



South Island Alliance - PALLIATIVE CARE WORKSTREAM

Survey Report - South Island Primary Health Organisations

Introduction

The South Island (SI) has seven Primary Health Organisations (PHOs). South Canterbury has the DHB fulfilling the functions of a PHO. The PHOs ensure the provision of essential primary health care services, mostly through general practices, to people in the SI who are enrolled. These services are designed to improve and maintain the health of the enrolled PHO population, as well as having responsibility for ensuring that services are provided in the community to restore people's health when they are unwell. It is intended that GP services are closely linked with other health services to ensure a seamless continuum of care.

General practice teams are the main providers of palliative care in community settings, including in aged residential care (ARC). Referrals are made to specialist palliative care services and/or hospices if patient or family needs are complex. Input from the specialist services can be intermittent or ongoing and the care provided by non-specialists is referred to as 'primary palliative care'. It is generally accepted that members of the general practice team need to conduct home visits (usually a doctor) as and when required to optimise care.

The South Island Palliative Care Workstream (the Workstream) undertook a survey of all SI PHOs in October 2016 to evaluate the provision of palliative care in the primary care setting (as opposed to specialist palliative care) and what progress has been made towards the implementation of the *Resource and Capability Framework for Adult and Palliative Care Services in New Zealand (2013)*¹. The aim was to gain a better understanding of how palliative care is provided and funded at the PHO/General Practice level and to establish the extent of integration and collaboration with local hospices and specialist palliative care services. The survey also enquired as to the role GPs have in providing palliative care in aged residential care (ARC).

The survey was sent to the 7 PHOs and South Canterbury DHB in the South Island. Only the 7 PHOs responded (see Appendix 1).

South Canterbury District Health Board (as the funder of primary care services) is not represented in the findings.

¹ Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand 2013

Survey responses with comments

1. FUNDING

Access to palliative or end of life funding

Timeframes for when patients become eligible for palliative care or end of life funding varied from 3 months to 15 months. The PHOs within CDHB consistently sit at the 3 – 6 months' timeframe, whilst other PHOs appear more generous with their timeframe.

PHO	Eligibility for palliative or end of life funding				
	3 months	6 months	9 months	12 months	15 months
WestCoast				x	X #
Nelson Bays PHO				x	
WellSouth		x			
Pegasus	x	x			
Rural Canterbury PHO		x			
Christchurch PHO	x				
Marlborough PHO		x	x	x	
SCDHB					

as determined by GP

Comments:

The reported variance raises the question of equity of access for patients depending on enrolment. It is also noted that some PHOs categorise patients under chronic disease management when in fact they are palliative. This may distort the data that PHOs collect and this issue may be worth further exploration.

Payment utilisation

There is variation in terms of how the palliative or end of life payments are managed and the degree of discretion General Practices can use to manage the payments. For those PHOs where the eligibility to access palliative or end of life funding is at 3 -6 months, once the patient has access it appears the fee structure would cover all visits in most settings. When timeframe are longer, funding packages are capped, with one PHO providing a variable amount of capped funding depending on whether the patient is rural or urban. One PHO indicated that payments covered GP visits into ARC.

There is variation in which professional groups can access palliative or end of life funding with most indicating medical access only. No PHOs within the CDHB provide payments to anyone other than the GP to deliver palliative care. NBPHO funds other practitioners within the General Practice team and WellSouth provide funding to other professionals as long as they are *contracted* by the General Practice.

Uptake of the funding is difficult to determine as answers were inconsistent, however it appears to be aligned with access. Two PHOs reported expenditure exceeding funding and both these PHOs have generous access criteria of 12 months.

In the larger DHBs / PHOs with greater enrolled populations patients do benefit from flexible funding including presentations to after-hours services where these services are provided by that PHO.

One PHO offers a funded post death/bereavement visit.

Comments:

It is apparent that flexible funding that follows the patient is possible (for example to ARC and after-hours surgeries) but is not routinely the case. This potentially limits access after-hours to primary care for the patient. It also raises the question regarding medical professional obligations to provide 24 hour access to primary care. There is an opportunity to ask the Medical Council to consider the implications of this.

With funding capped at \$300 urban and \$500 rural for up to 12 months of visits there is potential for demand to exceed available funding

The fact that funding is only used for doctors' visits has the potential to reinforce the message that 'only doctors can deliver palliative' care which is not the case. It is also counterproductive in utilising all professional groups and their advanced skills and knowledge in all settings.

Consumer knowledge of funding arrangements

Communication is variable across the PHOs in terms of patient and family/whanau awareness of whether funding for palliative care visits is available to them, how that funding is accessed, what it covers and for how long.

From the survey responses, it is difficult to ascertain how clearly schemes are communicated to patients beyond the fact that they are told they don't have to pay. Whether patients are aware that the visits are paid by the DHB is unknown.

Comments:

Most patients are reliant on their doctor, nurse or practice administrator to tell them about how funding works and what they are entitled to. Some PHOs use their websites but overall more transparency is required.

Funding model

All PHOs have a funding model for delivery of palliative or end of life care. It is difficult to interpret if all the CDHB PHOs have the same contract with CDHB as answers vary. WCPHO is capped at \$500 but access could be up to 15 months. There is variation between capping at \$250 - \$500 versus days. One PHO differentiated between rural and urban. Three of the PHOs provide additional funding for rural patients.

The majority of GPs do not on charge patients who receive palliative or end of life funding. The NBPHO believes it is up to the discretion of the patient and the GP to decide how to spend the funds.

In one PHO, a community Social Worker is able to navigate patients and family/whanau towards the palliative care funding. One PHO engages families with a social worker to assist with navigation to other resources.

Comments:

It is acknowledged that additional funding is necessary for both chronic care management and palliative care and that the two may overlap. The process whereby the patient moves from one package to the next as needs change is managed at the discretion of the GP and/or team. It is not clear if the administration of this is onerous or if the process is transparent. Emphasis should be on

diagnosing the changing needs of the patient and having the ensuing conversation, rather than effort going into time consuming administration. It was evident that there is still some misunderstanding between chronic care management and palliative care amongst survey respondents.

Further to this, the fact that some funding distribution is at the discretion of the GP could provide autonomy for the GP but inconsistency across populations. Outcomes in this situation may not be in the best interest of the patient.

It is worth noting that the burden of care can be high for family/whanau and there is a lack of any dedicated funding to supplement the national 'carer support' payment.

Service model

Three PHOs confirmed their GP members had direct integration with their local hospices. Referral to the specialist services for GP members in three PHOs is through either HealthPathways or the Electronic Request Management System (**ERMS**). Some GP practices have direct integration with their local hospice where that integration is not provided by their PHO. PHO members value the use of HealthPathways.

Access to psychological, social and spiritual care, including bereavement support, to palliative care patients and their family/whanau is variable. Most have access of some description; issues appear to be around bereavement support for families of patients not under a palliative care specialist service. There are existing services that could be accessed through general practice, for example, "Brief Intervention Coordination" for bereaved relatives of ARC residents.

Comment:

It is worth considering what the ideal model is in primary care for providing or facilitating psychosocial support at the end of life, particularly if hospice input is not otherwise required or available.

Quality

The survey asked about how the quality of care for patients receiving palliative or end of life funding is measured. Most PHOs noted they did not have a specific measure for palliative care however do use standard tools; audits, patient surveys, continuous quality improvement that generally run across all services/areas.

Comment:

This issue is being addressed nationally using validated outcome measures and it would be advantageous if this work included primary care.

2. Workforce

Education

Palliative care education is being routinely provided via PHOs. This could be related to the increasing recognition of palliative care as a core primary care role National Health Needs Assessment for Palliative Care Phase 2 Report: Palliative Care Capacity and Capability in New Zealand All PHOs engage with specialist services or provide palliative care education and training. This occurs to

varying degrees – as frequently as monthly or on an annual basis – some only 3 yearly. There is a range of education and training options which in some PHOs includes pharmacy staff.

Three PHOs have no dedicated palliative care roles in primary care (e.g. Hospice Medical Officer or Hospice on call) or a special interest position or access to a diploma in palliative medicine. Where such options are available, the roles vary. The GP liaison role although not a new idea is only in one PHO. The findings for nursing were the same.

Both CME (continuous medical education) and CNE (continuous nursing education) programmes include palliative care. The education cycles vary from monthly to 3 yearly although it is not clear if palliative care is included in all of the education scheduling.

Quality

Overall, there was no clear evidence of palliative care in accreditation programmes being used in general practice.

Allied Health

There are no funded roles within any PHO for members of the allied health workforce in palliative care.

Comment:

The question may have been slightly ambiguous so perhaps not entirely accurate answer however probably true.

3. Technology and data/IT

Shared records

HealthOne or the Electronic Shared Care Record View (ESCRV) is a secure record that stores health information including GP records, prescribed medications and test results and is the preferred electronic record for palliative care patients in general practice. It is used by members in four PHOs and being considered in another two PHOs when the connectivity is available.

Data

SI PHOs are increasingly collecting and evaluating enrolled population data and outcomes. Six SI PHOs collect data but there is no consistency with what data is collected by whom and for what.

Comment:

There is no ability to capture regional data. Potentially data collection could be more deliberate regarding data around palliative care for example a Gold Standard Framework type outcomes framework within general practice. If done this would need to be led by GP practices not the PHO. There is an opportunity via the national GP networks, for example, Dr David Wilson's manifesto for palliative and end of life care.

Innovation and Research

One PHO is involved in palliative care research in conjunction with multiple partners including their local specialist palliative care service/hospice.

Technology

Five SI PHOs have access to and use telehealth facilities. PHOs reported the usual problems associated with telehealth for example connectivity.

Policy and Guidelines

Three of the six PHOs were able to confirm their practices were using either the Liverpool Care Pathway for the Dying Patient (LCP) or the new Te Ara Whakapiri: Principles and Guidance for the last days of life. Two PHOs couldn't answer the question as to what is happening in practice. Overall there was a poor response to what, if any guidelines are being used.

The practices of six PHOs engaged in Advance Care Planning.

Comment:

It is encouraging that most of these initiatives are funded but further exploration is required to ensure accuracy of information.

Resources

Five of the seven SI PHOs practices surveyed can access general loan equipment, for example electric beds and commodes. This occurs mainly through nursing services via DHBs. Seven SI PHOs have access to syringe drivers 24/7. This occurs mainly through Hospice or District Nursing services

Summary of key findings

1. The definition of palliative care is inconsistent across the SI PHOs with a lack of distinction between specialist palliative care, primary palliative care and end of life care (Refer to the Palliative Care Glossary, MOH 2015).
2. Requirements to access palliative and end of life funding are highly variable and funding is practice-based not patient-based which limits coverage after hours. It is also variable as to what palliative funding covers e.g. surgery visits, after-hours visits, home visits.
3. Funding is not linked to participation in education or audit.
4. There is an apparent lack of transparency between practices, ARC facilities and eligible residents regarding how GP visits to ARC are remunerated both within and after hours.
5. Access to and funding of bereavement support is variable or absent.
6. Account is not routinely given to the increased support needs of vulnerable and rural communities.
7. There is limited use of GP or Nurse Practitioner liaison roles for palliative care.
8. Sharing of records to improve patient safety and communication between health professionals and providers is limited.
9. Equipment access for patients is variable.
10. Audit information on quality, access to care and outcomes for palliative patients is lacking.
11. There are limited ACP training opportunities for PHO staff.

12. Written information on palliative care funding criteria and benefits is not readily available.
13. Access to input from allied health professionals e.g. occupational therapy (where a referral to hospice is not otherwise necessary) is limited or absent.

Conclusion

PHOs across the South Island provide primary palliative care through a variety of funding streams and other methods. It is a role they take seriously and there is strong evidence that GP teams are actively supported by their PHO to care for patients and their families in collaboration with specialist services and hospices.

There is, however, a high degree of variability which leads to issues of consistency, equity and transparency. Improvements could be made across the board by collaborating on workforce, quality (including the consumer experience), policy, systems, data and education across the South Island.

Across the country, the cost of primary palliative care is born by PHOs (via their DHB) but the type of funding and its extent is highly variable. Funding streams are available via enhanced capitation and PHO based palliative care packages in most areas across the South Island (SI) and cover patients with any terminal illness (not just cancer). In some PHOs this funding is ring-fenced, in others it is not. Where it is ring-fenced, funding is available until it has been used up.

There is good access to educational support for palliative care throughout the SI. This is provided through partnerships with hospice or in-house. More could be done with ACP training for GPs and Practice Nurses. All areas have access to syringe drivers after hours via GPs, district nurses or community hospitals. Telehealth is being used in most areas but there are notable exceptions.

While the survey showed that some useful relationships had been established between PHOs general practices, hospices and hospitals, there remain clear inequities and gaps in service and where services do exist they are vulnerable to staffing absences and professional isolation. The practicality of providing after-hours general practice support is also unrealistic and/or unsustainable in some areas.

The ultimate goal is to improve equity and access to care , to achieve the vision of *high quality, person centred, palliative and end of life care available to the population of the South Island according to need and irrespective of location.*

Appendix 1

South Island Primary Health Organisations (PHOs)

WellSouth PHO is responsible for ensuring that primary health care services are provided effectively to the 293,114 patients enrolled (as at 1 July 2016) with the 84 general practices in the district.

Pegasus has an enrolled population of 396,227 with 322 GP members and 453 nurses (as at April 2016) in the Canterbury District

Christchurch PHO (CPHO) consists of six urban Christchurch medical practices, who are members. The CPHO coordinates the delivery of community based health care to meet the needs of over 32,000 enrolled patients in Canterbury

Rural Canterbury PHO has an enrolled population of 70,948, 54 General Practitioners and 114 Practice Nurses in 22 Practices. Their region covers Cheviot down to Ashburton in the south, west to Hanmer Springs, and east to Akaroa in Canterbury.

Nelson Bays Primary healthcare is provided in the community by 26 General Practices with almost 150 GPs and over 100 Practice Nurses who look after the health of over 99,000 enrolled patients throughout the Nelson-Tasman region.

Marlborough Primary Health contracts health professionals and organisations in the community, such as General Practices, to deliver quality primary health care services to an enrolled population of approximately 42,000 people and a total of eight (8) General Practices operating in Blenheim, Picton and Havelock.

WestCoast PHO provides healthcare to 29,775 enrolled patients through 8 general practices located between Karamea and Haast Pass in the West Coast district.