care Phases are not sequential. A patient can move back and forth between phases.

<table>
<thead>
<tr>
<th>Palliative Care Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Stable</td>
</tr>
<tr>
<td>All patients not classified as unstable, deteriorating, or terminal.</td>
</tr>
<tr>
<td>• The person’s symptoms are adequately controlled by established management. Further investigations to maintain symptom control and quality of life have been planned.</td>
</tr>
<tr>
<td>• The situation of the family/carer is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.</td>
</tr>
<tr>
<td>2. Unstable</td>
</tr>
<tr>
<td>• The person experiences the development of a new problem, or a rapid increase in the severity of existing problems, either of which requires an urgent change in management, or emergency treatment.</td>
</tr>
<tr>
<td>• The family/carers experience a sudden change in their situation requiring urgent intervention by member of the multidisciplinary team.</td>
</tr>
<tr>
<td>3. Deteriorating</td>
</tr>
<tr>
<td>• The person experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.</td>
</tr>
<tr>
<td>• The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.</td>
</tr>
<tr>
<td>4. Terminal</td>
</tr>
<tr>
<td>Death is likely in a matter of days and no acute intervention is planned or required.</td>
</tr>
<tr>
<td>• The typical features of a person in this phase may include the following:</td>
</tr>
<tr>
<td>− profoundly weak</td>
</tr>
<tr>
<td>− essentially bed-bound</td>
</tr>
<tr>
<td>− drowsy for extended periods</td>
</tr>
<tr>
<td>− disoriented for time and has a severely limited attention span</td>
</tr>
<tr>
<td>− increasingly disinterested in food and drink</td>
</tr>
<tr>
<td>− finding it difficult to swallow medication.</td>
</tr>
<tr>
<td>• This requires the use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues.</td>
</tr>
</tbody>
</table>
5. Bereaved

Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including counselling as necessary.

Australia-modified Karnofsky Performance Status (AKPS)

The Australia-modified Karnofsky Performance Status (AKPS) Scale is a measure of the patient’s performance across the dimensions of activity, work and self-care. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient’s ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status. To assess AKPS – use the AKPS definitions to determine the rating. The PCOC recommend assessing regularly e.g. at each contact (phone or in-person) and whenever there is a phase change.

<table>
<thead>
<tr>
<th>AKPS Assessment Criteria</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal; no complaints; no evidence of disease</td>
<td>100</td>
</tr>
<tr>
<td>Able to carry on normal activity; minor sign of symptoms of disease</td>
<td>90</td>
</tr>
<tr>
<td>Normal activity with effort; some signs or symptoms of disease</td>
<td>80</td>
</tr>
<tr>
<td>Cares for self; unable to carry on normal activity or to do active work</td>
<td>70</td>
</tr>
<tr>
<td>Able to care for most needs; but requires occasional assistance</td>
<td>60</td>
</tr>
<tr>
<td>Considerable assistance and frequent medical care required</td>
<td>50</td>
</tr>
<tr>
<td>In bed more than 50% of the time</td>
<td>40</td>
</tr>
<tr>
<td>Almost completely bedfast</td>
<td>30</td>
</tr>
<tr>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
<td>20</td>
</tr>
<tr>
<td>Comatose or barely rousable</td>
<td>10</td>
</tr>
<tr>
<td>Dead</td>
<td>0</td>
</tr>
</tbody>
</table>

Palliative Care Problem Severity Score (PCPSS)

The PCPSS is clinician rated and provides an assessment of a patient’s symptoms. The PCPSS facilitates the global assessment of four palliative care domains: pain, psychological/spiritual, other symptoms, and family/carer. It is an assessment of the overall severity of the problems. The family/carer domain measures the overall severity of problems relating to family or carer associated with the illness of the patient e.g. cultural, financial, denial, legal, conflict, accommodation, unrealistic goals, fatigue. Each domain is rated on a 4 point scale measuring the severity of the symptoms. Scores are used as triggers for referral, intervention or further assessment. PCPSS should be assessed routinely via telephone or in-person.

<table>
<thead>
<tr>
<th>PCPSS Domains</th>
<th>PCPSS Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>0 Absent</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>1 Mild</td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>2 Moderate</td>
</tr>
<tr>
<td>Family/carer</td>
<td>3 Severe</td>
</tr>
</tbody>
</table>
Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)

The RUG-ADL consists of four items (bed mobility, toileting, transfers and eating) and assesses the level of functional dependence, based on what a person actually does, rather than what they are capable of doing. This is best achieved by asking “Do you...?” rather than “Can you...?” The RUG-ADL describes the level of functional dependence. It is a four-item scale measuring motor function with activities of bed mobility, toileting, transfer and eating. There is no score of “2” for bed mobility, toileting and transfers. For bed mobility, toileting and transfers the change from independent/supervision to limited assistance was found to equate to a three-fold increase in resources. For eating, the same change equated to a twofold increase in use of resources.

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BED MOBILITY</strong></td>
<td></td>
<td>Ability to move in bed after the transfer into bed has been completed.</td>
</tr>
<tr>
<td>Independent or supervision only</td>
<td>1</td>
<td>Able to readjust position in bed, and perform own pressure area relief, through spontaneous movement around bed or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.</td>
</tr>
<tr>
<td>Limited physical assistance</td>
<td>3</td>
<td>Able to readjust position in bed, and perform own pressure area relief, with the assistance of one person.</td>
</tr>
<tr>
<td>Other than two persons physical assist</td>
<td>4</td>
<td>Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.</td>
</tr>
<tr>
<td>Two or more persons physical assist</td>
<td>5</td>
<td>Requires two or more assistants to readjust position in bed and perform pressure area relief.</td>
</tr>
<tr>
<td><strong>TOILETING</strong></td>
<td></td>
<td>Includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.</td>
</tr>
<tr>
<td>Independent or supervision only</td>
<td>1</td>
<td>Able to mobilise to toilet, adjusts clothing, cleans self, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.</td>
</tr>
<tr>
<td>Limited physical assistance</td>
<td>3</td>
<td>Requires hands-on assistance of one person for one or more of the tasks.</td>
</tr>
<tr>
<td>Other than two persons physical assist</td>
<td>4</td>
<td>Requires the use of a catheter/uridome/urinal and/or colostomy/bedpan/commode chair and/or insertion of enema/suppository. Requires assistance of one person for management of the device.</td>
</tr>
<tr>
<td>Two or more persons physical assist</td>
<td>5</td>
<td>Requires two or more assistants to perform any step of the task.</td>
</tr>
<tr>
<td><strong>TRANSFER</strong></td>
<td></td>
<td>Includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night.</td>
</tr>
<tr>
<td>Independent or supervision only</td>
<td>1</td>
<td>Able to perform all transfers independently or with prompting of carer. No hands-on assistance required. May be independent with the use of a device.</td>
</tr>
<tr>
<td>Limited physical assistance</td>
<td>3</td>
<td>Requires hands-on assistance of one person to perform any transfer of the day/night.</td>
</tr>
<tr>
<td>Other than two persons physical assist</td>
<td>4</td>
<td>Requires use of a device for any of the transfers performed in the day/night. Requires only one person plus a device to perform the task.</td>
</tr>
<tr>
<td>Two or more persons physical assist</td>
<td>5</td>
<td>Requires 2 or more assistants to perform any transfer of the day/night.</td>
</tr>
<tr>
<td><strong>EATING</strong></td>
<td></td>
<td>Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food. Does not include preparation of the meal.</td>
</tr>
</tbody>
</table>
### Symptom Assessment Scale (SAS) – For Patients (or proxy) to Complete

The Symptom Assessment Scale (SAS) is patient rated and describes the patient’s level of distress relating to individual physical symptoms. It can assist in identifying the effectiveness of clinical interventions, measuring changes, improvements or deterioration, and identifying patient priorities and tracking symptoms. The symptoms and problems in the scale are the seven most common experienced by palliative patients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain.

To use the SAS – utilise the SAS brochure and/or SAS patient form for the patient or proxy to rate symptom distress on a scale of 0-10. Symptoms that are not present are given a rating of ‘0’. Symptoms that are present are rated on a scale of 1 to 10. Additional symptoms (e.g. multiple pain sites, vomiting, cough) may be added in the blank spaces on the form and assessed in the same way. Highly rated or problematic symptoms may trigger other assessments.

The following SAS form, available in English and seven different languages, is available at [www.pcoc.org.au](http://www.pcoc.org.au).
Further Information

Further information on the following palliative care assessment tools is available on the University of Wollongong’s Palliative Care Outcomes Collaborative website at [www.pcoc.org.au](http://www.pcoc.org.au).

**Appendix 7: General Practitioner MBS Items**

**After Hours and Home Visits**

<table>
<thead>
<tr>
<th>Professional Attendance</th>
<th>Brief (Level A)</th>
<th>Standard &lt; 20 minutes (Level B)</th>
<th>Long 20-40 minutes (Level C)</th>
<th>Prolonged ≥ 40 minutes (Level D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consulting Rooms</td>
<td>3</td>
<td>23</td>
<td>36</td>
<td>44</td>
</tr>
<tr>
<td>Residential Aged Care Facility (RACF)</td>
<td>30</td>
<td>35</td>
<td>43</td>
<td>51</td>
</tr>
<tr>
<td>Place other than Consulting Rooms or RACF</td>
<td>4</td>
<td>24</td>
<td>37</td>
<td>47</td>
</tr>
</tbody>
</table>

**After Hours Attendance (Non-Urgent)**

<table>
<thead>
<tr>
<th></th>
<th>Brief (Level A)</th>
<th>Standard &lt; 20 minutes (Level B)</th>
<th>Long 20-40 minutes (Level C)</th>
<th>Prolonged ≥ 40 minutes (Level D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service</td>
<td>Duration</td>
<td>Organise, Coordinate &amp; Participate</td>
<td>Participate</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>--------------------------------</td>
<td>-----------------------------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>Consulting Rooms</td>
<td>Monday-Friday: before 8am or after 8pm Saturday: before 8am or after 1pm Sunday or public holiday: 24 hours</td>
<td>5000 5020 5040 5060</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential Aged Care Facility</td>
<td>Monday-Friday: before 8am or after 6pm Saturday: before 8am or after 12pm Sunday or public holiday: 24 hours</td>
<td>5010 5028 5049 5067</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place other than Consulting Rooms, RACF or Hospital</td>
<td>Monday-Friday: before 8am or after 6pm Saturday: before 8am or after 12pm Sunday or public holiday: 24 hours</td>
<td>5003 5023 5043 5063</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### After Hours Attendance - Urgent

<table>
<thead>
<tr>
<th>Service</th>
<th>Duration</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sociable Hours</td>
<td>Monday to Friday: 7am–8am and 6pm–11pm Saturday: 7am–8am and 12noon–11pm Sunday and/or public holiday: between 7am-11pm</td>
<td>597</td>
</tr>
<tr>
<td>Unsociable Hours</td>
<td>11pm-7am on any day</td>
<td>599</td>
</tr>
</tbody>
</table>

### Multidisciplinary Case Conference

<table>
<thead>
<tr>
<th>Duration of the Service</th>
<th>Organise, Coordinate &amp; Participate</th>
<th>Participate</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least 15 minutes and less than 20 minutes</td>
<td>735</td>
<td>747</td>
</tr>
<tr>
<td>At least 20 minutes and less than 40 minutes</td>
<td>739</td>
<td>750</td>
</tr>
<tr>
<td>At least 40 minutes</td>
<td>743</td>
<td>758</td>
</tr>
</tbody>
</table>

### Care Planning

<table>
<thead>
<tr>
<th>Patient Location</th>
<th>Service</th>
<th>Item No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient in the community (excluding Residential Aged Care)</td>
<td>Preparation of a GP Management Plan (GPMP)</td>
<td>721</td>
</tr>
<tr>
<td></td>
<td>Coordination of Team Care Arrangements (TCAs)</td>
<td>723</td>
</tr>
<tr>
<td></td>
<td>Review of a GPMP or TCAs</td>
<td>732</td>
</tr>
<tr>
<td>Patient living in a Residential Aged Care Facility</td>
<td>Contribution to a Multidisciplinary Care Plan (or to a review of a multidisciplinary care plan) for a resident in an aged care facility</td>
<td>731</td>
</tr>
<tr>
<td>Patient being discharged into the community from a hospital or hospice</td>
<td>Contribution to a Multidisciplinary Care Plan (or to a review of a multidisciplinary care plan) prepared by another provider</td>
<td>729</td>
</tr>
</tbody>
</table>
Appendix 8: Needs Assessment Tool: Progressive Disease (NAT:PD)
### SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>If dotted boxes are ticked, consider assessment by SPCS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient have a caregiver readily available if required?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Do you require assistance in managing the care of this patient and/or family?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### SECTION 2: PATIENT WELLBEING (Refer to the prompt sheet for assistance)

<table>
<thead>
<tr>
<th>Question</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is the patient experiencing unresolved physical symptoms (including problems with pain, breathlessness, sleeping, appetite, bowel, fatigue, nausea, oedema or cough)?</td>
<td>None/Severe/Significant</td>
<td>Directly managed by other care team member</td>
</tr>
<tr>
<td>2. Does the patient have problems with daily living activities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Does the patient have concerns about how to manage his/her medication and treatment regimes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Does the patient have concerns about spiritual or existential issues?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Does the patient have financial or legal concerns that are causing distress or require assistance?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Does the patient have concerns about his/her sexual functioning or relationship?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Does the patient require information about: (tick any options that are relevant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial/legal issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance directive/assisted decision order</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical/health/support services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social/emotional issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

COMMENTS: 

### SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR THE PATIENT (Refer to the prompt sheet for assistance)

<table>
<thead>
<tr>
<th>Who provided this information? (please tick one)</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family distressed about the patient’s physical symptoms?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family having difficulty providing physical care?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family having difficulty coping?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family having difficulty managing the patient’s medication and treatment regimes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family have financial or legal concerns that are causing distress or require assistance?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships, or is there a history of such problems?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the caregiver require information about: (tick any options that are relevant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical/health/support services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social/emotional issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What to do in event of patient’s death</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

COMMENTS: 

### SECTION 4: CAREGIVER WELLBEING (Refer to the prompt sheet for assistance)

<table>
<thead>
<tr>
<th>Who provided this information? (please tick one)</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family experiencing physical, physical, spiritual, existential, sexual or psychological problems that are interfering with their own wellbeing or functioning?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their own wellbeing or functioning?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

COMMENTS: 

### IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS REFERRAL SECTION

1. Referral to (Name) |
2. Referral to (Specialty) |
3. Priority of assessment: |
   - Urgent (within 24 hours) |
   - Non-Urgent (2-7 days) |
   - Non-Urgent (next available) |
4. Client consented to the referral: |
5. Referral from: |
   Name: |
   Position: |
   Signature: |

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# PATIENT WELLBEING

**Physical symptoms**
- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, diarrhoea, sleep problems or loss appetite?

**Activities of daily living**
- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

**Psychological**
- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

**Medication and treatment**
- Is the patient able to manage complex medication and treatment regimes?

**Spiritual/Existential**
- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

**Financial/Legal**
- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

**Sexual**
- Does the patient have concerns about his/her sexual functioning or relationship?

**Health Beliefs, Social and Cultural**
- Does the patient or family have beliefs or attitudes that make health care provision difficult?
- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.)

**Information**
- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?

# ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

**Physical symptoms**
- Are the patient's physical symptoms causing the caregiver or family distress?

**Providing physical care**
- Is the caregiver or family having difficulty coping with activities of daily living or practical issues such as equipment and transport?

**Psychological**
- Is the caregiver or family having difficulty coping with the patient's psychological symptoms?
- Is the caregiver or family requesting a hastened death for the patient?

**Medication and treatment**
- Is the caregiver or family having difficulty managing complex medication and treatment regimes?

**Family and Relationships**
- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

**Information**
- Does the caregiver or family want more information, eg about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)

# CAREGIVER WELLBEING

**Physical and psychosocial**
- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/ existential issues that are of concern?
- Does the caregiver have concerns about his/her sexual functioning or relationship?

**Bereavement Grief (pre and post death)**
- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

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Funded by the Australian Government Department of Health and Ageing and Cancer Council NSW.
Further copies are available at:  http://www.newcastle.edu.au/research centre/cherp/professional resources
Appendix 9:

GP Palliative Shared Care Program
Multidisciplinary Case Conference Record and GPMP with TCA

Introduction

Part 1 of this form has been designed as a step by step guide to assist GPs in the preparation, conduct and recording of a Multidisciplinary Case Conference as part of the GP Palliative Shared Care Program.

After the Multidisciplinary Case Conference has taken place, the later part of the form (Part 2) may also be used to complete a GP Management Plan (GPMP) with Team Care Arrangements (TCA).

Note: MBS Case Conferencing and GPMP/TCA items cannot be billed on the same day.

Part 1: Case Conference

INITIAL STEPS
(To be completed by the GP)

1. Obtain consent from the patient, Substitute Decision-Maker (SDM) or Person Responsible for the Case Conference to occur.

   Patient Name: ___________________________ Consent: [ ] Yes

2. Determine if the patient, SDM, Person Responsible, family members or carers will be attending/participating in the Case Conference and note here to allow confirmation of their attendance.

   Patient Attending? [ ] Yes [ ] No  Preferred Day/Time: ___________________________

   Name of others attending | Best Contact Number | Preferred Day/Time

3. From existing knowledge of the patient and their clinical situation, or in consultation with the patient, use the Key Issues Screening Questions in Part 2 of this document to identify and mark issues or problems relevant to discussion at the Case Conference or for action in a GPMP and TCA.
ARRANGING THE MULTIDISCIPLINARY CASE CONFERENCE
(This can be coordinated by GP, receptionist or practice nurse)

1. Phone the local Specialist Palliative Care Service (SPCS).
   - Northern Adelaide Palliative Service Phone: (08) 8161 2499
   - Central Adelaide Palliative Care Phone: (08) 8222 6825
   - Southern Adelaide Palliative Service Phone: (08) 8275 1732

   Inform the SPCS that you are calling on behalf of **Dr:** [Name] and ask to
   arrange a Case Conference for his/her **Patient:** [Name] who is a
   patient in the GP Palliative Shared Care Program.

   Note: You may need to speak with the Community Outreach Nurse for the patient to arrange the
   Case Conference. The Service will advise you of this.

2. Case Conference booked for **Date:** [Date] **Time:** [Time]

3. GP will attend the Case Conference at:
   - [ ] **GP Practice**
   - **Patient Home – Address:** [Address]
   - [ ] **Other location:** [Location]

4. SPCS will participate in the Case Conference by:
   - [ ] **SPCS team member/s attending in person**
   - **Teleconference:** GP to phone SPCS at the appointment time. **Phone:** [Phone]
   - **Teleconference:** SPCS to phone GP at the appointment time
   - [ ] **Videoconference:** Contact details [Details]

5. SPCS team member/s participating:

<table>
<thead>
<tr>
<th>Name of SPCS team member/s (if known)</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Confirm that the appointment is booked in the GP appointment book. **Appointment booked?** [ ]

7. Ensure that the patient, SDM, Person Responsible, family members or carers are notified of the time
   and location of the Case Conference if they are to attend (as above). **Other participants notified?** [ ]
CHECKLIST PRIOR TO ATTENDING THE APPOINTMENT/CASE CONFERENCE

Confirm (where relevant and appropriate):
- Teleconferencing or video conferencing technology to be used for the Case Conference is available and working
- GP Palliative Shared Care Patient Held Record is available
- Copies of Advance Care Directive and Resuscitation Plan-7 Step Pathway are available
- Patient medical history, medication list, allergy list and relevant correspondence are available

Patient

<table>
<thead>
<tr>
<th>Name:</th>
<th>DOB:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td>Medicare Number:</td>
</tr>
<tr>
<td>Address:</td>
<td>Pension Number:</td>
</tr>
<tr>
<td>Telephone:</td>
<td>DVA Number:</td>
</tr>
<tr>
<td></td>
<td>Private Health Insurance Details:</td>
</tr>
<tr>
<td>Primary Carer - Name &amp; Contact Details:</td>
<td>Family Contact - Name &amp; Details:</td>
</tr>
</tbody>
</table>

1. Record the Start time (and Finish time at the end of the Case Conference).

   Start Time: ________________ Finish Time: ________________ Duration: ________ minutes

2. Introduce the participants or allow participants to introduce themselves.

3. Record the names of the participants, their discipline and organisation

Case Conference Participants

(Required—At least 2 other care providers, in addition to the GP, who each provide a different type of care)

1. Name: ___________________________  Discipline: ________________
   Organisation: Specialist Palliative Care Service  Phone: ________________

2. Name: ___________________________  Discipline: ________________
   Organisation: Specialist Palliative Care Service  Phone: ________________

Other Participants (optional): e.g. Patient, family, carer
4. Some suggestions for opening discussion in the Case Conference:
   - Explain the reason for the Case Conference (e.g., a chance to meet treating team; identify and resolve problems; work out goals and actions required and by whom; plan for emergencies; and get everyone to be “on the same page”)
   - If the patient, SDM, Person Responsible, family members or carers are present, confirm what they know to be happening and allow them to state their goals or priorities
   - GP should clarify their knowledge of the situation, the priority issues (cover highlighted issues), and any questions
   - SPSC team members may clarify their knowledge of the situation, the priority issues, and any questions

5. Record all matters discussed in the section below or in the GP Management Plan and Team Care Arrangements section.

**Record of Case Conference**

*Import from Progress Notes*

**FOLLOWING THE CASE CONFERENCE**

1. Offer the patient and/or SDM, Person Responsible, family members or carers (if appropriate) a summary of the conference, provide the summary to the other team members and place in the Patient Held Record.

2. Discuss the outcomes of the conference with the patient and/or SDM, Person Responsible, family members or carers (if appropriate) if they were not present.

**MBS Multidisciplinary Case Conference Items**

<table>
<thead>
<tr>
<th>Duration of the Service</th>
<th>Participate</th>
<th>Organise, Coordinate &amp; Participate</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least 15 minutes and less than 20 minutes</td>
<td>747</td>
<td>735</td>
</tr>
<tr>
<td>At least 20 minutes and less than 40 minutes</td>
<td>750</td>
<td>739</td>
</tr>
<tr>
<td>At least 40 minutes</td>
<td>758</td>
<td>743</td>
</tr>
</tbody>
</table>

Note: In relation the MBS Items above, it is expected that a patient would not usually require more than five case conferences in any 12 month period.
Part 2: GP Management Plan and Team Care Arrangements

**GP MANAGEMENT PLAN CHECKLIST**

- Obtain patient consent for the development of a GPMP with TCAs
- Complete the **Key Issues Screening Questions**
- Clarify capacity of GP to be contacted by phone and hours that they can be contacted
- Clarify GP billing arrangements
- Clarify after hours arrangements
- Discuss Ambulance Response
- Discuss who to call and complete **Contact List**
- Place the following items in the Patient Held Record
  - Contact List
  - ACD if completed
  - Resuscitation Plan 7 Step Pathway
  - A copy of the Case Conference and/or GP Management Plan and Team Care Arrangements
  - An up to date medication list

**Planned review date: ____________________________**

<table>
<thead>
<tr>
<th>Patient</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td>DOB:</td>
</tr>
<tr>
<td></td>
<td>Gender:</td>
</tr>
<tr>
<td>Address:</td>
<td>Medicare Number:</td>
</tr>
<tr>
<td></td>
<td>Pension Number:</td>
</tr>
<tr>
<td>Telephone:</td>
<td>DVA Number:</td>
</tr>
<tr>
<td></td>
<td>Private Health Insurance Details:</td>
</tr>
<tr>
<td>Primary Care - Name &amp; Contact Details:</td>
<td>Family Contact - Name &amp; Details:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General Practitioner</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td>General Practice:</td>
</tr>
<tr>
<td>Provider Number:</td>
<td></td>
</tr>
<tr>
<td>Phone:</td>
<td>Fax:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Specialist Palliative Care Service</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Service: Northern/Central/Southern</td>
<td>Primary Contact:</td>
</tr>
<tr>
<td>Phone:</td>
<td>Fax:</td>
</tr>
</tbody>
</table>
**Other Care Providers – Team Care Arrangements**  
*e.g. Community Nurse (RDNS), Allied Health, Pharmacist, Domestic/Personal Care Provider*  

<table>
<thead>
<tr>
<th>Name:</th>
<th>Contact Details:</th>
<th>Treatment and services they have agreed to provide:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**CLINICAL**

**Medical Conditions:**

**Medication List:**

**Allergies/Alerts:**
Key Issues Screening Questions

Advanced Planning – consider:
- Does the patient understand the diagnosis and prognosis?
- Does the patient have a ACD? (if not and they remain competent, suggest that they complete one)
- Does the patient have a Resuscitation Plan-7 Step Pathway? (if not discuss and offer to complete)

<table>
<thead>
<tr>
<th>Identified Issues</th>
<th>Actions</th>
<th>Who will address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

Emergency Contacts and Substitute Decision Makers:
- Clarify SDMs/Persons Responsible
- If they are present clarify their responsibility to “act in the patient’s shoes”
- Clarification of other main contacts and who should be contacted in an emergency

<table>
<thead>
<tr>
<th>Identified Issues</th>
<th>Actions</th>
<th>Who will address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

Symptom Management
- Does the patient have distressing symptoms?
- Common symptoms: fatigue, anorexia, pain, depression, nausea, constipation, breathlessness

<table>
<thead>
<tr>
<th>Identified Issues</th>
<th>Actions</th>
<th>Who will address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Care Needs and Supports – consider:
- Can the patient manage their own ADLs?
- Does the patient have adequate supports?
- What is the capacity of those providing supports, and do they need further support?
- Are there any service providers currently involved, or that should be involved?

<table>
<thead>
<tr>
<th>Identified Issues</th>
<th>Actions</th>
<th>Who will address</th>
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</thead>
<tbody>
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</tbody>
</table>

Other Issues to Consider:
- Psychosocial issues
- Financial issues
- Housing

<table>
<thead>
<tr>
<th>Identified Issues</th>
<th>Actions</th>
<th>Who will address</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>
Appendix 10: Resuscitation Alert 7 Step Pathway

RESUSCITATION ALERT
RESUSCITATION PLAN –
7 STEP PATHWAY
(COMMUNITY VERSION)

Home / Facility

4. RESUSCITATION PLAN

Note: A treatment option or procedure (e.g. ICU, surgical procedure, dialysis) must not be offered, recommended, or inferred to be available, without prior discussion with, and the agreement of, the relevant clinical team which provides this treatment or procedure.

Indicate if the following decisions about resuscitation apply:

[ ] Patient/resident is Not for any Treatment Aimed at Prolonging Life (including CPR)
Or you may specify individually each or all of the following that apply:

[ ] Patient/resident is Not for CPR
[ ] Patient/resident is Not for invasive ventilation (i.e. intubation)
[ ] Patient/resident is Not for intensive care treatment or admission
[ ] Patient/resident is Not for the following procedures or treatment (specify):

Medical Emergency Response (MER) FOR HOSPITAL USE ONLY
To be completed by the admitting doctor upon admission if patient/resident is hospitalised.

Please circle which applies: MER Call Yes MER Call No
Hospital: ................................................................. Name of doctor: .................................................................
Date: ................................ Designation: ................................ Signature: .................................................................

Indicate treatment that will be provided:

Note:
• A decision not to provide CPR does not rule out other treatment or medical care (e.g. IV fluids, antibiotics) being provided.
• Treatment must include a plan (or a contingency plan) to maintain patient/resident comfort and dignity. This could include the prescription of medications to control symptoms such as pain and dyspnoea, or referral to Palliative Care.

☐ NOT FOR TRANSFER TO HOSPITAL unless palliative care measures fail to maintain the comfort and dignity of the patient/resident in their place of residence.

5. TRANSPARENCY

Resuscitation plan explained to: ☐ Patient/resident (mandatory if he/she has capacity) or
☐ Substitute Decision-Makers/Person Responsible Name: .................................................................
☐ Tick if an interpreter is used: Interpreter’s Name: .................................................................

Take practical steps to 6. IMPLEMENT the plan and to 7. SUPPORT the patient/resident and family through the process

Resuscitation Plan Date: / / This Resuscitation Plan is valid until:
Practical/ mobile number
Name of Doctor
Designation
Signature

To revoke this Resuscitation Plan (strike through and write VOID):
Date revoked: / / Name of Doctor revoking the plan:
Date: or
[ ] Indefinitely or until revoked
Designation:
Signature:

Original copy – file in the patient’s/resident’s medical record
Duplicate copies – provide to the patient/resident and the patient/resident’s facility/carer if applicable
Read accompanying instructions before completing.

This form is intended to be used by registered medical practitioners responsible for coordinating the medical care of a patient in South Australia. The medical practitioner should be competent in using the Resuscitation Planning - 7 Step Pathway process in accordance with SA Health Resuscitation Planning - 7 Step Pathway Policy, the South Australian Advance Care Directive Act 2013 and the Consent to Medical Treatment and Palliative Care Act 1995, and relevant professional practice standards. The SA Health version of this form should be used in SA Health services.

Interns are not permitted to complete this form.

1. TRIGGER
Complete this form early if the clinical situation requires decisions about resuscitation or end of life care. However, the urgency to complete this form needs to be balanced with sensitivity to the readiness of the patient/resident and family to discuss these issues. Refer to Resuscitation Plan - 7 Step Pathway instructions for the 5 trigger criteria.

2. ASSESSMENT
Is there adequate clinical information to allow decisions to be made about resuscitation and/or end of life care? If YES [ ] > Continue with the plan.

3. CONSULTATION
If possible, discuss the clinical situation (e.g. diagnoses, prognosis, treatment options and recommendations) with the patient/resident, Substitute Decision-Makers, and/or Person's Responsible (and where possible, individuals that the patient/resident wishes to be involved in this planning).

IMPORTANT: Interpreter use is recommended for non or limited English speakers.

Does the patient/resident have decision-making capacity?

Yes ☐ The clinical situation must be discussed with the patient/resident
No ☐ This must be documented in the case notes and a reasonable attempt should be made to consult at least one of the following documents (if the patient/resident has one) or individuals - in order of priority below:

1. Person with an Advance Care Directive under the Advance Care Directives Act 2013
   - Substitute Decision-Maker appointed for health care decisions under an Advance Care Directive
     Name/s: ...........................................................................................................
   - Advance Care Directive with relevant instructions and NO Substitute Decision-Maker

2. If they do not have a new Advance Care Directive (Advance Care Directives Act 2013)
   - A Medical Agent or an Enduring Guardian
     Name/s: ...........................................................................................................
   - Anticipatory Direction

3. If none of the above, a Person Responsible in the following legal order:
   - Guardian appointed by the SA Civil and Administrative Tribunal (formerly Guardianship Board)
     Name/s: ...........................................................................................................
   - Prescribed relative (adult with a close and continuing relationship, available and willing, and who is related to the person by blood, marriage, domestic partner, adoption or Aboriginal kinship rules/marriage)
     Name/s: ...........................................................................................................
   - Close adult friend who is available and willing to make a decision
     Name/s: ...........................................................................................................

   If there is no one in the above categories then:
   - Someone charged with the day-to-day care and well-being of the patient/resident (the person must be willing to provide consent and follow applicable employer policy)
     Name/s: ...........................................................................................................
   - SA Civil and Administrative Tribunal (SACAT), upon application

OR ☐ If the patient/resident does not have capacity, and it has not been possible to find one of the above documents or individuals in time, complete the Resuscitation Plan in line with Good Medical Practice*

Note: If there is an Advance Care Plan (e.g. Statement of Choices, Palliative Care Plan), it must be referred to by those making decisions above.
## Appendix 11: GP Checklist – Planning for an expected home death


### Considerations for End of Life (Terminal Phase) Care at Home

<table>
<thead>
<tr>
<th>Areas</th>
<th>Issues to Consider</th>
</tr>
</thead>
</table>
| Clarifying Patient and Carer Expectations | • Has the patient indicated that they want to stay at home to die?  
  > Confirm that the plan has been discussed with the family  
  > Consider young children and others with care needs in the household  
• Do those who live with the patient know about and share that wish?  
  > Consider their practical, hands on availability for round the clock care  
  > Encourage a roster, with time out  
  > It is possible to determine the patient’s prognosis, in order to help the family plan ahead and marshal their resources? e.g. is care likely to be needed or hours, days or for a week.  
• Are there enough people to share the care?  
  > Clarify and document the plan and ensure that it is realistic, and understood by all involved  
  > Consider whether there are specific services that can support families caring for someone who is dying at home  
  > Provide a letter (or Ambulance Plan) describing the palliative goals of care in case of a triple zero call, clearly stating that the patient is dying and that cardiopulmonary resuscitation is not appropriate. |
| Assess the Home Situation | • Will the patient be able to be cared for safely and comfortably in the home?  
  > Refer to home nursing or palliative care nursing services, and ask them to teach the family about how to provide care safely  
  > Confirm how much nursing support is available. Specifically, how many visits can the patient have?  
  > Assess complex nursing needs that will be difficult to manage at home e.g. difficult wounds, fistulas, spinal analgesia etc  
• Consider equipment that may be needed to nurse a bed-bound patient e.g. a hospital bed, mobility aids, commodes, and other personal care equipment (wheelchair, pressure mattresses etc)  
  > Specialist Palliative Care may arrange an occupational therapist (OT) and/or physiotherapy assessment to advise on and organise equipment.  
• Discuss the option of an in-dwelling catheter to reduce the burden on both patient and family in the terminal phase.  
• Encourage the family to think about any practical rearrangements that might make caring easier or safer, for example:  
  > Moving a patient’s bed to a different room, or  
  > Relocating the patient and carers to a different family member’s home (remembering however that move into a different area my disrupt their eligibility for services, so plan ahead with this)  
• Organise who will provide the “life extinct” form and “death certificate”. |
| Plan for Symptom Management | • Review long-term medications – cease any that no longer contribute to the patient’s comfort |
Prompts planning for symptoms and changing circumstances.

- Consider anticipatory prescribing
- Discuss with the family how the patient's symptoms will be reviewed and managed:
  - Consider whether home nurses will report to the GP
  - Explain how often GP visits will occur
  - Describe what the palliative care service will do
  - Arrange prescriptions in advance and check availability with usual pharmacy
  - Plan for predictable, common symptoms that occur at the end-of-life, which may include:
    - Shortness of breath
    - Anxiety
    - Nausea
    - Excessive secretions
    - Delirium; or
    - Pain
- Ensure PRN medicines are available in the house for when they are needed. This is best done well in advance as deterioration can be unpredictable.
  - Consider whether home nurses will report to the GP
  - Check whether home nurses will report to the GP
  - Discuss with the family how the patient's symptoms will be reviewed and managed:
    - Consider whether home nurses will report to the GP
    - Explain how often GP visits will occur
    - Describe what the palliative care service will do
    - Arrange prescriptions in advance and check availability with usual pharmacy
    - Plan for predictable, common symptoms that occur at the end-of-life, which may include:
      - Shortness of breath
      - Anxiety
      - Nausea
      - Excessive secretions
      - Delirium; or
      - Pain
- Ensure PRN medicines are available in the house for when they are needed. This is best done well in advance as deterioration can be unpredictable.
  - Subcutaneous medicines are preferred to ensure continuing symptom control, using with bolus medicines via:
    - subcutaneous butterfly needle, or
    - a syringe driver with a 24 hour infusion, or
    - a combination of these
  - Remember – dying patients cannot take oral medicines
  - Arrange for family member to be taught how to give breakthrough doses by the palliative or home nurses
  - Check that medicines are available at a community pharmacy, and that the carers have an adequate supply to get through after hours and weekends in particular
- Consider whether a plan is needed for high risk problems such as:
  - Bleeding risk
  - Bowel or airway obstruction
- If care needs are complex, or a high risk of bleeding or airway obstruction exists, seek early advice from a palliative care specialist.

For further advice visit the CareSearch GP HUB: ‘Guidance on managing end-of-life symptoms’ at www.caresearch.com.au.

Information Families Need

Highlights what information the families will need while caring and after death.

- Are the carers fully prepared for the fact that the patient will be dependent and bed bound?
- Dot the carers need information about eating and drinking in the palliative care situation? For instance:
  - That the loss of appetite is a common and predictable feature of advanced disease?
  - That swallowing deteriorates with the approach of the terminal phase?
  - Do they need ideas about what, and how much, to offer the patient to eat and drink, and how to do this safely?
- Do the carers need information about physical changes that occur as the patient is dying? For example:
  - Changes in breathing patterns, including the possibility of terminal secretions (“death rattle”)
  - Changes in skin colour and temperature
  - Changes in level of consciousness, including the possibility of terminal delirium.
- Ensure that the family has access to 24 hour phone advice about symptoms or changes in the patient’s condition, and that everyone providing care knows who to contact.
- Do the carers need information about what to do after the patient dies? For example:
  - Encourage them to think about choosing a funeral director
<p>| | |</p>
<table>
<thead>
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</table>

> Reassure them that there is no urgency to ring anyone after the patient dies.
> Ensure that they know which doctor has agreed to certify death, and the arrangements for contacting them.
Appendix 12: Prescribing Guidelines

Prescribing Guidelines for the Pharmacological Management of Symptoms for Adults in the Last Days of Life
Informal Copy when Printed or Downloaded

Prescribing Guidelines for the Pharmacological Management of Symptoms for Adults in the Last Days of Life

All patients at the end of life are entitled to treatment at optimising their comfort and dignity. The treating team – doctors, nurses and other clinicians – responsible for the care of a dying patient must work together with the patient and their nominated carers/family members to ensure that the patient receives appropriate, timely and adequate treatment to prevent and relieve distress. This will usually include the prescribing of medications for symptom management.

Anticipatory prescribing

There are several common symptoms that may cause distress in dying patients. Ordering medications ahead of time, ‘anticipatory prescribing’, is required so that prompt management of these symptoms can occur.

When to use these guidelines:

These guidelines outline recommended initial medications, doses and administration regimes for the management of common symptoms in the last days of life. The guidelines can be used:

- in response to a patient suffering from distressing symptoms, and/or
- in anticipation of distressing symptoms developing.

These guidelines have been developed for use in SA Health inpatient settings.

BEFORE WRITING UP MEDICATION ORDERS

- Discuss the need for medications to support symptom management with the patient and/or substitute decision maker(s). Record shared decisions made in the case notes.
- Review the patient’s current medications and consider:
  - ceasing any non-beneficial or burdensome medications and continuing essential medications via the subcutaneous route where possible
  - the potential development of distressing withdrawal symptoms if specific medications are abruptly ceased (refer to Medication Cessation for Adults in the Last Days of Life fact sheet)
- Be aware that the medications and doses outlined in these guidelines may be inadequate if the patient is already prescribed analgesics (particularly moderate to high dose opioids), anxiolytics, anti-emetics or anticonvulsants
- Check for allergies and for potential contraindications, interactions or side effects.

WHILE WRITING UP THE MEDICATION ORDERS

- Ensure that the reason for administering the medication is documented in the ‘indication’ box of each medication, using terms consistent with those used in the table overleaf.

AFTER MEDICATION ORDERS ARE WRITTEN UP

- Ensure the patient is monitored and commence medications as soon as symptoms are identified
- Review treatment outcome for effectiveness and side effects
- Regularly review the management plan with the patient and/or substitute decision maker(s).
- Ensure handover to all medical and nursing staff involved in the care of the patient; for example, at shift changes, on transfer of the patient to another ward or facility, or on discharge of the patient.

URGENT CLINICAL REVIEW is required if:

- there is inadequate relief of a symptom despite three maximum doses administered in succession at the shortest specified time interval, or
- there is any clinical concern.

Further information about symptom management, prescribing or administering medications, or other related issues may be obtained from:
- Therapeutic Guidelines: Palliative Care

Urgent phone advice can be obtained from Specialist Palliative Care Services: contact via the relevant hospital switchboard.
<table>
<thead>
<tr>
<th>INDICATION</th>
<th>MEDICATION</th>
<th>DOSE</th>
<th>ROUTE</th>
<th>FREQUENCY</th>
<th>PRACTICE POINTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain or Dyspnoea</td>
<td>Morphine</td>
<td>2.5mg to 5mg</td>
<td>Subcut</td>
<td>every hour as</td>
<td>&gt; Doses listed are for opioid naive patients.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>required</td>
<td>&gt; Where opioids are already prescribed, convert regular oral opioid dose to the appropriate 24-hour subcutaneous dose and administer by a continuous subcutaneous infusion.</td>
</tr>
<tr>
<td></td>
<td>Fentanyl</td>
<td>25 microgram to 50 microgram</td>
<td>Subcut</td>
<td>every hour as</td>
<td>&gt; HYDROMorphone is approximately FIVE times more potent than morphine.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>required</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hydromorphone</td>
<td>0.5mg to 1mg</td>
<td>Subcut</td>
<td>every hour as</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>required</td>
<td></td>
</tr>
<tr>
<td>Anxiety or Terminal Restlessness</td>
<td>Clonazepam</td>
<td>0.25mg to 0.5mg</td>
<td>Subcut</td>
<td>every 12 hours</td>
<td>&gt; Clonazepam has a long duration of action and is prone to accumulate and lead to over sedation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>as required</td>
<td>&gt; Midazolam has a very rapid onset and short duration of action. It is preferred if amnesia and sedation are required. A subcutaneous infusion is required to achieve sustained effect.</td>
</tr>
<tr>
<td></td>
<td>Midazolam</td>
<td>2.5mg</td>
<td>Subcut</td>
<td>every hour as</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>required</td>
<td></td>
</tr>
<tr>
<td>Delirium or Agitation</td>
<td>Haloperidol</td>
<td>0.5mg to 1mg</td>
<td>Subcut</td>
<td>every 2 hours</td>
<td>&gt; Avoid haloperidol in Parkinson’s Disease - olanzapine is preferred.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>as required, to</td>
<td>&gt; A benzodiazepine may be used in addition to an antipsychotic but should not be used alone.</td>
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<td></td>
<td></td>
<td>a maximum of</td>
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<td></td>
<td></td>
<td></td>
<td>10mg per 24 hours</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>Metoclopramide</td>
<td>10mg</td>
<td>Subcut</td>
<td>every 4 hours</td>
<td>&gt; Metoclopramide is contraindicated in suspected bowel obstruction</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>as required, to</td>
<td>&gt; Avoid using metoclopramide and haloperidol in Parkinson’s Disease or if extrapyramidal side effects are distressing - ondansetron is preferred</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a maximum of</td>
<td>&gt; Haloperidol is useful in patients with or at risk of concurrent delirium or agitation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>30mg per 24 hours</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Haloperidol</td>
<td>0.5mg to 1mg</td>
<td>Subcut</td>
<td>every 4 hours</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>as required</td>
<td></td>
</tr>
<tr>
<td>Gurgly / Noisy Breathing</td>
<td>Hyoscine butylbromide</td>
<td>20mg</td>
<td>Subcut</td>
<td>every 4 hours</td>
<td>&gt; Start early and evaluate response. Cease therapy if ineffective after 3 consecutive doses.</td>
</tr>
<tr>
<td>Required ward imprest list</td>
<td>Clonazepam 1mg/mL injection</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Midazolam 5mg/mL injection or 15mg/mL injection</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Haloperidol 5mg/mL injection</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Metoclopramide 10mg/mL injection</td>
<td></td>
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<tr>
<td></td>
<td>Hyoscine butylbromide 20mg/mL injection</td>
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</tr>
<tr>
<td></td>
<td>Fentanyl 100 microgram/2mL injection</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hydromorphone 2mg/mL injection</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For further information, refer to the Clinical Guideline for the Pharmacological Management of Symptoms for Adults in the Last Days of Life.

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Appendix 13: Medication Cessation for Adults in the Last Days of Life

Fact Sheet

Medication Cessation for Adults in the Last Days of Life

Many maintenance or preventative medications prescribed for a patient may no longer be appropriate in the last days of life. Therefore, a thorough medication review should occur. This review becomes urgent as patients lose the ability to safely and effectively swallow oral medications and medication uptake by the gastrointestinal tract becomes unreliable.

Prior to ceasing

While many medications can be stopped abruptly without significant risk, the following factors should be considered prior to doing so:

- pharmacology and pharmacokinetics of the medication
- the risk of recurrence of symptoms
- adverse drug withdrawal effects
- rebound phenomenon
- patient/substitute decision-maker preferences and shared decision-making

Options for managing potential problems

If there is concern about any of the above, the following options could be considered:

- practicality of a tapered withdrawal of medication in the last few days of life
- change to route of administration
- substitution with another medication with an appropriate formulation
- prescribing medications for symptomatic relief of withdrawal effects or recurrence of effects.

Where available, a pharmacist may be able to provide some guidance in these areas. If there is any uncertainty or concern, the relevant specialty area should be consulted for advice.

The medications and doses recommended in the Prescribing Guidelines for the Pharmacological Management of Symptoms for Adults in the Last Days of Life can be used to provide symptomatic relief of withdrawal effects where appropriate.

Shared Decision making and informed consent in the cessation of medications

Changes to or cessation of medications should be discussed with the patient, substitute decision makers (SDMs) and nominated carers/family members. The limited benefit of continuing medications in the last days of life should be explained and reassurance provided that medications can be prescribed to relieve troubling symptoms which may emerge.

The patient, SDMs or family may be greatly concerned when long term medications which have been emphasised as essential, are ceased. Cessation of these medications may also be perceived as a sign of ‘giving up’ and imminent death. Explain to the patient, SDM and family that stopping a medication neither intends to hasten death nor represents a decreased level or quality of care, but rather is part of the overall plan to provide best care and comfort.
Managing potential withdrawal effects

The table below lists some common medications or classes of medications, which may be associated with withdrawal effects. This is not a comprehensive list and only general recommendations have been made for treatments which may provide symptomatic relief from these withdrawal effects. Patient specific factors may influence management choice and the relevant specialty area should be consulted for advice if there is any uncertainty or concern.

<table>
<thead>
<tr>
<th>Drug Class</th>
<th>Potential Withdrawal Effects</th>
<th>Recommendations for Managing Withdrawal Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha-blockers</td>
<td>Rebound hypertension, agitation with sudden cessation</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>Anxiety, headache, dizziness</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td></td>
<td>Nausea, vomiting</td>
<td>Treat symptomatically with antiemetic.</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>Re-emergence of seizures</td>
<td>Treat with parenteral benzodiazepine. Seek relevant specialist advice.</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>Dysphoric mood, agitation, headache</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>Dyskinesia, nausea, vomiting, agitation</td>
<td>Convert to equivalent dose of regular parenteral antipsychotic. Seek specialist advice.</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>Withdrawal adverse effects, e.g., delirium, insomnia, seizures</td>
<td>Convert to equivalent dose of 12 hourly subcutaneous clonazepam or a continuous subcutaneous midazolam infusion. Seek relevant specialist advice.</td>
</tr>
<tr>
<td>Beta-blockers</td>
<td>Rebound tachycardia, palpitations, re-emergence of angina</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td>Digoxin &amp; other</td>
<td>Re-emergence of rapid atrial fibrillation or other arrhythmias</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td>antiarrhythmics</td>
<td>Re-emergence of fluid retention associated with heart failure</td>
<td>Treat symptomatically with opioid or benzodiazepine.</td>
</tr>
<tr>
<td>Diuretics</td>
<td>Re-emergence of angina</td>
<td>Convert to nitrate patch. Treat symptomatically with opioid.</td>
</tr>
<tr>
<td>Nitrates</td>
<td>Re-emergence of angina</td>
<td>Unlikely to develop acute adrenal crisis, but if concerned, seek relevant specialist advice.</td>
</tr>
<tr>
<td>Steroids</td>
<td>Hypothalamic-pituitary axis suppression in long-term use</td>
<td>Re-emergence of painful inflammatory condition</td>
</tr>
</tbody>
</table>

Adapted from J Pharm Pract Res 2011; 41: 146-51.

For more information:
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Appendix 14: BRI and BRAT

Modified Bereavement Risk Index$^24$

Form 6: Modified bereavement risk index

Name of Resident: 

Name of family carer: 

Relationship to resident: 

Contact details of family carer 

Address: 

Phone number: [H] [W] [M] 

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Anger</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Mild irritation</td>
<td>2</td>
</tr>
<tr>
<td>Moderate (occasional outbursts)</td>
<td>3</td>
</tr>
<tr>
<td>Severe (spoiling relationships)</td>
<td>4</td>
</tr>
<tr>
<td>Extreme (always bitter)</td>
<td>5</td>
</tr>
<tr>
<td>2 Self-reproach [self-blame/guilt, feeling bad and/or responsible for something]</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Mild (vague and general)</td>
<td>2</td>
</tr>
<tr>
<td>Moderate (some clear self-reproach)</td>
<td>3</td>
</tr>
<tr>
<td>Severe (preoccupied with self-blame)</td>
<td>4</td>
</tr>
<tr>
<td>Extreme (major problem)</td>
<td>5</td>
</tr>
<tr>
<td>3 Current relationships</td>
<td></td>
</tr>
<tr>
<td>Close intimate relationship with another</td>
<td>1</td>
</tr>
<tr>
<td>Warm, supportive family</td>
<td>2</td>
</tr>
<tr>
<td>Family supportive but lives at a distance</td>
<td>3</td>
</tr>
<tr>
<td>Doubtful (patient unsure whether family members are supportive or not)</td>
<td>4</td>
</tr>
<tr>
<td>Unsuitable</td>
<td>5</td>
</tr>
<tr>
<td>4 How will key person cope?</td>
<td></td>
</tr>
<tr>
<td>Well (normal grief and recovery without help)</td>
<td>1</td>
</tr>
<tr>
<td>Fair (probably get by without specialist help)</td>
<td>2</td>
</tr>
<tr>
<td>Doubtful (may need specialist help)</td>
<td>3</td>
</tr>
<tr>
<td>Badly (requires specialist help)*</td>
<td>4</td>
</tr>
<tr>
<td>Very badly (requires urgent help)*</td>
<td>5</td>
</tr>
</tbody>
</table>

* Will be automatically referred to specialist bereavement support

**Low risk score [less than 7]**
- Give a copy of the booklet – “Now What? Understanding Grief” (a copy is included in the PA Toolkit and can also be downloaded from the PA Toolkit website at www.caresearch.com.au/PAToolkit). 

**Moderate risk score [7-10]**
- Give a copy of the booklet – “Now What? Understanding Grief”
- Suggest they may like to contact one of the support agencies listed in the booklet

**High risk score [10 or more]**
- Encourage the person to contact a health professional e.g. GP, psychologist, counselling service, or bereavement counsellor
- Give a copy of the booklet – “Now What? Understanding Grief”

References

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19 The University of Queensland/ Blue Care Research and Practice Development Centre, 2012, *A Palliative Approach in Aged Care Toolkit – Module 2: Key Processes*, The University of Queensland, Toowong, QLD


32 Palliative Care Australia, 2005, *Standards for Providing Quality Palliative Care for all Australians*, Deakin West, ACT


