A Model for Community Palliative Care in Gippsland

Part 1 - Report
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1 Executive summary

The Gippsland Regional Palliative Care Consortium (GRPCC) commissioned this project to help community palliative care services meet the challenge of increasing demand. The purpose of the project is to support capacity building through the development of a model that may be adopted by services region-wide and is based on the national standards. It is intended that the model be adapted for local environments.

There are nine funded specialist community palliative care services in Gippsland and there is variation in how they provide palliative care. An overview of their practice was obtained through extensive consultation with six services and other stakeholders.

The participating services were:
- West Gippsland Healthcare Group;
- Bass Coast Community Health;
- Bass Coast Regional Health;
- Bairnsdale Regional Health Service;
- Gippsland Lakes Community Health; and
- La Trobe Community Health Service.

The main findings were:
- district nurses (DNs) and general practitioners (GPs) have historically been responsible for the palliative and end-of-life care of clients at home;
- in recent years the core teams of DNs and GPs have been augmented by a nurse practitioner (NP), nurse practitioner candidates (NPCs), palliative medicine specialists (specialists), volunteers and allied health (AH) professionals;
- the standard of palliative care has significantly improved and there is a great commitment to learning and improving outcomes for clients;
- some services are participating in the Palliative Care Outcomes Collaboration (PCOC) and the National Standards Assessment Program (NSAP) but lack of electronic support prevents benchmarking;
- many DNs have undertaken short courses in the palliative approach but few have post graduate qualifications in palliative care;
- a range of AH practitioners is available but their full potential in palliative care is not being realised;
- multidisciplinary care is generally not well integrated; and
- innovative initiatives are not widely recognised.

This report is linked with the model and includes recommendations to:
- optimise current resources;
- support DNs to achieve post graduate qualifications to achieve a critical mass of specialist expertise;
- appoint a DN to liaise between community and inpatient settings and actively develop relationships within the multidisciplinary (MDT) team to promote seamless and holistic care;
- integrate client notes and care plans;
- ensure robust collection and reporting of data; and

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1 Palliative Care Australia 2005, Standards for Providing Quality Palliative Care for all Australians, viewed August 2014
• publicise innovation and expertise.

Areas that are covered through other GRPCC programs and not addressed in detail in this project include:

• After-Hours Palliative Care Support;
• Nurse Practitioner Program;
• Specialist Palliative Care Consultancy Service;
• Palliative Aged Care Link Nurse Project;
• Palliative Care in Disability Accommodation Services; and
• volunteers.
2 Background

2.1 Palliative Care Service Capability Framework in Victoria

The Palliative Care Service Capability Framework articulates how services should be distributed across metropolitan and regional Victoria and describes the ability, means and resources that can be expected at different palliative care provider levels².

The requirements of Community Palliative Care Services – Level 1 include:

- range of services that include physical and psychological, social and spiritual care;
- nursing and other staff with knowledge of palliative care and/or qualifications in palliative care;
- provision or facilitation of, and protocols for, accessing, psychological, social and spiritual care, bereavement support and respite;
- assessment of client care needs and exploration of client goals, expectations and choices for place of care, including knowledge of advance care planning and end-of-life issues;
- participation in discharge planning and liaison with inpatient palliative care and acute hospital services; and
- self-assessment against the National Standards Assessment Program³.

2.2 Gippsland Regional Palliative Care Consortium

The Gippsland Region Palliative Care Consortium (GRPCC) seeks to promote and facilitate palliative care that is innovative, evidence-based, coordinated and responsive to individual needs.

The GRPCC’s leadership to its member services includes regional planning, capacity building and improvements to clinical service, resulting in this project.

2.3 Diversity of communities

The diversity of Gippsland communities is reflected in their locations, ranging from the remote areas of East Gippsland to the coastal areas of South Gippsland, from the burgeoning housing estates of West Gippsland to the hills of the Strzelecki Ranges. Populations include farmers, miners, professionals, people who are unemployed, retirees and tourists.

While being more ethnically homogenous than the other regions, Gippsland has a higher than average percentage of Aborigines⁴. Aboriginal communities are dispersed throughout the region with the greatest number living in East Gippsland and the smallest in South Gippsland⁵.

² Department of Health, Victoria’s Palliative Care Program Service Delivery Framework, viewed August 2014
⁴ Department of Planning and Community Development Victoria in Future 2012 Data Tables State Government of Victoria, Melbourne
2.4 Palliative care in Gippsland

There are nine funded community palliative care services in the Gippsland region that are required to operate at Level 1 and six of them participated in this project. They are:

- Bairnsdale Regional Health Service (BRHS);
- Gippsland Lakes Community Health (GLCH);
- Latrobe Community Health Service (LCHS);
- West Gippsland Healthcare Group (WGHG);
- Bass Coast Regional Health (BCRH); and
- Bass Coast Community Health Service (BCCHS).

BCRH and BCCH have since merged to form Bass Coast Health.

The other three funded services are:

- Yarram and District Health Service;
- Central Gippsland Health Service; and
- Gippsland Southern Health Service.

Koo Wee Rup Health Service, Omeo District Health, Orbost Regional Health and South Gippsland Hospital all provide unfunded generalist palliative care services and there are also a number of smaller bush nursing services in the East Gippsland area.

There are 11 designated palliative care inpatient beds in the region located at Bairnsdale (1), Sale (2), Traralgon (4), Leongatha (1), Wonthaggi (1) and Warragul (2).

Map 1. Location of palliative care services – Gippsland region

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2.5 Diversity of community palliative care services

The structures of district nursing services that provide community palliative care, and their relationships with their local hospitals, vary considerably.

The services that are funded to provide community palliative care and participated in this project include:

- stand alone community health centres, with allied health on-site or at other sites; and
- DN centres that come under the organisational umbrella of local hospitals, two co-located and one located elsewhere in the town.

2.6 Palliative Care Nurse Practitioner Program

The development of the Palliative Care Nurse Practitioner Candidacy Program was one of 11 recommendations of the GRPCC’s Specialist Palliative Care Consultancy Service Plan for Gippsland (2011)\(^7\). It is a key component of GRPCC’s strategy to provide palliative care when and where it is needed.

GRPCC is currently funding three services to support the employment, specialist clinical supervision and clinical placements of four Nurse Practitioner Candidates (NPCs). This funding assists each of the lead services to provide a fractional sub-regional service and to support training for the NPCs to gain endorsement\(^8\).

A Nurse Practitioner Candidate is a highly experienced registered nurse employed by a service or organisation in an expanded role while they meet the academic and clinical requirements for endorsement as a Nurse Practitioner (NP)\(^9\).

A Nurse Practitioner is a registered nurse who is educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role. The NP’s scope of practice is determined by the context for which the NP is endorsed [e.g. community palliative care] and aligned with the needs of the NP’s employer and client base\(^10\).

In November 2012 GRPCC appointed a Nurse Practitioner Mentor (NPM) to provide mentorship, support and clinical guidance to palliative care NPCs in the region.

BCCHS also employs a part-time endorsed Nurse Practitioner in palliative care.

The role of the NP/NPCs in Gippsland is to provide:

- local specialist knowledge;
- enhanced relationships with local GPs, nurses and allied health professionals to improve palliative care outcomes;

\(^7\) Gippsland Region Palliative Care Consortium 2014, Framework for the Nurse Practitioner Candidacy Program, p. 5

\(^8\) Ibid

\(^9\) Centre for Palliative Care, Victorian Palliative Care Nurse Practitioner Collaborative 2014, What is a Nurse Practitioner, viewed March 2014, http://centreforpallcare.org/index.php/education/vpcnpc/

\(^10\) Department of Health (WA) 2012, Nurse Practitioner Candidacy, Implementing nurse practitioner candidacy opportunities across WA Health Government of Western Australia, Perth, p. 5
• a triage and referral service for complex patients throughout the sub-region;
• client assessment and consultation;
• participation and leadership in local multi-disciplinary team (MDT) meetings;
• advice about advance care planning;
• education to health professionals, clients and the community;
• initiation and implementation of quality improvement activities; and
• research\textsuperscript{11}.

2.7 Specialist Palliative Care Consultancy Service

Under A Specialist Palliative Care Consultancy Plan for Gippsland 2011 – 2015, Calvary Health Care Bethlehem, Monash Health and Peninsula Health provide palliative medicine consultancy to services in Gippsland. The forms of consultancy vary across services and include:

• primary and/or secondary consultation to designated community and inpatient services;
• primary and/or secondary consultation to GPs;
• participation in multidisciplinary team meetings (face-to-face, teleconference or videoconference) and GP lunchtime meetings;
• participation in the Clinical Practice Group;
• modelling of practice;
• formal education sessions;
• clinical supervision and leadership for NPCs; and
• telephone support, in and out of business hours, for GPs, NP/Cs and DN.

2.8 Palliative care volunteers

Palliative care services are responsible for recruiting, training, managing and educating palliative care volunteers\textsuperscript{12}. In Gippsland, line management sits with dedicated part-time Volunteer Managers (six health services), Palliative Care Managers (two health services), District Nursing Managers (one health service) or Ambulatory Care Managers (one health service)\textsuperscript{13}. Many of the services do not have a dedicated budget for volunteer recruitment, training or reimbursement\textsuperscript{14}.

Palliative Care Victoria is responsible for developing and implementing a strategy to assist services to recruit, train and support volunteers\textsuperscript{15} and GRPCC facilitates a coordinated regional approach. This includes assisting in the compilation of standardised policies and procedures\textsuperscript{16} and the provision of education\textsuperscript{17}.

\textsuperscript{11} Gippsland Region Palliative Care Consortium 2014, Framework for the Nurse Practitioner Candidacy Program, p. 12
\textsuperscript{12} Gippsland Region Palliative Care Consortium, 2013, Review of Palliative Care Volunteer Support across the Gippsland Region, p. 1
\textsuperscript{13} Ibid
\textsuperscript{14} Ibid
\textsuperscript{15} Ibid
\textsuperscript{16} Ibid pg. 3
\textsuperscript{17} Ibid pg. 4
3 Project purpose

The purpose of the project is to develop a community model of palliative care that is based on the national standards\textsuperscript{18} and may be adopted and adapted region-wide.

It is intended that the model will support capacity building so that increasing demand for services may be met.

4 Project objectives

The objectives are to work with stakeholders of community palliative care in Gippsland to:

- obtain an overview of six community palliative care practices;
- explore their similarities and differences;
- identify strengths and areas for improvement;
- identify opportunities for consistent care, language and evaluation; and
- optimise current resources.

5 Methods

A mixed method approach was taken, including:

- face-to-face and telephone interviews with stakeholders (see Appendix 4 for a list of participants);
- desktop review of documents and websites;
- data analysis; and
- development of recommendations.

\textsuperscript{18} Palliative Care Australia 2005, Standards for Providing Quality Palliative Care for all Australians, viewed August 2014 http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf
6 Findings

6.1 Palliative Care Teams

In Gippsland, as in other rural regions, DNs and GPs have historically been responsible for the care of clients who remained at home during the last hours, days and weeks of life. This remains the case for DNs. They form the largest sector of community care and maintain a continuing presence in clients’ homes. While GPs also remain as the primary health professionals for palliative care clients, many are no longer able to make home visits.

In recent years the core teams of DNs and GPs have been augmented, to a lesser or greater degree, by palliative medicine specialists (specialists), volunteers and various combinations of AH professionals such as occupational therapists and physiotherapists, grief and bereavement counsellors, social workers, speech pathologists and dieticians.

6.2 Local services for local people

The DNs and their managers consider that they provide a ‘local service for local people’. Many work in small towns where they ‘know everyone’ and ‘bump into people in the supermarket’. They are proud of ‘the country element’ – going above and beyond the call of duty – and value the good opinion of their communities.

6.3 Disciplines involved in community palliative care

6.3.1 District nursing

All the DNs, apart from NP/Cs, are generalists who work across a variety of programs as well as palliative care. They attend to all the nursing needs of palliative care clients, including assistance with hygiene. One team allocates a key contact to palliative care clients to ensure accountability.

Strengths

All of the teams identified palliative care as a priority and profess their passion and commitment to the specialty and their clients and families. They are proud of their responsiveness, their flexibility and resourcefulness.

Two of the teams have experienced the departure of experienced staff and subsequent loss of skills and experience but in general the DNs consider the standard of palliative care they deliver is high. They cited such evidence as:

- feedback from clients, carers (verbal and thank you cards) and the community;
- feedback from NPCs and team leaders;
- high numbers of deaths at home or site of choice; and
- positive feedback from the National Standards Assessment Program (NSAP).

The DNs attributed their high standard of palliative care to teamwork, dedication, retention of staff and longevity. Some nurses have worked in their services and communities for decades.
Colleagues (NP/Cs, GPs, specialists and AH) generally affirmed the DNs’ assessment of their palliative care. Specialists reported that the standard has significantly improved in recent years and there is a great commitment to learning and improving outcomes for patients.

**Potential weaknesses/threats**

While all of the interviewees acknowledged and admired the DNs’ commitment to palliative care clients and carers, a number of them qualified this with the view that generalist nurses, albeit educated in the palliative approach, ‘don’t always know what they don’t know’.

A senior colleague suggested that frequent visits are sometimes a substitute for articulating the reasons why a client is unstable and identifying appropriate actions: ‘five visits per week do not equal good symptom management’. One of the Nurse Managers also referred to her team’s ‘unstinting commitment to clients, although that’s not always appropriate’.

Commenting on the workload of DNs, some colleagues noted that DNs have to be ‘all things to all people’. Linked with this is the observation that some teams ‘work in silos’ and may not have a full appreciation of other disciplines’ scope of practice.

**Challenges**

The DNs all commented on the benefits and burdens of working as a team across palliative care and other programs that include:

- Hospital in the Home;
- Department of Veterans’ Affairs;
- Post Acute Care; and
- Home and Community Services (HACC).

Some think that the variety prevents burnout but it does hold the challenge of managing targets, statistics, documentation and specific time allocations for visits. While the visits for other programs generally involve standard tasks, the DNs said that visits to palliative care clients are more likely to be unpredictable - ‘the unpredictability can be really hard work and time consuming’ and ‘time management is tricky’. They gave examples such as coming upon a client who is vomiting or a carer who is struggling with her dying partner; both situations required thorough assessment and management.

On occasion, visits of such a sensitive nature are at risk of being interrupted by a ringing telephone. Some DNs noted that when there is no one in their office to answer the telephone, all calls are rerouted to one of them.

**District nurses and palliative care qualifications**

Two of the services have one or two DNs with postgraduate qualifications (certificates and one with a diploma). This is in addition to the NP/Cs who have, or are working towards, Master’s degrees.

A number of DNs across the services have completed short courses in the palliative approach, including 50% of DNs in a larger service and several DNs in a smaller service. The most commonly completed courses are:
• Chisholm Institute of TAFE: Deliver Care Services using a Palliative Approach. This unit details the care and support required when working with clients with a life limiting illness. It explores grief and loss, quality of life issues, advanced care directives and end of life care; and
• Introduction to Palliative Care Short Course for generalist healthcare practitioners and developed by Monash in partnership with GRPCC.

DNs at most of the services had undertaken placements under the Program of Experience in the Palliative Approach (PEPA). The PEPA program provides free placements in palliative care services for health professionals over 2 -5 days.

DNs have taken advantage of education offered by GRPCC, such as training in triage, and some are planning to attend the forthcoming Gippsland Palliative Care Conference. One nurse manager observed that recent training had increased the nurses’ confidence and competence.

6.3.2 Nurse Practitioner and Nurse Practitioner Candidates (NP/Cs)

The NP/Cs are part of the DN teams at:

• Bass Coast Community Health Service in San Remo (NP);
• West Gippsland Healthcare Group in Warragul (NPC x 2: one has subsequently resigned);
• Latrobe Community Health Service in Morwell (NPC x 1); and
• Gippsland Lakes Community Health in Lakes Entrance (NPC x 2: one who has been in the role for a short time and another who is returning after 12 months’ in a related role).

Strengths

There is general acclaim of the NP/Cs with interviewees identifying the role as ‘the biggest innovation in palliative care’. They are seen to have made a significant impact in improving the standing of palliative care in their communities and with GPs.

The DNs appreciate the leadership and support of the NP/Cs. They and other disciplines noted that the NP/Cs lead by example.

Colleagues appreciate the role’s focus on palliative care and its promotion of evidence-based responses to dilemmas. A Nurse Manager gave the example of a client enquiring about the use of vitamin C. The DN approached the NPC who researched the issue and enabled the DN to return to the client with a considered and informed response.

Similarly, AH colleagues appreciate the NP/Cs’ holistic perspective and clinical expertise.

Colleagues are also grateful for the NP/C role in coordinating client care. This includes tasks that are considered to be time consuming such as liaising with specialists and GPs, organising meetings, sending reminders and acting as the conduit for information between the service and inpatient units – ‘she is the go-to person’.

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19 Chisholm home and community care Training. viewed July 2014
https://hacc.chisholm.edu.au/Training/Deliver_Care_Services_Using_A_Palliative_Approach
20 Monash University Medicine Nursing and Health Services, viewed July 2014
Specialists believe that the NP/C role has been instrumental in improving the standard of palliative care in Gippsland. The NP/C ‘reinforces the notion of local management with specialist input’, maximises the specialist role by screening and triaging clients, maintaining continuity of care and finding clients who would otherwise fall through the cracks - ‘she’s our man on the ground’.

The NP/Cs’ knowledge and links with specialist centres enable appropriate management of difficult and complex symptoms. A specialist gave the example of a NPC who recognised the inadequacy of ‘ever-increasing Oxycontin’ for a client with intractable pain. The NP/C facilitated a cordotomy at a tertiary centre and the client’s pain was finally relieved.

Potential weaknesses/threats

NP/Cs tend to do the work of assessing and admitting palliative care clients, writing care plans, obtaining appropriate medications and establishing relationships with GPs and specialists. They continue to visit the more complex clients and are ‘trouble shooters’. Two groups of DNs expressed concern over their loss of skills through lack of practice with complexity. They also said there is a lack of clarity about the NP/C role.

Other colleagues suggested that NP/Cs fill a gap in GP service when GPs are unavailable or are uncertain about how to manage a particular issue.

Linked with lack of role definition is the worry of NP/Cs about the size of their role – ‘I can’t do it all’. Some expressed concern about sustaining the role when:

- there are few DNs in their team, if any, with post graduate qualifications (as distinct from short courses); this contributes to professional isolation;
- executive management does not always demonstrate recognition and valuing of the role and the specialty;
- executive management does not always recognise that the role includes more than clinical work and that time is required for tasks such as developing structures to facilitate palliative care; and
- the role often requires travelling over ‘huge’ areas involving geographic isolation, islands, mountains and snow.

6.3.3 General Practitioners

Working relationships between DN services and GPs vary from mutually respectful and collegial to difficult, although there are more of the former than the latter.

Over recent years, opportunities have increased for GPs to interact with DNs, specialists and the multidisciplinary team (MDT). They include:

- liaison with a specialist via the NP/C;
- videoconferences where the DNs and the GP sit together in the same room while consulting with a specialist;
- regular (e.g. fortnightly) lunch meetings at the GP clinic, attended by a specialist and/or NP/C and/or DNs;
- regular (usually monthly) MDT meetings where the GP attends in person or by teleconference for discussion of specific clients; sometimes GPs request that a client be added to the agenda.; and
• case conferences for more complex clients (face-to-face or teleconference).

DNs and specialists observed that some GPs are reluctant to engage with specialists because they see their input as unnecessary or interfering.

On the other hand, referrals from GPs to DN services for palliative care have increased significantly over recent years. A tendency of some GPs to wait until the terminal phase was, in part, the impetus for the GRPCC to develop the *Palliative Care Service Access and Management Flowchart for General Practitioners*. This document supports decision making about referral to palliative care services.

DNs value GPs who give out their mobile numbers and visit clients at home after hours. One GP noted, however, that GPs who do not live where they practise are unable to offer these services.

Some GPs expressed concern about ‘being left out of the loop’. They gave the example of DNs going directly to the specialist and couriering drug charts to the practice for implementation of the specialist’s recommendations. These GPs consider such management to be deleterious to the patient as the specialist is unaware of what has already been done. They suggested that, at a minimum, the DN give them a list of issues about which they intend to approach the specialist, thus giving them a chance to comment. They also requested a copy of the specialist’s recommendations before the patient is informed.

GPs would appreciate acknowledgement of them as the primary health professionals and of their relationships, often of long-standing, with patients and families.

Their preferred means of communication with DNs vary. Some prefer phone calls, especially if the matter is urgent, as ‘emails get buried’. Others find that phone calls interrupt consultations. One suggested using the practice nurse as a link and having a standard form, not requiring a response, to communicate information about patients.

DNs and NP/Cs have found other ways of navigating barriers to communication with GPs:

• developing relationships with practice managers;
• finding evidence of an appropriate course of action, highlighting the source and leaving it in the patient’s file for the GP;
• responding to crises at the GP’s request; this is ‘not ideal’ but it is a means of ‘earning my stripes’ and developing the relationship; and
• using a newly developed *GP Liaison Sheet* has improved communication and ‘GP buy-in’.

6.3.4 Palliative Medicine Specialists

Calvary Health Care Bethlehem, Monash Health and Peninsula Health provide visiting palliative medicine specialist consultancy to palliative care services in Gippsland. Specialists from these metropolitan centres have been allocated to specific community and inpatient services in Gippsland over a number of years.
6.3.5 Allied Health

Most of the DN services are co-located with AH disciplines, either in the same building or on the same property. Nevertheless, relationships between some DN teams and AH disciplines are limited with two groups of co-located DNs having difficulty naming any AH colleagues.

Some of the AH interviewees spoke of their frustration about the lack of recognition of their scope of practice. They believe that this is sometimes a barrier to the comfort and safety of palliative care clients and carers.

They also identified that keeping client notes separate from those of the DNs is a barrier to integrated care. Regular attendance at DN and MDT meetings mitigates this.

Many of the DNs find the commonly used Service to Service (S2S) referral system a barrier to making referrals to AH as it is cumbersome. Although the AH interviewees acknowledged that this system could be more concise, they prefer the information contained in S2S to an emailed ‘snapshot’ or a ‘sticky note that can get lost’ because it is comprehensive and current and the referral can be tracked.

Costs and fees

While palliative care clients tend to have the loan of equipment free of charge from service pools, they usually incur the cost of delivery. Clients also fund home modifications such as the installation of rails and ramps. Application to the State-wide Equipment Program for funding is considered too long and complex a process for palliative care.

The Lymphoedema Compression Garment Program provides some financial assistance for eligible pension holders and low-income earners but clients otherwise incur the significant costs of garments and bandaging.

Similarly, clients often incur costs associated with AH visits in the community. For example, clients may be charged the Health and Community Care fee. One AH worker observed that palliative care clients expect visits to be free and the charge can ‘make things awkward’ as well as adding an extra financial pressure.

6.3.6 Social work

Clients are referred to social work for assistance with a range of issues including:

• carers dealing with the shock of their loved one’s diagnosis;
• children needing additional support;
• powers of attorney and wills;
• finances;
• housing; and
• domestic violence.

Social work links with DN teams are forged through shared office space, attending handover, carers’ support groups and the annual memorial service. Regular and consistent contact enables identification of clients and carers who would benefit from social work involvement and mutual feedback.
6.3.7 Spiritual and psychological care

Few of the participating services explicitly address the spiritual issues of palliative care and most services refer clients and carers with complex psychological issues to their GP for a Mental Health Treatment Plan. One service can refer clients with complex spiritual or psychological issues to a psychotherapist in the inpatient setting and another service has a Pastoral Care Nurse. A third service said that the DNs visit clients who have psychological issues daily and gave the example of a client with suicidal ideation. This service reported that the client found the visits reassuring.

6.3.8 Grief and bereavement counselling

Not all services provide bereavement care. The DNs of two services are able to refer carers at risk of complicated grief to their social worker and they use the Bereavement Risk Index to facilitate assessment, triage and referral. If carers require ongoing care after the client has died they are referred to their GP for management through a Mental Health Treatment Plan.

In another service the NP/C fills the gap where there are no formal channels for bereavement care.

A fourth service has recently appointed a Grief and Bereavement Counsellor and part of her role is to consider how she and the nurses might work together. She sits in the DNs’ office one afternoon per week as they come back from ‘the road’, hears their conversations and is beginning ‘to pick things up’. She has found that accompanying a DN on a visit to the bereaved parents of a toddler was an effective means of introduction and she plans to be with the DNs when they make their first calls to carers after clients have died.

6.3.9 Occupational therapy

The occupational therapy (OT) interviewees said they treat palliative care referrals as a priority.

Common triggers for referral to OT are the client’s need of:

- equipment;
- access to bathroom, shower and toilet; and
- postural support.

OT interviewees said they could improve clients’ quality of life and comfort if given the opportunity to offer strategies for:

- pressure care;
- energy conservation; and
- relaxation, which would contribute to pain relief.

Some OTs said that where there is a central pool of equipment, nurses often lend pressure cushions and mattresses to clients without consulting an OT. OTs are concerned that for more complex clients nurses do not have the specialised knowledge to ensure correct fit, size and type of aid.
OTs said that formal and informal opportunities for them to meet DNs enhance their communication about palliative care clients. One OT finds the regular MDT meeting is helpful for prompting referrals while another makes it her business to ‘pop in’ to the DN office for chats.

An OT who took part in a new program where graduate OTs rotate through the DN team for periods of six months said that this helped her to appreciate the work they do and feel part of the team. Nurses now stop her in the hall to talk about potential referrals. This program is yet to be evaluated.

6.3.10 Physiotherapy

Triggers for referral to physiotherapy include:

- need of mobility and walking aids;
- improvement and preservation of strength; and
- musculoskeletal pain.

The physiotherapy interviewee has formal communication with the DNs about palliative care clients through the referral system of S2S and the regular MDT meeting. The small size of the team promotes continuity of care and clarity about who is involved.

6.3.11 Speech pathology

The speech pathology interviewee estimated that referrals for palliative care clients in the community have fallen by 50% since her department moved away from the DN team. She also attributed fewer referrals to recent turn over of DNs, causing a drop in knowledge about speech pathology’s scope of practice.

Reasons for referral to speech pathology include clients who are experiencing:

- reduced function;
- dysphagia; and
- coughing with fluids.

Apart from being located away from the DNs, barriers to speech pathologists working effectively with community palliative care clients include:

- not attending related meetings; and
- a lack of communication from speech pathology in the inpatient setting on discharge of a client.

The interviewee believes that her department and the DN team would work more effectively for the benefit of clients if:

- they shared an office, enabling DNs to become more aware of her role through informal discussion; and
- speech pathologists attended the MDT meeting where everyone hears the same information from the specialist as well as learning about the client from a social perspective.
6.3.12 Dietetics, nutrition and food

The dietician interviewee receives the occasional referral from community palliative care to address a client’s loss of appetite and weight; she would like receive more referrals. Clients usually come to her office but she is happy to see people in their own homes as well.

This dietician believes that there could be fewer nursing visits if clients and carers received appropriate advice and nutrition. Dieticians can contribute to symptom management by advising on foods to:
- alleviate nausea;
- increase energy; and
- make clients feel better.

The barriers to referrals of community palliative care clients include:
- general lack of understanding of what a dietician can do;
- association of ‘dietician’ with being ‘put on a diet’;
- the time it takes to generate a referral on S2S; and
- nurses and the dietician keeping separate notes.

The interviewee suggested solutions could include:
- acceptance of ‘one liner’ referrals and willingness to look up histories herself;
- common client files;
- the opportunity, as at regular MDT meetings, to go through registered palliative care clients so that she can ‘pick up’ clients who would benefit from her expertise;
- the opportunity to present case studies;
- participation in nurse and carer education, as in her service’s current program where she is presenting on management of fatigue; and
- shared visits with nurses, giving her an opportunity ‘to sell’ her role.

6.3.13 Volunteers

The coordinators of volunteers interviewed for this project represent both dedicated coordinators and nurse managers who have dual roles. Their teams range from two to sixteen volunteers.

The themes they raised are:
- volunteers tend to be introduced towards the end of life; there is a lack of understanding about what a volunteer can do when the client is still relatively well;
- a nurse with a dual role ‘can pick up cues’ and ‘see the match’ at regular meetings’;
- volunteers ‘have to feel part of it’, ‘connected’ and ‘embedded’ in the team; and
- a joint nurse/volunteer visit early in the episode of care demonstrates ‘we’re a team’.

The interviewed coordinators who are not nurses do not attend MDT meetings but one is co-located in a common area where her presence prompts discussion and referrals from nurses. She is currently working with the nursing team on:
• encouraging the idea that volunteers are a ‘normal’ part of palliative care;
• different ways to have a conversation with clients and carers about volunteers; and
• how to ‘leave the door open’ if a client or carer declines a volunteer.

These coordinators have found that local hospital nurses welcome volunteers visiting their clients during inpatient admissions. In addition, some teams have volunteers who work across different domains, such as palliative care and aged care, which can also lead to continuity of care.

6.4 Episodes of care

6.4.1 Admissions

All of the participating services give priority to palliative care referrals. Referrals may come from GPs, hospitals, residential aged care facilities (RACFs), specialists, clients and carers.

While two of the participating services are trialling a Referral/Triage tool created by the GRPCC and Clinical Practice Group, most services do not use admission criteria for palliative care beyond ascertaining that referrals come from a doctor or are supported by a doctor. This is thought to ensure diagnosis of ‘an untreatable terminal condition’ and that a doctor has informed the client there is no further active treatment. One service rejects referrals only if concerned about the safety of staff.

Most referrals are for cancer diagnoses, where doctors are more able to predict that it would not be surprising if the client died in the next six – twelve months. Uncertainty around the prognosis of people with non-malignant diseases is a barrier to referrals. On the other hand, clients are referred to palliative care as a means of obtaining home oxygen free of charge. One service said that ‘we accept some we shouldn’t and they sit on the books for years’. They gave examples of clients with chronic cardiac failure and a client waiting for a lung transplant.

One of the specialists expressed concern that services are at risk of creating too great a demand, being ‘swamped’ with inappropriate referrals to the point of being unable to manage, and being seen to fail. The specialist believed that services have to identify who is eligible to receive specialist palliative care and they need to be careful about what they commit to deliver.

6.4.2 Discharges

Most services do not actively discharge palliative care clients unless they move out of the area or decline care. Examples were cited of clients remaining in the palliative care stream for years, including one who remained for well over a decade.

There are a variety of reasons for services being reluctant to discharge clients, including:

• difficulty for nurses: ‘DN disengagement can be traumatic; staff and clients get emotional about this’;
• perceived potential for damage to the service’s reputation in small communities;
• confusion for clients and carers when the same nurses work across all programs, implying an arbitrary distinction;
• burden of readmission if stability is of short duration;
• unwillingness of clients, carers and/or GPs to accept transfer or discharge;
• palliative care is free, other programs are not: this can come as a shock to clients and carers; and
• bureaucratic and financial implications of changing the arrangements for equipment and home oxygen.

Nurses gave examples of keeping clients on the palliative care program long term, such as a client whose partner had a significant health issue and another client who had an unstable psychosocial issue, albeit unrelated to their palliative care diagnosis. Services ‘got stuck’.

Services often strike a compromise; they keep clients ‘on the books’ and phone or visit them fortnightly, monthly or less frequently. They may also ‘keep people on the books’ as ‘inactive’.

On the other hand, two services do actively manage transfer or discharge from the palliative care stream – ‘people are realising that it’s not a bottomless pit of money’. In a brochure given to clients and carers on admission, one service articulates:

- the potential for discharge if they remain stable from a palliative care perspective; and
- the service will fund equipment for three months with the expectation that the client will pay after that.

The service activates this plan if the client is stable and staff said that clients usually don’t notice any difference except for a small fee. This service is mindful of when and why it is putting equipment in a home.

The second service collaborates with GPs to achieve safe and effective transfer or discharge. The potential for discharge is established when the client is admitted. If a client has been stable for about twelve months, the expectation of discharge is flagged over several visits and transfer to more appropriate care or discharge is implemented. GPs monitor their clients and alert the service to relevant changes.

### 6.4.3 Interpreters

When services see the few clients and families who speak little or no English they use family members to interpret. They do not use professional interpreters.

### 6.4.4 Children

The services rarely provide palliative care for children but two of them gave examples from recent years. In each case some DNs preferred not to participate and a select number of DNs, including senior DNs, managed the care. They felt well supported by Monash Medical Centre.
6.4.5 Anticipatory prescribing

All participating services try to ensure emergency medications and appropriate orders for symptoms such as pain and nausea are obtained for some or most clients’ homes. This is often referred to as ‘anticipatory prescribing’ and usually includes injectable opioids such as morphine. Not all GPs are happy to prescribe in this way. Some prefer to manage the symptoms as they arise, although services find this challenging if unexpected or exacerbated symptoms occur during the night and on weekends.

Two services are trialling guidelines for anticipatory practice developed by the GRPCC and Clinical Practice Group.

Triggers for requesting anticipatory medications vary across services and include:

- admission to palliative care;
- a symptom causing the client distress above a designated score on the Symptom Assessment Scale;
- planning for a weekend if the GP is going to be away; and
- individual client need.

One service keeps prescriptions in the client’s home and the DN has them filled and collects the medications if they are needed after hours. Another service keeps a supply of some medications while it is possible for others to access medications from their local hospital ‘if desperate’.

At least one of the smaller services does not commonly teach carers to give injections. DN s visit to administer all injectable medications as required. They also ensure continuous subcutaneous infusions are in place before the weekend to mitigate the potential need of intermittent injections.

6.4.6 Progress notes

While at least one service is considering electronic client files, the files of all participating services are currently paper-based, either in the DN office or in the home. Where they are located in the DN office, there is usually a communication file in the home and the GP, volunteers and AH workers can leave notes. AH workers cannot easily access client files kept in the DN office.

None of the progress notes follow a standard format although one service makes a point of elaborating on outstanding issues only and another service documents variances from their palliative care pathway. Colleagues observed that progress notes can be verbose, unclear, ‘hit and miss and bits and pieces’.

Some services have now instigated the GRPCC’s draft Palliative Care Summary to draw information together in a concise and coherent format. In part, this form is used for MDT and specialists.
6.4.7 Care plans

Most services complete initial care plans with clients and carers.

Some services keep them in the home, requiring at least one service to ‘re-type’ care plans in the office before returning them to the home some time later. Another service provides a copy for the home if asked.

The care plans are usually generic and tailored to individual clients. One service has no formal process for updating them while others update them weekly, monthly, every three months and/or as required. While the NPC at one service is usually responsible for establishing care plans and key workers allocated to the clients of another service are responsible for updating them, in most cases all visiting DNs maintain them.

6.5 Evidence: tools and benchmarking

6.5.1 Palliative Care Outcomes Collaboration (PCOC)

To varying degrees all six services use the Palliative Care Outcomes Collaboration (PCOC) as recommended in *Strengthening palliative care: Policy and strategic directions 2011 – 2015*.

PCOC is a national program that aims to improve patient outcomes through:

- routine clinical outcome measurement using standardised validated clinical assessment tools;
- periodic surveys; and
- benchmarking.

The five validated PCOC tools for clinical assessment are:

- Australia Modified Karnofsky Performance Scale;
- Symptom Assessment Scale (SAS) covering difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain;
- Palliative Care Problem Severity Score for pain, other symptoms, psychological and spiritual distress for the client and issues for the family and carer;
- Resource Utilisation Groups – Activities of Daily Living Scale (RUG-ADL); and
- Phase of Care.

One service has been using these tools for four years and they are ‘now embedded in the language’. A service that has been using them for one year said that they ‘pinpoint’ and ‘quantify’ problems and alert staff to carer stress. In a third service only the NPCs are educated to use the tools while a fourth is just about to introduce PCOC.

Some senior nurses observed that the use of PCOC tools alone does not guarantee management of client or carer distress. They gave examples such as:

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• documentation of a client scoring his distress from pain at 7/10 on the SAS with no indication of subsequent action; and
• use of the tools only when the client appears unwell.

While all services are able to include the tools in their practice, to date none of them are able to participate in periodic surveys or benchmarking as their systems do not support electronic collection of data. At least two services are considering future management of this issue.

6.5.2 Other tools

Other tools used, but not consistently within or across services, include:

• Abbey Pain Scale;
• pain assessment tools;
• Carer Support Needs Assessment Tool;
• Distress Thermometer – ‘we don’t use it routinely but it’s routinely in the history’;
• genogram – a ‘very practical and contained way of demonstrating the psychosocial situation of clients and carers. It’s good for farmers and includes pets .... and allows planning for them’.
• Bereavement Risk Index;
• clinical care pathways (devised by services);
• Pathway for Improving Care of the Dying (PICD) – ‘palliative care is not the focus for some DNs and the PICD draws their focus and makes them think about symptoms' and ‘when you’re used to palliative care it can be superfluous’.

6.5.3 Advance Care Planning

Few services participate in Advance Care Planning (ACP). One group of DNs reported a variable level of comfort with it, saying that they needed ‘to build rapport and find the right time’. Three DNs at another service have done the training but the process has not been implemented. A Nurse Manager expressed the need to be realistic about the capacity of her service to implement ACP – ‘we can offer an introduction, support and coaching but not the bells and whistles’.

6.5.4 National Standards Assessment Program (NSAP)

The Department of Health’s Strengthening palliative care: Policy and strategic directions 2011 – 2015 encourages services to participate in the National Standards Assessment Program (NSAP).

NSAP is a framework for continuous quality improvement built on Palliative Care Australia’s Standards for providing quality care for all Australians. NSAP provides services with the tools and resources to assess themselves against the national standards with the aim of supporting them to move towards best practice.

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25 Palliative Care Australia How NSAP works, viewed August 2014
Several services have completed the initial self-assessment ‘snapshot’ and subsequent second yearly cycles.

### 6.6 Occupational Health & Safety

#### 6.6.1 Physical

There was little discussion about the triggers for DNs to recommend the placement of electric beds with adjustable heights and other aids. One group of DNs, however, said that the presence of equipment in the home is confronting and they wait for carers to allow it to be brought in. This means that sometimes nurses give personal care to clients in double beds.

#### 6.6.2 Emotional

Each of the services emphasised the closeness of their teams and their informal support of each other in difficult times. This seems particularly so for smaller teams. Small teams, however, have less flexibility to give a stressed colleague an easier day – ‘people are exhausted for a couple of days and there’s no way of protecting them’. Larger teams also struggle to give nurses ‘downtime’ owing to the skill mix of their staff – ‘it’s thin at the top and the senior staff tend to bear the brunt’.

One team cited individual clinical supervision as an avenue for support while members of another team can approach their social worker. Others rely on their NP/Cs. However, DNs tend not to take advantage of formal opportunities for support and debriefing. Such opportunities include access to pastoral care, Employee Assistance Programs (EAPs), formal death reviews and debriefing sessions – ‘they were not that functional’ and ‘they fell over quickly’. Ad hoc groups at one service were not successful for lack of facilitation skills. One team tries to have DNs conduct challenging visits in pairs but this is time consuming. Another team has occasional time release to share a lunch break to review complex cases.

The DNs observed that the part time nature of their work is protective but it also contributes to emotional stress. They may miss organised supportive activities as well as the deaths of clients with whom they were involved. By the time they come back to work, ‘everyone else has moved on’.

Some DNs see debriefing as ‘an opportunity to unload’ but they find the timing and frequency do not always suit them – ‘you need it when you need it’ and ‘the moment went’. One DN went on holidays immediately after a difficult case and she ‘just sucked it up’; ‘it stayed with me for the whole holiday’. Another ‘had a cry when I was hanging the clothes on the line’.

A senior nurse believes the solution to supporting DNs who do palliative care is clinical supervision outside their organisation. Her service pays the invoice and the DNs attend in their own time. The organisation strongly encourages external supervision after a difficult death for support and reflection.
6.7 Innovations and developing expertise

During the course of interviewing health professionals involved in palliative care, innovations and areas of developing expertise came to light:

**Latrobe Community Health Service**

- rotation of graduate OTs through the DN team;
- use of allied health assistants under the *Supervision and delegation framework for allied health assistants*\(^{26}\). They work under the supervision of OTs and perform such tasks as delivering equipment;
- facilitation of in-home overnight respite using personal care attendants;
- fatigue Management Program run by allied health staff over four sessions:
  - Energy conservation (OT)
  - Strength (physiotherapist)
  - Nutrition (dietician)
  - Mindfulness (leadership coach).

**Bass Coast Regional Health**

- Bereaved Carers’ Group

**Gippsland Lakes Community Health**

- employment of a Clinical Nurse Consultant in aged care and dementia to work with GPs around early diagnosis, timely referrals and care planning; and
- co-location with the Lakes Entrance Aboriginal Health Association.

6.8 Moving between the community and inpatient settings

6.8.1 Funded palliative care beds in Gippsland

There are eleven designated palliative care inpatient beds in Gippsland in groups of one, two and four\(^{27}\):

Palliative care beds can be used in coordination with community palliative care services to stabilise a client’s symptoms and enable them to return home for ongoing care. Palliative care beds can also be accessed when families can no longer care for the client at home, particularly during the last days of life. In these instances, people are cared for in the palliative care bed until they die.\(^{28}\)

The beds in Gippsland may be ‘virtual’, i.e. any bed that happens to be available when needed, or specifically nominated beds in wards where there is expertise in palliative care.

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\(^{27}\) Gippsland Region Palliative Care Consortium 2013, *Annual Report*, p.13

care and a quiet atmosphere. However, these wards are often full and dying clients may be sent to other areas that are oriented to acute surgery, medicine and midwifery. Palliative care clients may also have to wait on trolleys in the emergency department (ED) – ‘palliative care beds are seldom available for palliative care’. Lack of guaranteed access to funded beds engenders disquiet amongst inpatient Nurse Unit Managers (NUMs) and community palliative care teams.

There seems to be a dislocation between some inpatient units and some community teams, characterised by community teams’ lack of confidence that their inpatient colleagues will take a palliative approach, recognise the need to treat reversible conditions or involve them in discharge planning.

Other inpatient and community teams, however, collaborate. Such collaboration is demonstrated through an agreement to admit registered palliative care clients directly into beds without going through the ED. Other shared activities include discharge planning, programs across both settings and palliative care education.

Most interviewees would love to see a hospice in or close to their communities.

6.8.2 Respite

The Aged Care Assessment Service assesses clients aged 65 years and over so they can be admitted to aged care facilities for respite. Those with private health insurance can be admitted to a private hospital – this is a rare commodity in Gippsland. It is difficult to place a client locally if they are under 65 and are not privately insured.

6.8.3 Discharges from acute settings

Services consistently spoke of precipitate discharges and poor planning from the acute setting, both local and metropolitan. They recognise that palliative care is a small part of the work of acute hospitals and that interns who are new to the complexity of community care often instigate discharges. Examples of poor planning included the ‘classic example’ of an elderly person being sent home alone on a Friday afternoon ‘with a high RUG and low Karnofsky’, i.e. dependent on others for care and almost bedbound.

One specialist is particularly concerned about poor communication from oncology units and the potential for community services to misinterpret symptoms related to chemo or radiotherapy as disease progression and deterioration. Inappropriate management may follow.

6.9 Data

Services are mandated by the Department of Health to collect palliative care data for the Victorian Integrated Non-Admitted Health (VINAH) Minimum Dataset. The purpose of the dataset is to provide information about client demographics and the quantity and types of activities that palliative care services provide. In the current environment, this dataset informs service planning.

All the participating services collect and submit data related to nursing visits and some services do the same for social work or grief and bereavement counselling. AH contacts are generally not funded through palliative care and data related to AH visits are
collected under other systems such as HACC or Rural Primary Care. They do not have a specific diagnostic code for palliative care and are therefore not identifiable as such. AH contacts with palliative care clients can only be estimated.

The district nursing teams range in size from about 20 Effective Full Time (EFT) to about 4 EFT. They all emphasised the growing profile of palliative care. From a ‘helicopter’ perspective it is difficult to gauge what this means in practice. While most services were able to state the numbers of deaths occurring at home and in hospital, the average length of stay was not readily at hand and services said it would be difficult and/or time consuming to calculate.
7 Discussion

7.1 Qualifications of DN

In recent years DN services have encouraged and supported nurses to undertake education in palliative care. The education has generally taken the form of short courses about the ‘palliative approach’, PEPA placements and training offered by the GRPCC. This has done much to assist the DN, as primary care providers, to develop their knowledge and skills in the care of people with life limiting illness.

The ‘palliative approach’ describes:

‘... the key skills and attributes required of any health professional who is caring for a person at the end of life in any setting – symptom management, communication skills, meeting the holistic needs of the person and being respectful of their needs and wishes’.

In some services, the specialist expertise of the NP/C augments and supports this approach. The role of NP/C is universally lauded and few of the interviewees could now imagine being without it. In their part-time positions the NP/Cs do everything from facilitating highly sophisticated treatment modalities to sending out reminders for meetings. They are everyone’s ‘man on the ground’.

This points to the difficulties the NP/Cs encounter in trying to manage their role:

- lack of clarity about the role, resulting in the NP/C being the ‘go-to person’ for all aspects of palliative care;
- lack of colleagues with post graduate qualifications in palliative care, contributing to a ‘huge’ workload and professional isolation;
- the neglect of some aspects of their work, such as developing structures to support evidence-based palliative care and research; and
- the inability to realise the full potential of the role, to the detriment of clients and services.

These difficulties put the NP/Cs and the NP/C Program at risk of individuals ‘burning out’.

Strategies that services could employ to sustain, enhance and protect the role of NP/C while increasing the critical mass of specialist expertise include:

- clarify the role of NP/C, including criteria for referral;
- encourage and support DN to undertake post graduate qualifications (perhaps two per team, including the NP/C);
- enable career progression with the creation of senior DN roles in palliative care that are based on post graduate qualifications and appropriate experience; and
- increase the hours of part-time NP/Cs.

See Appendix 3 for a representation of how the education, research and leadership domains should be couched within the clinical work of the complete NP/C role.

30 Gippsland Region Palliative Care Consortium 2014, Framework for the Nurse Practitioner Candidate Program, p. 13
7.2 Relationships

Allied health and volunteers

Some services are more successful than others in fulfilling the aims of the Department of Health’s palliative care program to achieve an integrated service across all aspects of care. These aims are underpinned by principles such as:

- care is holistic and multidisciplinary;
- care includes AH and volunteers;
- grief and bereavement support are offered to carers; and
- service delivery is seamless 31.

AH practitioners and coordinators of volunteers believe that some DN teams do not understand their full scope of practice and the degree to which they could improve outcomes for clients and carers while reducing the DN workload.

Examples of DNs managing elements of care that could be more appropriately and safely referred to AH colleagues include the monitoring of a suicidal client, managing bereavement and supplying equipment to clients who would benefit from occupational therapy assessment and advice.

In some services DNs work more effectively with their AH and volunteer colleagues for one or more of the following reasons:

- DNs and AH staff know each through sharing office space and/or attending regular meetings together;
- the development of relationships has been intentional, either on the part of nursing management and/or on the part of individual practitioners;
- there are formal referral channels; and
- DNs attend visits with AH or volunteer colleagues and introduce them as part of the palliative care team. This is uncommon.

All of these practices promote seamless and holistic care, enhance understanding of each other’s roles and enable mutual support. They could be supplemented by strategies such as:

- the integration of progress notes and care plans - it is difficult to offer an integrated service if individual disciplines maintain separate notes and plans. This is particularly so where access is inconvenient or, in the case of referral to the GP for a Mental Health Treatment Plan, impossible;
- regular attendance of AH practitioners and coordinators of volunteers at MDT meetings;
- location of AH practitioners and coordinators of volunteers in or near the DN office;
- establishing criteria for initial assessments or visits attended by the DN together with an AH practitioner and/or coordinator of volunteers;
- an open invitation for AH practitioners and coordinators of volunteers to attend daily handover; and

• an open invitation to volunteers to attend the MDT meeting or daily handover to participate specifically in discussion about the client they are supporting.

Most of these strategies would require change for DN who have, until recent years, been accustomed to travelling alone and shouldering most responsibilities.

**General Practitioners**

GPs remain the client’s primary doctor and are an essential part of the palliative care team. Owing to palliative care being only a part of the work of busy GPs, promoting and supporting their liaison with team members is challenging. DN services are beginning to address this by streamlining their communication with them. They are devising standard letters to inform the GP of the admission of a client, to update the GP when changes occur and to request anticipatory medications.

Some GPs are able to participate in MDT meetings and consult with specialists via:

- co-location with DN teams in community health centres;
- communication with the NP/C;
- videoconferences where the DNs and the GP sit together in the same room while consulting with a specialist;
- regular (e.g. fortnightly) lunch meetings at the GP clinic, attended by a specialist and/or NP/C and/or DNs;
- regular (usually monthly) MDT meetings where the GP attends in person or by teleconference for discussion of specific clients; sometimes GPs request that a client be added to the agenda; and
- case conferences.

Such strategies promote seamless and holistic care, enhance understanding of each other’s roles and enable mutual support.

Other strategies suggested by GPs to support communication between them and DN teams include:

- recognising that GP-client relationships are often long-established;
- consulting the GP or practice manager about the best way to communicate with them regarding non-urgent and urgent matters that require discussion, e.g. email or phone calls; and
- consulting the GP before a specialist is approached and, if possible, including the GP in the discussion.

**Funded palliative care beds**

Although Gippsland has eleven designated palliative care beds, MDT members and NUMs expressed concern about the lack of guaranteed beds in an appropriate environment. Some MDT members also noted a perceived lack of palliative care expertise in the inpatient setting, partly related to the rotation of junior doctors.

While it seems that no hospital is prepared to quarantine beds for palliative care clients, some do their best to ensure that clients avoid the emergency department, are admitted directly to a bed and transferred to a more appropriate area as soon as possible. This seems to occur where the NUMs and community teams are well known to each other and work together for their shared client. Their sense of mutual respect and working as a team seem to be facilitated by:
• the inpatient unit and DN team working together to implement programs across both settings, e.g. ACP;
• the inpatient unit and DN team sharing palliative care education;
• the NUM attending meetings with specialists and GPs;
• ‘working in tandem to get patients home’;
• DN participation in discharge planning meetings;
• the DN team alerting the NUM to the potential need for a bed;
• DNs who have moved from the inpatient setting to the community, retaining their knowledge of the inpatient environment and relationships; and
• the NP/C acting as the ‘link’ between settings.

Other strategies to foster a shared approach to palliative care between the inpatient and community settings could include:

• the appointment of a designated liaison nurse in the DN team;
• the opportunity for nurses to experience each other’s work places; and
• the development of shared protocols.
7.3 Episodes of care

7.3.1 Triage and management of palliative care referrals

The raised profile of palliative care in each of the participating services reflects the fact that demand for palliative care in Victoria is growing at nearly five per cent per annum. This is influenced by two key trends:

- the incidence of cancer and other non-malignant chronic illness is increasing due to the ageing population; and
- the number of people with a chronic illness (cancer and non-cancer) who would benefit from palliative care is growing at a faster rate than the total population.

In recent years the field of palliative care has recognised and promoted the need to care for people with non-malignant illnesses. The implications of this recognition are a work in progress but in future it is likely that ‘the role of palliative care will be more clearly defined by the diagnosis pathway to which it is applied’. In the meantime, palliative care services are under pressure to accept increasing numbers with potential risks for equity of access, quality of care, patient satisfaction and the wellbeing of staff.

The triage and rejection of some palliative care referrals may be challenging for generalist services, and indeed for specialist services. Acceptance of most with a policy of assessing needs, regular review and the potential for redirection to other services and/or discharge may be a more palatable means of avoiding long-term and inappropriate admissions.

Strategies to support the triage and management of palliative care referrals include:

Triage and management of discharges from acute settings

Services consistently spoke of precipitate discharges and poor planning from inpatient units, both local and metropolitan, putting the wellbeing of clients at risk and services under stress. Few services reserve the right to refuse a referral until the referrer supplies all relevant information and the service can ensure that the client, carer and staff will be safe.

It is in the interests of clients, carers and staff to insist on planned discharges except in specific circumstances such as accommodating sudden deterioration and the client’s wish to die at home. Strategies that may positively influence discharge planning include:

- the appointment of a designated liaison nurse in the DN team; and
- the development by the community services in Gippsland of an agreed approach and policy.

Episodic palliative care

NSAP Standard 10 supports the provision of episodic palliative care, where appropriate, with episodes based on the level and nature of client needs:

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33 Ibid p. 27
34 Ibid p. 36
Direct care from a specialist palliative care service may be episodic rather than ongoing, and based on specific complex needs\(^{35}\). These needs may be physical, psychosocial or emotional but they should be related to the palliative care diagnosis.

Similarly, the Department of Health cites Lynn and Adamson’s three end-of-life trajectories that people with life-threatening illnesses are most likely to experience\(^{36}\):

People with a life-threatening illness are likely to experience one of three end-of-life trajectories: care delivered over a short period of decline (such as cancer), long-term limitations with intermittent serious episodes of decline (such as heart and lung failure) and prolonged decline (such as frailty and dementia).

**Figure 1. Palliative care trajectories**

![Trajectories Diagram](source: Lynn & Adamson 2003)

The arrows indicate triggers for palliative care involvement at diagnosis or early in the illness, during episodes of decline and at end-of-life\(^{37}\).

**Assessment of the referral** with the assistance of:

- the GRPCC’s Palliative Care Service Access and Management Flowchart for General Practitioners and consultation with the referrer if the reasons for referral are not clear or do not accord with this document; and
- consultation with the NP/C and/or specialist to ascertain appropriateness.

**Reservation of the right** to:

- suggest that a referral may more appropriately be directed to a different program or service;

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\(^{36}\) Lynn, J & Adamson, D 2003, ‘Living well at the end-of-life: adapting healthcare to serious chronic illness in old age’, RAND Corporation, Santa Monica

• acknowledge uncertainty about the appropriateness of the referral and state the intention to the referrer, client and carer to assess over a period of time; or
• reject the referral with clear rationale.

**Transfer and/or discharge of clients**

The ability to transfer and/or discharge clients from the palliative care program would help services to:

• conserve their palliative care resources for clients and carers with demonstrable palliative care needs;
• maintain equitable access and limit waiting times;
• limit infringement on capacity to meet the demands of other programs;
• promote high quality care, safety and client satisfaction; and
• engender a sense of control, contributing to capacity for active care of staff and their wellbeing.

Two services have implemented policies and procedures that enable them to transfer and/or discharge clients. They achieve this, in part, by:

• articulating, on admission, the policy of discharging clients in the happy event that they are stable from a palliative care perspective for a reasonable period of time. This is written in a brochure handed to the client and carer and, where appropriate, the DN specifically refers to this policy;
• articulating, verbally and in writing, that the service will fund equipment for three months with the expectation that the client will pay after that; and
• collaborating with GPs who will alert the service to deterioration from a palliative care perspective.

Other strategies could include:

**Establishing transfer and/or discharge criteria, such as:**

• the client has been symptomatically stable for six-twelve months, demonstrated through consistent and regular scoring with the PCOC tools, e.g.: Phase – stable, ESAS scores below 4;
• consultation with treating doctors, specialists, NP/Cs and the GP regarding prognostic indicators confirms that the client’s stability is likely to continue;
• consultation with the MDT confirms there are no outstanding issues;
• the client moves out of the catchment area;
• the client requests discharge; and
• delivery of care poses an unacceptable risk to the safety of staff.

**Recognition of the capacity for DN services to provide a continuum of care**

The perceived disadvantage of working across a number of programs is turned to advantage when it becomes clear that a client is stable from a palliative care point of view but does have specific needs. Familiarity with other programs and referral processes supports continuing and integrated care as well as stepped or staged transfers.

The **transfer and/or discharge procedure** should include:

• consultation and planning with the client and carer;
• referral to more appropriate services if required; and
• provision of information related to Advance Care Planning and Medical Power of Attorney, if not already attended to.

While clients can and do deteriorate quickly and unexpectedly, taking care to plan and consult will help avoid the need for rapid readmission and the perceived waste of time and energy.

Keeping clients ‘on the books’ and visiting them infrequently or monitoring by telephone raises the question of whether the service is meeting its duty of care to the client and carer. This practice also means that the client continues to occupy the ‘head space’ of staff.

7.3.2 Interpreters

Participating services see few clients with minimal English but when they do they use family members to interpret. Some clients genuinely do prefer their family, often adult children, to undertake this role. However, this practice undermines the obligation to inform and involve the client and carer, often the elderly spouse, in the planning of care. It also undermines the opportunity for family to be family and to voice their own needs, concerns and feelings.

It cannot be assumed that a client or carer who speak sufficient English to respond to basic questions will be able to communicate effectively in the face of life-threatening illness. Communicating through a professional interpreter ensures that the words, needs and wishes of the health professional and the client and carer are accurately conveyed, with the result that there is:

• understanding between staff and client and carer;
• improved compliance with recommended treatments;
• clearer expectations;
• fewer errors and adverse events;
• improved attendance at appointments;
• improved client and carer satisfaction; and
• fewer avoidable hospital admissions.

Having current documentation from the local interpreting service on hand would assist staff in navigating unfamiliar circumstances.

7.3.3 Children

Members of DN teams have been unwilling to participate in the care of children on the rare occasions it has been required. DNs most likely have not chosen to care for children and the prospect of being asked to do so is potentially confronting.

It is highly probable that services will receive paediatric referrals in the future, albeit not many, and this contributes to the lack of confidence. Strategies to assist services include:

• establishing contact with the Victorian Paediatric Palliative Care Consultancy Program, an alliance between The Royal Children’s Hospital, Monash Medical

39 Department of Health 2011, Cultural responsiveness framework – Guidelines for Victorian Health Services, State Government of Victoria, Melbourne, p. 33
Centre and Very Special Kids. It operates using a consultation – liaison model of care, consists of paediatricians, allied health professionals and nurses, supports services in the provision of care and holds discretionary funding for equipment and other supports.

- ensuring that the MDT is actively involved in all paediatric palliative care.

7.3.4 Anticipatory prescribing

Anticipatory prescribing of medications is a common if not universal practice for Victorian community palliative care providers. The medications are kept in the client’s home along with orders giving nurses discretionary authority to administer them and enabling services to respond rapidly to symptom crises. There is lack of consensus, however, as well as a lack of evidence, around how anticipatory prescribing should be managed, giving rise to questions such as:

- when should standard anticipatory medications be prescribed? Routinely on admission or based on clinical need?
- how is clinical need ascertained?
- how often are these medications not used and discarded? and
- are there potential harms or risks associated with anticipatory prescribing?

Other concerns are:

- frequently encountered problems obtaining orders, making the process time consuming and inefficient;
- concern that carers feel pressured to administer medications themselves; and
- concern about potential legal ramifications of nurses drawing up medications for carers to administer.

The literature clearly identifies the benefits of anticipatory practice for timely symptom control and the provision of high quality end-of-life care yet it does not address how to manage it. In this environment, organisations can support nursing staff with clear policies and procedures. Organisations should seek guidance in these matters from the GRPCC and Clinical Practice Group.

7.4 Occupational health and safety

Personal care and electric beds

One example of a group of DNs delivering personal care to clients in double beds does not necessarily indicate that this practice is widespread but it does raise the need for a clear policy that meets:

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43 Ibid
44 Ibid
45 Calvary Health Care Bethlehem 2014 ‘Anticipatory Medications in a Community Palliative Care Service’, 9th Biennial Palliative Care Victoria Conference
46 Cotton, P 2013, ‘Anticipatory prescribing of injectable medications in Victorian community palliative care services: a review of current practice’, Australian Palliative Care Conference
• the organisation’s responsibility to provide a safe and healthy workplace; and
• the DNs’ duty of care to ensure that they work in a manner that is not harmful to
  their own health and safety or the health and safety of others.\textsuperscript{47}

It is difficult for individual DNs to refuse to provide care in an unsafe manner when
colleagues are prepared to do so and have set a precedent. As well as the risk of injury
for nurses, this represents legal and financial risks to the organisation.

A policy that is documented and articulated to clients and carers on admission should
include items such as:

• the client’s home is the DNs’ workplace;
• the service is obligated to ensure the safety of its staff in their workplace; and
• a single bed with adjustable height for clients requiring frequent care also protects
carers from injuries arising from manual handling.

**Couriering medications**

It seems to be a practice in some services for DNs to occasionally have prescriptions filled
and to courier the drugs back to the client’s home. Particularly where Schedule 4 and 8
drugs are concerned, this could pose health and safety risks for vulnerable individuals.

**7.5 Measurable outcomes**

The ‘tyrannies of palliative care’ have been said to ‘limit the extent to which palliative
care can be self-critical and reflective’.\textsuperscript{48} One of these is the tyranny of the ‘glowing
testimonial’.\textsuperscript{49}

> ‘Why should palliative care look critically at itself if every day those who
> are cared for provide glowing testimonials to the worth of what we do?
> There can be few other public services where you are always told you are
> an angel without wings …?’\textsuperscript{50}

These expressions of gratitude and positive feedback from colleagues are heart warming
and affirming but they can appear to negate the need to measure outcomes of care
more objectively.\textsuperscript{51} While numbers of deaths at home or at the site of choice is one
measure, the use of PCOC tools and participation in NSAP form a platform on which
services can objectively measure their care.

Several services are discovering the value of using the validated PCOC tools. They
provide evidence of where they are doing well and where there is room for
improvement. However, the tools are not always used consistently and appropriate
action is not always guaranteed. Clear policies and procedures would mitigate this and
assist in the rational planning of visits to clients. Consultation with other Gippsland services
implementing PCOC and PCOC educators would also be of assistance.

Consideration of PCOC and electronic collection of data for future software upgrades
would enable benchmarking.

\textsuperscript{47} Victorian WorkCover Authority, viewed August 2014
\textsuperscript{50} Ibid
\textsuperscript{51} Ibid
Services should also be guided in their use of additional tools by the work of the Palliative Care Clinical Network (PCCN), the GRPCC and Clinical Practice Group. The PCCN provides clinical leadership in the implementation of the Department of Health’s palliative care policy and program initiatives. Work done for the PCCN includes Clinical tools to assist with specialist palliative care provision.

**Progress notes and care plans**

Progress notes and care plans pose a perennial challenge for community services: where should they be kept and how are they to be updated? Individual organisational policies and procedures should address this issue, although perhaps not to 100 per cent efficiency. This is particularly so for paper-based records.

What may be more easily addressed, again through policy and procedure, is the need for:

- a comprehensive care plan that reflects the significant items for the client and mandatory palliative care items;
- consistent formatting of progress notes, aligned with the goals in the care plan, that enables tracking and auditing of specific items;
- the capacity for all involved health professionals to contribute to both documents, making them a reflection of integrated multidisciplinary care and enabling disciplines to learn from and inform each other.

**Advance Care Planning and end-of-life care pathways**

The Department of Health expects that palliative care services will implement Advance Care Planning and end-of-life care pathways; GRPCC recommends the Pathway for Improving Care of the Dying (PICD). Thus far community services have made little progress with either. This is unsurprising given services’ rate of recent change and the resources accorded to education.

While it can be argued that these approaches are fundamental to effective palliative care, it can also be argued that other challenges should take priority in the first instance. These challenges might include the development of multidisciplinary (or interdisciplinary) care and comprehensive implementation of validated tools. This is not to say that staff should not discern clients’ wishes about where and how they wish to be cared for, or that best practice should not guide and inform end-of-life care. It is simply that all of the cited initiatives require significant time, energy and resources to implement them properly.

**7.6 Data**

DN services could not easily produce data related to palliative care clients, such as the proportion of clients registered as palliative care and their average length of stay. AH data, apart from some related to social work and loss and grief, were not available at all.

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52 Department of Health, Palliative Care, viewed August 2014

53 Bostanci, A., Hudson, P, Philip J 2012, ‘Clinical tools to assist with specialist palliative care provision’, Centre for Palliative Care c/o St Vincent’s and The University of Melbourne, Australia,

AH contacts with palliative care clients do not have specific codes and are collected and aggregated within the data of other programs. They are invisible.

Failure to collect all relevant data related to the delivery of palliative care and difficulty in producing accurate reports creates the risk that future funding will not reflect the level or diversity of activity.

7.7 Professional and emotional support of DN teams

Strategies to support DNs in their diverse and unpredictable roles in rural district nursing are important for recruitment, retention and quality assurance. They should be part of routine support of staff, rather than just a response to crises. Such support:

- addresses organisations’ duty of care through promoting the safety and wellbeing of staff; and
- mitigates the stress and burnout that can affect quality of care, patient satisfaction, and may ultimately lead to treatment errors, absenteeism and loss of staff.

The participating DN teams are clearly committed to palliative care and individual DNs generally derive great satisfaction from caring for clients dying at home. Nevertheless, there are times when they are adversely affected by the ‘continuous intimate engagement with people who are suffering’. This is particularly so for DNs who may not have chosen to practise in palliative care and who work in a time-poor environment where the values of palliative care are sometimes at odds with the constraints and requirements of district nursing.

Services encourage and support DNs to undertake education in palliative care through short courses, PEPA placements and GRPCC training. They also provide avenues for DNs to access professional and emotional support, although DNs often seem unable or unwilling to take advantage of them. Barriers include lack of time and lack of ‘the right time’.

People, and of course DNs, ‘will grieve in different ways depending on their personality and previous experiences with attachment, resilience and grief’, so there is ‘no one size fits all approach’. However, organisational acknowledgement that nurses can experience a client’s death with sorrow, loss, fear and regret is a sound basis on which to promote personal growth, resilience and optimism. Indeed,

‘an institutional value placed on the development of resources, including staff support, supervision and educational training, is fundamental to developing a culture that promotes job satisfaction and an environment

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60 Vachon, M 2011, ‘Caring for Ourselves as we Care for the Bereaved’, Grief Matters, vol. 14, no. 2, pp. 58
61 Allison, M 2012, ‘Grief, Bereavement and Self-Care in Nursing’, Grief Matters, vol. 15, no. 1, p. 16
that is conducive to the management of stressors inherent in the work."^62.

While acknowledgement of the importance of support for clinicians to maintain their professional and emotional wellbeing is widespread, the level of evidence to guide the development of specific programs is low –

‘concepts such as clinical supervision, mentoring, and various types of peer support groups have not been well evaluated in palliative care, despite being frequently identified as potential strategies for providing staff support’^63.

Nevertheless, organisations have a responsibility to help nurses who are experiencing grief in response to their work and nurses have a responsibility to care for themselves^64.

The range of supportive and protective processes may include:

**Improving DN’s control over their workload** by enhancing policies and procedures related to admission to, and discharge from, palliative care.

**Protecting DN’s shared culture of care and team** that creates the opportunity for supportive relationships and the storytelling that helps nurses make meaning out of experiences such as the death of a client^65.

**Maintaining encouragement and support for education and extending it** to ensure each team has two DNs with post graduate qualifications in palliative care. This will enhance the opportunity for mentorship, in part by supporting the NP/C.

**Developing relationships and trust** between the DN and AH teams. This would bring other dimensions to client care as well as providing different avenues of peer support.

**Clinical (or professional) supervision.** to provide ‘a useful means of reflecting on practice, building resilience, reducing stress and avoiding burnout’^66.

This is a practice of mentoring that involves support, education, ‘debriefing’ and consultation. It occurs on a regular basis, has specific goals and may be of an individual, group or peer format^67. The trusting relationship between supervisee and supervisor is intended to develop the ability to reflect critically and honestly on work practices, role boundaries and areas for development^68.

The external and individual format is likely to be preferable for DNs who may find it easier to organise appointments in their own time and who may prefer to unburden themselves in a more private and safe environment. The process would require an experienced clinical supervisor from outside the organisation and, in this case, one who is familiar with the environment of rural district nursing^69.

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^64 Hall, C 2012, ‘Editorial’, Grief Matters, vol. 15, no. 1, p. 3
^66 Kenny, A, Allenby, A. p. 165
^68 Ibid
7.8 Innovations and developing expertise

A central, accessible and compact repository of innovations and areas of developing expertise in palliative care in Gippsland would be a resource for the field. The willingness of project managers to share what they have learnt would:

- give other services ideas;
- help other services embarking on similar projects;
- save other services from wasting resources and repeating others’ mistakes;
- provide opportunities for collaboration;
- provide a resource where other services have little experience; and
- promote pride in significant achievement.

Such a repository could be a page on the GRPCC website, as in Figure 2:

**Figure 2. Innovation and expertise**
7.9 Program logic

The program logic links the components of community palliative care programs and demonstrates how they flow through to optimal palliative care in Gippsland.

Figure 3. Program logic
Glossary for Program Logic

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>DN</td>
<td>District Nurse</td>
</tr>
<tr>
<td>NP/C</td>
<td>Nurse Practitioner/Candidate</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>Funded beds</td>
<td>Designated beds for palliative care clients in Gippsland hospitals</td>
</tr>
<tr>
<td>PCCN</td>
<td>Palliative Care Clinical Network</td>
</tr>
<tr>
<td>CPG</td>
<td>Clinical Practice Group</td>
</tr>
<tr>
<td>GRPCC</td>
<td>Gippsland Regional Palliative Care Consortium</td>
</tr>
<tr>
<td>MDT</td>
<td>Multidisciplinary Team</td>
</tr>
<tr>
<td>Liaison Nurse</td>
<td>Nurse who liaises between the community and inpatient settings</td>
</tr>
<tr>
<td>Episodic care</td>
<td>Care that is provided during times of specific palliative care needs.</td>
</tr>
<tr>
<td>Validated tools</td>
<td>Tools that have been developed scientifically, such as those of the Palliative Care Outcomes Collaboration (PCOC) e.g. Symptom Assessment Scale (SAS) covering difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain.</td>
</tr>
<tr>
<td>Reflective practice</td>
<td>Thinking critically and honestly about work experiences, practices and relationships, role boundaries and areas for development. This may be done individually or in groups and formally or informally. It may or may not be professionally facilitated.</td>
</tr>
<tr>
<td>Staff resilience</td>
<td>The ability of individuals and teams to manage the stresses of working with clients and families living with life threatening illness.</td>
</tr>
<tr>
<td>Holistic care</td>
<td>Care that encompasses physical, emotional, psychosocial, cultural and spiritual aspects of life.</td>
</tr>
<tr>
<td>Seamless care</td>
<td>Care that continues smoothly during transitions from one service to another, such as from hospital to home.</td>
</tr>
</tbody>
</table>
8 Conclusion

Referrals for palliative care in Gippsland are increasing. GRPCC commissioned this project to help community services meet current and future demand and to facilitate care that is evidence-based, holistic, safe and effective.

This report takes a high level view of how individual services currently work in this field and proposes a model that will assist them to optimise resources and build capacity to the benefit of palliative care clients, their families and carers. The model is based on Palliative Care Australia’s national standards.

9 Recommendations

The following recommendations arise from the findings:

Recommendation 1 Actively develop relationships among all disciplines of the MDT, and with GPs and local hospitals, to promote holistic and seamless care as well as mutual support and education.

Recommendation 2 To enable accurate representation of multidisciplinary activity, ensure robust collection and reporting of data.

Recommendation 3 To facilitate collaboration, enable all disciplines to share and contribute to integrated progress notes and care plans.

Recommendation 4 Consider the appointment of a DN in each team to the role of Liaison Nurse to enhance relationships and promote safe, seamless and effective transitions between inpatient and community settings.

Recommendation 5 To promote equitable access and appropriate use of resources, each organisation will have policies and procedures to guide admissions to, and discharges from, palliative care.

Recommendation 6 To increase specialist capacity, consider supporting two DN’s per team to achieve palliative care post-graduate qualifications. DN’s with such qualifications include NP/Cs.

Recommendation 7 Build evidence-based practice with comprehensive implementation of PCOC and NSAP, supported by appropriate information systems. Over time, consider the introduction of additional tools as recommended by the PCCN and GRPCC.

Recommendation 8 To promote resilience and mitigate stress and burnout, enhance the range of options available to palliative care staff for professional and emotional support.

Recommendation 9 To promote collaboration across services and to conserve resources, develop a central location for the publication of areas of innovation and expertise.
Appendices

Appendix 1  References


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## Appendix 2 Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td>AH</td>
<td>Allied Health</td>
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<tr>
<td>CPG</td>
<td>Clinical Practice Group</td>
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<tr>
<td>DN</td>
<td>District Nurse</td>
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<tr>
<td>EFT</td>
<td>Effective Full Time</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>GRPCC</td>
<td>Gippsland Regional Palliative Care Consortium</td>
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<tr>
<td>HACC</td>
<td>Home and Community Care</td>
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<tr>
<td>Karnofsky</td>
<td>Australia Modified Karnofsky Performance Scale</td>
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<td>MDT</td>
<td>Multidisciplinary Team</td>
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<td>NPC</td>
<td>Nurse Practitioner Candidate</td>
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<td>Nurse Practitioner Mentor</td>
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<tr>
<td>NSAP</td>
<td>National Standards Assessment Program</td>
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<td>OT</td>
<td>Occupational Therapist</td>
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<td>PCCN</td>
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<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
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<tr>
<td>PICD</td>
<td>Pathway for Improving Care of the Dying</td>
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<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<tr>
<td>RUG-ADL</td>
<td>Resource Utilisation Groups – Activities of Daily Living Scale</td>
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<td>SAS</td>
<td>Symptom Assessment Scale</td>
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<td>Specialist</td>
<td>Palliative Medicine Specialist</td>
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<td>S2S</td>
<td>Service to Service referral system</td>
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<td>VINAH</td>
<td>Victorian Integrated Non-Admitted Health</td>
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</table>
Appendix 3  The domains of the nurse practitioner

The education, research and leadership domains are couched within the clinically focused standards of the Nurse Practitioner

Source: Nursing and Midwifery Board of Australia (2014) Nurse practitioner standards for practice
## Participants

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<th>Stakeholder group</th>
<th>Name</th>
<th>Title/Organisation</th>
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<td><strong>Nurse Practitioner/Candidates/ Mentor (NP/C/M)</strong></td>
<td>Maryann Bills</td>
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<td>NPC/LCHS</td>
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<td></td>
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<td></td>
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<td><strong>Coordinators of district nurses</strong></td>
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<td></td>
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<td>Nurse Manager Ambulatory Care/LCHS</td>
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<td></td>
<td>Barbara Phillips</td>
<td>Coordinator/GLCH</td>
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<td></td>
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<td>Executive Manager, Clinical and Nursing Services/GLCH</td>
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<td>Rosie Steele</td>
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<td>Michael Franco</td>
<td>Monash Health</td>
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<tr>
<td><strong>General practitioners</strong></td>
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<td>Tom Alwyn</td>
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<tr>
<td></td>
<td>Susan Clarke</td>
<td>Tanjil Place Medical Centre (Moe)</td>
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<td></td>
<td>Malcolm McKelvie</td>
<td>Yarragon Medical Clinic</td>
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<td><strong>Allied Health</strong></td>
<td>Melanie Knight</td>
<td>Occupational therapist/LCHS</td>
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<td>Jessica Chambers</td>
<td>Speech pathologist/LCHS</td>
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<td>Dietician/LCHS</td>
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<td>Meredith Burton</td>
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<td></td>
<td>Michelle McMahon</td>
<td>Physiotherapist and Registered Lymphoedema Practitioner/BCCH</td>
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<td>Marijana Mirak</td>
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<tr>
<td>Coordinators of volunteers</td>
<td>Lesley Adams</td>
<td>Gippsland Southern Health Service (GSHS)</td>
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<td>Erika Wassenburg</td>
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<td>Joanne Ramselaar</td>
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<td>Holders of funded inpatient palliative care beds</td>
<td>Brent Causon</td>
<td>Nurse Unit Manager/Latrobe Regional Hospital</td>
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<td>Kerryn Griffiths</td>
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<tr>
<td>Additional</td>
<td>Mary Ross-Heazlewood</td>
<td>Clinical Nurse Consultant/GSHS</td>
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<td>Anny Byrne</td>
<td>Nurse Unit Manager Day Oncology/WGHC</td>
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<td>Jo Smylie</td>
<td>Manager, William Buckland Radiotherapy Centre, Gippsland Cancer Care Centre</td>
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<td></td>
<td>Nicola Gorwell</td>
<td>Project Officer/GLCH</td>
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<tr>
<td></td>
<td>Nadine Sloan</td>
<td>Advance Care Planning and Palliative Care Nurse/Latrobe Regional Hospital</td>
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