



SOUTH ISLAND ALLIANCE - PALLIATIVE CARE WORKSTREAM

Primary Palliative Care Executive Summary

The New Zealand Palliative Care Glossary (MOH 2015) defines primary palliative care as *care provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team. Primary palliative care is provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional.*

Surveys were undertaken by the Palliative Care Workstream to explore the extent that primary palliative care is occurring and how services are supported in three main areas - Aged Residential Care (ARC), Primary Health Organisations (PHOs) and DHB Planning and Funding. Many examples of collaboration, innovation and service development were identified. It is apparent, however, that primary palliative care is provided through a variety of funding streams and other methods with a high degree of variation. This has resulted in a number of gaps and there is clear evidence of inequity of service.

The main findings from the three individual surveys are reported below.

ARC Survey

The response rate to this survey was low, so findings should be interpreted with a degree of caution. Strong relationships were however reported between individual ARC facilities and their local Hospice/specialist palliative care service and many initiatives were described which need to be fostered across the sector. Such initiative include ACP which is now a key priority for the SIA and major efforts are needed to improve the uptake of ACP in ARC.

With the release of the Toolkit for *Te Ara Whakapiri – care in the last days of life*, comes the challenge of implementation. It is an excellent opportunity for collaboration and education, but will be challenging without a consistent approach and an appreciation of the resource required. Access to Community HealthPathways in ARC would be an excellent vehicle for this and progress in this area is being made.

The survey highlighted major deficiencies in after-hours GP availability which places considerable burden on nurses to fill the gaps. There is also a problem with access to newly prescribed medications from community pharmacies after-hours which can lead to needless suffering or unnecessary hospital admissions. These issues need urgent attention at a DHB level and potential solutions evaluated and shared. Access to equipment in a timely way can also be a problem with additional costs falling on facilities. This issue should also be raised with DHBs to establish a consistent approach.

By working collaboratively with the ARC sector, it should be possible to ensure equality of palliative care delivery across the SI. This will require a better understanding of the interface between GPs, ARC facilities and specialist palliative care needs so that available resources can be optimally directed in a consistent way.

PHO Survey

Survey responses were received from seven out of eight PHOs. 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. 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. The definition of palliative care is inconsistent across the 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). Funding is not linked to participation in education or audit.

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. Funding streams are available via enhanced capitation and PHO based palliative care packages in most areas across the SI and cover patients with any terminal illness (not just cancer). In some PHOs this funding is ring-fenced, in others it is not. There is very limited use of GP or Nurse Practitioner liaison roles for palliative care.

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. Equipment access for patients is variable and access to and funding of bereavement support is variable or absent.

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. Account is not routinely given to the increased support needs of vulnerable and rural communities. The practicality of providing after-hours general practice support is also unrealistic and/or unsustainable in some areas and the impact this has on care provision has never been formally evaluated.

Requirements to access funding for palliative and end of life care 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 and written information on palliative care funding criteria and benefits is not readily available. Access to input from allied health professionals e.g. occupational therapy (where a referral to hospice is not otherwise necessary) is limited or absent.

It appears that awareness of additional funding for GPs to visit palliative care patients in ARC is limited along with a lack of transparency between practices, ARC facilities and eligible residents regarding how GP visits to ARC are remunerated both within and after hours. These issues require further exploration.

Sharing of records to improve patient safety and communication between health professionals and providers is limited. Audit information on quality, access to care and outcomes for palliative patients is lacking.

Planning and Funding Survey

Responses were received from all SI DHBs and it was pleasing to see that palliative care appears in all District Annual Plans (DAPs). However, an integrated, visionary plan for Palliative Care Services is not evident in any DAP with the exception of specialist palliative services in Canterbury. It is clear that the approach to provision of palliative care varies widely among the five DHBs and there is no consistency in funding of Hospice Services, inpatient Hospital Specialist Palliative Care Services, Community Specialist Palliative Care Services or Primary Palliative Care Services.

A major area of concern is that funding and access to specialist paediatric palliative care varies greatly across SI DHBs and support services to families/whanau caring for children at end of life is also highly variable. There is no dedicated funding and service provision is ad hoc. A coordinated approach is needed and given that volumes are low this should be possible to achieve with a unified vision and approach.

None of the DHBs are evaluating outcomes from Palliative Care Services which is an issue that has recently been highlighted nationally. Any progress in this area will require input from DHBs as well as hospice services.

Funding and eligibility for palliative and end of life care in aged residential care facilities varies depending on DHB and is one area that should be addressed as a matter of priority.

A number of opportunities to identify how current funding mechanisms might be creating barriers to integration of palliative care services were highlighted. There is an opportunity for the Workstream to assist with discussions around improved equity and consistency going forward.

Conclusion

The ultimate goal is to improve equity and access to care, to realise 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*. This will require cross-sector collaboration and strategy development to ensure that this can be achieved.