

**ANGLICAN CHURCH SOUTHERN QUEENSLAND
SUBMISSION**

**QUEENSLAND PARLIAMENTARY HEALTH,
COMMUNITIES, DISABILITY SERVICES AND DOMESTIC
AND FAMILY VIOLENCE PREVENTION COMMITTEE**

**INQUIRY INTO AGED CARE, END-OF-LIFE PALLIATIVE
CARE AND VOLUNTARY ASSISTED DYING**

EXECUTIVE SUMMARY:

- This submission represents the position of the Anglican Church Southern Queensland (ACSQ), which covers all parishes with around 500,000 Anglicans from Bundaberg in north central Queensland to Coolangatta and west to the borders of South Australia and the Northern Territory
- In 2017, the Anglican Church General Synod addressed the issue of “Assisted Dying”, passing a motion which “affirmed the sanctity of life; that life is God’s gift ...” and opposed any legislation in favour of assisted dying. It urged all State and Territory governments to “better resource palliative care services, including in regional and remote communities, Aboriginal and Torres Strait Islander communities and nursing homes, and to provide better training in palliative care for all health professionals.”
- There is a need to restore dignity and humanity to death, which can be achieved with consistent delivery of quality palliative care. Death needs to be viewed as a natural consequence of living
- Respect for human life is not just a religious value, but a foundational value of all societies in which reasonable people would want to live. The life of each individual has an equal claim to respect, because the value and dignity of each person is not diminished by age, gender, disease, dependence or disability
- The euphemism ‘assisted dying’ aims to mask the fact that voluntary assisted dying (VAD) and physician assisted suicide (PAS) are actually forms of suicide. Legalising euthanasia and PAS will send mixed messages about suicide prevention. To approve suicide for some but not others is inherently discriminatory, and indicates that some lives are considered of more value than others
- Autonomy (the ability to be in control of one’s own life) is at the core of the ethical arguments in supporting VAD. However, autonomy is always tempered by the rights of others to also experience public goods and prevention of harm. It is not an unfettered right of Queenslanders to have public policy that supports their desire to maintain a completely autonomous life
- The option of a ‘good death’ – supported by high quality and accessible palliative care - should be available for all Queenslanders irrespective of their status, age, geographical location, citizenship status, sexual orientation or criminal background
- It’s estimated that up to 80 percent of people who die in Queensland will benefit from palliative care with between 51,000 and 71,000 of the Queensland population requiring care
- Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs
- Anglican Church SQ provides and funds its own hospital chaplaincy service with over 70 Anglican volunteers providing pastoral and spiritual care to patients in hospitals and prisons
- As the only state which doesn’t fund hospital chaplaincy services, ACSQ calls on the Queensland Government to provide an appropriate level of shared funding for these services (including more hours and greater access to chaplains in hospitals, prisons and aged care facilities)
- It is important for palliative care services to understand the individual needs of Aboriginal and Torres Strait Islander people and for the services to be more culturally attuned as well as being more accessible to those from rural and remote parts of Queensland
- We recommend improved funding and resources to ensure equity of service and access to palliative care regardless of age, geographical location, citizenship status, sexual orientation

or criminal background with Home Care packages to include funding for pastoral and spiritual care

- We recommend improved funding and resources for general community death literacy and palliative care education
- It is the role of faith based organisations such as the Anglican Church Southern Queensland to speak for the vulnerable; for those who may be harmed because precious health care funding is re-directed on fallacious moral and legal grounds; for those whose suffering is increased because their access to end of life services (good quality palliative care) and or death literacy, is low
- There is the great danger of the most vulnerable in our community, the elderly who are suffering from a life-threatening health condition becoming subjected to undue pressure and coercion (either through social or family pressures), to feel more socially isolated and to feel as if they are a burden on their families and on society
- The promotion and legal/political approval of VAD laws in Victoria (and potentially in Queensland) has the likely effect of making the elderly feel that burden. If an ageing individual is unable to take care of themselves, has reduced decision-making capabilities and/or financial management issues, there is a likely increase in their vulnerability to be pressured into euthanasia by family members or others responsible for their care. The overseas experience in Belgium and the Netherlands shows us how the slippery slope can become steeper and more slippery with children (in Belgium this can be a child of any age) with a terminal illness able to request euthanasia
- The Victorian review of VAD laws - characterised predominantly by “bad dying stories”, which belied the fact that many good deaths occur in Australia, hence creating a climate of fear in the mind of the public - lacks some important safeguards – most notably the requirement for psychological assessment and the lack of guidance as to how doctors can establish there has been no coercion of the patient's request (with the prospect of elder abuse being significant).

INTRODUCTION:

In February, 2019, the Queensland Parliament passed the Human Rights Bill 2018, which had as a main objective, “to protect and promote human rights” with the right to life being defined as follows:

“Every person has the right to life and has the right not to be arbitrarily deprived of life.”

Upon appointment, medical practitioners take an oath to not do any deliberate harm to their patients.

These legal, and legally enforceable, commitments to the sanctity of human life are in sharp contrast to a growing and alarming trend in Australia and overseas to allow the rights of the individual to override all other considerations amidst the push for voluntary assisted dying laws.

In 2017, the Anglican Church General Synod addressed the issue of “Assisted Dying” in a debate at its annual gathering (General Synod functions as a forum for determining policy matters for the 23 Dioceses of the Anglican Church of Australia). A motion was passed which “affirmed the sanctity of life; that life is God’s gift ...” and opposed any legislation in favour of assisted dying. Furthermore it urged “all Australian State and Territory governments to better resource palliative care services, including in regional and remote communities, Aboriginal and Torres Strait Islander communities and nursing homes, and to provide better training in palliative care for all health professionals.”

The Anglican Church Southern Queensland (ACSQ) welcomes the spotlight and public consultation that the Queensland Parliament Inquiry, through the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, will bring onto the issues of aged care and palliative care - the latter we believe has been severely underfunded and under-resourced for far too long. ACSQ also understands and appreciates that the views and beliefs of the Queensland community are shifting which has prompted the Parliament to consider reforms into end-of-life choices including the possible introduction of voluntary assisted dying laws.

In 2018 ACSQ, through its Social Responsibilities Network made a submission a contribution to the Queensland Health Palliative Care Services Review. In that submission, ACSQ outlined how the need for palliative care is projected to grow significantly over the next 5-10 years due to the ageing Australian (and Queensland) population and the concomitant increase in chronic diseases, such as heart disease, diabetes, dementia, and cancer. Unfortunately, the availability of palliative care is currently not meeting community needs in Queensland. It is estimated that 80 percent of people who die in Queensland would benefit from palliative care.⁽¹⁾ The option of a ‘good death’ should be available for all Queenslanders irrespective of their status, age, geographical location, citizenship status, sexual orientation or criminal background. Access to good palliative care has historically provided a mixed and unjust level of access and availability across Queensland with sub-optimal access to palliative services for those living in rural and remote Queensland. This is also the case for the marginalised in our community and those with specific needs – including the homeless, the LGBTIQ community, those suffering from mental illness, refugees, former prisoners and equally importantly, those from Aboriginal and Torres Strait Islander backgrounds. This submission will separately address the three different focus areas of the Parliamentary Inquiry – aged care, palliative care and voluntary assisted dying.

ACSQ AND AGED CARE IN QUEENSLAND

As noted in the Issues Paper No. 3, distributed by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, the issue of Aged Care, Quality and Safety is currently being closely examined by a Royal Commission based in Adelaide. ACSQ, through its aged care provider Anglicare Southern Queensland (Anglicare SQ) is working closely and cooperatively with the Royal Commission and has publicly reaffirmed to the Commission its commitment to providing high quality and safe care in all of its services and outlets. Given that submission, it is not intended to spend an inordinate amount of time and space in this paper on the major issues surrounding aged care in Queensland with much of the funding, oversight and jurisdiction controlled by the Commonwealth Government.

Anglicare SQ is a member of the Anglicare Australia Network. The Network consists of social service organisations linked to the Anglican Church in Australia that shares a belief in the value and the potential of every person, and the principles of justice, hope and compassion. Collectively the network provides services to older Australians include financial counselling, emergency relief, housing and homelessness, and community-based mental health programs; as well as the provision of community-based and residential aged care services to more than 62,000 elderly Australians, employing 9,000 staff and drawing on more than 3,000 volunteers. Because of our common values across the Anglicare Australia Network, we are committed to delivering the highest quality of care to older Australians, with a particular focus on those most vulnerable and marginalised in our community. This is especially vital with an ageing and growing population in Queensland.

As a network we pool our experiences in order to collectively identify and advocate for system-level improvements in aged care. Despite the considerable improvements in aged care and numerous reviews over the last 15 years, the Anglicare Australia Network believes there remains a dissonance between the quality of life and care to which we aspire for our elders as a society – especially in Queensland - and the reality of the level of government funding and design of funding models. We believe that our notion of the kind of society we want is not simply an abstraction, but actually determines the material reality of the human services we provide. Conceptualising person-centred care in economic terms, where resources for care are perceived as scarce and people are considered solely as consumers', is narrow and potentially limiting when envisioning the best quality of care for the elderly. Encouraging people to see themselves in this consumer role can drive a focus on price rather than quality of care. It can also exacerbate or create conflicts regarding the ability of experts to give people the best advice about their care, as a transactional focus can lead to assumptions that recommendations that cost more are driven by a profit motive, not care for the person. Anglicare SQ recognises that the care sector is a major employer and contributor to Australia's overall economic wellbeing, as well as the quality of life we want our elders to enjoy. We work together to support the development and implementation of care models that place people and their wishes for their care at their heart, and recognise that to deliver relational care relies equally on care and support for our workforce.

The current funding quantum and models, however, hamper our efforts as they are based on a premise of maximising funding efficiency over quality of care. Relational care is fundamentally based on the elderly and staff alike having enough time for care to move beyond a mechanical list of physical requirements met. Our experience in delivering spiritual and pastoral care as part of our aged care services particularly strengthens this view. The recognition of the importance of spiritual care as part of the new Aged Care Quality Standards is welcome, but we believe will be challenging to deliver if funding for models of care is still based on lowest cost for delivery.

We need to reconceptualise the aged care system as a continuum of care model that meets community expectations, calibrated to Australia's demographic trends and accessible and equitable for all. At its core must be a commitment to responding to individual circumstances by partnering with older Australians in the design and management of the care they receive. This is not only a good design principle, but also reflects the right (and high expectations of an ageing baby boomer population) of people to make decisions about their own lives. It is critical that the care model for older Australians begins well before specialist aged care services are required. An adequate income in retirement, an affordable place to call home including one that can be modified to allow care and re-ablement, and being connected to and valued as part of their communities, are vital for all Australians as they age. These components are as important as building a properly valued and compensated workforce, increasing the accessibility and quality of in-home and residential care facilities, and responding to complex challenges such as dementia and palliative care.

Australia's aged care system should be underpinned by a legislated minimum standard of high quality for home and residential-based care, which then forms the benchmark for determining adequate and sustainable funding. This is essential to ensure that every Australian can access high quality aged care services regardless of their background, location, circumstances or individual ability to pay.

Anglicare SQ believes that the following principles should be followed and key actions required:

- Ensuring no one enters the aged care system from a position of poverty: raise all government income payments so that people can live dignified, healthy and happy lives as they age. This must include payments to carers
- Legislate a minimum high standard of aged care for everyone who is eligible for care, regardless of their capacity to pay or where they live. This standard must be properly funded
- Create an aged care system that offers a continuum of care right up to the end of life including:
 - Funding and supporting community-based initiatives that build social connection and inclusion for people as they age;
 - Reform of the home care system;
 - A new residential aged care funding model;
 - Greater investment and reconfiguration of respite services; and
 - Significant investment in dementia and palliative care.
- Commit public investment to implement the Aged Care Workforce Strategy Taskforce Report, to create an aged care workforce that is properly paid, valued and specialised with clear career pathways
- Commit urgent investment to close the many service and workforce gaps in regional, rural and remote Australia.

ACSQ AND PALLIATIVE CARE IN QUEENSLAND

The need for palliative care is projected to grow significantly over the next 5-10 years due to the ageing Australian (and Queensland) population and the concomitant increase in chronic diseases, such as heart disease, diabetes, dementia, and cancer. Unfortunately, the availability of palliative care is not meeting community needs in Queensland. It is estimated that up to 80 percent of people who die in Queensland would benefit from palliative care.⁽¹⁾ The option of a 'good death' should be available for all Queenslanders irrespective of their status, age, geographical location, citizenship status, sexual orientation or criminal background.

There is a need to restore dignity and humanity to death, which can be achieved with consistent delivery of quality palliative care. Death needs to be viewed as a natural consequence of living – a natural part of the life process and life cycle rather than an enemy and something to be feared and resisted. ACSQ believes that people should be supported holistically on the inevitable journey to death – including their spiritual needs. Therefore we concur with the 2017 position statement of *Palliative Care Queensland* and *Meaningful Ageing Australia* that spiritual care is an integral part of palliative care. A palliative approach includes spiritual assessment with appropriately trained staff. There are significant gaps in understanding and education about spirituality and spiritual care in palliative care settings across the Queensland community, including among aged care staff and health providers. The Anglican Church Southern Queensland (ACSQ) aims to address this important area of need with skilled and highly-trained staff, reflecting a view of palliative care as holistic, integrating physical, social, psychological, spiritual and cultural aspects of care – across all areas of end-of-life care: hospitals, community, residential aged care and hospices. There is also a requirement for a range of options that also cater for the fact that while the majority of palliative care patients are aged over 65, there are significant numbers of young and middle aged people requiring these services.

Consistent with broader community trends, however, increasing numbers of people are ageing at home, and not entering aged care facilities until they have a need for high care support. This has two implications. Support for those living and dying at home will increasingly be funded through Home Care packages, which currently include no provision for spiritual or pastoral care. Such support will therefore be unavailable to many people in need.

Secondly, aged care facilities are facing a growing need to support individuals with palliative care needs, as people enter residential aged care (RAC) facility closer to the ends of their lives. Many will access palliative care in the RAC; but others will require or desire palliative care in a hospital-based unit; or transfer to a hospice environment where it is available. This trend necessitates greater palliative care funding, resources, education and training in the aged care sector (and across the general community) but also particular attention to funding a diversity of services, in different places, to meet the physical, personal, spiritual and cultural needs of individuals.

According to Dr John Buchanan, a long-time psychiatric practitioner in palliative care and oncology, "the reality is that there are not patients dying in agony (as is often represented by the pro-euthanasia lobby) in specialist palliative care units."⁽²⁾ Expert palliative care is able to relieve terminal clinical distress in patients if the necessary skills and knowledge are available. However, the required skills, knowledge and infrastructure are not currently equally accessible to all Queenslanders, regardless of location, income or particular cultural or other needs.

Palliative care awareness

Queensland Health's Palliative Care Services policy recommends the provision of multidisciplinary care delivered by coordinated medical, nursing, allied health, pastoral care and social services. Palliative care integrates the "physical, psychological, social, spiritual and cultural aspects of care."⁽³⁾ Similarly the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care developed by the Australian Commission on Safety and Quality in Health Care ⁽⁴⁾ states that:

- Dying is a normal part of life and a human experience, not just a biological or medical event
- Patients must be empowered to direct their own care, whenever possible. A patient's needs, goals and wishes towards the end of life may change over time
- Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs
- Recognising when a patient is approaching the end-of-life is essential to delivering appropriate, compassionate and timely end-of-life care.

A review of future demand and services by Queensland University of Technology, estimates that between 51,000 and 71,000 of the total Queensland population would require palliative care services ⁽⁵⁾. While exact estimates are difficult on how many people required palliative care in Residential Aged Care Centres operated by ACSQ, the Anglicare facilities in Southern Queensland would cater for the end-of-life needs of around 100 residents each year. We know the need is increasing with an ageing population. This is exacerbated by the rise in the number of single person households (it's estimated that 26% of people who live on their own don't have access to a carer) and the increase in diseases and illnesses such as cancer, diabetes, dementia and heart disease. Every year Anglicare continues to take in more residents requiring high levels of care for periods of between a few months to several years.

Anglicare SQ aged care facilities are committed to providing quality end-of-life care within residential aged care facilities and generally have low hospital transfer rates for residents in need of palliative care, particularly when the wishes of the resident and family members are for them to be comfortable in their current facility.

Our commitment to appropriate staffing levels, especially with Registered Nurse staffing models, means that Anglicare SQ facilities provide quality palliative care to those who need it. Our highly trained and accredited staff – clinical nurse consultants, registered nurses, community nurses, diversional therapy practitioners and pastoral care staff – work closely and collaboratively with residents and family and GPs to accede to medical requirements as well as personal, spiritual and cultural wishes. However there would be enormous benefit for residents and the community more broadly if there was further funding and opportunities to upskill and educate nursing staff especially in post-grad qualifications.

Funding levels

Peak bodies for aged care in Australia report that approximately 75 per cent of people aged at least 65 years who die in Australia use aged care services in the 12 months before their death. Yet relatively few access palliative care in residential aged care. A 2017 survey conducted by Palliative Care Australia, however, shows strong support for the provision of palliative care in aged care services, with more than 80 per cent considering it either important or extremely important.⁽⁶⁾

Across Queensland there is a general and growing need for better and more resources for palliative care provided in a range of settings – aged care facilities, hospitals, hospices and in the home. There are just 29 hospital and hospice facilities providing palliative care across Queensland – leaving much of the community burden to aged care facilities and to individuals and families to provide vastly varying levels of care and comfort for dying people across the rest of the state – many in homes, while some homeless men and women die on the street with little or no care. While there is some Queensland Health funding for hospices, it is widely argued across the health and aged care sector that the Queensland Government needs to step up and do more and inject significantly more funding, including for support and wraparound services such as pastoral care, counselling, nursing staff, diversional therapy and music therapy practitioners.

Daily services to palliative care patients include provision of general medical treatment, administration of pain relief, general health, hygiene and access to pastoral care and counselling for family members. In our aged care facilities, Clinical Nurse Consultants (CNC) provide expert clinical advice to patients/residents, their carers and other health care professionals. This includes complex healthcare management, liaison and care planning from a multidisciplinary perspective across all of Anglicare's Aged Care facilities. Although there are varying levels of palliative education across the aged care sector, which often requires the need for RACs to seek external input from the local hospital/health service palliative care team. Diversional therapy practitioners spend up to 30 minutes a day with palliative care patients, while music therapy is a form of supportive therapy which has proven to be of benefit to patients in palliative care. Activities are designed to support the psychological, spiritual, emotional and physical wellbeing of individuals. While Queensland Health may recognise the multi-disciplinary aspects of palliative care, it has not to date been matched with appropriate funding to ensure the frontline delivery of the broad range of multidisciplinary services.

Anglicare SQ staff provide the highest level of care to relieve pain and suffering for palliative patients in a holistic approach while ministering to the spiritual self of patients – a critical and significant component of caring for the sick as they near end-of-life. While Anglicare prides itself on providing well-trained staff who are skilled and experienced in providing good symptom and pain management at end-of-life, the same cannot be said uniformly across the aged care sector – both public and private. A lack of adequate and appropriate government funding, and/or confusing or constraining funding rules, means that best-practice palliative care is not able to be delivered across the full spectrum of those who require it.

Bureaucratic red tape, for example, mires the path to palliative care for residents in regional Queensland towns, where the hospital provides a nurse practitioner who will pay limited visits to the local Anglicare aged care facility. But the Resident GP must document that they want their involvement in care, and the nurse practitioner is located in and employed by another aged care facility. There is no education component with this service and it is not advisory, with the nurse practitioner taking over pain management from the GP.

A more integrated service provider model is required to avoid situations for providers and patients where a split combination of cobbled-together funding from State and Commonwealth Governments is required to ensure a higher level of quality community in-home palliative care. Palliative care provision should be integrated and seamless for the patient/client, while minimising anxiety regarding how to leverage multiple health and aged care systems and programs to achieve a level of care. Our philosophy, holistic model of care and experience reinforces the fact that quality palliative care needs to also have as an integral part of the service, spiritual care which many Queenslanders currently miss out on due to the fact that spiritual care is unfunded.

ACSQ AND CHAPLAINCY SERVICES

Anglican Church SQ provides and funds its own hospital chaplaincy service with over 70 Anglican workers and volunteers providing pastoral and spiritual care to patients in hospitals in its area of operation – from the New South Wales border up to Wide Bay and west to the Northern Territory border. Hospital chaplains minister to more than 15,000 patients each and every year (in a vast variety of health settings and to patients in varying degrees of health) – to those who have requested the presence of a chaplain. Anglican chaplains are also available in most correctional centres in Queensland and can be the person who stays with the incarcerated person until their last moments.

Hospital and prison chaplains provide comfort, guidance and reassurance to patients at end-of-life (EOL) when they are vulnerable and in their greatest hour of need. Some hospital chaplains can individually attend to more than 100 EOL patients in a year, including supporting them through to their moment of passing – and sometimes up to three patients in one evening. They also provide practical assistance to some patients in completing Advanced Care Planning and Statement of Choice documents. Anglican Church chaplains are highly-trained and well-skilled to attend to people of all faiths – not just Anglican.

Pastoral Care (Chaplain) Coordinators are based in hospitals in the Southern Queensland region as part of that hospital's Palliative Care team. This involves them attending a weekly Palliative Care Team meeting (in the case of one Coordinator, this involves the whole of Metro South Health Region) for two hours with the meeting bringing together a multidisciplinary team of Medical Consultants, Doctors, Nurses and others (both in hospitals and community) along with Clinical Support Services which includes the Pastoral Carer/Chaplain, Social Workers, Counsellors, Community workers, and Psychologists. Each week they discuss in depth each palliative care patient, including current and those who have just recently passed away. Each day as part of the Palliative Care Team, they receive a list of all palliative patients. While some Health and Hospital Services (for example Metro South) manage to fund the administrative services of the Chaplain Coordinator, this practice is not widespread and it is desirable if this practice was extended to other HHS.

Queensland is the only state in Australia where hospital chaplaincy services are not funded by the state government. ACSQ would warmly welcome the opportunity to enter into discussions with the Queensland Government and its agencies to explore avenues and models for how chaplains in hospitals can be better resourced to fulfil a pastoral and spiritual need.

Across both Anglicare and ACSQ's chaplaincy services, the Diocese provides a range of palliative care services and support to over 600 people every year.

Additional Queensland Government funding is required to enable ACSQ to deliver additional chaplaincy services across ACSQ Queensland:

- More hours and greater access to chaplains in hospitals, prisons and aged care facilities
- Accommodation facilities for interstate family members
- Greater education and advisory services and resources on palliative care for aged care facility staff
- Increased access to counselling services for family members
- Massage therapists to alleviate pain for residents and to help relieve inevitable stress and tension – this service could also be extended to immediate family in the residents' final days

Palliative care and Indigenous Queenslanders

Quality care at the end of life is realised justly and fairly across Queensland when it is culturally appropriate to the particular needs of individuals and groups of Aboriginal and Torres Strait Islander descent. It is important for palliative care services to understand the individual needs of Aboriginal and Torres Strait Islander people and for the services to be more culturally attuned as well as being more accessible to those from rural and remote parts of Queensland. Indigenous communities have a close association with death and dying – in part because rates of morbidity for their people are among the highest in the world. An intimate awareness among Indigenous Queenslanders is also facilitated by the close involvement of extended family in supporting a patient during terminal illness and in the ceremonies that follow a death – gatherings that may extend over several weeks.

Except where there are well-established Indigenous medical services, healthcare facilities are often used reluctantly by many Indigenous peoples. Major conditions such as cancer often come to the attention of Queensland Health's medical attention only late in the course of illness. The services offered by Indigenous healthcare providers often have no link with mainstream services and may be unaware of what local palliative care services can offer. Similarly, mainstream providers may have little awareness either of the special needs of Indigenous patients or the services, networks or cultural supports available to them. In many communities, Indigenous people have not or do not access palliative care services to any great extent – to the extent that they are available anyway in many rural and remote regions.

To facilitate appropriate clinical interactions, palliative care workers must take note of cultural considerations that affect all clinical encounters, some of which are particularly relevant to situations of death and dying. ACSQ would defer to the greater knowledge and culturally appropriate information and insights from Indigenous advocates and organisations and specific resources including the ***Program of Experience in the Palliative Approach: Providing end of life care for Aboriginal peoples and Torres Strait Islander peoples*** (Commonwealth of Australia 2014).

Future palliative care needs

On the question of future palliative care services, while definitive numbers are difficult to predict, it is likely that the number of patients across all of the services and communities provided by Anglican Church Southern Queensland will increase between 10 and 25% over the next decade. While it may be more cost efficient for governments to prefer that an increasing number of people spend their end-of-life in their own home (and this is acknowledged as the preference of some people) the lack of access to proper care for people in single person dwellings make this undesirable for the majority of the population. There are bureaucratic obstacles to transitioning people who quickly deteriorate in their ageing years into accredited aged care facilities, hence a greater emphasis on significantly increased funding for palliative care and associated services as well as increased funding for hospices is also a preferred model – with a fully supported infrastructure for requisite volunteers (with appropriate training and education) which are vital to the proper functioning of this system.

There is also a distinct lack of palliative services and access for the marginalised in our community and those with specific needs – including the homeless (around 20,000 people in Queensland – many in poor and deteriorating health), the LGBTIQ community, those suffering from mental illness, refugees and former prisoners; as well as those requiring greater cultural sensitivity and capability from carers and service providers, including (as noted above) Aboriginal and Torres Strait Islander peoples.

The diversity of need and preference that characterises people at end-of-life means that, as mentioned above, there is a corresponding requirement for diverse palliative care options. In addition to in-home palliative support, hospital in-patient palliative units, and palliative care in residential aged care facilities, hospice care needs to be urgently funded. Infrastructure and staffing are both critical, but this is also about building a 'hospice culture' in Queensland through education and awareness raising, so that community members understand the supportive environment that hospices can offer to both the person who is at end of life and their families.

Hospices can offer a meaningful and important space to negotiate complex end of life concerns about identity, relationships and what it means to have a 'good death', away from the medicalised environment of a hospital or the stresses and tensions of in-home care by family members. Community hospice models can be deeply embedded in the local area, with a mix of appropriate government and community funding, with volunteers also playing a critical role in their operation. In the UK, for example, the hospice model supports more than 200,000 people with terminal and life-limiting conditions each year and more than 125,000 people volunteer for hospices annually. This amounts to more than four in ten people of those estimated to need expert end-of-life care. A total of 46,000 people in the UK also receive bereavement support from hospices each year. The majority of hospice care (84 per cent) is provided in community-based settings, including home care/ hospice at home, outpatient services and hospice day care.

The Anglican Church is proud to provide services to those of all religious faiths and spiritual backgrounds. We note that the 2016 Census shows Australia's relationship with religious affiliation and faith rises and falls through the first 30 years of life - and then rises again throughout the latter part of the life cycle. As people age and their health deteriorates, they have a steady return to faith and religion, with it peaking when they are aged in their 70s 80s and 90s and they are more likely to require spiritual support and assistance as part of a holistic approach to palliative care. Funding of our best practice Chaplaincy model will be able to meet this predicted upswing in need.

In summary, Queenslanders continue to live longer, yet the increase in illnesses like dementia, cancer and cardiac disease and the growth in single person households (meaning decreased availability of family care) will put a significant strain on existing services.

To improve palliative care services in Queensland, ACSQ makes the following recommendations:

1. Improved funding and resources for general community death literacy and palliative care education
2. Improved education and information for the general community regarding Advanced Care Planning and use of legally recognised documentation
3. Improved funding for provision of expertly trained nursing and allied health staff
4. Improved funding and resources for hospices and hospice palliative care
5. Improved funding and resources to ensure equity of service and access to palliative care regardless of age, geographical location, citizenship status, sexual orientation or criminal background with Home Care packages to include funding for pastoral and spiritual care
6. Improved funding and resources for hospital chaplaincy services which should be recognised as a vital component of end-of-life care and ideally should be at least partly funded by the State. Queensland is the only state in Australia where hospital chaplaincy services are not funded by the state government.

ACSQ AND VOLUNTARY ASSISTED DYING IN QUEENSLAND

Patients should not be forced, by inadequate palliative care, into seeking death as an escape from treatable pain and other suffering. End of life care, education and research require additional funding so that people do not 'die badly' due to a lack of palliative services. It is the strong view of ACSQ that voluntary assisted dying (VAD) should remain legally prohibited. Respect for human life is not just a religious value, but a foundational value of all societies in which reasonable people would want to live. The life of each individual has an equal claim to respect, because the value and dignity of each person is not diminished by age, gender, disease, dependence or disability. The two major arguments for permitting voluntary assisted dying (VAD), used separately or together, are the argument from the principle of respect for patient autonomy and the argument based on the obligation to relieve suffering where possible. Both arguments are flawed. VAD cannot and will not be limited to competent patients or to the terminally ill, or even the physically ill. The moral logic of the two justifications for VAD demands the extension of the practice both beyond those who are able to decide for themselves and beyond those who are suffering. The extension of both practices is seen clearly in the changes to the law and practice in jurisdictions where euthanasia and VAD have already been legalised. The euphemism 'assisted dying' aims to mask the fact that VAD and physician assisted suicide (PAS) are actually forms of suicide. Legalising euthanasia and PAS will send mixed messages about suicide prevention. To approve suicide for some but not others is inherently discriminatory, and indicates that some lives are considered of more value than others.

Autonomy (the ability to be in control of one's own life) is at the core of the ethical arguments in supporting VAD. However, autonomy is always tempered by the rights of others to also experience public goods and prevention of harm. It is not an unfettered right of Queenslanders to have public policy that supports their desire to maintain a completely autonomous life. There are multiple constraints on living designed to promote public health and safety including limiting alcoholic intake whilst driving, the smoking of cigarettes and the wearing of seatbelts. These restrictions to human liberty are based on potential infringements of the public goods available to others and the protection of the public. A high level of protection will need to be built into any legislation that supports VAD. This translates to high levels of cost for administration met from funds likely to benefit a small sector of the community, largely comprised of white middle to upper class citizens. Informed discussion about voluntary euthanasia is hindered by our failure as a society to guarantee access to quality care at the end of life in which people's rights to articulate the terms of their care are respected. It is also hindered by limited community capacity to engage in frank and open discussion about dying and death.

It is incongruous that states such as Queensland and Western Australia are following the lead of Victoria in moving to legalise these practices at the same time as there is so much emphasis on suicide prevention. Suicide is a major social problem. Queensland and Federal Governments and not-for-profit sectors quite rightly spend vast resources aimed at reducing the suicide rate. Usually when someone is suicidal, we try to help them to live, not to die. If euthanasia and/or VAD was legalised in Queensland, we would on the one hand be promoting suicide prevention, and on the other, promoting suicide as a legitimate choice – especially for one of the most vulnerable demographics of our society, the elderly and ageing. The strength of a sense of obligation on the part of doctors and other professionals to try to prevent suicides will be significantly weakened. Suicide is no less tragic when a person is old rather than young, disabled rather than 'normal', or sick

rather than healthy. To approve suicide for some but not others is inherently discriminatory, promotes double standards and hypocrisy and indicates that some lives are considered of more value than others.

A 2018 review of Physician Assisted Dying in the USA indicated that those who had tended to use the law were predominantly white, financially well-off, educated and had a "dismissive" personality style focussed on control. While personality style is difficult to discern from public utterances it would appear those driving the arguments in Australia are similar to those using euthanasia in the USA. There is nothing new in interest groups driving policy change and it is often the white, wealthy educated citizens who are most successful in doing this. The problem in the case of VAD is that others may be harmed by the outcome. Questions need to be asked about high profile advocates for pro-VAD groups (especially from interstate) who promote "dying with dignity" and whether the polls and surveys they quote (citing that a large majority of Queenslanders are in favour of VAD) are truly valid and representative of everyday Queenslanders. General polls which pose the question whether "people with a terminal illness who are experiencing unrelievable suffering should have the choice to allow a doctor to assist them to die" can barely accord for the complexity of this topic area. Questions like this tend to be framed to elicit positive (supportive) responses. Asking a person in our culture whether they want a "choice" or not in something, is almost a truism, especially when teamed with a lack of "dying literacy" in the general population.

The current Royal Commission into aged care, quality and safety has put the national spotlight firmly and appropriately on elder abuse. The promotion and legal/political approval of VAD laws in Victoria (and potentially in Queensland) has the likely effect of making the elderly feel as if they are a burden on their families and on society. There is an obsession in our culture with youth and appearances of youth, and the older generations can tend to feel neglected. The propagation of VAD laws further demeans the value of the lives of elderly Australians, and *does not promote the dignity or humanity of vulnerable older Australians in an environment in which our elderly feel undervalued, ignored and forgotten. Instead, it further will entrench ageist views, desensitise us to voluntary assisted dying and ultimately lead to a devaluation of life and premature death for many.* Elder abuse is a major concern, with a report last year from the Australian Law Reform Commission recommending a detailed study into the prevalence of elder abuse in this country. If an individual is unable to take care of themselves, has reduced decision-making capabilities and/or financial management issues, there is a likely increase in their vulnerability to be pressured into euthanasia by family members or others responsible for their care. Given that there is currently no robust system that has effectively prevented elder abuse, there is no reason to believe that adequate safeguards can be put in place for euthanasia. Under no circumstances should an individual feel the need to opt for euthanasia because they don't have confidence that they will receive adequate end-of-life care.

The overseas experience with voluntary assisted dying – most notably in Belgium and the Netherlands gives Queenslanders an alarming insight into the "slippery slope" that lies ahead with the introduction of VAD laws. In February 2014, Belgium made international headlines when it became the first country in the world to allow euthanasia for children of any age. The Netherlands has legalised euthanasia for children over the age of 12 if the request is "voluntary and well-considered", the patient is "suffering unbearably" with no prospect of improvement and if there is parental consent.

Under the new Belgian law, a child of any age can request euthanasia if they are 'conscious of their decision', have a terminal illness, and are in great pain with no treatment available to alleviate their distress. The request must be approved by their parents and their medical team. A psychiatric evaluation is also a requirement to ensure that the child is not suffering any mental illness and has

the required competence—that they understand the gravity of the request. It is argued that because of these strict criteria, Belgium will effectively have an age limit for children (probably similar to that in the Netherlands) and that the criteria are more stringent than for adult euthanasia.

However, there is a great deal of evidence from both Belgium and the Netherlands of the way that the practice of euthanasia is expanded to include more and more of those who would have been excluded from the initially strict criteria. For example, in Belgium last year, Nathan Verhelst, who was born a girl and had been depressed for many years, was euthanised after gender reassignment surgery left him ‘disgusted with himself’. Another controversial case involved a pair of 45-year-old identical and ‘inseparable’ twins who were born deaf and euthanised after blindness began to threaten their ability to communicate with each other.

Even more alarming is the extension of euthanasia practice to very young children including infants and to people with dementia. In the Netherlands, the *Groningen Protocol*, created in 2004, specifies criteria under which physicians can perform “active ending of life on infants” without fear of legal prosecution. The final decision is in the hands of the parents, with physicians and social workers agreeing to it. Criteria for euthanasia include “unbearable suffering” and an assessment of “expected quality of life”. The Royal Dutch Medical Association (KNMG), which represents doctors in the Netherlands, has said that of the 175,000 babies born every year in the Netherlands, about 650 might be cases which would warrant euthanasia.

Why is it that the legalisation of active euthanasia for competent adults with strict guidelines has so quickly led to the practice and eventually legalisation of active euthanasia for children and even (effectively) infants? Despite the fact that respect for patient autonomy is always front and centre of the argument, it is because advocacy for the legalisation of euthanasia is really not so much about respect for patient autonomy but about a society deciding that it can be—perhaps definitely is—in some people’s best interests to die. The new law in Belgium makes this abundantly clear.

Again, the moral logic of the two justifications for euthanasia—respect for patient autonomy and the relief of suffering—demands the extension of the practice beyond both those who are suffering and beyond those who are able to decide for themselves. Hence the argument runs: If adults can have access to it, why can’t children who are judged to be sufficiently mature? And if older children, why not younger children and infants? And why not the intellectually disabled and those with dementia? If people who are terminally ill, why not the chronically ill or disabled who are suffering unbearably? If those with physical suffering, why not those with mental or emotional suffering such as severe depression? Where do you draw the line – and even if you do, history and the overseas experience shows us that the line quickly becomes greyer and more blurred.

It is the role of faith based organisations such as the Anglican Church Southern Queensland to speak for the vulnerable; for those who may be harmed because precious health care funding is re-directed on fallacious moral and legal grounds; for those whose suffering is increased because their access to end of life services (good quality palliative care) and or death literacy, is low.

Victorian VAD legislation

Looking at the Victorian legislation, the criteria to enable one to exercise autonomy at end of life is likely to be limited to just a dozen or two people, based on 2017 death data from the Australian Institute of Health and Welfare. In 2017, there were 160,909 deaths in Australia (82,858 males and 78,051 females). The leading causes of death in Australia for 2017 were: ischaemic heart diseases, dementia, cerebrovascular diseases, chronic lower respiratory diseases, and cancer of the trachea, bronchus and lung. Of these five categories it is highly likely that only those in the fifth leading cause

category of death will be able to access VAD under the Victorian legislation. This is because the four leading causes of death in Australia are likely to involve cognitive impairment and or an unpredictable trajectory to death, meaning that prognostic abilities are compromised. Patients who are deemed to be experiencing high levels of suffering and intractable pain, who are cognitively well, terminally ill, and likely to die with 6 months, (or 12 months with a neurological condition) will be allowed to be autonomous decision makers at end of life. Indeed because of the costs of establishing a program to enable VAD those who have an unpredictable prognosis or a mental health condition are less likely to receive the care needed to get a good death.

There have been reviews of the Victorian euthanasia debate, and data indicates that the submissions to that state's review of End of Life Choices were characterised predominantly by "bad dying stories" evoking pathos-based arguments. These type of arguments belie the fact that many good deaths occur in Australia. Additionally, they skew decision-making by creating a climate of fear in the mind of the public. These fear based arguments take hold because, in general, Australians and Queenslanders have low levels of death literacy. Death literacy is where citizens gain an understanding of the natural processes of death, how to plan for end of life care and how to navigate the healthcare system to access the services they need. Programs to assist death literacy are largely non-existent in Queensland. In Queensland access to palliative care services is already suboptimal and varied due to funding priorities within Queensland Hospital and Health Service regions. The funding involved in VAD (access to medical specialist review, counselling, increased training of doctors, support for the conscientious objector) needs to be additional to the current health budget to maintain fairness to others in the healthcare system. This means that funding for these services and education for those who partake is being diverted from other areas of great need ensuring that VAD becomes an attractive and indeed humane option for those who are unable to access public services that ensure good end of life care and community in general.

There are a number of vital safeguards missing from the Victorian legislation, which have been identified in various reviews and discussion forums (including the Queensland Law Reform Commission-Caxton Legal Centre's "Justice in Focus" forum on February 21). One notable element was raised by Dr Kym Boon (Director of Consultation Liaison, Psychiatry and Pain Specialist, Royal Brisbane and Women's Hospital) that there is no requirement for psychological assessment when we know from overseas experience that psychological reasons for asking for assisted suicide (for example, depression, social isolation, diminishing purpose in life/ hopelessness, fear of being a burden) rather than the presence of terminal illness and unmanageable pain. Victoria also lacks any prior assessment of the benefits of, or requirement for, a palliative care assessment. While Victoria requires the assessment of two medical practitioners, there is no guidance as to how doctors can establish there has been no coercion of the patient's request with the prospect of elder abuse being significant.

In summary, ACSQ is opposed to the introduction voluntary assisted dying laws in Queensland on multiple grounds. Patients should not be forced, by inadequate palliative care, into seeking death as an escape from treatable pain and other suffering. VAD laws should be delayed for a prescribed period of time until the medium to long term benefits of increased access to high-quality palliative care can be assessed. The right of the individual to autonomy should not be all-encompassing. The right to an autonomous existence and death should be tempered by the rights of others to also experience public goods and prevention of harm. The right to life is the most basic of human rights. Respect for life is a foundational, value of a modern, progressive society - not just a religious value, it is a foundational value of all societies in which reasonable people would want to live. The generally accepted moral wrongness of killing may be framed in a number of ways, but it is based on the

intrinsic value of human life which has been accepted since the beginning of time. The life of each individual has an equal claim to respect, because the value and dignity of each person is not diminished by age, disease, dependence or disability.

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