

# Palliative Care Survey

SUMMARY REPORT  
NSW HEALTH

MAY 2018



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# Introduction

NSW Health is developing a framework for palliative and end-of-life care services. From April to October 2017, roundtable meetings and consultation workshops on palliative care were held across NSW to hear directly from communities, clinicians and service providers about what they saw as the priorities for palliative care.

In November 2017, a consultation paper and a survey with 16 questions were publicly released to report on the roundtable meetings and consultation workshops, and to provide participants and people and organisations who were unable to attend an opportunity to have their say on priorities for palliative care. 2000 responses were received from a wide range of people who work in palliative care services or who have experienced the services directly or indirectly.

This report provides a summary of the responses. It includes an initial quantitative breakdown of respondent perspectives, priorities and support for the roundtable themes and ends with a qualitative, thematic analysis of written comments. The survey featured 10 opportunities for long-form responses, and so the qualitative analysis reported in this document is not necessarily statistically significant but rather an attempt to summarise those points that frequently emerged.

The information gained from the roundtable meetings, the survey and additional stakeholder engagement will inform the development of the NSW Health End of Life and Palliative Care Framework to be released in 2018.

Many of the issues raised are being addressed by the NSW Government through a record investment in palliative care services. In June 2017, the NSW Government announced an additional \$100 million dollars funding over the next four years for palliative care in NSW to support people suffering from terminal illness. This is in addition to the estimated \$210 million spent annually on palliative care services.

The 2017-18 budget includes \$17.4 million of the additional funds, providing:

- Palliative care training for 300 nurses and allied health staff
- 300 scholarships for rural and regional staff to enhance palliative care skills
- An additional nine palliative care specialists in rural and regional areas
- Two specialist positions to provide relief to other specialists in rural and regional areas
- An additional 30 palliative care nurses providing care in hospitals, homes and nursing homes
- Improving medication management for palliative care patients through community pharmacy initiatives.

**2000**  
responses  
received



**Online Survey**



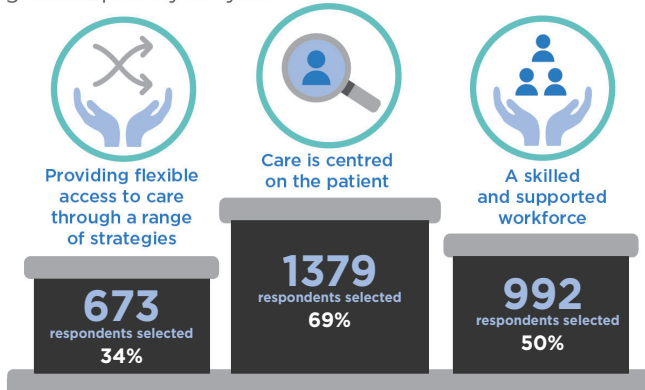
**Hardcopy  
Surveys**

**Respondents:**



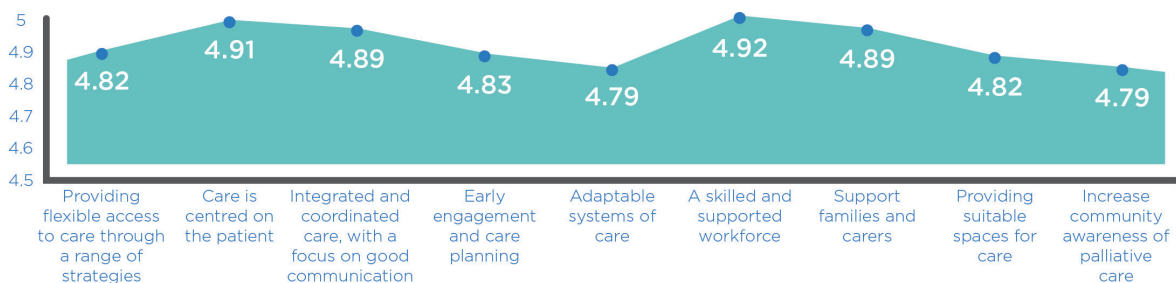
**78** of you indicated that you had attended one of the Roundtables

Which roundtable themes were of greatest priority for you?



These top 3 priorities were shared by all of the groups identified on the right, except for academics who considered 'Integrated and coordinated care with a focus on good communication' to be a greater priority than 'Providing flexible access to care through a range of strategies'.

**You showed overwhelming support for the roundtable themes when asked to rate them out of 5**



All groups indicated high levels of support for the themes, with no group scoring a theme lower than 4.43 out of 5.

## Your main points

Some points were frequently made in your responses to many of the survey questions. The below are indicative summaries of these key points.

**Care should be patient centred:** Palliative care should be about the unique and holistic needs and wishes of the patient. This means early assessment and development of care plans that are regularly updated. Patients should be kept well informed of available services, with advocates available to represent their wishes when they can no longer communicate themselves.

**Service delivery should be flexible:** Flexible service delivery means adaptive services and facilities available to all, regardless of their geographic location, age, socio-economic needs, cultural background or languages spoken. You suggested examples such as 24/7 telephone support, out-of-hours pain management, home visits, respite and day care and dedicated beds.

**Care should be integrated and well-coordinated:** Integrated and well-coordinated care makes for a streamlined patient experience and more efficient use of staff time and palliative care resources. Care coordination is required for the patient as they move through the palliative process. Accessible electronic records and care plans would help make this possible. Evaluative methods for assessing care will also improve service delivery.

**Additional resources and training are required:** Funding should be better coordinated across NSW to achieve more equitable service delivery and better support for staff. This includes improved funding for dedicated palliative care spaces and services, attracting and retaining more palliative staff, and upskilling palliative care specialists and multidisciplinary teams. Consistent assessment of available data will aid future planning for palliative care, especially as we prepare for the needs of an ageing population.

**Palliative care should be clearly defined and recognised:** Further research is required to define palliative care in comparison to end-of-life care, including what works and what is required across NSW. Informing the community and improving awareness of available services will help address the stigma around death and dying. Palliative care should be recognised as a specialty and funding increased as needed, with specialist staff and multidisciplinary teams.

**The role of carers and support services should be recognised:** Carers play a critical role in supporting the health care system and so, in turn, require support in the form of personal and home care, counselling, respite care and other services. They should also be consulted during the development of patient care plans as they may play a key advocacy role. Each carer's capacity should be assessed, as should their available and required resources.

## Other issues you raised

The following were also frequently mentioned but did not receive the same emphasis in the Consultation Paper. These will be considered when developing the End of Life Palliative Care Framework.



**Pain management:** Better pain management, including improved access to medication and equipment in the home, would help reduce the need for hospital admissions and medical intervention. Clear communication is also required to provide continuity of pain management for patients moving between care settings.



**Respite care:** Respite care is an essential service for supporting carers and, in turn, supporting in-home care and preventing premature patient admissions into health care facilities. More carers should be given access to respite care, including flexible options ranging from in-home care, to day care and longer term respite.



**General practitioners:** General practitioners (GPs) – particularly in regional and remote areas – play a critical role in assessment, referral and delivery of palliative care services. In many cases, GPs have known the patient for a long time and are well informed of the patient’s needs. GPs could be provided with information about palliative care – so that they know when and where to access specialist support – and should be remunerated accordingly.



**Monitoring and assessment:** Assessment and monitoring tools need to be uniform to improve the patient experience and support palliative care planning, funding and reporting across NSW. This might mean early, standardised patient assessment, as well as regular reporting on common health care performance indicators across the state.



**Chronic and degenerative disease:** The prevalence of chronic and degenerative diseases (especially dementia) is increasing. It will be important to plan for the impact this will have on palliative care. Planning and appropriate allocation of funding will be required to cater for the specific needs of these patients.



**Euthanasia:** Approximately 35% of responses were received in the three days after the Assisted Dying Bill passed the Upper House in the State of Victoria, some of which made reference to euthanasia. Views varied; for instance, some responses suggested that voluntary euthanasia should be an option for palliative patients, while others suggested that palliative care and pain management can reduce the need for euthanasia.

# What does flexible access mean to you?

## You said you want:

- More choice for patients, including affordable access to care
  - Increased involvement of patients and carers in care planning, to allow for tailored care and individualised pain management
  - Recognition of a patient's unique needs, including patients from different cultures or age groups
  - Regular reviews of care plan to assess a patient's changing needs
  - 24/7 access to specialist telehealth services and after-hours access to equipment and medication, all of which will help support GPs, community health teams and in-home care
  - Feedback and review mechanisms, including benchmarking against other states and countries, to assess whether patients do have flexible access to quality care
  - Community engagement to promote good palliative care options and available services, including a palliative care guide and/or case managers or advocates to coordinate care for patients
  - A multidisciplinary team approach and standardised referral process, with health providers who are familiar with the palliative care system
  - Stronger links between services, including shared electronic records, to support continuity of care from home to hospital, acute to palliative care, public to private and more
- Patient centred care
  - Continuity of care
  - Support for carers
  - Adequate resources and training
- Improved support for carers, including review of the My Aged Care assessment process, better access to financial support for in-home care, and increased access to and awareness of services such as home support services, respite care and bereavement support
  - Increased use of multidisciplinary teams and extended palliative care training to include a wider range of health care professionals
  - Adequate resources for palliative care positions
  - Support volunteer programs to reduce the workload on staff and better meet patient needs
  - More diversity in the options available, such as hospital beds, hospices and in-home care support, particularly in rural and regional areas
  - Strategic, cost-effective allocation of funds for palliative care at the community level to provide more flexible access to care

People's needs change through the stages of life, from simple pain relief to 24/7 care, so the system should adjust to the person's needs

- Comments by family/carers



# What does patient-centred care mean to you?

## You said you want:

- Earlier referral and education so that patients, families and carers can make informed decisions and multidisciplinary planning can begin
  - Care plans that document a patient's care history and holistic needs and wishes, focusing on quality of life rather than just symptom management
  - Regular reviews of care plans to reflect changes in patients' needs and wishes
- Patient voice and advocacy
  - Care plans and patient assessments
  - Support for carers
  - Adequate resources and training
- Flexibility to allow for patients' requests, including treatment refusal and alternative therapies
  - Electronic patient records that incorporate care plans to allow for integrated care
  - Clear communication and consultation between patients, families, carers and health care professionals at all stages of care
  - Patient advocacy and care coordination to reduce duplication and waiting times and improve continuity of care
- Improved awareness of cultural and personal differences, including the specific needs of younger patients and Aboriginal patients in remote and rural areas
  - Improved and well-coordinated access to support services, including patient transport, home services and respite care, to reduce carer stress and provide best patient care
  - A definition of what patient-centred care means in practice
  - Integrated and supported palliative care services, especially in rural and regional areas
  - Pain management support, equipment and other services to be provided, to help support in-home care
  - A feedback and complaints process to drive improvements to the standard of palliative care
  - Increased support for:
    - Specialist palliative care services to support and educate health care professionals
    - Multidisciplinary community care teams to support 24-hour in-home care and provide continuity of care
    - Public hospices, dedicated palliative care beds and alternative services to reduce hospital admissions



**We should respect a person's right to be involved in their own care by engaging in open communications about their medical and holistic needs**

*- Comments by advocates/non-government organisations*



# What does integrated and coordinated care mean to you?

## You said you want:

- Clear, honest and regular communication between all parties to keep patients, families and carers fully informed of available options throughout the palliative care process
- Accessible communication methods (including case conferences, teleconferences, joint home visits, patient messaging services, written and/or online) that:
  - Minimise patient, family and carer stress
  - Assist understanding
  - Offer opportunities for feedback
- Awareness of cultural and linguistic differences and other communication challenges, including the use of professional health care interpreters and patient advocates where appropriate
- A consistent standard of care, including through standardised guidelines and policies
- Remove 'silos' of care
- Greater coordination between services and providers to ensure the best care and efficient use of available resources, including regular discussions of patient care plans
- GPs to be provided with patient updates and included in case conferences, given the critical part they play in coordinated care
- Local multidisciplinary teams or palliative care 'squads' available to support patients at home and in the transition to other services

- Patient assessment and consultation
- Continuity of care
- Technology
- Resourcing and training

- Coordinated care, managed by a palliative care coordinator or manager, to avoid duplication of services
- A central person in management of a patient's care so they do not need to be re-assessed each time a new service is engaged
- Patient records to be updated and shared between providers and different levels of government to enable continuity of care (e.g. My Health Record)
- Further investment in new systems and technologies
- Specialist services funded and available to support GPs and local health care teams, especially in rural areas (including telephone or online 24-hour support and/or more out-of-hours palliative care nurses and social workers)
- Further palliative care training for health care staff including communication skills development



**Errors, mismanagement and unnecessary treatments and costs can be avoided through coordinated and collaborative care**

*– Comments by academics*

# What does early engagement and care planning mean to you?

## You said you want:

- Guidelines to assist palliative care discussions and planning, including around privacy and confidentiality
  - Standardised referral pathways and risk assessment tools for all healthcare services
  - A review of current referral processes to minimise premature, late or unnecessary referrals to palliative care services
  - Early referrals and assessment so patients are aware of – and have access to – patient advocates/care coordinators and appropriate services and options
  - Patient-centred, Care Plans and/or legally enforceable Advanced Care Plans that reflect patient wishes and are regularly updated to meet changing needs
  - Palliative care services and clinical care to be coordinated by GPs, specialist medical practitioners or palliative care specialists
  - Improved communication, service provider partnerships and sharing of patient records to provide continuity of care for patients and carers
  - Assessment of palliative care requirements in each local health district (LHD), including in rural and regional areas, to improve access to services, enhance service delivery and increase efficiency
  - Resources to support early assessment services and improved patient referral systems and records
- Assessment and planning to improve service delivery
  - Education and training
  - Resources
- Telehealth and other technologies to be used to connect specialists with GPs and healthcare practitioners during referral and assessments
  - Healthcare practitioners to be educated on advanced care plans, referral opportunities and on how to discuss death and dying, so that they can better help patients, families and carers
  - Community education – including through media campaigns and other resources – about palliative care, including available options and the benefits of early planning
  - More community-based staff trained and experienced in palliative care – including nursing staff, medical specialists, social workers – especially in rural and regional areas
  - Recruitment of care coordinators to manage complex cases, as well as staff who are aware of cultural and language differences



**Early conversations about palliative and end-of-life care can help people access services early**

*– Comments by healthcare practitioners*

# What do adaptable systems of care mean to you?

## You said you want:

- Adaptable services that meet a patient's unique needs and expectations, including flexible rosters, 24/7 support, pain relief after hours, and in aged care facilities
  - Customised and comprehensive care plans, informed by cultural considerations, which are prepared early and regularly assessed
  - Regular, open and honest communication and collaboration between palliative care teams, service providers and patients/carers
  - Multidisciplinary palliative care teams, with increased number of allied health positions, to provide outreach care from specialised units
  - Appropriate equipment, staff and training, including senior nurses and community palliative care nurses, to better support patients at home
  - Investment as needed in palliative care infrastructure, especially in rural and regional areas
  - Research conducted into models of care used in other countries, to improve our understanding of palliative care
  - Opportunities for community engagement and feedback
  - Improved awareness of palliative care, including in Emergency Departments
- Service flexibility and patient-centred care
  - Continuity of care
  - Resources and training
- Clear information for patients and carers about the range of services and support available
  - The unique needs of patients under the age of 65 to be recognised and appropriate services provided
  - Standardised assessment, reporting and review of care
  - Technology to be used to enhance communication and avoid duplication of patient records
  - Case coordinators to facilitate and manage care needs



**Person-centred care means that services should adapt to each individual's unique needs**

*– Comments by healthcare practitioners*

# What does a skilled and supported workforce mean to you?

## You said you want:

- Specialist palliative care support for health care practitioners, including GPs, especially in rural and remote areas
  - Medication management to enable patients to receive adequate pain relief, given pain management is of critical importance to palliative care patients
  - Staff with strong communication skills and cultural awareness
  - Nurses to have skills and abilities to work with people who are palliative
  - Educational courses and pathways available for staff who wish to study the field in more depth
  - Evidence-based and funded palliative care training and education for all healthcare staff – including in regional areas – through conferences, webinars, clinical supervision and more
  - The ageing of the palliative care workforce to be acknowledged and addressed through scholarships and other incentives that encourage people to take up palliative care education and training, particularly in remote areas
  - Palliative care staff to be recognised and valued
  - Appropriate staffing levels to ensure adequate levels of care and staff support
  - Adequate resources to be incorporated in local health district service planning for palliative care, especially in rural and regional areas
- Recognised speciality
  - Education and training
  - Recruitment and retention
  - Supportive resources
- Support for staff doing palliative care work, including counselling, debriefing, rostering to provide relief and scheduled time away from face-to-face delivery
  - Regular reviews of palliative care service delivery, including opportunities for both palliative care staff and the community to give feedback
  - Support from volunteers, including non-medical staff



**As Australia's population ages, a highly skilled palliative care workforce will be critical to reducing the pain and distress that comes with life-limiting illness**

*– Comments by academics*

# What does family and carer support mean to you?

## You said you want:

- Recognition of the critical role carers play in supporting the healthcare system by providing a large portion of palliative care services
  - Information for employers, GPs and the community on the value of caring to the patient, carer responsibilities and the impact of palliative care on carers and family members
  - Information for carers on palliative care, last days of life, medication and physical care requirements, as well as services available to support carers and how to access them
  - Support for carers from trained palliative care staff, including 24 hour phone support, video conferences, overnight care, and access to medication and equipment
  - A review of the quality of the palliative care system, particularly services available for carers
  - Multidisciplinary palliative care teams to involve carers and family in care planning
  - Early assessment of the patient's carer/s and ongoing checks, to understand the carer's capability, well-being, resources and supports available to the carer, and any family conflict
  - Early identification of the primary carer and confirmation of the decision-making process
- Recognition of carers
  - Carer assessment and planning
  - Support services
  - Resources
- Clear and honest communication, recognising cultural and linguistic differences and using translation and interpreting services where necessary
  - Regular respite care to support carers, including in home respite care, dedicated respite care beds, overnight in-home care or day care beds
  - Increased support and promotion of carer support groups, community-based support networks and advocates
  - Carer access to case managers, financial and legal advice and grief counselling and bereavement services
  - Increased financial support for carers, including for those caring for patients under 65 years of age or with chronic disease



**Families and informal carers play a critical role in caring for people with life-limiting illness – providing additional care that the health system could not afford to provide**

*– Comments by academics*

# What do suitable spaces mean to you?

## You said you want:

- Access to palliative care services for patients close to where they live and when needed
  - Fully staffed and integrated palliative care services that meet the needs of each LHD, upgraded where necessary to meet modern standards
  - A register of available palliative care services and facilities
  - Palliative care options for patients of different ages and cultural backgrounds
  - Palliative care to be a specific requirement in health care planning and development
  - A range of adaptable spaces to suit different and changing patient needs, from short hospital admissions to assess pain management to outpatient clinics, day care and more
  - Access to specialist equipment and/or home modifications to support in-home care
  - Guidelines, based on consumer feedback, for the re-design of existing facilities and the design of new facilities to meet palliative care needs
  - Dedicated specialist spaces in hospitals for palliative care patients, with trained staff
  - Private and homely non-clinical settings in palliative care or aged care facilities, including family accommodation
  - Flexibly designed palliative care spaces that can be easily modified to suit individual requirements
- Access to care
  - Flexible and well-designed spaces
  - Resources and training
- Respite beds and/or respite care in the home
  - Smaller, community-based and supported care facilities, including hospices
  - More in-home palliative care support, including extending services to meet needs of the last month of life
  - Palliative care partnerships to be established to provide more services, including incentives for private operators



**Equipment for the home and local in-patient beds and wards are required if patients are to receive support where and when they need it**

*– Comments by advocates/non-government organisations*

# What does increased community awareness mean to you?

## You said you want:

- A clear definition of palliative care, including what it can and cannot do and the services available
- The benefits of palliative care to be communicated, including the link to quality of life not just 'end of life' care
- Death and dying to be normalised in the community, including through funding to support existing initiatives and new awareness campaigns in the form of advertising, collateral, events, TV/film stories and other mediums

- Community awareness and education
- Care planning
- Resources and training

- Early planning, including through Advanced Care Directives and eHealth records, to assist patients and carers to be fully prepared and more in control of their own care
- Palliative care training and incentives for health care staff, including GPs, so they can provide early advice/referrals for patients and families
- Resources for adequately trained health care staff and for community groups to lead discussions and decision making about palliative care



**Increased awareness of the benefits of palliative care services and reduced stigma around death would enable more early referrals, prevent unnecessary treatments and lead to better patient outcomes**

*– Comments by healthcare practitioners*

