



**Queensland Parliamentary Inquiry into
AGED CARE, END-OF-LIFE AND PALLIATIVE CARE, AND VOLUNTARY ASSISTED
DYING**

**Prepared by
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EXECUTIVE SUMMARY

Responses to the Inquiry's issues for consideration

COTA Queensland believes **older people, their family and community supports play a key role in the delivery of aged and end of life care and support**. It is essential the service providers and health professionals are knowledgeable and respectful of the role of the person's informal support system and ensure user-friendly information and good communication at all times.

COTA Queensland recognises that **the aged care system is maintained by vast numbers of informal and unpaid carers** who provide the majority of care received by older Queenslanders. Support for these carers must be a priority.

COTA Queensland believes that aged care services in Queensland can continue to be improved through a **person and relationship-centred approach** that supports healthy ageing, **wellness in all its forms (physical, mental, social, spiritual) and inclusion**. Services must be **designed around consumers' needs**, not providers' needs. Person-centred care supports services in responding to the **diverse needs** of individual Queenslanders.

COTA Queensland believes that the **aged care system is failing to meet the needs of all Queenslanders**:

- Older Queenslanders express a clear preference for home-based care, with demand currently outstripping supply.
- Waiting times for both residential aged care and home-care packages suggest that current levels of demand are not being met. Waiting times for home-care packages are a particular concern, most notably for higher-level packages.
- Population projections suggest that service availability must rapidly increase simply to maintain current service levels.
- Aged care services are not consistently available across Queensland, with supply in outer regional, rural and remote locations of particular concern.

COTA Queensland believes that **the aged care system is unnecessarily complex**. Many Queenslanders do not understand what services are available. It is likely that many Queenslanders who would be eligible for aged care support do not apply because they do not understand how to navigate the system. The current system places responsibility on consumers to understand what is possible and to complete the necessary applications.

COTA Queensland believes that most Queenslanders are satisfied with the aged care services they receive. However, some pockets of **concern** are evident, particularly about the **quality and safety of services**, the **administration charges** for home-care services, and the **availability of services to meet the needs of diverse or vulnerable groups**. Monitoring and review is required to ensure that standards for **quality, safety and consumer satisfaction are continually improved**.

COTA Queensland believes that **the aged care sector needs to develop the skills of its workforce** to ensure that suitably qualified staff are available to meet the care needs of older Queenslanders. Current concerns relate to staff qualifications and ensuring that appropriately trained staff are available when needed. Longer-term staffing concerns relate to a potential skills shortage, particularly in regional areas. COTA Queensland does not support mandated staffing ratios in residential aged care, but advocates for accepted care standards and published staffing levels.

COTA Queensland argues that **hospitalisations for older people should be minimised**, particularly hospitalisations at the end of life. Unnecessary hospitalisation is a burden on the health system, often with little gain for patients.

COTA Queensland proposes that **aged care services in Queensland should focus on home-based and community-based approaches that capitalise on existing community support and readily available technology**. Communications technology offers great potential for providing equitable, home-based care for older Queenslanders.

COTA Queensland believes that **palliative and end-of-life care services are not meeting the needs of older Queenslanders**. Palliative and end-of-life care is poorly understood and little discussed. Older Queenslanders are frequently asked to make decisions about their end-of-life care at times of stress and ill-health. **Queensland needs to have a community conversation about the role of palliative and end-of-life care. Queenslanders must be encouraged to plan ahead for their end of life.**

COTA Queensland believes that **Queenslanders are ready for a genuine conversation about voluntary assisted dying**. Our research suggests that it is supported by most Queenslanders, provided suitable legal safeguards are in place.

Key Priorities for the Future

- 1. Individuals and communities need easy-to-access user-friendly information which enables people to plan ahead and make well-informed decisions.** This information sharing and decision making ideally occurs within communities prior to the need for interaction and negotiation with the health and aged care systems. Facilitated conversations and group discussions assist people in identifying what and who is important for them and can assist in documenting and sharing their wishes and preferences for aged, disability and end-of-life care. COTA Queensland would welcome the opportunity of collaborating with Palliative Care Queensland and older members of the community in co-designing and delivering community-led education and information that supports people to make well-informed decisions through ageing, disability, dying, loss and grief phases of life.
- 2. Individuals, carers, family and trusted decision makers want to be involved in decisions that impact their lives and those of their loved ones.** People want to be recognised as partners in the provision of health and aged care, and treated with respect and inclusion in decision making, including in the design and evaluation of services, policies and processes, and information. COTA Queensland assists and advises organisations and government departments to engage with older Queenslanders.
- 3. Government responses to aged and end of life care must extend beyond the aged and healthcare systems.** Government support for community services, housing, transport, financial security, information provision and social inclusion are all relevant to supporting adequate care for older Queenslanders. COTA Queensland encourages the Queensland Government to continue to advance their Age-Friendly Strategy and actions, and to ensure that people are engaged and supported in living - and dying - as well as possible, within their communities.

1. INTRODUCTION

COTA Queensland welcomes this opportunity to provide a submission to the Queensland Parliamentary Inquiry into Aged Care, End of Life and Palliative Care, and Voluntary Assisted Dying.

COTA's consultations and engagement with older people, their families and trusted decision makers repeatedly highlight the difference that having access to user-friendly information, helpful relationships, adequate resources and shared decision making can make in negotiating and receiving care and support that is respectful, responsive and dignified.

COTA Queensland promotes and supports individual and community capacity building and strongly urges the Queensland Government to prioritise and adequately resource health promotion programs and activities aimed at:

- Improving the individuals' health and wellbeing through the life course
- Reducing the need for costly health interventions and aged care services delivered in acute care and residential-care settings
- Promoting age-friendly communities that support people to remain active and connected, thereby addressing some of the social and environmental determinants of health.

2. ABOUT COTA QUEENSLAND

The Council on the Ageing (COTA) Queensland was founded in 1957 as the Old People's Welfare Council. For more than 60 years, COTA Queensland has supported older Queenslanders through advocacy and support.

COTA Queensland is a state-based organisation committed to advancing the rights, interests and futures of people as they age. We actively seek input from older Queenslanders, their families, their carers and their organisations on matters that are important to them. We aim to mobilise people, communities and government to create an age-friendly Queensland for all. We advocate for older Queenslanders across many areas, including aged care, health, palliative care, end-of-life care, cost of living, energy, transport, housing and retirement living, and elder abuse. We are the Queensland government's peak seniors' organisation and are currently contracted to manage Seniors Week activities.

COTA Queensland provides peer education, information sessions and resources for older people throughout Queensland. We gather feedback from consumers and the community about their experiences of the aged care system and use this feedback to inform our advocacy and policy discussions. We represent the consumer experience of aged care reforms at state-based and national forums.

COTA Queensland is a member of the COTA Federation, which includes all state and territory COTA organisations. COTA Australia is the national policy organisation representing the COTAs on the National Aged Care Alliance and working at the national level to influence policy and initiatives relevant to older Australians.

COTA Queensland and COTA Australia are actively involved in supporting the Australian Government's reforms in the aged care sector, particularly by enabling older people, carers and community members to be informed and active partners in the reform process.

COTA Queensland's vision is that ageing in Australia is a time of possibility, opportunity and influence. Our Mission is to advance the rights, interests and futures of people as they age.

COTA Queensland is committed to the following values:

1. **Respect** – we respect and value the contribution and lived experience of people as they age and support each person’s right to make choices and participate in their community
2. **Diversity** – we value the great diversity that characterises people of all ages and commit to genuine exchange and engagement
3. **Collaboration** – we communicate and work collaboratively with older people, with each other, with our partners and with the Queensland community to achieve our vision and purpose
4. **Integrity** – we operate ethically, openly, honestly and with accountability in all our interactions.

COTA Queensland’s strategic goals

1. The lives of people as we age in Queensland will be better
2. Queensland will become an age-friendly state
3. We will be a valued, responsive and sustainable organisation.

COTA Queensland’s policy and advocacy

COTA Queensland is committed to removing ageism and age discrimination in all its forms and advancing in practice the full citizenship rights of people as they age. We work with the COTA Federation on national issues such as aged care and retirement incomes. In Queensland our policy priorities are:

- **Cost of living** with a particular emphasis on energy
- **Health** including aged and community care
- **Housing and homelessness**
- **Transport**
- **Work.**

3. GUIDING PRINCIPLES UNDERLYING COTA QUEENSLAND’S VIEWS ABOUT AGEING, AGED CARE, END-OF-LIFE CARE, PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

COTA Queensland is committed to principles and strategies that support ageing well, dying well and grieving well. These include:

- A wellness approach that sees ageing as a time of possibility, opportunity and active community engagement
- A consumer-focused approach to policy development and implementation that builds social policy around the needs and concerns of citizens
- A person-centred approach that places individuals at the centre of decisions about their care.

3.1 Ageing well

Right around the world, populations are ageing. But while people are living longer than ever before, there is little evidence that those extra years are spent in good health.¹ It is possible that for some, population ageing is adding years lived with disability and chronic disease, rather than years of healthy living.

Ageing well requires a focus on wellness and prevention throughout the life course. Ageing is not simply about the short time before death, but is a process that begins at birth. A focus on healthy ageing recognises that decisions made in early life will influence ageing. It recognises that health is influenced by complex factors – including genetic inheritance, life choices, and the social determinants of health. It recognises that health is dynamic, constantly changing in ways that can be both positive and negative. It recognises that subtle changes in mid-life may be indicators of future care needs.

¹ WHO, 2017, *10 priorities towards a decade of healthy ageing*.

Healthy ageing and aged care cannot be considered separately from broader issues of health promotion, equality, social inclusion and the social determinants of health.

A traditional view of ageing sees older people as suffering increasing ill-health and frailty. They may be considered as out-of-touch, burdensome or dependent.² But this view is outdated and inaccurate. Increasing numbers of older people live active, healthy lives, with no need for formal support. However, ageism remains socially acceptable, strongly institutionalised, largely undetected and largely unchallenged. We live in a society that glorifies youth and turns a blind eye to age discrimination. **The World Health Organization (WHO) argues that ageism remains a powerful barrier to good public policy because it limits the ways problems are framed.**³

Discussions on ageing typically assume that chronological age is a valid marker of health and behaviour. This approach is clear in Australian policy making, where age is used as the key criterion for access to aged care support. However, evidence suggests that **chronological age is not a marker for health. Instead, diversity is a hallmark of older age.** Some 80-year-olds have physical and mental capacities similar to that of young people. Others have multiple chronic conditions and require extensive support. **The WHO points out that public policy must be framed to maximise the number of people who experience positive trajectories of ageing.** A comprehensive policy must meet the needs of all older people, at all stages on the health continuum.⁴

In line with the WHO, **COTA Queensland advocates for an approach to health and ageing that considers the life course from a human rights perspective.**⁵ We advocate that appropriate care and support include informed choice for consumers and accommodate their preferences for the setting and location of care. We advocate that all people should be treated with dignity and respect, with access to the full range of services available in their communities.

COTA Queensland recognises that the goal of public policy is to ensure the fair distribution of society's resources. This does not require that all people are treated in the same way, but it does require that people are treated fairly. **A human rights focus demands that governments monitor access to services.** It is based on the idea that all people – including all older people – should have opportunities to actively participate in their lives and make informed decisions about their care.

3.2 A global strategy for healthy ageing

Healthy ageing involves prioritising strategies that develop and maintain functional ability to enable wellbeing in older age. In this context, 'functional ability' exists at the intersection between individual capacity and environmental support. For example, functional ability to move about the community will be influenced not only by individual mobility and health status, but also by access to suitable transport. In the same way, functional ability to live independently will be influenced not only by individual self-care skills, but also by the availability of supportive aids.

In 2016, the WHO member states adopted the *WHO Global Strategy and Action Plan on Ageing and Health* as a global response to healthy ageing. The WHO defined 2020–2030 as the decade of healthy ageing, with a series of actions to ensure the decade is a success.

² WHO, 2015, *World report on ageing and health*.

³ WHO, 2017, *10 priorities towards a decade of healthy ageing*.

⁴ WHO, 2015, *World report on ageing and health*.

⁵ WHO, 2015, *World report on ageing and health*.

3.3 Queensland's strategy for age-friendly communities

COTA Queensland recognises the Queensland Government's efforts to develop age-friendly communities as outlined in the *2016 Strategic Direction Statement* and subsequent *Action Plan* and *Report Card*.⁶ We recognise the efforts made by the Queensland Government to extend age-friendly approaches into policies for housing, financial protection and health through the *Residential Transition for Older Queenslanders* Report, the *Parliamentary Inquiry into the Adequacy of Existing Financial Protections for Queensland's Seniors*, Queensland Health's 10-year strategy *My health, Queensland's future: Advancing health 2026*, and the proposed *Older Person's Statewide Health Policy* and an *Older People's Statewide Health Services Plan*.

We look forward to the planned survey about age-friendly services across Queensland's Hospital and Health Services and the \$35 million Integrated Care Innovation Fund to support integrated and coordinated health care pathways, connecting hospitals with community and primary health networks.

COTA Queensland endorses the aims of the *Age-Friendly Strategic Directions Statement*:

- Enable people at all ages to participate in community life
- Ensure that people are free from age-related barriers that prevent participation
- Value the contribution of seniors and help ensure their access to all aspects of life.

We acknowledge the close alignment between the Queensland Government strategy and the WHO's goals for healthy ageing. We recognise the Queensland Government's goals and actions across eight areas: outdoor spaces and buildings, transport, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services. **We particularly endorse the Queensland Government's recognition that healthy ageing is not simply a health issue, but a community-wide concern that extends across government portfolios.**

Of particular relevance is the commitment of the Queensland Government under the *Queensland Housing Strategy* to support housing security for older people through housing assistance and homelessness services, increasing the supply of affordable housing, providing social housing, supporting seniors to enter private residential tenancies, helping seniors to maintain tenancies, and supporting seniors to remain in their own homes. Our research suggests that housing security sits alongside health care as priority issues for older Queenslanders.⁷

COTA Queensland encourages the Queensland Government to continue its work in this area and to ensure that a human rights perspective on healthy ageing is considered in all relevant policy development.

3.4 Person-centred care and current aged care reforms

Person-centred care involves ensuring that people have access to services that respond to their preferences, are coordinated around their individual needs, and are safe, effective, timely, efficient and of acceptable quality.⁸ It involves a comprehensive and coordinated approach designed around the needs of the older person, not the needs of care providers. It works to prevent, slow or reverse declines in capacity and, when losses are unavoidable, help people to compensate in ways that maximise functional ability.

COTA Queensland recognises that the Australian aged care system is on a journey towards person-centred care and consumer control. Recent reviews have recommended an improved consumer focus, and reforms are setting the aged care system well on the path to consumer control. In particular, the Tune Review 2017 and

⁶ Queensland Government, 2016, *Strategic directions statement; Action plan*; Queensland Government, 2018, *Age-friendly report card 2017-18*.

⁷ COTA Queensland, 2019, *Kitchen table conversations*.

⁸ WHO, 2015, *World report on ageing and health*.

the Living Longer Living Better Reforms in 2012-14 (designed in response to the Productivity Commission's 2011 report *Caring for Older Australians*) resulted in:⁹

- Additional support and care to help older people remain at home
- Additional help for carers to have access to respite and other support
- A gateway to help people find information and navigate the system (My Aged Care,)
- Changes to improve services for those with dementia.

Important recent reforms in the sector include:

- The New Aged Care Quality and Safety Commission (from January 2019) which brings together previously separated functions for complaints handling and accreditation
- New Aged Care Quality Standards (from July 2019) which will have consumer outcomes as central to each standard
- A trial of the Aged Care Navigator system (from January 2019).

These reforms are evidence of a gradual move towards consumer-led, market-based, quality incentivised aged care system that is fully responsive to consumers' needs, choice and capacity to pay. COTA Queensland stands alongside COTA Australia in endorsing these developments at the national level. **We advocate for a system that places individual consumers and their family and friends at the centre of planning and reform.**

The current Royal Commission into Aged Care Quality and Safety and Queensland's Parliamentary Inquiry into Aged Care, End of Life and Palliative Care, and Voluntary Assisted Dying are further putting the spotlight on aged care in Australia. COTA Queensland notes the unique opportunities presented by these reviews and joins COTA Australia's call that ongoing policy reforms must not be delayed by the current enquiries. **COTA Queensland notes that the policy reforms at the national level need to be supported by complementary reforms at the state level.**

COTA Australia has called for five immediate actions to maintain the momentum of reform:¹⁰

1. More home-care packages to reduce waiting times (estimated 30,000 additional high-level home-care packages needed)
2. Shift control over residential care funding to residents and their families (rather than the current system that allocates 'bed licences' to providers)
3. More information and increased transparency for consumers
4. More funding to build workforce capacity
5. Random, targeted, unannounced inspections in residential care.

There is some evidence that consumer demand is supporting the shift to person-centred care. Consumers expect basic services to be right every time, and they expect support to maintain a reasonable quality of life. Many of today's consumers have, and increasingly into the future will have, more knowledge, more access to choices, increased literacy, wider knowledge of products and services, higher expectations about ageing well, higher expectation of easy access and integrated services, and a preference for personalised services. Ageing well is the expected norm, with older people no longer seeing old age as a synonym for disease and dependency.¹¹

⁹ Department of Health, 2017, *Legislated review of aged care*; 2019, *Aged care reform*; Productivity Commission, 2011, *Caring for older Australians*.

¹⁰ COTA Australia, 2018, *Keep fixing Australia's aged care system*.

¹¹ Macnish et al, 2017, *Future of aged care*.

4. QUEENSLAND'S AGED CARE CONTEXT

4.1 Queensland's ageing population

It is well documented that the Australian population is ageing. The number of older Australians will grow rapidly in coming decades, with clear implications for the supply of aged care services. Queensland is part of this trend, with the population of older Queenslanders set to increase significantly in the next 20 years.

In June 2018, 15.4 per cent of the total Queensland population was aged 65 years and over (768, 121 people). By 2041, the 65 plus age group is predicted to be 21 per cent of Queensland's population (1.5 million people).¹²

Given the population predictions, a 'business as usual' scenario would require a significant increase in the number of aged care places in Queensland in the next 20–25 years with a corresponding increase in all aspects of aged care support.

4.2 Queensland's decentralised population

Queensland is a highly decentralised state, with more than one-third of Queensland's older people living outside major cities. Of those Queenslanders aged 70 years and older, 59 per cent live in major cities and 25 per cent live in inner regional areas. The remaining 16 per cent live in outer regional, remote and very remote areas, where access to services can be limited (see Figure 1).¹³

Outside the major cities, Queensland's older population is clustered in coastal regional communities, which have a high proportion of their total population in older age groups. In 2016, 10 Local Government Areas in Queensland had an older population (65-plus) that was more than 20 per cent of the total population: Tablelands, Hinchinbrook, Bundaberg, Fraser Coast, Gympie, Noosaville, Southern Downs, North Burnett, South Burnett and Flinders. By 2041, almost half of Queensland's Local Government Areas will have at least 20 per cent of their population in the 65-plus age bracket. In 10 Local Government Areas, the population aged 65-plus is expected to be around 30 per cent of the total.¹⁴

This clustered growth in the older population has important implications for local area planning that extend beyond aged care provision to issues such as health infrastructure and accessibility, housing accessibility, transport infrastructure and employment opportunities. An important aspect of this anticipated growth is the availability of a skilled workforce to meet the needs of the ageing population. Some regions are already experiencing a critical shortage of skilled health care and aged care workers. The statistics suggest this trend is likely to continue.

Queensland does not offer equal access to aged care based on geographical location. As shown in Figure 1, in major Queensland cities, 47.3 per cent of people aged 70 and over have access to aged care in some form. In outer regional areas, this figure is 37.8 per cent and in very remote areas this figure falls to 32.5 per cent.

Health outcomes and life expectancy are poorer in regional and remote areas than in major cities.¹⁵ This means that it is impossible to conclude that Queenslanders living in regional and remote locations have less need for services than their city counterparts. It implies that the current allocation is failing to meet the care needs of older Queenslanders living in rural and remote areas.

¹² QGSO, 2018, *Population projections*.

¹³ AIHW, 2018, *Aged care data snapshot*.

¹⁴ QGSO, 2018, *Population projections*.

¹⁵ AIHW, 2017, *Rural & remote health*.

Figure 1: Queensland Total 70 Years and over population (estimated) by Remoteness Area(a) at 30 June 2018 with Aged Care Participation¹⁶

Remoteness Area	70 Years & Over Population per cent Share by Area	Residential Care Number of Clients per cent Share by Area	Home Care Number of Clients per cent Share by Area	Transition Care Number of Clients per cent Share by Area	Home Support Number of Clients per cent Share by Area	All Aged Care Number of Clients per cent Share by Area	Percentage 70 years & over popn cohort accessing Aged Care within Area
Major Cities	306,219 59%	21,437 66%	11,406 64%	385 66%	111,555 62%	144,785 63%	47.3%
Inner Regional	131,303 25%	6,740 21%	4,398 25%	143 24%	42,068 24%	53,350 23%	40.6%
Outer Regional	73,067 14%	3,888 12%	1,945 11%	56 10%	21,636 12%	27,525 12%	37.8%
Remote	5,753 1.0%	172 0.53%	41 0.23%	0	2,023 1.1%	2,236 1.0%	38.9%
Very Remote	5,716 1.0%	106 0.3%	137 0.76%	0	1,616 0.90%	1,859 1.0%	32.5%
Total	522,057	31,030	16,746	528	179,006	227,310	43.5%

The Royal Flying Doctor Service notes that poor provision of aged care in the bush leads to older patients being relocated to areas of higher provision. They report that people in remote locations feel they have no option about leaving their communities for aged care, becoming ‘... socially disconnected from all they knew and loved and forced into exile’. The study found that feelings of aloneness were common, with many participants believing their loved ones died more quickly due to being relocated from their rural and remote communities.¹⁷

COTA Queensland advocates that a person-centred approach to aged care in a decentralised state requires equity of access, regardless of geography. Policy and planning decisions need to ensure that aged care services do not discriminate on the basis of geographical location. It is likely that communication technology will have an increasing role to play in ensuring equity of access, particularly through remote monitoring and video-conferenced consultations.

4.3 Queensland’s Aboriginal and Torres Strait Islander peoples

As part of the effort to Close the Gap in health outcomes between Australia’s Indigenous and non-Indigenous populations, Aboriginal and Torres Strait Islander people are entitled to aged care services if needed once they reach 50 years of age. In June 2018, Queensland’s Aboriginal and Torres Strait Islander population aged 50 and over was estimated at 32,441.¹⁸

¹⁶ AIHW, 2018, *Aged care data snapshot*.

¹⁷ Gardiner, et al., 2018, *Healthy ageing in rural and remote Australia*.

¹⁸ ABS, 2018, *Estimates*.

Aboriginal and Torres Strait Islander people are more likely to live outside major cities than their non-Indigenous counterparts. In June 2018, of the Aboriginal and Torres Strait Islander people aged 50 and above, 28 per cent lived in major cities, 19 per cent lived in inner regional areas, 33 per cent lived in outer regional areas, 7 per cent in remote areas, and 13 per cent in very remote areas.¹⁹

The problems faced in accessing services in rural and remote locations are greater for Aboriginal and Torres Strait Islander people. Older members of Indigenous communities are often reluctant to leave their country and family to access aged care. The importance of older Indigenous people remaining close to their community is well document. They are likely to see residential facilities as a place where people are sent to die. The need to investigate effective approaches to ageing well in Indigenous communities has been largely ignored.²⁰

Given that Indigenous people are more likely to suffer poor health outcomes, and given that services are typically poorer in regional and remote areas, this has important implications for ensuring equity of access to aged care.

In providing aged care services to Aboriginal and Torres Strait Islander people, important issues to consider include:

- The geographical reach of providers
- The availability of Indigenous-specific services and services employing Indigenous health care workers
- The cultural competence of all aged care workers
- Exploring ways to integrate aged care services into other culturally appropriate services.

4.4 Queenslanders with diverse needs and from diverse backgrounds

Queensland's population is increasingly diverse, and aged care strategies need to respond to the community's full diversity. Diversity spans a wide range of concepts including cultural background, disability, sexual preference, mental health, socio-economic status, mental health, education and cognitive impairment. **Some aspects of diversity mean that consumers have high care needs or particular vulnerabilities.**

Diversity presents great opportunities for learning, sharing and richness. But it also presents challenges for ensuring that policies and services respond to people's needs. COTA Queensland believes that policies and services must acknowledge the diversity of the community and be developed to maximise opportunities for inclusion. **We are guided by a human-rights and social justice perspective that advocates for equity, respect and justice for all people, regardless of their background, identity and experience.**

The Aged Care Diversity Framework is an important guiding document for ensuring that aged care services respond fully to the community's diversity.²¹ Action Plans have been developed for consumers and service providers to guide and advocate for respectful, safe and appropriate care for people from Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) backgrounds, Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex (LGBTI), and soon to be released Action Plan for people experiencing homelessness or are at risk of homelessness.

¹⁹ AIHW, 2018, *Aged care data snapshot*.

²⁰ LoGiudice, 2016, *The health of older Aboriginal and Torres Strait Islander peoples*.

²¹ Department of Health, 2017, *Aged care diversity framework*; 2019, *Aged care diversity action plans*

5. CONSUMERS' OPINIONS ABOUT AGED CARE AND RELATED ISSUES

5.1 Consumers' wants and needs

Planning for person-centred care must be based on a sound understanding of the issues and concerns experienced by consumers. A series of recent studies inform our understanding of consumers' wants and needs.

Conversations with the Federal Minister for Mental Health and Ageing

Between August 2011 and February 2012, then Federal Minister for Mental Health and Ageing, Mark Butler, hosted 32 conversations throughout Australia focused on caring for older Australians. Approximately 3,400 people attended these conversations. The Minister spoke about the Productivity Commission's report, *Caring for Older Australians*, and outlined the key reforms proposed. He then had an open discussion with people attending.

Five top messages emerged from those conversations.²² Older Australians want:

1. Quality services available when and where needed
2. Support in their home as much as possible
3. Simplified and streamlined access to information
4. To obtain services in a seamless way
5. As much control as possible over their death, with access to palliative care at home.

A wide diversity of issues was raised during the conversations, demonstrating that aged care is not the responsibility of a single portfolio nor a single jurisdiction. Aged care planning is relevant for all three levels of government and is relevant across all portfolios. At the Queensland Government level, aged care planning is particularly relevant in the portfolios of health, housing, transport, community services, disability services, justice, emergency services and police.

State of the (older) nation report

In 2018, COTA Australia commissioned a nationally representative survey of Australians aged over 50. The survey sampled 2,562 Australians in a 25-minute survey.²³ The survey revealed:

- **Physical health is by far the strongest measure determining quality of life**
- Women fare better than men when it comes to overall happiness
- Non-working people who rent their home fare significantly worse than others in their age group
- Under-employment is evident: 57 per cent of those aged 50 to 64 are in paid employment, along with 15 per cent of those aged 65-plus; 28 per cent of those want more paid work
- Poor quality of life is more prevalent amongst those who rate their financial position poorly, have a disability, are renting, are unemployed, have children living in the household, are single and are younger; of those stating they have poor quality of life, the highest reasons are physical health, mental health and financial difficulties
- Of those reporting high quality of life, the highest reasons include physical health, mental health, financial situation, living environment, freedom to make choices, independence and family life
- **Indicators of vulnerability include low income, disability, language other than English, bereavement in the past year, being from an Indigenous background, experience of domestic violence in the past year and homeless in the past year**
- Widespread concern (41 per cent) that things are getting worse for older Australians

²² COTA Australia, 2012, *Summary report on the conversations on ageing*.

²³ COTA Australia, 2018, *State of the (older) nation report*.

- **Widespread support for assisted dying (84 per cent support), with results highly consistent across the states and territories.**

Kitchen table discussions with Queenslanders

In March 2019, COTA Queensland was part of a collaborative with Palliative Care Queensland, Health Consumers Queensland and Carers Queensland which coordinated 20 conversations with 183 older Queenslanders through the Kitchen Tables Collaborative funded by Queensland Health. The aim of this engagement strategy was to hear about what is important for people who do not usually participate in formal consultations and inquiries, and whose voices are not always heard. Through facilitated conversations discussing issues relevant to them, older Queenslanders reflecting a broad diversity of living arrangements and lived experiences said that:

- Housing is a priority issue; older Queenslanders want to remain in their own homes with the support they need to live, age and die well
- They want access to improved information that will help them to navigate the system and make informed choices
- They want access to quality and timely care and support, with a workforce that is understanding, skilled and sensitive
- They want recognition of the huge contribution made by their family and others in supporting them to live at home, and programs and services which enable these informal carers to also have a quality of life, both now and when/if their caring role finishes
- Voluntary Assisted Dying needs to be discussed and should be an individual choice
- People need to plan ahead with advance care planning and decisions about resuscitation

5.2 Consumers' opinions about home-care packages

The demand for home-based care is growing. Most older people prefer to remain in their own home for as long as possible. Almost 60 per cent of people aged over 70 would rather receive formal care at home than in a residential environment.²⁴ This desire to remain living in one's own home, or a home-like environment, dominated the preferences for the 183 people who participated in the recent Kitchen Table Discussions engagement with a diverse group of people across Queensland.

Recent reforms have developed a consumer-driven approach to home-care packages, with consumers now able to choose a provider best able to provide their services.

Research by COTA Australia identified that 88 per cent of those receiving a home-care service were satisfied with their care (rating their satisfaction with the service as 7 out of 10 or above).²⁵ However, of those who had tried to access home-care or aged care services in the past year, 20 per cent reported difficulties in doing so. The difficulties they reported included cost, waiting lists, and lack of suitable services.

In a recent COTA Queensland survey of older Queenslanders, we asked for feedback about home care.²⁶ Participants said that:

- They receive no independent support once a package is approved, and may find it difficult to locate an appropriate service provider
- Consumers in rural and regional Queensland often lack choice in providers
- Higher-level packages often involve a long waiting period
- Services often use subcontractors, which can increase the cost to the client

²⁴ Macnish, et al., 2017, *Future of aged care*; COTA Queensland, 2019, *Kitchen table conversations*.

²⁵ COTA Australia, 2018, *State of the (older) nation report*.

²⁶ COTA Queensland, 2018, *Aged-care services survey*.

- Many providers charge high administration costs
- Scheduling of services can be difficult, with scheduling based on the priorities of the service provider not on the needs of the client.

Participants in our survey were generally happy with the home-care services they received. Concerns raised by participants included:

- The staff who visit are excellent, but they're often let down by the provider's administrative team
- Staff are given minimal time to undertake tasks, leaving little or no time for personal interaction
- Cleaning and home maintenance services may be of low quality
- Staff may not be trained to notice signs of physical or cognitive decline (decline would indicate that services need to be reviewed)
- Providers are focused on making money ahead of providing care
- Staff shortages mean that consumers' care provider changes.

5.3 Consumers' opinions about residential care

In 2017-18, the average age on entry into residential care was 82 years for men and 84.5 years for women. The average length of stay was 34.6 months.²⁷

In the COTA Queensland 2018 survey of older Queenslanders, the most significant issues raised about residential aged care related to access (waiting times and lack of availability) and health care (staffing, after-hours care and palliative care).²⁸

A 2018 study of consumers' experience in residential aged care found:²⁹

- The two questions receiving the lowest responses were: *Do you like the food here* and *If I'm feeling a bit sad or worried there are staff here I can talk to*
- Across all questions, small facilities received higher ratings than medium facilities, and medium facilities received higher ratings than large ones
- Queensland tended to have more large and medium facilities than the other states
- Queensland's satisfaction scores tended to be at the lower end of the mid-range; Queensland's score was second from the bottom on the question *Do you feel safe here* and third from the bottom on *Do staff treat you with respect* and *Do staff follow up when you raise things with them*.

Opinions about aged care staffing

Despite the increased age and frailty of aged care residents, in recent years there has been a decline in the number of skilled health professionals employed in facilities. Registered nurses made up just 14.9 per cent of the workforce in 2016 (down from 21.4 per cent in 2003). Enrolled nurses made up 7.6 per cent of the workforce (down from 14.4 per cent) and allied health professionals made up 1.1 per cent (down from 9.3 per cent). In contrast, semi-skilled personal care attendants accounted for 71.5 per cent of the workforce in 2016 (up from 56.5 per cent in 2003).³⁰

These statistics are not necessarily any reason for alarm. Researchers recognise there have been substantial improvements to the quality of aged care in Australia.³¹ Non-compliance across the sector is low, and the majority of providers consistently deliver good-quality care. However, COTA remains concerned that poor practice may go undetected. As is consistently being reported to the Royal Commission into Quality and Safety

²⁷ Department of Health, 2018, *Streamlined consumer assessment discussion paper*.

²⁸ COTA Queensland. 2018. *Aged-care services survey*.

²⁹ Wells & Solly, 2018, *Analysis of consumer experience report data*.

³⁰ ACFA, 2018, *Sixth report*.

³¹ COTA Australia 2018, *Submission to the Inquiry*.

in Aged Care, poor-quality care exists and can be traumatic for both residents and their families and friends. Poor care also has an impact on consumer confidence across the sector. Changes in the accreditation process, particularly unannounced visits, will go a long way to address this concern.

There is a widespread concern about staffing in residential aged care, related to the number of staff available, the quality and experience of staff, and the organisational and staff culture they work within. There is a clear need for greater transparency, efficient and effective regulatory processes, and systems to promote the protection of human rights. People need to feel confident that quality of life will not suffer when people go into a residential facility.

For residents in aged care, access to a GP can be an issue. The 2017 AMA Aged Care Survey showed that GPs often discontinue visits to residential facilities because unpaid non-face-to-face time increases, their practices are too busy, the patient rebate is inadequate and the patient rebate doesn't compensate for time lost in the surgery. The AMA proposes that facilities need to improve the availability of experienced nurses and other health professionals, increase funding for medical practitioners to attend aged care facilities, improve access to palliative care services, improve access to mental health services, reduce polypharmacy, and improve access to specialist care.

In our survey of older Queenslanders, participants commented that:³²

- Residential-care staff are not all trained to the appropriate clinical standard
- Residential-care staff often lack adequate experience
- Residential-care staff may not be adequately qualified to care for the residents suffering from dementia
- Residents can be hospitalised unnecessarily or denied needed pain medication (an example included a terminally ill resident denied pain medication as it could become addictive).

With aged care staffing in the public spotlight, there are questions about whether fixed ratios should be set to ensure minimum numbers of qualified staff. Along with COTA Australia, COTA Queensland argues that fixed, mandated ratios are not the answer to staffing in residential aged care.³³ Mandated ratios cannot, on their own, resolve issues with staff quality and availability. In addition, staff ratios cannot address concerns about organisational culture or ensure that a particular resident will, on any day, receive a guaranteed number of hours of care.

COTA Queensland supports COTA Australia's call for four commitments about staffing in residential aged care: (1) staffing levels that are appropriate for the care needs of residents, (2) the requirement for service providers to publish their staffing levels, (3) for a registered nurse to be on staff at all times, and (4) mechanisms to ensure that qualified medical practitioners are available when required, including after hours.

Complaints and feedback

Aged care facilities may not provide adequate opportunities for residents and their families to submit complaints and feedback. The consumer feedback process included within accreditation reviews may not be sufficient.

COTA Australia notes that consumers often fear retribution if they complain or advocate for their rights.³⁴ Aged care residents may feel vulnerable because there is a clear power imbalance between residents and providers. In addition, COTA's research suggests that residents and their families frequently don't understand that they are able to give feedback during formal review processes.

³² COTA Queensland, 2018, *Aged-care services survey*.

³³ COTA Australia, 2018, *Keep fixing Australia's aged care system*.

³⁴ COTA, 2018, *Submission to the Inquiry*.

Adequate complaints processes, where feedback and complaints are encouraged as part of normal customer service, need to be implemented in facilities as part of a customer-service culture. The outcomes of these complaints need to be widely shared and discussed as a way of learning how to provide better quality care.

Links to outside activities and care

Once people move into residential care, it's commonly accepted that all their needs will be met by the provider. There's no clear reason why this should be the case and why residents should be cut off from other sectors of the community.

Transfers between aged care and health services are a particular problem area. Aged care services may transfer residents to hospital unnecessarily because of concerns that they will be held responsible for not providing adequate care. Hospitals may fail to communicate adequately with residential care providers when patients are discharged.

5.4 Consumers' opinions about their access to information

Australia's aged care system is complex. From the consumer perspective, this complexity is typically encountered at a time when people are seeking support because advanced age, frailty and poor health mean they are no longer coping with independent living. People applying for aged care may experience physical or cognitive impairment that prevents them from fully investigating the options available. In addition, they are likely to have preconceived ideas about aged care, based on the stories they have heard from friends and in the media.

Consumers need access to impartial, detailed information that helps them make informed decisions about their care needs. In 2016, the Australian Government introduced the My Aged Care system to address this need, offering online and telephone support for consumers.

In our 2018 survey of older Queenslanders, COTA Queensland asked participants to comment on the availability of reliable information.³⁵ Several participants commented that they have little idea about what services are available and what services are likely to be most suitable for them. They need independent advice to make informed choices between the options.

Participants' responses about accessing information were diverse:

- Some expressed complete satisfaction with My Aged Care and with the range of advice available; many of those who were satisfied said they were confident users of the internet
- Some commented that they did not know where to find information about the options available to them
- Some suggested that My Aged Care lacks detail and questioned its reliability (particularly where it relates to service providers)
- Some questioned whether call-centre staff are trained to work with older people who have hearing problems or other health issues that make talking on the phone difficult
- Some commented that My Aged Care is useful for providing general information, but not for seeking answers to specific questions.

A report by the Aged Care Financing Authority notes that some consumer groups are not aware of My Aged Care. In particular, people from Aboriginal and Torres Strait Islander communities and culturally diverse communities may not know about the system and may need support to navigate the system.³⁶

In the 2018-19 budget, the Australian Government allocated funding to improve accessibility of My Aged Care and to trial a system navigator service. The My Aged Care System Navigator Trial, which commenced in January 2019, is testing different types of navigator types: information hubs, community hubs, specialist

³⁵ COTA Queensland, 2018, *Aged-care services survey*.

³⁶ ACFA, 2018, *Sixth report*.

support workers in consumer-focused organisations, and aged care financial information service officers within the Department of Human Services. The navigators are designed to support people to get the best outcome from the aged care system and support them to reach the point where care can begin. COTA Queensland is leading the Wide Bay Community Hub Trial and is working in close coloration with ADA Australia who are leading the Wide Bay Information Hub Trial.

In recent years there has been an emerging industry of user-pays aged care brokers who offer to handle all the paperwork and locate a service provider to meet an individual's needs.

Both the Aged Care Navigator Trials and the emergence of aged care brokers are evidence of the complexity of Australia's aged care system. A person-centred system should not require a navigator to help consumers ensure the system can meet their needs. While COTA Queensland supports the Australian Government's decision to trial system navigators and anticipates the navigators will fill a great community need, we call for ongoing efforts to simplify the system and improve its consumer focus.

A recent Queensland Health initiative offers Nurse Navigators to help ensure patients' treatment is well managed across multiple providers. Nurse Navigators coordinate patient-centred care, create partnerships and improve patient outcomes. They're part of the care team, providing care coordination, liaison between providers and access to information. COTA Queensland calls on the Queensland Government to ensure that all HHS regions have sufficient Nurse Navigators to service the needs of older Queensland and to ensure they have experience in geriatric and palliative care.

It is important to note that older people's information needs extend beyond the need for information about residential aged care and home care. Fewer than 45 per cent of older Queenslanders receive some type of formal care package, and the vast majority of care is provided in the community by family, friends and informal carers. **Consumers and their carers need access to reliable information about the full range of services available to ageing Queenslanders.**

6. AGED CARE IN QUEENSLAND

COTA Australia is the national policy organisation representing the state and territory COTAs at the national level in informing and influencing policy and initiatives relevant to older Australian. COTA Australia is making detailed submissions to the Royal Commission on Aged Care Quality and Safety. However, **there are a number of matters which directly impact on a person's ability to access appropriate and timely aged care, with the potential therefore to have an impact on end of life care.**

6.1 Waiting times

Queenslanders often face extended waiting times between their approval for care and the date their care begins. Even when care eventually begins, it is possible that it isn't at the approved level. Consumers frequently receive a Level 2 service when they have been approved at Level 4 because the number of high-level places is not sufficient.

In Queensland in 2013, the median wait time for entry to residential aged care was close to 50 days. By 2016-17, the wait time had extended to 135 days.³⁷ The trend to longer wait times appears to be continuing: in 2017-18, the median wait time had increased to 141 days.³⁸

Consumers often face an extended wait from the time when an ACAT Assessment is completed to the time when they receive a Home Care Package. The waiting time for access to Level 1 and 2 services has decreased from 108 days in 2015-16 to 85 days in 2017-18. While this drop in wait times must be applauded, it is worth

³⁷ AIHW, 2017, *Explore admissions*.

³⁸ Productivity Commission. 2018. *Report on government services*.

noting that the average waiting time for the most basic level of home support, provided to older people who have been assessed as needing that support at the time of the assessment, still averages almost three months. In addition, the waiting time for higher level services has increased, from 65 days in 2015-16 to 140 days in 2017-18.³⁹ It is noted that additional home care packages have been released since this reporting period.

In COTA Queensland's 2018 survey of older Queenslanders, many participants expressed concern about lengthy wait times.⁴⁰ They felt that not enough packages are available, particularly higher-level packages. One participant noted:

Mum was not reviewed for about 18 months (plus) after being assessed as a Level 2 'low care' initially, despite requests. After her general condition and dementia deteriorated, it was another year before she was re-assessed as a Level 4 with dementia specific funding.... Getting a written diagnosis was the biggest hurdle.

COTA Queensland recognises that waiting times are linked to Australian Government decisions about ratios and package numbers and the national queue, with the Queensland Government conducting ACAT assessments on the Australian Government's behalf. COTA Queensland calls on the Queensland Government to ensure that ACAT assessments are completed in a timely way with minimal waits. COTA Queensland also calls on the Queensland Government to advocate for Queenslanders to encourage an Australian Government commitment to minimise waiting times and ensure that no Queenslanders wait more than three months for a service at the level approved.

6.2 The cost of residential aged care in Queensland

Aged care services are primarily funded by the Australian Government. In 2017-18, the Australian Government spent \$3.439 billion in Queensland on aged care programs. The residential component of this was \$2.274 billion, and the average annual subsidy per occupied place in Queensland was \$66,462.⁴¹

In 2017-18, approximately 47 per cent of Queensland's residential aged care residents depended on Australian Government subsidies to fund their access to residential care.⁴² This is higher than the national average of 43.4 per cent receiving government subsidy.

The Australian Government subsidises residential aged care based through a means test. All aged care users are expected to contribute to the cost of providing their service. The number of subsidised places in Queensland has fallen in recent years.⁴³ It is possible that consumer demand may have fallen. However, current wait times for care (discussed above) suggest that this is not likely to be the case.

A residential care provider receives up to 85 per cent of an individual's pension as a contribution towards care costs. This means that a person in subsidised residential aged care receives just \$207 per fortnight for their living expenses (based on a pension with allowances of \$916 per fortnight). While it's clear that residents in aged care have low living expenses because their care needs are provided, it's possible that this low income limits the possibilities available to people in residential aged care, who may find themselves unable to afford simple interactions with their community and simple services such as a telephone.

Low incomes are a concern for many older Queenslanders, which influence their access to care and support outside the aged care sector. Important issues include the cost of health care, transport, housing and related costs such as utilities, and having sufficient spare funds to support active participation in their local community. **Older Queenslanders need equitable access to relevant services, regardless of their capacity to pay.**

³⁹ Productivity Commission, 2018, *Report on government services*.

⁴⁰ COTA Queensland, 2018, *Aged-care services survey*.

⁴¹ AIHW, 2018, *Aged Care data snapshot*

⁴² Productivity Commission, 2018, *Report on government services* (based on Chapter 14, Table 14A.21).

⁴³ Department of Health, 2018, *Stocktake of places*.

7. OTHER ISSUES RELEVANT TO AGED CARE IN QUEENSLAND

7.1 Access to health care

The World Health Organisation (WHO) notes that health systems in most countries are designed to deal with acute health conditions rather than the more complex, chronic health needs that tend to arise as people age.⁴⁴ In addition, the systems for health care and the systems for long-term aged care tend to operate independently of each other, resulting in poorer health outcomes, inefficient use of health services and cost shifting.

Queensland is not immune from this global trend. Queensland is seeing a shift towards health care that is oriented to the long-term management of chronic health conditions and a shift towards person-centred care. However, our primary health system remains designed to diagnose and solve time-limited health issues. Consumers assume that medical services will provide a quick fix for every problem they face, including the chronic health conditions they experience with age. The health issues and social needs faced by an ageing population are complex and long term. It is common for older people to see multiple health professionals, often with little communication between them.⁴⁵

Research suggests that access to health care is a priority issue for older people.⁴⁶ Consumers want access to reliable, understandable, affordable, quality care that is built around their needs. Consumers want care to be provided in a convenient and suitable location that does not involve extensive travel and long wait times.

Health care is provided in multiple settings and through a combination of state funding, federal funding and user-pays approaches. The interface between these settings and funding systems is frequently poor, particularly in an environment where an older person is likely to see multiple care providers for a variety of conditions and vulnerabilities. Information breakdowns may occur, for example, between GPs and hospitals, between specialists and GPs, between allied health providers and GPs, between community care providers and medical practitioners, and between residential-care providers and hospitals. While Nurse Navigators and My Health Record may help to alleviate some concerns in this area, more work needs to be done to develop a fully connected, integrated system.

Home-care packages are often used to support older people's access to health care – including by providing transport and support to get to appointments and visit the pharmacy. It is important to consider whether new technologies may provide opportunities to reduce this type of support, with in-home monitoring, remote consultations and home deliveries from pharmacies freeing up home-care workers to provide more meaningful support to older people.

Improved integration between the health and aged care systems would enable greater continuity of care as well as a more efficient use of resources.

7.2 Housing for older Queenslanders

In COTA Queensland's 2017 survey of older Queenslanders, affordable and appropriate housing emerged as the most important issue that older Queenslanders want the Queensland Government to address.⁴⁷ This was closely followed by the housing utility costs of energy and water. Older Queenslanders typically feel that their housing options are limited (it is difficult for them to move) and that housing maintenance absorbs a large portion of their budget.

⁴⁴ WHO, 2015, *World report on ageing and health*.

⁴⁵ WHO, 2015, *World report on ageing and health*.

⁴⁶ COTA Queensland, 2018, *Aged-care services survey*; COTA Australia, 2018, *State of the (older) nation report*.

⁴⁷ COTA Queensland, 2017, *Queensland seniors' views*.

Appropriate, affordable and safe housing is essential to enable people to continue living safely and independently in their own homes and communities. Anxiety is increased when one partner has to enter a Residential Aged Care facility leaving the other uncertain about their own housing tenure. This fear and uncertainty was echoed in the words of a participant in the recent Kitchen Table Discussions engagement: *Will I be homeless if my husband has to go in to a home?*

7.3 Satisfaction with government services

COTA Queensland's 2017 survey of older Queenslanders explored their satisfaction with the services they receive from government.⁴⁸

The results showed that participants were most likely to be satisfied about age-friendly communities (61 per cent), hospital care (61 per cent), community safety and disaster preparedness (60 per cent), community and home support (48 per cent) and local government (45 per cent).

Participants were most likely to be dissatisfied about energy and water costs (71 per cent); infrastructure, planning and development (55 per cent); affordable and appropriate housing (49 per cent); seniors concessions (49 per cent); and public and community transport (48 per cent).

7.4 Elder abuse

The World Health Organisation (WHO) estimates that **one in ten older people experience some form of elder abuse.**⁴⁹ **Those with cognitive impairment and those living in residential aged care may be at particular risk.**

Australia needs a national response to elder abuse. In 2015, almost 40 percent of calls to Seniors Rights Victoria related to elder abuse. In response, the Australian Law Reform Commission has argued that financial abuse should become a reportable incident by aged care providers. The Commission has also called for a serious incidents response scheme for aged care services.⁵⁰

Most elder abuse occurs in the community, between family members. However, as the Royal Commission into Quality and Safety in Aged Care has revealed, elder abuse is a significant concern in aged care services.

COTA Queensland acknowledges the Australian Government's commitment to addressing elder abuse in the 2017-18 budget, with funding to support workforce and consumer responsiveness and funding to support an elder abuse knowledge hub. We call on the Queensland Government to support the Australian Government's proposal for a national register of enduring power of attorney appointments.

7.5 Health promotion

Older people's information needs extend beyond their need for information about aged care. All consumers need access to information about health more broadly and, in particular, **they need access to information that will support them to maintain their health.** This needs to be supported with information about how to remain active in their communities and information about how to meet their basic needs for housing security, income security and transport.

In older age, most of the burden of disease is from non-communicable, chronic disease. Many older people live with multiple long-term conditions. Chronic disease is largely preventable and, as such, chronic disease risk factors are important topics for health promotion targeting people of all ages. Health promotion work needs to start early in life and continue right across the life course.

⁴⁸ COTA Queensland, 2017, *Queensland seniors' views*.

⁴⁹ WHO, 2015, *World report on health and ageing*.

⁵⁰ COTA Australia, 2018, *Submission to the Inquiry*.

There is growing evidence that key health behaviours, such as engaging in physical activity and maintaining adequate nutrition, may exert powerful influences on the intrinsic capacities of older people. Physical activity increases longevity. Yet, despite clear evidence of the benefits, many people fall short on the guidelines for adequate nutrition and physical activity.⁵¹ Other clear targets for health promotion include alcohol consumption, smoking, drug use and community connectedness.

COTA Queensland calls on the Queensland Government to recognise the long-term value of health promotion and to prioritise health promotion information to Queenslanders of all ages. Consumers need a wide range of materials available, in formats that include print, online, video and audio. Material needs to be provided in multiple languages, including in Auslan. Consumers need tailored information, separate to what is available for health professionals.

COTA Queensland has been delivering peer-led community education for over 20 years on topics including medication management, falls prevention, depression, aged care and enduring powers of attorney. Unfortunately these projects are through one-off funding grants and short-term (frequently 12-18 months maximum) and do not enable long term individual and community capacity building initiatives, sustainability of active partnerships, or efficiencies in terms of costs.

7.6 Disaster preparedness in residential aged care

COTA Queensland has been lobbying over the past five years to strengthen evacuation arrangements for residents in aged care facilities. Current legislation focuses on evacuation in the case of a fire, with providers required to nominate a safe place to which evacuated residents can be moved, typically a car park. Under state emergency legislation there are no specific provisions that relate to residential care facilities.

The Commonwealth Department of Health has guidelines in place that require facilities to maintain quality of care and to have plans in place for emergency events.⁵² The guidelines note that state and territory government have primary responsibility for emergency management, and local governments have an important role in planning, preparedness, response and recovery. Providers are expected to assess risk and respond to the advice of local emergency management authorities.

Following Cyclone Debbie, the Office of the Inspector General Emergency Management noted that aged care providers require significant support and encouragement in planning and exercising evacuation.⁵³ The Inspector General's report noted a lack of consistency across providers, which resulted in varying levels of preparedness. In a 2018 report, Volunteering Queensland called for increased action to safeguard older people during disasters and for Queensland legislation to be strengthened in relation to emergency evacuation requirements for a range of disasters.⁵⁴

COTA Queensland calls on the Queensland Government to implement the recommendations of Volunteering Queensland as part of its current review of the Fire and Emergency Services Act 1990.

8. THE DELIVERY OF PALLIATIVE AND END-OF-LIFE CARE IN QUEENSLAND

In 2017, COTA Australia co-facilitated a report on principles for palliative care and end-of-life care in the residential aged care setting.⁵⁵ The report identified eight principles for palliative and end-of-life care in

⁵¹ WHO, 2015, *World report on health and ageing*.

⁵² Department of Health. 2018. *Risk management for emergency events in aged care*.

⁵³ Office of the IGEM, 2017, *The Cyclone Debbie review*.

⁵⁴ Volunteering Queensland, 2018, *Disaster preparedness*.

⁵⁵ Palliative Care Australia, et al., 2017, *Principles for palliative and end-of-life care*.

residential aged care to prioritise consumers' needs and wishes, provide care with dignity and respect, involve consumers in planning, support holistic and integrated care, respect consumers' cultural and psychosocial needs, and support families, carers and staff in bereavement. These principles sit alongside the palliative care service development guidelines developed by Palliative Care Australia.⁵⁶

8.1 Palliative care

The WHO defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.⁵⁷

Research suggests that approximately 75 per cent of Australians aged over 65 will access aged care services in the 12 months before their death, yet relatively few of these access palliative care. Consumers support the provision of palliative care within the aged care setting, with more than 80 per cent considering it to be important or extremely important.⁵⁸

COTA Queensland has long advocated for increased adoption of palliative care throughout Queensland.

Palliative care should be available for all consumers who need it. It should be available in a setting chosen by the consumer and provided in the way most suited to the consumers' needs. COTA Queensland believes that access to palliative care must be broadened.

Palliative care is difficult to access in Queensland. There is a general lack of knowledge about what palliative care is and the benefits it can offer to the patient, family and friends. COTA Queensland understands that the lack of knowledge about good palliative care extends to the medical profession, hospitals and aged care providers. There is a lack of trained medical specialists, GPs, nursing staff and allied health staff in palliative care. **The lack of palliative care options in Queensland is likely to mean that older Queenslanders experience unnecessary pain and suffering in the final stages of their lives.** It also means that **older Queenslanders are likely to be unnecessarily hospitalised near the end of life, when palliative care would be more appropriate.**

Residential aged care facilities are important providers of palliative care, but their palliative-care delivery appears to be highly variable and under-recognised. Addressing the palliative care needs of aged care residents should be part of the core business of residential aged care. When residents are near the end of life, it makes little sense to transfer them to hospital for intervention and treatment. Duckett argues that an appropriate approach to funding would incorporate an allowance for additional palliative care services for residents.⁵⁹

8.2 End-of-life care

A relevant question for end-of-life care is to ask when the end of life occurs. COTA Victoria addressed this question in its submission to the Victorian Voluntary Assisted Dying Bill,⁶⁰ and advocated that the definition of end of life should be broadened to include the end of independence and autonomy. A useful way to consider the question is for a medical professional to ask: *Would I be surprised if this person died within the next six*

⁵⁶ Palliative Care Australia, 2018, *Palliative care service development guidelines*.

⁵⁷ WHO, 2018, *10 principles for a decade of healthy ageing*.

⁵⁸ Palliative Care Australia, 2017, *New survey shows Australians don't plan for the end*.

⁵⁹ Duckett, 2018, *Aligning policy objectives and payment design in palliative care*.

⁶⁰ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*.

months? While a precise definition of end of life is difficult, the prognosis of no more than six months to live is useful, and is recognised in other jurisdictions (including Oregon and Washington in the USA).

There has been a significant shift in how Australians die. Today, approximately two-thirds of Australians die when they are old, mostly from chronic diseases and disabilities experienced towards the end of life.⁶¹ Older people who are diagnosed with a terminal illness now have an extended time to contemplate their death and may be overwhelmed by the choices available to them. They may be asked to make choices and decisions about their care without fully understanding the implications of those choices.

In many cases, Australians now have an opportunity to plan for their death and consider what they need to support a good death. However, **many people do not consider nor plan for the end of their lives.** Evidence suggests that, in the last year of life, many people do not receive enough palliative care and many find themselves caught up in interventions and services designed to prolong their lives.⁶² The Grattan Institute notes that a good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs.⁶³

Most Australians want to die at home, with minimal pain and suffering. However, only 14 per cent of Australians do die at home, making death in Australia more institutionalised than in the rest of the world. There is great disparity between what people want and what is happening.⁶⁴ People want to know when death is coming. They want time to say goodbye. And they don't want life prolonged pointlessly.

COTA Australia's study of older Australians found that most had done some type of planning for the final stages of their lives:⁶⁵ 77 per cent had completed a Will, 38 per cent had enacted an Enduring Power of Attorney, 17 per cent had a funeral plan, and 10 per cent had written an advanced care directive. However, **46 per cent of respondents had not looked at information intended to support their personal planning for the final stage of life.** While respondents in older age brackets were more likely to have considered end-of-life planning, only 16 per cent of those aged 75 and over had completed a formal advanced care plan.

This research suggests that most older Queenslanders do not plan ahead for their end-of-life care. Very few Queenslanders record their wishes in an advance care directive, leaving them vulnerable to having their wishes ignored in the final stages of their lives. If they become unable to express their treatment preferences themselves, these decisions will be made by their family, caregivers, or medical professionals.

A current initiative to respond to this need being developed by ELDAC (End of Life Directions for Aged Care), which is offering grants for community and residential care organisations wishing to develop palliative care and advance care planning activities. ELDAC seeks to help build capacity to provide care for older people nearing the end of life, develop and strengthen linkages between the service and other care providers, and improve initiatives in palliative care.⁶⁶

If consumers are to be supported to make informed decisions about their end-of-life care, they need clear, direct information about their current state of health, treatment options and likely consequences. In particular, they need information about how treatment options are likely to impact on their quality of life.⁶⁷ Doctors want to provide their patients with hope and options for prolonging life. This means that end-of-life care and conversations are often delayed, and treatment focuses on prolonging life rather than providing quality of life.⁶⁸ **Many people, if given a choice, would choose quality of life over aggressive intervention.**

⁶¹ Swerissen & Duckett, 2014, *Dying well*.

⁶² COTA Vic, 2015, *Inquiry into end-of-life choices submission*.

⁶³ COTA Vic, 2015, *Inquiry into end-of-life choices submission*.

⁶⁴ Swerissen & Duckett, 2014, *Dying well*.

⁶⁵ COTA Australia, 2018, *State of the (older) nation report*.

⁶⁶ ELDAC, 2019, *Sector engagement*.

⁶⁷ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*.

⁶⁸ COTA Vic, 2015, *Inquiry into end-of-life choices submission*.

In 2015, COTA Victoria conducted a series of *Dying to Talk* events to explore people's questions about death and dying.⁶⁹ Important themes emerging from the conversations included that people wanted more information about:

- How to start conversations about end-of-life care with their family and doctor
- The process of dying (and particularly addressing their fear of dying)
- Ensuring their wishes and choices are respected
- How to plan for the unknown in drawing up an advance care directive
- How to keep out of hospital and die at home
- What support or services are available for people without family support
- The doctor's role at end of life.

The role of professionals at the end of life needs to be redefined to support the person to die well, according to their own values. This means that medical professionals must communicate the prognosis clearly, communicate the impact of treatment, and not assume that medical intervention should be geared towards prolonging life.

Evidence suggests that **the Queensland community needs to have a conversation about end-of-life care:**

- Aged care workers and medical professionals need more training in end-of-life care to support older people's access to palliative care and supportive end-of-life care that emphasises dignity and individual choice ahead of medical intervention⁷⁰
- Consumers, families and carers need more information about advanced care planning, palliative care and end-of-life care; they need to be encouraged to have conversations early, make informed decisions, and be ready to communicate those decisions to medical staff.
- All Queenslanders need to be more aware of the documents available for end-of-life planning, in particular the advanced care directive.

A human rights approach to healthy aging recognises that older people must be:

- Treated with dignity and respect
- Empowered to make informed decisions about their end-of-life care
- The chief decision makers in their end-of-life care.

Whilst conversations with health professionals are important discussions about a person's end of life wishes need to occur in the community. COTA Queensland recommends a peer-led community education program based on international best practice.

9. VIEWS ON VOLUNTARY ASSISTED DYING

Recent legislative reform in Victoria about voluntary assisted dying provides a rich source of evidence for this Queensland review. The Victorian Legislative Council's Standing Committee outlined the following guiding principles (adapted from the Joint Centre for Bioethics at the University of Toronto), which may be relevant in the Queensland context:⁷¹

- Valuing human life and the quality of life until death
- Relief from pain and suffering
- The critical role of palliative care

⁶⁹ COTA Vic, 2015, *Inquiry into end-of-life choices submission*.

⁷⁰ COTA Australia, 2019, *Pre-budget position statement*.

⁷¹ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*; Parliament of Victoria, 2016, *Inquiry into end of life choices*.

- Patient-centred care and informed decision making
- Safeguards and protections for people who are vulnerable and for health practitioners
- Equality of access and support for carers and loved ones
- Clear and transparent laws that support end-of-life planning, decision making, and the rights and responsibilities of all involved in end-of-life care.

In COTA Queensland's recent survey of older Queenslanders, we sought their views about whether Queensland should begin a conversation about voluntary assisted dying.⁷² Most respondents supported further exploration by the Queensland Parliament. Our research suggests that opinion is divided amongst our cohort in Queensland.

Comments from respondents included:

- I fully believe that the rights of the individual should be observed if they are mentally sound. More needs to be done to ensure legal and medical support is provided to those wishing to take matters into their own hands.
- On religious grounds I would have a problem but can understand it.
- It's a tough choice. I don't really want to die but when I do I want my life immediately beforehand to be decent. If that means I have to kill myself rather than suffer the indignities I have witnessed well I would like to have the option of assisted dying I suppose but it seems a bit Soylent Green to me I am a strong supporter of Voluntary Assisted Dying and hope it is available legally for me when required.
- I disagree because I do not trust the medical system or decisions made by family members. However, if the person is fully able to make their own decisions and are receiving optimal care to minimise pain and discomfort and are not being starved to death, then it is the person's decision. In many instances if the person was given good care and support, they may in fact want to live a bit longer.

COTA Australia's 2018 national survey of older Australians asked participants whether they supported or opposed assisted dying for their state or territory.⁷³ The majority of participants (84 per cent) indicated that they supported the introduction of assisted dying, provided the right protections and legislation were in place. Just 16 per cent of participants opposed assisted dying. Support was highest amongst those with no religion (95 per cent) and lower among Catholics (74 per cent) and Baptists (53 per cent). Those aged 80-plus were more likely to oppose assisted dying. There was no clear difference in the results of participants from Queensland.

The COTA Australia survey also asked participants whether they would consider assisted dying as an option for themselves if they were suffering from a terminal illness or incurable condition. A large majority (69 per cent) agreed they would consider it. This response rose to 81 per cent among those who supported the legislation and 83 per cent among those with no religion.

A relevant question to voluntary assisted dying is how the condition permitting its use is determined. In Victoria this is called a 'serious and incurable condition'. COTA Victoria argued that individual consumers must be the final decision makers. Only they can assess what is intolerable and unbearable for themselves. The definition of a serious and incurable condition therefore should include that the condition is causing intolerable and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.⁷⁴

Another relevant question to voluntary assisted dying is whether safeguards can be built into the system to ensure the request is voluntary. An agreed process must be defined in legislation. In Victoria, this includes an initial verbal request, followed by a formal written request signed by two independent witnesses, and a final verbal request.⁷⁵

⁷² COTA Queensland, 2018, *Aged-care services survey*.

⁷³ COTA Australia, 2018, *State of the (older) nation report*.

⁷⁴ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*.

⁷⁵ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*.

Also relevant for voluntary assisted dying is where it would be offered. If voluntary assisted dying is to be approved in Queensland, it must be available in place. Individuals must not be transferred to a new location because they wish to access voluntary assisted dying. In addition, individuals should not be transferred from their hospice or palliative care services because they wish to access voluntary assisted dying.⁷⁶

If voluntary assisted dying were to be approved in Queensland, medical professionals must retain the right to conscientiously object. Queensland may follow the Victorian lead and require medical professionals to refer the patient to an alternative practitioner and require the medical practitioner to communicate this to the patient.

COTA Queensland is unclear whether Queensland's recent Human Rights Bill 2018 will have any impact on the discussion about voluntary assisted dying. For example, Clauses 16 and 17 of the Bill could be used to support a legal case allowing access to assisted dying. Having a person prolong their life against their wishes while suffering pain and suffering could be classed as cruel, inhuman or degrading treatment.

COTA Queensland argues that voluntary assisted dying should be the individual consumer's choice and that appropriate legislative safeguards should be in place to support this.

⁷⁶ COTA Vic, 2017, *Voluntary Assisted Dying Bill submission*.

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