

Findings and recommendations (Report No. 33)

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

Paper No. 4, 56<sup>th</sup> Parliament, March 2020

#### This paper

This paper provides a summary of the findings and recommendations from Report No. 33 on aged care, end-of-life and palliative care. The report is one of two reports and a volume of additional information from the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

#### Inquiry terms of reference

On 14 November 2018, the Legislative Assembly referred an inquiry to the committee with the following terms of reference:

- That the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee inquire into aged care, end-of-life and palliative care and report to the Legislative Assembly on:
  - a. the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems; and
  - b. Queensland community and relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.
- 2. That in undertaking the inquiry, the committee should consider:
  - a. in relation to aged care, the terms of reference and submissions made to the Australian
  - b. Government's Royal Commission into the Quality and Safety of Aged Care and, in recognising the Commission will occur in parallel, how to proactively work with the Commission to ensure an appropriate exchange of information to inform the conduct of the inquiry;
  - c. outcomes of recent reviews and work including Queensland Health's Palliative Care Services Review; and
  - d. the current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian Government's Inquiry into end-of-life choices, *Voluntary Assisted Dying Act 2017* (Vic) and implementation of the associated reforms.
- 3. That the committee report to the Legislative Assembly by 30 November 2019.

On 22 August 2019, the Legislative Assembly agreed to a motion that the reporting date for the inquiry be extended from 30 November 2019 to 31 March 2020.



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#### Context for the Inquiry

#### Aged care

The delivery of aged care across Queensland has never been more topical, or its improvement more urgent. Stories of abuse and neglect of society's most frail in residential aged care facilities, along with substantial waits for home care packages that see many hospitalised, moved into residential aged care facilities or dying before receiving the package, have been shocking.

Queensland's rapidly growing and ageing population will present further challenges for aged care and health care providers. The incidence of disabilities among the state's older age groups is significant. Many older Queenslanders depend on informal aged care rather than government-subsidised aged care. This informal care, while mostly unpaid, is invaluable to those individuals receiving it and to the wider community.

Most older people (95%) continue to live in their own homes — known as ageing in place. Similarly, most aged care is also delivered to people in private homes or other community settings. The remainder of older people receiving aged care live in care accommodation such as nursing homes or, in modern terminology, residential aged care facilities. Based on assessments for care, around half of all residents in aged care facilities have dementia.

The need for aged care, and the intensity of care that is required, increases markedly with age. Between the ages of 70 and 85 years, there is a tripling in the proportion of people using home care or residential aged care. Future expectations of aged care services are also evolving. Queenslanders needing aged care, or those supporting them in future, are likely to be more aware of health issues and more willing to take advantages of advances in technology and care. It is also likely that people will continue to prefer to remain in their own homes as they age.

Over the next 16 years, the number of Queenslanders aged over 65 is expected to double, and the number

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The state's population also remains highly decentralised. More than 40 percent of residents aged 65 years or older live outside of major cities. This includes over 10,000 people living in remote areas and a further 6,400 living in very remote areas. The challenge of providing care to elderly people dispersed across a large state is exacerbated by the increasing prevalence of disabilities, dementia, frailty and chronic disease among older Queenslanders.

These conditions are expected to increase demand for a more diverse range of aged care and health care services in the future.

#### End-of-life and palliative care

Access to quality palliative care and end-of-life care is as important as health care at any other stage of life, yet for many it is not readily available. There is a strong expectation that all Queenslanders and all communities can access services 24 hours a day seven days a week, if and when they need to. Sadly, access to services at a local level is often problematic, particularly for Queenslanders in regional, rural and remote communities.

Mortality data indicates that between 41 percent and 76 percent of people living with life-limiting illness would require palliative care services. It is estimated that between 51,000 to 71,000 of Queensland's total population, and between 52,000 and 57,000 people aged over 65 would require palliative care services. Between 2,700 to 4,900 children in the Queensland population under 19 years old could require palliative care services. As Queensland's population continues to increase and people live longer, the need for end-of-life and palliative care will only increase.





Caloundra public hearing, 3 May 2019.

#### **Inquiry process**

The committee undertook a range of activities to raise awareness of the inquiry and to assist groups and individuals contribute their views, including distributing an issues paper, providing information about the inquiry to over 4,000 groups and individuals registered to receive regular email updates about the committee's work, advertising the inquiry and calling for submissions in major newspapers, along with further advertising to raise awareness of each of the public hearings and forums for the inquiry.

In total, the committee accepted 4,719 written submissions for the inquiry. The committee conducted 34 public and private hearings and briefings for the inquiry across the state, and heard evidence from 502 invited witnesses. These included public hearings across regional centres along the east coast of Queensland as well as in Mount Isa, Longreach, Mossman and Palm Island. The committee also visited a cross section of residential aged care facilities, hospices and palliative care facilities during the inquiry.

The committee held an additional seven hearings and briefings and accepted 10 submissions for the Earle Haven investigation, with 33 witnesses appearing.

#### 41 hearings – 535 witnesses – 4,729 submissions



#### Recommendations

For further information please refer to comments by committee members in the full report.

#### 1. Trial of nurse practitioners

The committee recommends that the Australian Government allocate funding through the Primary Health Networks in Queensland to trial the use of nurse practitioners in residential aged care facilities. The trial could include expanding their scope of practice to prescribe certain medications and order certain pathology testing for residents in consultation with general practitioners.

### 2. Consistency of access to health services while in residential aged care

The committee recommends that the Australian Government in consultation with individual providers ensure that residents in residential aged care facilities enjoy the same level of access to health service providers as other elderly in their local community living outside of those facilities.

### 3. Review of item numbers for visits by general practitioners to residential care

The committee recommends that the Australian Government review the schedule of item numbers that general practitioners, specialists and other allied health professionals can access to claim the costs of care they provide for patients, and their travel to and from residential aged care facilities or patients' homes and the formula used for calculating payment amounts. In reviewing the formula, the government should ensure the formula provides reasonable compensation for doctors and other health professionals for their time whilst removing incentives for practitioners to bulk visit facilities.

### 4. Care for frail elderly residents in aged care facilities

The committee recommends that Queensland Health examine opportunities to expand programs such as the Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment program that focus on streamlining the care pathway for the frail elderly residents of aged care facilities.

### 5. Utilisation of nurse navigators in aged care to improve access to primary care

The committee recommends that the Queensland Government explore opportunities to better utilise nurse navigators in aged care to improve access to primary care for older people and supplement the care provided by general practitioners.

### 6. Sharing of electronic patient/resident records

The committee recommends that the Queensland Government, through Queensland Health, explore the feasibility of improving access to The Viewer to enhance the sharing of electronic patient/resident records between residential aged care facilities, hospitals, ambulance service staff, general practitioners and other health service providers to improve the continuity of care for residents/patients.

#### 7. Redesign of the My Aged Care website

The committee recommends that the Australian Government redesign the My Aged Care website to make it easier for all to use.

#### 8. Information on aged care

The committee recommends that the Australian Government provide information on aged care in a form that meets the information needs of all users and is targeted at potential recipients of aged care services and their families, including Aboriginal people, Torres Strait Islander people and people from culturally and linguistically diverse communities.

### 9. Performance targets for assessments and reassessments

The committee recommends that the Australian Government reassess performance targets for the completion of assessments and reassessments as part of My Aged Care to minimise delays.



### 10. Increased funding for the Home Care Packages Program

The committee recommends that the Australian Government significantly increase the level of funding it provides to the Home Care Packages Program to ensure packages are sufficient to meet the costs of the required hours of care required for each level package, to clear the current backlog of packages that haven't been provided.

### 11. Removal of caps on Home Care Packages

The committee recommends that the Australian Government remove its cap on the number of packages available, at all levels, and provides as many packages as are needed.

# 12. Clearing of backlog in Home Care Packages that have not provided

The committee recommends that the Australian Government clear the current backlog of packages that haven't been provided.

### 13. Maximum waiting times for Home Care Packages

The committee recommends that the Australian Government ensure wait times for packages are reduced to a maximum of three months for delivery of all packages across all levels from the date of approval.

# 14. Access to interim care while waiting for Home Care Packages

The committee recommends that the Australian Government commit to provide interim care arrangements, close to the approved package level, for applicants for home care packages while waiting for their package to be provided.

### 15. Mandatory reporting by home care staff of elder abuse

The committee recommends that the Australian Government requires that the reporting of elder abuse is a mandatory requirement for all staff working in home care.

# 16. Qualifications and training for personal carers providing in-home aged care

The committee recommends that the Australian Government consider whether there should be mandatory minimum qualifications and training for personal carers providing in-home aged care.

### 17. Controls on physical and chemical restraints

The committee recommends that the Australian Government continues to examine and reform practices regarding physical and chemical restraints to discourage providers from using restraints as substitutes for appropriate levels of care and supervision.

#### 18. Better nutrition

The committee recommends that the Australian Government require that meals provided in residential aged care facilities meets the nutritional guidelines for older people provided by the National Health and Medical Research Council's *Australian Dietary Guidelines*.

### 19. Funding for activities to increase residents' social connectedness

The committee recommends that the Australian Government consider providing funding for activities to increase residents' social connectedness as well as physical and mental engagement in residential aged care facilities.

### 20. Disclosure of staff to resident ratios at residential aged care facilities

The committee recommends that the Australian Government require providers to display in a public common area at each residential aged care facility the staff to resident ratios at that facility across each shift, for the information of residents, prospective residents and their representatives.

# 21. Publication of staff to resident ratios on the My Aged Care website

The committee recommends that the Australian Government require that information about residential aged care facilities that is published in the Schedule to the My Aged Care website includes staff to resident ratios at each of those facilities.



# <u>22. Advance Health Directives in residential</u> aged care facilities

The committee recommends that the Australian Government require residential aged care facilities to provide information and encourage residents to complete an Advance Health Directive as soon as possible after entry to the facility. This information should be readily available for relevant health care workers.

### 23. Establishment of a funded aged care community visitor scheme

The committee recommends that the Australian Government consider establishing a funded aged care community visitor scheme to help address risks of elder abuse for older people receiving aged care.

### 24. Training and resources about special needs clients

The committee recommends that the Australian Government consider requiring aged care providers to ensure all aged care staff have access to training and resources to promote awareness and understanding of the special needs of clients who are from groups with special needs such as clients:

- suffering from mental health issues
- from culturally and linguistically diverse backgrounds
- from Aboriginal and Torres Strait Islander communities, and
- from LGBTIQ+ communities.

# 25. Training opportunities for Aboriginal and Torres Strait Islander people

The committee recommends that the Australian Government fund trainee positions for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for Aboriginal and Torres Strait Islander people.

### 26. Mandatory dementia care training for all aged care workers

The committee recommends that the Australian Government mandate that accredited dementia care training is undertaken by all aged care workers.

### 27. Reducing the number of young people in aged care facilities

The committee recommends that the Australian Government act immediately to reduce the number of young people with health issues entering residential aged care facilities, and to provide them alternative housing arrangements that meet their requirements.

### 28. Expanded criteria for audits of residential aged care facilities

The committee recommends that the Australian Government require that the criteria covered by audits of residential aged care facilities be expanded to cover internal processes, resident safety, capacity to meet residents' needs and the standard of accommodation.

### 29. Graded scale for compliance with aged care standards

The committee recommends that the Australian Government require that the current system of pass/fail for compliance with standards be replaced with a graded system.

### 30. Separation of accreditation and compliance systems

The committee recommends that the Australian Government require that the accreditation system is separated from the regulatory system.

#### 31. No prior notice of audits of facilities

The committee recommends that the Australian Government cease the practice of providing prior notice to providers of compliance audits of residential aged care facilities.

### 32. Ground truthing of audit findings by residents

The committee recommends that the Australian Government require that, as part of the audit process, residents and their representatives are provided with the opportunity to contribute to the audit process and audit findings are shared with residents and their representatives for comment before finalising the audits.





# 33. Publication of compliance monitoring reports

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to publish all compliance monitoring update reports.

# 34. Publication of accreditation reports after a change of provider

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to explain the commission's practices in relation to the removal from publication of accreditation reports of facilities after any change of approved provider occurs.

#### 35. More accessible complaints system

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system for aged care be made more accessible and responsive to complaints.

### 36. Process for medical practitioners to report problems

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system promote mechanisms to encourage medical practitioners and allied health professionals to report problems they observe with the potential to compromise the safety and welfare of residents and other clients, on a confidential basis if necessary.

### 37. Disclosure of staff qualifications and experience

The committee recommends that the Australian Government require that providers of residential aged care services disclose to residents, prospective residents and their representatives the qualifications, training and experience of their staff at the facility.

### 38. Audit of accredited aged care training courses

The committee recommends that the Australian Government ensure accredited training courses for aged care are producing graduates with the required

skills and competencies to perform the tasks required of them.

### 39. Aged care staff training and development

The committee recommends that the Australian Government call on providers to promote a culture in the aged care industry of ongoing staff training and development.

### 40. Certificate 3 qualifications for personal carers

The committee recommends that the Australian Government consider requiring that training equivalent to Certificate 3 in aged care is mandatory for all personal care workers in the aged care sector. For existing employees with certificate 2 qualifications, there should be recognition of experience on the job in lieu of undertaking additional training.

### 41. Better pay and conditions for aged care workers

The committee recommends that the Australian Government raise the minimum pay and conditions of employment for personal carers, nurses, administrators and other workers in the aged care industry to levels equivalent to their peers in the health sectors.

#### 42. Workforce strategy for aged care

The committee recommends that the Queensland Government, in conjunction with the Australian Government, unions representing aged care workers, peak bodies representing the aged care providers and training providers devise a strategy to recruit and train workers for Queensland's aged care providers to meet future staffing requirements, to meet the increasing aging population, and demand for services in Queensland.

### 43. National strategy implementation plan and monitoring and evaluation plan

The committee recommends that the Australian Government finalise and publish the Implementation Plan and the Monitoring and Evaluation Plan for the *National Palliative Care Strategy 2018* as soon as possible.



# 44. Revision of the 2015 *End-of Life-Strategy*

The committee recommends that the Queensland Government revise and update the *Statewide Strategy for End-of-Life Care 2015* in conjunction with the Australian Government, Primary Health Networks, Palliative Care Queensland and other peak bodies, consistent with the Clinical Services Capability Framework, to:

- specify what palliative care services and endof-life care services are to be provided and in
  what form by government and nongovernment providers, including: specialist
  care services, telephone support, access to
  pharmacy services, grief and bereavement
  support, the delivery of awareness programs
  for health professionals and the general public,
  and interactions with aged care
- provide clear, meaningful targets for accessibility to, and the delivery and timeliness of, palliative care and end-of-life care services to all Queenslanders regardless of their location, including communities with special cultural and other needs, who are located in regional, rural and remote areas
- require that Queensland Health is responsible for coordinating and implementing the strategy across all Hospital and Health Services, and that department report annually on the performance by all Hospital and Health Services against the accessibility, delivery and timeliness targets for palliative care and endof-life care services
- provide goals and actions related to the delivery of training and education for palliative care and end-of-life workers
- link to other strategies and plans for the recruitment and retention of staff, and
- acknowledge that a key principle of palliative and end-of-life care is person-centred care.

#### 45. Person-centred care

The committee recommends that any changes to the delivery of and access to palliative care services in Queensland promote person-centred care.

### 46. Increased transparency and accountability for palliative care services

The committee recommends that the Queensland Government increase transparency and accountability of palliative care services, by mandating reporting of data and setting clear performance standards.

### 47. Assistance for people wishing to die at home

The committee recommends that the Queensland Government and Primary Health Networks explore ways to fund and provide further assistance to communities and families to enable people to die at home supported by end-of-life care through: expansion of community and in-home nursing services; expansion of community care programs; supporting community-based medical aids and equipment loan schemes; and increased resources for the Hospital in the Home program which provides high-level care in the home when patients require it.

#### 48. Assistance for regional hospices

The committee recommends that the Queensland Government with assistance from Primary Health Networks examine ways to help establish viable hospices outside of South East Queensland.

#### 49. Pediatric palliative care

The committee recommends that all levels of government explore the opportunity to establish a paediatric palliative care hospice outside of South East Queensland.

#### 50. After hours palliative care

The committee recommends that the Queensland Government explore options to improve after-hours access to palliative care services, to ensure all Queensland palliative care patients have access to after-hours palliative care regardless of whether they are at home or in a residential aged care facility, hospice or hospital.





#### 51. Centralised 24/7 telehealth service

The committee recommends that priority funding be allocated to establish a centralised 24-hour, seven day telehealth service available to practitioners caring directly for palliative patients throughout Queensland, and to develop a statewide supportive information system to allow practitioners to access real-time patient information for rapid response and appropriate treatment recommendations.

#### 52. Capacity building for telehealth services

The committee recommends further development and capacity building of telehealth or other digital services for patient consultations to enable people in regional, rural and remote areas to access health services not locally available.

### 53. Increased Australian Government funding for palliative care

The committee recommends that the Australian Government increase the amount available through the subacute funding for the delivery of palliative care to address the unmet need for services.

# 54. Increased Queensland Government funding for palliative care

The committee recommends that the Queensland Government increase its funding for palliative care in Queensland.

### 55. Options to prevent palliative care funding being diverted

The committee recommends that the Queensland Government examine options to ensure that palliative care funding is not diverted to other subacute areas.

# <u>56. Palliative and end-of-life care for</u> residential aged care residents

The committee recommends that the Australian Government properly fund palliative care and end-of-life care services provided to residents living in private homes or in residential aged care facilities so residents can access the clinical care, nursing and specialist palliative care services they require. This will involve providing greater flexibility in the home care package system and a redesign of the Aged Care

Funding Instrument to incorporate funding for palliative and end-of-life care.

### 57. Clinical capability framework for palliative care

The committee recommends that the Queensland Government, as a matter of urgency, mandate the application of the Clinical Services Capability Framework for Public and Licensed Private Health Facilities for palliative care planning and delivery by all Hospital and Health Services as part of their funding agreement, and monitor Hospital and Health Service performance in meeting this framework with explicit use of performance metrics and reporting.

#### 58. Funding for specialist palliative care

The committee recommends that the Queensland Government consider as part of any broader review whether to develop a needs-based funding model for specialist palliative care which includes packages of care instead of time-limited funding models.

# <u>59. Develop a palliative care workforce</u> strategy

The committee recommends that the Queensland Government, in conjunction with the peak bodies and unions representing the palliative care workers, model current and future workforce needs and develop a palliative care workforce strategy that aligns with the national strategy and that it includes strategies for:

- increasing the number of palliative care specialists, nurse practitioners, and palliative care nurses via specialised palliative care training and education
- professional development training for all providers of palliative care within the medical, nursing and allied health professions
- educating health workers who may need to provide palliative care as part of their normal health care delivery, for example, general practitioners, nurses and residential aged care facility workers, so they have a basic understanding of palliative care
- recruiting and retaining palliative care staff, and
- addressing issues of fatigue and isolation amongst palliative care staff.



#### 60. Develop specialist support services

The committee recommends that the Australian and Queensland governments develop specialist support services to assist general practitioners, nurses, allied health workers and the aged care workforce, including ways to integrate services to provide support to care workers, such as through mentoring.

### 61. Incorporate palliative care into tertiary education and training

The committee recommends that the Australian and Queensland governments work to identify strategies to incorporate palliative care training into tertiary courses for medical, nursing and allied health staff, including through Palliative Care Curriculum for Undergraduates (PCC4U), and aged care training providers.

### <u>62. Mandatory basic training for personal</u> care workers

The committee recommends that basic palliative care training be made mandatory for personal care workers in residential aged care facilities.

# 63. Continue funding for professional development programs

The committee recommends that the Australian and Queensland governments continue financial and other support for professional development programs, such as Program of Experience in the Palliative Approach (PEPA) and Centre for Palliative Care Research and Education (CPCRE).

#### 64. Nurses in palliative care

The committee recommends that the Queensland Government explore opportunities to better utilise nurses, nurse navigators and nurse practitioners in the Queensland palliative care system to assist and provide palliative and end-of-life care.

#### 65. Respite care for informal carers

The committee recommends that the Australian Government improve the availability of respite services for informal carers providing end-of-life care to the dying, and provide for more flexible delivery to allow for short-term respite.

### <u>66. Palliative care community education</u> strategy

The committee recommends that committee recommends that the Queensland Government work with relevant stakeholders to develop a community awareness campaign to promote palliative care and increase knowledge of services available to patients and carers.

### 67. Community understanding of death, dying and options for end-of-life care

The committee recommends that the Queensland Government support Palliative Care Queensland and other stakeholders to increase the community's understanding of death, dying and options for end-of-life care.

#### 68. Support for community initiatives

The committee recommends that the Queensland Government consider supporting the community initiatives recommended by Palliative Care Queensland in their submission.

#### 69. Implement public education campaigns

The committee recommends that the Queensland Government work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning and its benefits amongst the community and within the health service to encourage people to discuss their preferences and choices for end-of-life care with health professionals.

### 70. Simplify Advance Care Planning documents

The committee recommends that Queensland Health continue to work with the Department of Justice and Attorney-General to ensure that Advance Care Planning documents are simple and accessible for users and health professionals.

### 71. Amend the *Guardianship and*Administration Act 2000

The committee recommends that the Queensland Government consider amending the *Guardianship* and *Administration Act 2000* to ensure that directives made at common law are legally binding.



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### 72. Improve clinician access to Advance Care Plans

The committee recommends that the Queensland Government continue to roll out its system for registering advance care documents on The Viewer to ensure they can be accessed when necessary by treating clinicians, especially in times of emergency.

#### 73. Promote clinician use of The Viewer

The committee recommends that the Queensland Government continue to promote the use of The Viewer to health professionals, so that its benefits can be more fully realised.

# 74. Dedicated Medicare Benefits Schedule rebates for advance care planning

The committee recommends that the Australian Government introduce dedicated Medicare Benefits Schedule rebates for clinicians undertaking advance care planning activities with their patients.

### 75. Simplify advance care planning guidelines for health professionals

The committee recommends that the Queensland Government amend and simplify existing Advance Care Planning guidelines for health professionals to ensure that they understand their responsibilities as they relate to Advance Care Planning and can effectively undertake these responsibilities.

### 76. Further consideration of Queensland Law Reform Commission Report

The committee recommends that the Queensland Government consider the recommendations made by the Queensland Law Reform Commission in their report: A Review of Queensland's Guardianship Laws including omission of section 36(2) from the *Powers of Attorney Act 1998* to ensure a patient's directions to withdraw life-sustaining treatment are followed in accordance with their Advance Health Directive.

#### 77. Prescribing of opioids

The committee recommends that the Queensland Government undertake an education campaign for health professionals working in palliative and end-of-life care to ensure understanding of the appropriate use of opioids for palliative and end-of-life care medication.



Findings and recommendations

#### Recommendations from the Earle Haven investigation

In its report, the committee also restated the recommendations of the Report No. 30: Investigation of the closure of the Earle Haven residential aged care facility at Nerang, tabled on 28 November 2019. Further explanation of these recommendations can be found in the committee's report no. 30.<sup>1</sup> The Queensland Government has responded to recommendations 1, 2 and 5 that relate to it.<sup>2</sup>

#### 1. Returning home

The committee recommends that all options be explored to allow the residents evacuated from the facility to return to their home.

### Strengthen evacuation planning measures

The committee recommends that the state government explore options to strengthen evacuation planning measures for residential aged care facilities, in consultation with federal government agencies responsible for aged care, to ensure they adequately cover the evacuation of residents and staff from facilities due to the sudden loss of care services.

### 3. Business continuity measures in aged care

The committee calls on the federal government to immediately institute business continuity checks, including equivalent vetting processes in relation to sub-contractor relationships, to prevent any recurrence of the Earle Haven disaster in other residential aged care facilities.

#### 4. Equal accountability of aged care subcontractor

The committee calls on the federal government to make sub-contractors equally accountable alongside approved providers for meeting quality and safety standards in the aspects of care they are sub contracted to deliver.

#### 5. Sharing of 'Red Flag' information

The committee calls on the federal government to better share 'red flag' information about operators of residential aged care facilities with state and territory governments and other regulatory bodies to prevent any recurrence of the Earle Haven disaster in other residential aged care facilities.

#### 6. Improving aged care sector reporting

The committee calls on the federal government to improve transparency by implementing improvements in aged care sector reporting.

#### 7. Independent Aged care commissioner

The committee calls on the federal government to set up an independent Aged Care Commissioner to provide oversight of the aged care system in Australia.

### 8. Increased penalties for non-compliance with quality and safety standards

The committee calls on the federal government to increase penalties for significant non-compliance with quality and safety standards and review the capacity and powers of the Aged Care Quality and Safety Commission to effectively undertake this role.

# 9. Review and redesign of aged care funding model

The committee calls on the federal government to immediately review and redesign its aged care funding model to guarantee the ongoing financial viability of the aged care sector, ensuring the funding model reflects the actual cost of care and makes adequate provision for the increasingly complex care needs of aged care residents.

Report No. 30, 56th Parliament - Investigation of the closure of the Earle Haven residential aged care facility at Nerang (Inquiry into aged care, end-of life and palliative care and voluntary assisted dying).

<sup>&</sup>lt;sup>2</sup> Queensland Government Response to Report No. 30 – Investigation of the closure of the Earle Haven residential aged care facility at Nerang (Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying).





### 10. Wage parity for aged care sector employees

The committee calls on the federal government to ensure that a redesigned funding model includes an increase in wages for aged care employees with a long-term aim to achieve wage parity with other health care sectors.

# <u>11. Introduction of aged care staffing ratios</u> and minimum care hours

The committee calls on the federal government to mandate the introduction of minimum nurse, care worker and support worker skill mix ratios and minimum average daily resident care hours in private aged care facilities.

#### 12. Physical and chemical restraints

The committee recommends that the federal government urgently examine and reform practices regarding physical and chemical restraints, and mandate staffing levels that will avoid these practices being used as substitutes for appropriate level of care and supervision.



#### Summary of findings – aged care

#### Aged care in Australia

The aged care system in Australia caters for Australians aged 65 years and over (and Indigenous Australians aged 50 and over) who can no longer live without support in their own home. It comprises three main levels of Australian Government-subsidised aged care services: home support, home care and residential aged care. Other aged care programs provide short-term or intermittent services (such as respite care or to assist the transition from hospital), or are targeted to people with specific needs including dementia, or to particular population groups.

Aged care services in Australia are funded by governments (federal, state, territory and local governments), non-government organisations (charities, religious and community groups), and personal contributions from those receiving care. For decisions on aged care funding, the Australian Government receives advice from the Aged Care Financing Authority (ACFA), a statutory committee established in 2012.

The Australian Government has primary responsibility for aged care policy, the provision of aged care funding through subsidies, supplements and grants, managing the supply of places in aged care facilities and for the regulatory framework supporting the quality and safety of aged care services and prudential regulation.

State and territory governments employ and manage Aged Care Assessment Teams (ACATs) which assess people's eligibility for particular types of aged care services. Two of the flexible aged care programs, the Transition Care Programme and the Multi-Purpose Services Program, are jointly funded by the states and territories and the Australian Government.

Queensland Health operates 16 residential aged care facilities, across seven Hospital and Health Services, with 1,112 places. This represents approximately three per cent of residential aged care places in Queensland. The remaining 97 per cent of places are provided by non-government and private organisations. In addition, Queensland Health operates 33 multipurpose health services, with 542 places across Queensland.

However, the care needs of older Australians require not just those services provided by the aged care sector, but also the health and human services sectors. The Australian Government provides the majority of funding for health and aged care services in Australia, however all three levels of government and the non-government sector are involved in the provision of these programs and resources. Both the Australian and state levels of government are involved in the provision of healthcare. Of particular importance is the interface with the primary and acute health systems.

The aged care system in Australia has been reviewed and reformed almost constantly since at least the mid-1990s with each review making substantial, and often similar, recommendations to improve the aged care system. Not all of the recommendations from these reviews have been implemented, despite successive reviews supporting similar approaches or addressing similar gaps. These reviews have articulated very clearly the dual challenges of rapidly increasing demand for aged care services and, within that demand, a growing need for high care services, particularly residential aged care service, as the number of people aged 80 and over, increases with rising life expectancy in Australia.

Most recently, the Royal Commission into Aged Care Quality and Safety (the Royal Commission) was established, and released its interim report which reflected similar issues and evidence as that provided to this inquiry.

### <u>Funding and interface of aged and health</u> care services

The Australian Government's funding model for aged care services does not meet the costs of providing this care. This limits the quality of care that providers can provide. As a consequence of this funding shortfall, an estimated 43 per cent of aged care providers are currently operating at a loss. The lack of funding for aged care is also starving vital pilot projects within the aged care industry which are vitally important for achieving better standards of care and driving efficiency improvements.





In addition to current funding issues in aged care, it is not clear how the projected increase in demand for aged care services will be met in future. The aged care funding model clearly requires a radical rethink.

### <u>Interface between the aged care system</u> and public health systems

The interface between aged care provided by the Australian Government and the primary and acute health care systems provided by state and territory governments is a critically important one for people receiving aged care. The complexities of both systems, combined with the separation of funding responsibilities, impact on the care given and imposes additional costs for care recipients and government.

Initiatives already implemented by the Queensland Government to improve this critical interface show promise. They include the deployment of nurse navigators in aged care and the Residential Aged Care Facility Acute Care Support Services which enables acute care to be delivered in residential aged care settings.

A number of further e-health initiatives are also improving patient outcomes including: the Integrated Electronic Medical Record (ieMR) project; and the Viewer, which provides health service and care providers with improved to a wide range of patient information.

### <u>Interface between hospitals and residential</u> aged care facilities

The quality and dignity of care for the elderly is constantly being compromised by poor relationships between hospitals and aged care facilities.

Some movement of the elderly between aged care facilities and hospitals may be linked to their shared funding responsibilities between the Australian and state/territory governments which provide incentives to 'game' patient care so it is funded by someone else. Given the projected increases in aged care, it is imperative that these issues are resolved.

# Access to general practitioners, specialists and allied health professionals

Older people in aged care, particularly those living in residential aged care facilities, should not lose their access to medical and allied health care when they move to a residential aged care facility, but they often do. This in spite of their elevated need for care. Areas where access to services is particularly poor include dental care, mobile x-ray, mental health support, hospital outreach for complex care and after-hours palliative care. This needs to change.

At least some of the blame for these difficulties must rest with the remuneration arrangements under the Medicare Benefits Scheme. These arrangements act as a disincentive for general practitioners to visit patients at residential care facilities. This is because the payment provided under the Medicare Benefits Scheme does not reflect their cost to provide that care.

The Australian Government should review the payment amounts provided under Medicare Benefits Scheme item numbers for care for older people in residential facilities and in the community, and ensure they provide reasonable compensation for doctors, and ensure that the items are also available to a wide range of allied health services that are providing care of aged care recipients. The committee has also proposed some lifting of restrictions on prescribing be considered so nursing staff at residential care facilities can prescribe some medications and order tests for residents.

Better funding and incentives are required for the delivery of allied health services in residential aged care facilities - particularly physiotherapists.

#### Opportunities for the Queensland Government to take a lead role to improve age care

Stakeholders supported initiatives implemented by Queensland Health and hospital and health services to improve the interface between aged care and the public health and hospital system.

The two programs implemented by the Queensland Government showing promise for improving the standard of aged care being provided are the Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment (CARE-PACT) model of care and the nurse navigator model of care.

### <u>Better communications and access to</u> patient records

A number of stakeholders commented on the absence of good communications between hospitals and ambulance service workers, residential aged care facilities and general practitioners and how this disrupts the continuity of care for elderly patients. These problems appear to be particularly significant for residential aged care facility residents as they enter or exit hospitals and during their discharge from hospitals. There are clearly opportunities where the sharing of patient/resident information between residential aged care facilities, general practitioners, hospitals and ambulance service staff could lead to worthwhile benefits in terms of patient care and efficiency gains for all parties involved. There is also scope to make better use of modern communication technologies to ensure prescription information and other patient information is provided to clinical care staff at residential aged care facilities, and that these records are shared efficiently and reliably with patients' general practitioners.

Given Queensland's expertise in integrated electronic medical record systems and providing electronic access to patient records using The Viewer, this is an aspect of aged care where Queensland could make significant inroads.

#### Accessing aged care services

Australia's aged care system is complex and confusing for many users, and needs to be redesigned and simplified. The My Aged Care website and call centre system remain a source of great frustration.

This is problematic for a key government program that should have been designed to be used by older people who may have cognitive impairment and other disabilities due to the effects of illness, advancing age and frailty.

Consumers of aged care services need access to impartial, detailed information in a form they can readily use that helps them make informed decisions about their care needs. For older people who may be suffering cognitive impairment, hearing loss and or speech difficulties, providing information on a website or via the phone may simply be unsuited to their information needs. As a result, people who are

entitled to care may be missing out on services and their quality of life may be compromised. Better, clearer information is required for consumers of aged care services and their support people.

Further frustrations involve the assessment processes undertaken as part of the My Aged Care entry procedures. Issues raised with the committee include inconsistencies in the assessment process, the wait times for assessments and reassessments, issues with the information provided and the need for support for older people once they have had their assessment.

#### Home Support and Home Care Programs

In evidence to the Royal Commission, it was revealed that 127,000 people were waiting for their approved home care packages. For level 4 packages, the highest level of assistance for people with high care needs, the waiting period has been reported as 22 months. The committee heard of instances where people have waited even longer.

Many thousands of people have died while waiting for their home care packages. It was reported to the Royal Commission that 16,000 people died waiting for their approved package during one year, 2017-18. Many others occupy acute care beds in hospitals while waiting for a package to return to their homes. This imposes significant costs on the State's public health system in terms of direct clinical and other costs, as well as on their ability to care for other patients. Others have moved to residential aged care against their wishes and the wishes of their families.

Such delays in providing care would not be permitted in a health service environment and are simply unacceptable in aged care. In some cases the care needs of the package recipient has increased while waiting for a package, and the package provided no longer meets their needs. The extended waiting periods for packages also impose extraordinary burdens on the informal carers who are caring for those people.

These statistics are a damning indictment of the failures of the Australian Government's home care package program. The program needs to be significantly better resourced to increase the numbers of packages that are available, particularly







for the higher level 3 and 4 packages. It is also imperative that the Australian Government commits to limiting the unmet demand for home care packages, and to adopting maximum waiting times for packages to be allocated. Three months has been suggested to the Royal Commission by the Council of the Ageing and Leading Aged Services Australia as a reasonable maximum wait period.<sup>3</sup> Whatever waiting period is accepted, it is essential that the Government commits to providing interim care arrangements, equivalent to the level of care approved, for applicants from the time a package is approved until it is provided.

Further issues were raised about the adequacy of the amounts provided for packages, the fees charged for administering home care packages, the difficulties for package recipients in exercising choice, the timing of care services, the quality of care provided and the training received by care staff.

Stakeholders also raised concerns that elder abuse detected during in-home care may not be reported to the same extent as abuse in a residential care setting.

#### Residential aged care

Despite the Australian Government's significant expenditure, under-resourcing remains a problem for the residential aged care program. Changes the Australian Government made in 2016 and 2017 effectively cut providers' revenue whilst their operating costs, particularly staff costs, continued to increase. Faced by difficult financial conditions, it appears that some operators have shifted their focus from quality of care to cost of care out of necessity, resulting in poorer care outcomes for residents.

The problem of increasing waiting times to access residential care was raised often by stakeholders during the committee's inquiry, even with a rise in vacancies. There is a particular shortage of places in residential aged care facilities in rural and regional areas. This leads to extended delays in the placement of residents in these areas, limits the choice for residents and, in many cases, forces residents to

accept places in locations away from their homes and loved ones. The current wait times impose enormous pressures on the elderly, their families and carers.

The lack of residential care places also results in acute beds in hospitals being used to house elderly patients waiting to be placed in residential care. These circumstances place increased pressure on the Queensland public health system and contribute to 'bed blockage' or 'access block'.

Stakeholders also raised concerns about the high entry and daily charges levied by residential care providers, the level of information provided by providers to residents about the charges levied, the lack of transparency in how residential aged care facilities spend funds they receive from government and residents.

Demand for short-term planned or emergency residential care, known as respite care, is rapidly increasing — more than three times as fast as the rising demand for residential care. Demand for high level respite care is particularly strong. Respite care is offered through residential aged care facilities, though respite residents do not make any meanstested accommodation or care contributions.

#### Care provided

The Australian Government has established a charter of Aged Care Rights, Aged Care Quality Standards, a Mandatory Quality Indicator Program and a Serious Incident Response Scheme to guide the delivery of aged care by providers. Further controls on the use of restraint on residents exist under the Quality of Care Principles made under the Aged Care Act 1997 (Cwlth). The committee reported on excessive use of restraint in its report on the closure of the Earle Haven residential aged care facility. The Australian Government's controls on the use of restraint in aged care were strengthened in late November 2019. They now refer to state and territory legislation for prescribers' responsibilities regarding informed consent. The committee welcomes this tightening of controls. It remains concerned however that restraint

Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 162.





is being overused on residents as a substitute for adequate staffing levels and supervision by staff in facilities.

#### **Staffing**

A common theme in submissions and other evidence about aged care is that there are insufficient staff and too few registered nurses in residential aged care facilities, and that this impacts on the time allocated to caring duties in residential aged care facilities. This leads to compromises in the quality of care being provided. Understaffing issues are more critical at night times and on weekends. The committee heard that inconsistencies in pain management and missed medications, increased falls, poor management, poor timeliness for toileting of residents, the overuse of incontinence pads, increased pressure injuries and skin tears, the overuse of restraint on residents, reduced structured activities for residents, and rushed meals are examples of missed care issues that are symptomatic of the lack of staffing.

The committee heard that care for frail residents and those with dementia is particularly affected by staffing shortfalls. The committee also heard that the amount of care provided to residents in Australian facilities compares poorly with care provided in facilities in the United States of America and against recommended care benchmarks of 4.3 hours of care per day for residents.

Further issues were raised about the qualifications and experience of staff in residential aged care, particularly the lack of experienced registered nurses in facilities. Concerns about the qualifications and training of staff raised issues with the care of residents with dementia. The lack of clinical care staff was also linked to increased numbers of residents being sent from residential care facilities to hospitals for treatment of relatively minor medical conditions.

The short-staffing of residential aged care facilities also impacts on the welfare of staff.

The committee supports the introduction of the transparency measures legislated in the *Health Transparency Act 2019* (Qld) to establish minimum standards for staffing and care for public residential aged care facilities and to encourage the disclosure of

staffing levels in private residential aged care facilities in Queensland.

The committee also notes the Royal Commission Interim Report calls for more transparency across the aged care sector.

### Access to palliative care in residential aged care facilities

Palliative care is not acknowledged as core business within residential aged care facilities. Funding responsibility for palliative care in facilities is also unclear. Staff providing palliative care in residential facilities require additional qualifications, training and skills. Yet the committee heard of instances where the care of residents at the end of their life has fallen largely to personal carers. The committee endorses the view of the Queensland Law Society that 'Significantly increased attention, upskilling and resources are required to facilitate palliative care provision in aged care'. This should be a joint responsibility of the Australian and Queensland Governments.

Further discussion of this issue and relevant recommendations are made at section 15.2.5 of this report.

### Other issues in residential aged care facilities

Activities to increase social connectedness as well as physical and mental engagement are a critically important component of aged care for maintaining dignity and quality of life, particularly for residents suffering dementia and cognitive decline. These programs need to be properly integrated into aged care. For this to be achieved, these activities need to be funded by the Australian Government.

#### Flexible care

The Australian Governments invested \$516 million in 2017-18 on a suite of flexible care programs designed to provide alternative approaches to residential and home-based aged care. These programs provide 9,644 places nationally across a range of transitional care, short term, multi-purpose and innovative care programs in addition to the National Aboriginal and Torres Strait Islander Flexible Aged Care program. Other support programs





The Older Persons Advocacy Network has been engaged to deliver advocacy services for the Australian Government's National Aged Care Advocacy Program since 2017. Advocacy support is essential to ensure that older people and their families have access to confidential and independent information about aged care matters. This is valuable work to assist people protect their rights and interests in aged care.

#### The Community Visitor Scheme

In 2018-19, the Australian Government provided funding of \$18.0 million for the Community Visitor Scheme which supports volunteer visits to residents in residential aged care facilities, people receiving home based aged care and groups in care who are at risk of social isolation. During the year, volunteers conducted around 240,000 such visits. This program should be continued.

The Australian Government should consider establishing a funded aged care community visitor scheme, based on the Queensland community visitor program under the *Public Guardian Act 2014* (Qld), to help identify incidences of elder abuse and provide support to aged care clients who may be at risk of elder abuse.

#### Accessibility for people with special needs

Aged care should be provided in a way that is respectful of the diverse needs of older people with special needs. This includes the needs of older people who are suffering from mental health issues; are from culturally and linguistically diverse backgrounds; are from Aboriginal and Torres Strait Islander communities; or are from LGBTIQ+ communities.

Clients in the aged care system who have dementia, and their representatives, have a more difficult journey than most. Given the prevalence of dementia and the high proportion of clients with dementia in residential aged care, it is timely that all aged care workers undertake basic dementia care training. Staff

cannot be expected to understand dementia care if they have not received the appropriate training.

Young people do not belong in residential aged care facilities, however are ending up in these facilities as there are a lack of alternatives for supporting young people with health issues. Residing in a residential aged care facility for a young person has been described as an 'isolating and daunting experience'.<sup>4</sup> The Royal Commission in its Interim Report, identified the need for urgent action to 'to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out'.<sup>5</sup>

#### The regulation of aged care

The audit process for residential aged care facilities needs to be improved. The criteria covered by audits should be expanded to cover more aspects of facilities' operations that have a direct bearing on the quality of care provided to residents.

For accreditation reports the current system of pass/fail for compliance with standards provides little information and should be replaced with a graded system of results to more accurately reflect the audit findings. The accreditation system should also be separated from the regulatory system. This has been recommended by previous reviews.

The practice of providing prior notice to providers of compliance audits of facilities should cease. As part of the audit process, the findings should be shared with residents and their representatives for comment before finalising the audits. This would help to check whether the findings are accurate. As part of the audit process, residents and their representatives should be notified by the Aged Care Quality and Safety Commission and provided with information about how to contribute to the audit process.

The publication of audit reports is an important mechanism for ensuring transparency. The Aged Care Quality and Safety Commission should publish with those accreditation reports a statement to explain which reports have not been published and the

Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 4.

Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 10.





reasons for non-publication. Further, it should explain its practices in relation to the publication of reports for accreditations of facilities conducted while the facilities were owned by different provider entities. Better public reporting and increased transparency would assist persons to make informed decisions about their choice of residential aged care facilities.

The complaints system for aged care should be made more accessible and responsive. The complaints system should also provide a mechanism to encourage medical practitioners and allied health professionals to report problems they observe, on a confidential basis if necessary, to the Aged Care Quality and Safety Commission.

To further improve transparency in relation to staffing at residential aged care facilities, the providers should disclose to residents, prospective residents and their representatives the qualifications, training and experience of their staff.

The Health Ombudsman identified gaps in the coverage of complaints and other issues related to aged care in Queensland. The committee agrees with the Health Ombudsman, and recommends that the Queensland Government consider legislating to provide the Health Ombudsman with the power to refer less serious health, conduct or performance issues pertaining to unregistered practitioners to another agency such as Australian Health Practitioner Regulation Agency.

At the core of many issues identified by stakeholders with the standard of aged care is the lack of adequate staffing. The committee believes the Australian Government should set minimum staff to patient ratios for residential aged care facilities.

#### Aged care workforce

The efficacy of training provided to prospective aged care workers needs to be improved. To achieve this, the Australian Government will need to audit and review courses to ensure they are effective at producing graduates with the minimum skills and competencies required to work in the aged care industry.

Given the demands of working in aged care and the complex needs of clients in care, ongoing training and development should become a feature of the industry, as in other health fields. Given the important role of personal carers in aged care, certificate 3 level training should be considered as the minimum standard for the industry. For existing employees with certificate 2 qualifications, there should be recognition of experience on the job in lieu of undertaking additional training.

To make the aged care industry a viable, attractive proposition to prospective employees and to aid employers to retain staff, the minimum pay and conditions for workers in the industry should be raised to levels equivalent to similar workers in the health sector.

Given the projected demand for aged care, current staffing issues and the ageing workforce, the government should devise a strategy to recruit and train the future aged care workforce for Queensland. This should include specific training and recruitment for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for their communities.

#### Future approaches to aged care

Regardless of the current challenges in aged care, the combination of innovative models of care and the development of technology have the potential to revolutionise the delivery of culturally appropriate aged care services in the future. The provision of greater choice and flexibility in how care is provided to a population of users who are more aware of their rights as consumers, more demanding and more independent is integral to what the future models of aged care need to be.



#### Summary of findings – end-of-life and palliative care

#### Delivery and access

End of life and palliative care services provide high level pain relief and other clinical support as well as counselling for those who have been diagnosed with a life limiting illnesses or who are actively dying. These services also extend to counselling support for the family and friends caring for a dying loved one.

Access to quality palliative care and end-of-life care is as important as health care at any other stage of life, yet for many it is not readily available. There is a strong expectation that all Queenslanders and all communities can access services 24 hours a day seven days a week, if and when they need to. Sadly, access to services at a local level is often problematic, particularly for Queenslanders in regional, rural and remote communities. Because of Queensland's system of regional hospital and health services which determine how funding allocated by the government is spent, the delivery of palliative care and end-of-life care services varies across the state, particularly after normal office hours. As Queensland's population continues to increase and people live longer, the need for palliative and end-of-life care will only increase.

Where they are available, privately operated hospices provide end-of-life care to complement the services provided by the hospitals, but there are no hospices located outside of South East Queensland. The committee encourages Primary Health Networks, Hospital and Health Services and community organisations to collaborate on other ways to deliver palliative care services particularly in relation to community hospices in regional, rural and remote Queensland.

Strategic planning for the delivery of palliative care services at the national level acknowledge the need to improve the delivery of services, but lacks action-level plans to implement the improvements that are needed. The Australian Government should finalise and release its implementation plan and the monitoring and evaluation plan for the *National Palliative Care Strategy 2018* as a priority. The Queensland Government should update its *Statewide Strategy for End-of-Life Care 2015* to provide clear targets and standards for access to and the delivery

of palliative care and end-of-life care services across Queensland, including to Aboriginal and Torres Strait Islander communities, CALD communities, LGBTIQ+communities and people living in regional, rural and remote areas. The strategy should also include specific reporting obligations for hospital and health services responsible for the delivery of palliative and end-of-life care services to report their performance against the targets and standards to be included in the strategy.

All Queenslanders should have the right to a 'good death' with the support of palliative care and end-of-life care services.

#### Person-centred care

Reflecting on the current palliative care model in Queensland, a number of stakeholders consistently raised the need for person-centred care, despite the complexity in delivering holistic care that acknowledges the medical, psychological, physical and cognitive needs of patients.

Submissions to the inquiry raised the importance of person-centred care in its ability to recognise a patient's own life story, culture, interests and beliefs through the provision of individualised care that meets their unique needs. The committee also heard that person-centred care should recognise the important role of a patient's significant others.

To improve the quality of palliative care in Queensland, stakeholders advocated for a personcentred model; however, it was noted that funding is the main obstacle in ensuring the delivery of a person-centred palliative care.

The committee recommends that any changes to the delivery of and access to palliative care services in Queensland promote and uphold the principles and values of person-centred care.

#### <u>Coordination of care in a fragmented</u> <u>system of delivery</u>

The committee notes the importance of a coordinated approach to palliative care in Queensland.



Evidence provided by stakeholders suggests the current system is fragmented and interface of services is complex and disjointed.

Although there are both state-wide and national strategies for end-of-life care and palliative care, evidence suggests these are not effective in ensuring an integrated and coordinated approach to palliative care in Queensland.

Concerns were raised that the Queensland End-of-Life Strategy is not being implemented appropriately, with a lack of consistency and piecemeal approach being undertaken by individual Hospital and Health Services.

Suggestions were made that the department should take oversight and responsibility for implementation and provide more specific guidelines and targets to achieve the plans aims.

The positive impact of nurse practitioners was highlighted by stakeholders, and it was suggested that they should be further utilised to maximise their role in the coordination of care.

#### Performance Reporting

The committee notes the call for increased transparency and accountability of palliative care services in Queensland.

There is limited data available to assist in determining need for palliative care services, as well as outcomes being achieved by these services.

The committee commends the work of the Palliative Care Outcomes Collaboration (PCOC) to consolidate available data and to measure and benchmark patient outcomes in palliative care, however notes the data is limited by those services which agree to contribute data and reporting is not mandatory.

The committee recognises the need to obtain more data to allow for accuracy in predicting service demand and quality of services.

### <u>Palliative care in residential aged care</u> facilities

Difficulties accessing good palliative care and end-oflife care also affect people who have made their homes in residential aged care facilities. The committee heard that the funding provided by the Australian Government to enable facility operators and general practitioners to provide palliative and end-of-life care in these facilities is insufficient to provide the clinical care dying residents require.

Specialist palliative services should be integrated into residential aged care facilities or have close connections and be able to provide the necessary services and supports to residential aged care facilities.

#### Palliative care at home

Action needs to be taken to allow more people who want to remain at home, to be supported.

Communities need to be further resourced to be able to provide services and assistance to meet the needs of palliative care patients. This includes exploring ways to provide palliative care in aged care packages.

#### Hospice models of care

Positive accounts were provided to the committee about hospice models of palliative care. The committee notes the dedicated work undertaken by many community volunteers and paid workers to provide palliative care support in a range of settings. The committee notes there are several community based funded hospices in South East Queensland.

There are established palliative care facilities operated by Hospital and Health Services, such as the Gordonvale 12 bed facility and the Caloundra Hospital Dove Cottage facility the committee visited during its inquiry.

Despite this, the committee heard there are a limited number of hospices in regional, rural and remote Queensland.

See section 3.13 for a discussion on paediatric palliative care services in Queensland.



### <u>Providing after-hours palliative care</u> services

The committee acknowledges the inadequate access to after-hours palliative care services particularly in regional Queensland. In some instances, lack of access to after-hours palliative care, leads to distress for palliative care patients. The committee agrees that after-hours palliative care should be available to all Queenslanders suffering from a life-limiting illness.

#### Regional, rural and remote communities

The committee was encouraged by the announcement of Hon Dr Steven Miles, Minister for Health and Minister for Ambulance Services, that the Queensland Government had provided an additional \$17 million in the 2019-20 State Budget for 2019-20 and 2020-21 'for initiatives in rural and remote areas to support the delivery of palliative care to people in community-based settings'.

The committee considers the enhancement of telehealth services, with funding for digitally delivered clinical services and the delivery of better patient information systems, as immediate way to address the lack of specialist palliative services available to communities in regional rural and remote areas of Queensland.

The committee heard of circumstances in which there was a lack of ability to contact palliative care staff after-hours. This led to other services, such as the Queensland Ambulance Service, to be called whereby the patient would be transferred to a public health facility. This creates a further burden on the public health system in Queensland.

#### Paediatric palliative care

The committee notes the important specialised services provided by paediatric palliative care providers, and the increasing demand for these services.

The committee visited Hummingbird House and highly commends the dedicated work of its staff and volunteers and indeed all who perform paediatric services in Queensland, including the Paediatric Palliative Care Service.

### <u>Culturally and linguistically diverse</u> communities and other vulnerable cohorts

The committee notes the additional challenges faced by culturally and linguistically diverse communities in accessing palliative care.

Palliative and end-of-life care needs to be equally available and accessible to all persons, regardless of their culture or other differences.

There is a need for further training and education of staff and facilities to understand and best meet the needs of persons in culturally and linguistically diverse communities.

The committee notes the innovative models and initiative being undertaken by groups such as Jeta Gardens and encourages other service providers to increase their cultural awareness and provision of culturally appropriate services.

#### Spiritual and pastoral care

The committee acknowledges the important role of spiritual and pastoral care at end of life. The committee notes the calls for additional resourcing to ensure these services continue to be delivered.

Stakeholders highlighted the significance of supporting not only a person physically, but spiritually in the delivery of high quality, person-centred palliative care. Incorporating an individual's spiritual and pastoral care needs supports a holistic approach that integrates physical, social, psychological and cultural aspects in the provision of palliative care. Witnesses to the inquiry acknowledged the importance of providing this dimension of care in all settings.

### <u>Funding for end-of-life care and palliative</u> care

Funding is a key issue which impacts on many aspects of the delivery of palliative care including provision of





services, workforce and training development, education and public awareness, resourcing, infrastructure and coordination of services.

The committee heard from stakeholders throughout the inquiry that inadequate funding, coupled with the current funding models, is impacting on equitable and timely access to good quality palliative care for those who are eligible. This is particularly so for those living in rural and remote areas, residents of residential aged care facilities and those wanting to receive palliative care at home. It is simply not good enough that your postcode, your diagnosis or your place of residence could impact upon your ability to access palliative care.

#### <u>Australian Government funding and</u> <u>delivery of palliative care</u>

A number of inquiry participants stated that palliative care funding is not keeping up with current demand, let alone preparation for the future demand for palliative care. Stakeholders indicated that Australian Government funding for palliative care needs to be responsive to the growing population and the health demographic to enable person-centred care to be provided to all those who seek it. Increased funding was a key recommendation by stakeholders

The remuneration received by general practitioners for visiting residential aged care facilities or palliative care patients at home was another key issue. It was clear to the committee that general practitioners are not properly remunerated for such visits, jeopardising the care these patients receive. These patients either risk receiving a reduced quality of care or are forced to go to hospital, where they may not wish to spend their final days. Hospitalisation subsequently results in an economic burden to the Queensland Health Service.

Similarly, the funding provided to residential aged care facilities via the Aged Care Funding Instrument does not provide for palliative care to be delivered in residential aged care facilities, leaving residents with

little option but to attend hospital or risk receiving inadequate care.

The committee acknowledges that its suggested improvements are the responsibility of the Australian Government.

The committee has already made recommendations under the aged care section of this report for the Australian Government to review Medicare Benefits Scheme item numbers to ensure equitable access to general practitioners services for those living in residential aged care facilities or at home.

The committee has also recommended that the Australian and Queensland governments collaborate to consider co-funding integrated palliative care to those in residential aged care facilities, hospice or those who would prefer to receive their care at home.

#### <u>Queensland Government funding and</u> delivery of palliative care

The committee commends the Queensland Government's increase in palliative care funding to palliative care providers in the non-government organisation sector to assist with the delivery of community-based palliative care.

The committee also commends the Queensland Government's \$17 million funding commitment to increase palliative care services in regional and remote areas.

Likewise, the committee commends the Queensland Government's funding announcement in October 2019 of \$8.25 million over five years to Queensland's only children's hospice, Hummingbird House.

However, more needs to be done to ensure hospital and community-based palliative care can be delivered to those in need according to their preferences, particularly those outside of the South East corner of Queensland.

Current palliative care funding is bundled with the funding for other sub-acute services, resulting in a lack of transparency regarding Queensland Health's palliative care budget and expenditure. It is up to





each Hospital and Health Service how they distribute that funding between the sub-acute services. While the committee understands that there are benefits to designing health services to meet local needs, the evidence provided by stakeholders indicated that this approach leads to the varying provision of palliative care services.

Furthermore, there is no mandated policy or performance measurements attached to the funding to Hospital and Health Services for the delivery of palliative care as part of their agreement. As a result, the committee heard that palliative care delivery is inconsistent and dependent on the Hospital and Health Service administrator's recognition of the importance of palliative care. The committee was surprised to hear that there were no guidelines or performance standards, and that medical directors are not involved with budget or activity decisions when preparing the Hospital and Health Service Annual Service agreements.

The committee notes the recommendations on funding made in the report tabled by the Health and Community Services Committee in May 2013, titled Palliative and community care in Queensland: toward person centred care.

The first of these recommendations was that the Minister for Health ensure that Queensland Health report on palliative care service provision and expenditure as part of its annual reporting, including a breakdown of funding sources. Implementation of such a recommendation would help provide the transparency that Palliative Care Queensland has stated was lacking.

The Queensland Government at the time did not accept the recommendation, stating 'The Queensland Government considers that the current level of

reporting strikes a balance between transparency and the burden of reporting which can have an impact on front line services'. 6

Given the call for greater transparency on funding, particularly in relation to the how the Hospital and Health Services distribute funding between the subacute services, the committee considers that the current Queensland Government should re-consider this recommendation. If the calls to separate palliative care funding from the funding for other subacute services as outlined below is not heeded, then this recommendation becomes even more important in terms of accountability for the provision of palliative care in Queensland.

The second of these recommendations was that the Minister for Health write to the Commonwealth Minister for Health in support of the Senate committee's Recommendation No. 2 that palliative care funding should be separated from 'subacute' funding.<sup>7</sup> Stakeholders to this inquiry also called for palliative care funding to be separated to prevent sub-acute funding from being distributed to support other sub-acute services to the detriment of palliative care provision.

Once again, the Queensland Government at the time did not accept the recommendation, stating:

Palliative care currently has its funding structure within the sub-acute and non-acute classification system. This system includes 12 different payment categories for of [sic] overnight palliative care. In addition, there is a separate payment which applies to outpatient palliative care. Separating funding from other sub-acute services is likely to diminish the importance of sub-acute services as well as palliative care services when compared with other health services.<sup>8</sup>

Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards personcentred care (Report No. 22), p 15.

Health and Community Services Committee, Palliative and community care in Queensland: toward person centred care, May 2013, p 113.

Government Response to Recommendations Health and Community Services Committee Palliative and





It is not immediately obvious to the committee how separating palliative care funding from other subacute services funding would diminish the importance of either palliative care or the remaining sub-acute services. During the inquiry, the committee repeatedly heard about the importance of providing good quality palliative and end-of-life care, and the difficulties in providing equitable, person-centred care under the current funding models.

To ensure all Queenslanders are able to access good palliative care, regardless of their location or diagnosis, adequate funding needs to be allocated, along with service guidelines and performance measurements to direct the funding. Separate funding would ensure funds couldn't be redistributed to other services and would allow for specific measurement of the implementation of those funds.

The third, and last, recommendation in relation to funding made by the Health and Community Services Committee was that the Minister for Health write to the Commonwealth Minister for Health for two purposes: to support the Senate committee's Recommendation No. 3 that the Independent Hospital Pricing Authority establish a palliative care advisory committee to advise on appropriate costing of palliative care services; and propose that the Independent Hospital Pricing Authority ensure that activity based funding does not limit the provision of palliative care consultancy and liaison with primary health providers, services in community settings, and services delivered by multi-disciplinary teams.<sup>9</sup>

This recommendation was also rejected by the thenstate government. Besides advising that an advisory group was not considered necessary to manage palliative care costing issues, the state government at the time advised that the Independent Hospital Pricing Authority list of in-scope public hospital services includes home and community based palliative care services, including palliative care day hospices, where it can be shown that such services are:

- directly related to an inpatient admission or emergency department attendance
- intended to substitute directly for an inpatient admission or emergency department attendance
- expected to improve the health or better manage the symptoms of persons with a physical or mental health conditions who have a history of frequent hospital attendance or admissions.<sup>10</sup>

Activity-based funding was raised as an issue again during this inquiry, including concerns about the 'incentivisation' of hospital use over community-based services. On the evidence provided to the committee, current funding models don't allow for comprehensive, flexible delivery of palliative care. The committee believes that funding for Hospital and Health Services and community-based services needs to be aligned to ensure that hospital use isn't incentivised over community based services as a result of activity-based funding.

Stakeholders also raised concerns about time-limited funding models, and the committee agrees that such an approach doesn't harmonise with the objective of person-centred, needs-based care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Hence, the committee supports the recommendation that the Queensland Government develop a needs based funding model for specialist palliative care

community care in Queensland: towards personcentred care (Report No. 22), p 15.

Health and Community Services Committee, Palliative and community care in Queensland: toward person centred care, May 2013, p 115.

Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards personcentred care (Report No. 22), p 16.



which includes packages of care instead of timelimited funding models. The committee considers this should be considered by the Queensland Government as part of a broader review of palliative care.

#### The palliative care workforce

Evidence provided to the committee demonstrates that there are severe workforce shortages in palliative care, and it's likely to get worse due to the ageing workforce and growing demand for palliative care. Measures need to be taken immediately and over the long term to address this staffing shortfall.

The committee agrees with the findings of the Palliative Care Service review that the availability of an accessible, specialist and sustainable palliative care workforce is a critical component of delivering quality palliative care services. The need for such a workforce was widely reflected in the evidence provided during the inquiry. What is less clear, is how the Queensland Government intends to do this.

While the committee acknowledges that there are a number of Queensland Health workforce strategies in place, the committee believes that a palliative care workforce strategy, aligned with the national strategy, and that is based on workforce and population-based modelling, is needed if the Queensland Government is going to develop the necessary workforce.

The strategy will need to remedy shortages in the specialist palliative care workforce (including in the specialist medical, nursing and allied health fields), both to help deliver palliative care services, as well as support other health workers in providing palliative care.

The strategy should also consider the barriers that medical, nursing and allied health staff experience in taking up existing professional development and training as well as further tertiary education, and develop training pathways for those workers. The Queensland Government should consider improving support strategies for current palliative care staff to address issues of fatigue and isolation.

Currently there is a heavy reliance on palliative care specialists, most of whom are based in South East Queensland in the public hospital system. However, it will be important to develop a workforce that can provide palliative care outside of the hospital system — at home, in residential aged care facilities and in the community. This is particularly important to help reduce or avoid inappropriate or unnecessary emergency department presentations, and support people to remain in their home, if that is their preference.

To achieve greater flexibility in the provision of palliative care, when and where a person requires such care, investment will need to be made in the training and development of all staff who may be involved in providing palliative care, including non-specialists. Currently, there appears to be a gap in the training of doctors, nurses, other health staff and personal care workers in recognising and supporting a person's palliative care needs.

Specialist support for care staff who aren't specialists, such as general practitioner, nurses and residential aged care facility workers is key to ensuring good palliative care is provided to the community.

The committee also agrees with the recommendation that a tiered approach to training and development be taken for all health and aged care workers, particularly non-specialists who are likely to still be involved in providing palliative care, such as residential aged care facility workers, general practitioners, nurses and allied health workers in regional, rural and remote areas.

The committee has already recommended that priority funding be allocated to establish a centralised 24-hour, seven day telehealth service to support practitioners throughout the state. Again, this will be particularly important for regional, rural and remote areas.

Of course, funding will be key to workforce staffing, support and development needs. Workforce attraction and retention strategies will also play an important part of any workforce strategy. The recruitment and development of nurse practitioners



will play an important part of developing the workforce.

The committee commends the programs that have been developed to provide training and resources in palliative care, and the committee believes these should continue to be funded. However, the Australian and Queensland governments also need to work with tertiary providers and aged care training providers to encourage them to incorporate palliative care into their courses and training, such as through Palliative Care Curriculum for Undergraduates (PCC4U).

#### Supporting informal carers

The committee recognises the extraordinary commitment of partners, other family members, friends, neighbours and others who provide informal care for the dying. It acknowledges the physical, emotional, and financial burden of caring for a loved one at home and after their loved one has passed. The complexities involved in the delivery of services to patients at home places an additional burden on informal carers.

Providing practical and emotional support, including the provision of professional and financial support, and adequate access to respite services is imperative for informal carers, and enables people to die at home rather than in a hospital or aged care environment. Inquiry stakeholders reported that carers needed access to timely information and support which often came after a considerable waiting period. The committee acknowledges the important work of Carers Queensland, with financial support provided by the Queensland Government, in delivering self-help and self-care for carers through appropriate support, information, education and training.

The evidence presented to the committee indicates that the paucity of respite care for periods of less than two weeks is impacting on informal carers personally and on their capacity to care for their loved ones at home. Lack of respite care should be addressed as a matter of urgency.

The committee recommends that the Australian Government look at ways to increase the availability of respite care available to carers.

#### <u>Public Awareness and Community</u> <u>Involvement – Palliative Care</u>

The committee considers public awareness and community involvement in palliative care vital in reducing fear and misconceptions about end-of-life and palliative care as well as providing better outcomes for patients and their loved ones. Education is needed across the community about palliative care and dying to enable the community to support those who wish to die at home.

The committee acknowledges the exceptional work being done by Palliative Care Queensland and others to promote and normalise discussions about death and dying. It appreciates the initiatives already in place to increase death literacy and the importance of the compassionate communities' response in supporting the dying.

The committee commends the recent initiative by Palliative Care Queensland and the Queensland Ambulance Service, supported by the Queensland Government, to facilitate the Ambulance Wish Queensland program.

However, it is clear to the committee that more needs to be done to create public awareness of palliative care and enable a community-based palliative care approach.

#### Planning for when capacity is lost

The committee recognises the value and importance of Advance Care Planning for ensuring that people's wishes are known and respected at the end of life. Making plans and discussing those plans with loved ones is particularly important when a patient is entering palliative care. It assists family members and reduces the risk of unwanted outcomes at what can already be a difficult time.

The committee welcomes efforts by Queensland Health to enhance Advance Care Planning in Queensland. In particular, evidence received during



the inquiry demonstrated the value added by Advance Care Planning facilitators.

However, the committee also heard that there are a number of barriers to people participating in Advance Care Planning, including a reluctance to discuss death, the complicated Advance Care Planning documentation process, the status of advance directives made at common law, the accessibility of Advance Care Planning documents for medical practitioners, the funding available for Advance Care Planning documentation and support for health professionals to have Advance Care Planning discussions.

The committee acknowledges the work undertaken to date to promote and normalise discussions around death; however, it is clear more needs to be done. The committee recommends that the Queensland Government continue to work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning.

The committee notes evidence received by inquiry stakeholders that the existing Advance Care Planning documentation process is considered complex and confusing. The committee acknowledges the work being undertaken by Department of Justice and Attorney-General to review Advance Health Directives and Enduring Power of Attorney Forms, and believes it is imperative the Queensland Government ensures documentation is simple and accessible for users and health professionals.

To reduce the ambiguity regarding advance care directives made at common law, the committee is of the view that the *Guardianship and Administration Act 2000* should be amended to reflect the premise that decisions made and recorded by a person as part of a formally documented Advance Health Directive or a common law directive at a time when they have competency should be respected in full by doctors and other health service providers after the person has lost capacity.

The committee welcomes recent initiatives undertaken by Queensland Health to enhance the accessibility of patient Advance Care Planning

documents for health professionals. However, it would appear that treating clinicians are still experiencing difficulties accessing relevant documents in a timely manner, particularly in emergency situations. This situation needs to be rectified to avoid uncertainty and unwanted medical care being provided.

It is also important that health professionals are supported and understand their responsibilities as they relate to Advance Care Planning.

Despite the recognition of the importance of Advance Care Planning and the efforts made to encourage people to undertake this process, the committee notes the absence of dedicated MBS rebates to properly remunerate clinicians for assisting patients with Advance Care Planning. This should be addressed to remove an obvious impediment to clinicians in all settings working with patients to ensure they have an Advance Care Planning in place.

### How effective is end-of-life and palliative care?

The committee acknowledges the excellent work of palliative care and other health professionals working to improve the lives of people approaching the ends of their lives. This dedicated group of people help those diagnosed with a life-limiting illnesses to live as well as possible.

The committee appreciates the comments from stakeholders who outlined the many benefits to patients who have access to end-of-life and palliative care services.

#### Are symptoms adequately managed?

Some health professionals advised the committee that whilst most people who received end-of-life and palliative care had their symptoms adequately managed others did not. There was some difference amongst health professionals as to the size of that cohort. Some health professionals provided the committee with a description of symptoms other than pain that were complex and difficult to manage. The committee appreciates the frank advice received





from the health professionals who gave their time to participate in the inquiry.

Stakeholders other than health professionals told the committee of stories of situations where symptoms were not adequately managed. These harrowing accounts demonstrated that there were many people who suffered severe distress as they neared the end of their life. The committee appreciates the very personal stories that stakeholders shared with the committee. The committee considers that even where end-of-life and palliative care is available, symptom management is not always well controlled and there are a number of people suffering severe distress at end of life.

The committee recognises that many submissions about palliative care were accompanied by a request that the committee recommend that legislating for voluntary assisted dying be introduced in Queensland. The committee will consider voluntary assisted dying in Report No 34.

### When symptoms cannot be controlled: the use of palliative sedation

The committee appreciates that in some circumstances symptom control is only achieved through palliative sedation (otherwise known as terminal sedation). Palliative sedation is a normal and compassionate part of responsible patient care at the end of life for the management of intolerable pain and other debilitating symptoms.

The committee considers that the intent of palliative sedation is to provide symptom relief for patients, not to hasten their death. The committee notes the legal protections for health professionals where the palliative care was provided in good faith with reasonable care and skill. It acknowledges the guidelines published by Australian and New Zealand Society for Palliative Medicine (ANZSPM) on palliative sedation therapy for palliative medicine specialists. <sup>11</sup>

The committee notes the concerns of some health professionals that often patients do not choose palliative sedation and there exists a lack of safeguards around this practice.

### When symptoms cannot be controlled: patient options

The committee acknowledges the tragic plight of those suffering at the end of their lives, without quality of life, and 'wanting to go out on their own terms' who felt the only course of action available to them to end their suffering was to refuse nutrition, hydration or medical treatment.

As evidenced by the experiences shared during the inquiry, the committee notes that dying under these circumstances, can be extremely unpleasant and painful for the victims as well as their loved ones and clinical staff providing care. The committee also notes the unpredictable nature of the dying process in the absence of nutrition and hydration which can lead to a period of distress lasting many days and even weeks.

The committee notes that where a patient has lost capacity, decisions about the withdrawal and withholding of life-sustaining treatment becomes complex and subject to restrictions imposed by the *Powers of Attorney Act 1998*. It considers that a patient's autonomy is paramount, and a directive made in a valid Advance Health Directive to withdraw or withhold life sustaining treatment including artificial food and hydration should not be subject to legislative restrictions.

The committee recommends that the Government ensure that patients' directions to withdraw or withhold life-sustaining treatment are followed in accordance with their Advance Health Directive.

ANZSPM, 2017, Guidance Document – Palliative Sedation Therapy.



#### <u>Providing effective palliative care:</u> <u>constraints on health professionals</u>

Medical professionals who worked in palliative care advised the committee that the current law in Queensland was complicating the work of health professionals particularly in circumstances where a patient has lost the capacity to make decisions about their health.

The committee appreciates the difficulties experienced by health professionals in applying complex laws in circumstances where the time for the decision making is limited and patients and their loved ones may be experiencing distress.

The committee notes that where a person has impaired capacity, and the treatment involves the withdrawal or withholding of a life-sustaining measure, the doctor requires consent from that person's substitute decision-maker even if that treatment is futile or non-beneficial. It further notes that, in Queensland, clinicians who seek to withdraw futile treatment without consent commit an offence pursuant to section 79 of the *Guardianship and Administration Act 2000*.

The committee notes that the Queensland Law Reform Commission Report: A Review of Queensland's Guardianship Laws, contains a number of recommendations yet to be implemented which would provide greater clarity for both doctors and patients in Queensland in relation to end-of-life care matters.

# Are patients suffering because medical professionals fear legal sanctions?

Inquiry stakeholders reported that patients were suffering because doctors were reluctant to prescribe medication in sufficient doses owing to a fear that they may be prosecuted, sued, sanctioned or blamed for hastening a person's death. Some stakeholders drew the committee's attention to letters posted by the Australian Chief Medical Officer to the GPs who were identified as being within the top 20% of opioid prescribers. Other stakeholders noted that under-

treatment in aged care homes and hospitals was common.

The committee notes with concern that the confusion and fear amongst health professionals around lawful treatments for end-of-life and palliative care may result in the denial of adequate symptom relief to patients who go on to experience unnecessary suffering.

The committee recommends that the Queensland Government provides training and information to dispel fears about the law and appropriate medication delivery in palliative and end-of-life care.





#### The committee



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The Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee is a portfolio committee of the Legislative Assembly responsible for:

- Health and Ambulance Services
- Communities, Women, Youth and Child Safety
- Domestic and Family Violence Prevention, and
- Disability Services and Seniors.

#### **Further information**

The reports, submissions to the inquiry, transcripts of hearings and briefings, tabled documents and other information published by the committee from the inquiry, are available from the inquiry page on the Parliament of Queensland website. Alternatively contact the committee's secretariat:

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