

18 April 2019

Our ref: VK-ELC/HDLC/SLC

Committee Secretary
Health, Communities, Disability Services and Domestic and Family Violence Prevention
Committee
Parliament House
George Street
Brisbane Qld 4000

By email: [REDACTED]

Dear Committee Secretary

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Thank you for the opportunity to provide comments on the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (the **Inquiry**). The Queensland Law Society (QLS) appreciates being consulted on these important issues.

QLS is the peak professional body for the State's legal practitioners. We represent and promote over 13,000 legal professionals, increase community understanding of the law, help protect the rights of individuals and advise the community about the many benefits solicitors can provide. QLS also assists the public by advising government on improvements to laws affecting Queenslanders and working to improve their access to the law.

This response has been compiled by the QLS Elder Law Committee, Health and Disability Law Committee and Succession Law Committee whose members have substantial expertise in this area. With respect to the inquiry we provide the following for your consideration:

The Aged Care Royal Commission

1. *Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?*

The Royal Commission into Aged Care Quality and Safety is ongoing and will address many of the concerns in relation to the practice of providing aged care in Queensland. Additional funding commitments announced in the federal government's recent budget announcement are acknowledged and welcomed, however QLS has received feedback to suggest that this will not sufficiently address many ongoing challenges experienced by both staff and residents of the sector. Listed below are the key issues which are routinely raised:

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- a. Restrictive practices – these practices include chemical restraint, environmental restraint (locked doors, secure units), physical restraint, mechanical restraint, etc.¹ It is noted that on 17 January 2019, the Federal Minister for Ageing announced the development and implementation of regulations for chemical and physical restraint, effective 1 July 2019.² While its stated goal is to achieve the minimised use of such restraints, it is the Society's view that it does not go far enough to provide a patient with sufficient opportunities to refuse the imposition of these practices, nor the substitute or supported decision-maker.

QLS is concerned that the introduction of guidelines which enable the use of these practices in the absence of adequate consent considerations in relation to the affected resident and without a robust overview framework, will have the opposite effect, particularly in light of issues around capacity. This will be seen to rubber stamp an existing practice which is inconsistently applied and if insufficiently regulated, presents a risk to a vulnerable cohort of our aged population.

- b. Ratios and skillset – unlike hospital or childcare settings, staffing in residential aged care settings is not subject to ratios. It is reported that without a mandated ratio the impact is seen directly in the reduced quality of care received by the residents. Insufficient Registered Nurse (RN)/Enrolled Nurse (EN) numbers therefore dictate that most care needs are being provided by the lower skilled and paid Personal Care Workers (PCWs).³ An exception is where the facility is a state government owned property, for example Gannet House, Brighton. In these types of properties there is a requirement to comply with Queensland Health staffing regulations. A review of appropriate ratios should have regard to factors including acuity and skill mix as is necessary to ensure that appropriate care is provided.
- c. Systemic elder abuse – we note that more information will be disclosed as a result of the current Royal Commission. Our members report the following as examples of systemic failings, which were also recognised in the final report by the Australian Law Reform Commission, 'Elder Abuse – A National Legal Response',⁴ which contribute to ageism and elder abuses:
- i. Isolation – routine discouragement of engagement with friends and family, as an example, a phrase commonly used for new admissions, *'allow the adult to settle'*, also used as a means of removing engagement with friends and/or family who may be at odds with substitute decision-makers;
 - ii. Activities – limited interest activities, female-orientated, providing only low expense offerings, infantilize (treating adults like children);
 - iii. High reporting requirements – these requirements take up considerable amounts of time of available care workers, resulting in task-focus time-management, rather than care-focus time-management.⁵

¹ https://www.justice.qld.gov.au/_data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf; https://www.justice.qld.gov.au/_data/assets/pdf_file/0003/584931/opa-qld-submission.pdf.

² <https://www.legislation.gov.au/Details/F2019L00511> Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019

³

https://www.qnmu.org.au/QNMU/PUBLIC/MEDIA_AND_PUBLICATIONS/Media_release_uploads/2018/Ratios_061218.aspx

⁴ Australian Law Reform Commission, 'Elder Abuse – A National Legal Response' (ALRC Report 131)

<https://www.alrc.gov.au/publications/elder-abuse-report>.

⁵ http://www.anmf.org.au/documents/reports/National_Aged_Care_Staffing_Skills_Mix_Project_Report_2016.pdf

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- iv. Residential Aged Care Facilities (RACFs) which focus on profit margins do so at the expense of quality of care. The use of agency staff who have no ongoing relationship and understanding with the client compounds care concerns.
 - v. Assaults by co-residents – these incidents are non-reportable when the assailant co-resident has cognitive impairments.⁶
- d. Staff training –
- i. PCWs - this position requires little if any formal qualifications, however, it would be preferable for the position to be filled by a person holding a minimum of a Certificate III in aged care, which includes a mandatory practical placement component. Often there is no formal education or cultural awareness qualification required, and alternative courses may be only comprised of online modules without any pre-requisite personal interaction. The award for a PCW fulltime worker level 1 is \$20.12/hr, and increases to level 7 at \$24.44/hr.⁷
 - ii. RNs – as already stated, there is no regulated ratio of nurses to clients. Given that RNs are more qualified, and therefore more expensive than PCWs, the outcome in aged care facilities is insufficient numbers of RNs employed and available to improve care standards. This deficiency has a further flow on effect, impacting on the retention rates of RNs as a result of issues such as burn out.⁸ It is also reported that RNs employed in aged care facilities are paid less than their counterparts in hospitals, which is likely to increase turnover and serve as a disincentive to retention of experienced nursing staff.
- e. Rehabilitation – rarely provided and may not be in alignment with realistic expectations, however, is often expected when a patient is discharged from an acute hospital setting. Any rehabilitation which is given will usually become the responsibility of PCWs, who are not likely to be appropriately qualified in the provision of the designated therapy.
- RACFs are not hospitals, and too often there is a conflation between the promised or expected services, and realistic outcomes regarding provision of services. Further, a perception exists, and is reported to our members by RACFs, patients and their support persons, that RACFs should not send residents to hospital for medical care and attention. It should be recognised that RACFs are accommodation with some services added, they are not fully equipped hospitals which provide some social and residential activities.
- f. Food –
- i. Standard – Studies have found that spending on food in RACFs has declined in 2016/17 in comparison to previous years' data. This is consistent with achievement of lower profit margins, which is seen to put pressure on the costs of food and food management.⁹ Clients have reported concerning trends such as that, '*Sunday nights are the worst meals because there's no visitors around then.*', and that meals might consist of just two party pies or sausage rolls.

⁶ <https://agedcare.health.gov.au/ensuring-quality/aged-care-quality-and-compliance/guide-for-reporting-reportable-assaults>

⁷ <https://www.fairwork.gov.au/awards-and-agreements/awards/award-summary/ma000018-summary>

⁸ http://www.anmf.org.au/documents/reports/National_Aged_Care_Staffing_Skills_Mix_Project_Report_2016.pdf

⁹ *What does it cost to feed aged care residents in Australia?* Cherie Hugo Elisabeth Isenring David Sinclair Ekta Agarwal First published: 25 July 2017 <https://doi.org/10.1111/1747-0080.12368>
<https://onlinelibrary.wiley.com/doi/full/10.1111/1747-0080.12368>

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- ii. Assistance to eat – it is reported that staff, mostly PCWs, do not have sufficient time to assist each resident to eat, resulting in poor nutrition outcomes for many residents.

*'Malnutrition is associated with a cascade of adverse outcomes, including increased risk of falls, pressure injuries and hospital admissions, leading to poorer resident quality of life and increased health care costs... Diminished sensory perception along with the physiology of ageing may increase malnutrition risk.'*¹⁰

Clients who require considerable assistance are seen to first, and it is reported that others who require minimal assistance are not seen to as regularly.

- iii. Dementia based nutrition research indicates that a variety of meal time strategies can be implemented to improve residents' nutrition and functioning, however these rely on appropriately trained and qualified staff.¹¹

g. Admission condition –

- i. Whilst there are more people moving into residential care, the length of time spent in residential care has not changed in the last ten years. On average, an adult remains in residential care for approximately 30 months. What has changed is the percentage of 'exits' due to death. This has increased from 71% in 2007/08 to 82% in 2016/17.¹²
- ii. There is evidence that adults are prematurely moved into RACFs, often against their will, due to hospital and family needs and views.¹³

2. Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

QLS understands that the recent federal budget announcement includes a commitment to invest in additional home care packages (10,000 nationally), however this is still significantly below demand.

a. Residential:

- i. Regional areas report delays in placements into aged care can eventuate in a placement many kilometres from the adult's last address.
- ii. Metropolitan areas do not appear to have significant waiting periods for entry into an aged care facility, however there may be significant waiting periods for a resident to gain entry into their preferred aged care facility.

b. Home Care Packages:

- i. It is well recognised that the available numbers of level 3-4 packages are appreciably insufficient. There remains wait periods of 12+ months,¹⁴

¹⁰ Ibid.

¹¹ Effectiveness of Mealtime Interventions on Behavior Symptoms of People With Dementia Living in Care Homes: A Systematic Review Rebecca Whear MSc, *, Rebecca Abbott PhD, Jo Thompson-Coon PhD, Alison Bethel MA, Morwenna Rogers MSc, Anthony Hemsley BMedSci, MD, FRCP, Will Stahl-Timmins PhD, Ken Stein MB, ChB, JAMDA 15 (2014) 185e193.

¹² <https://www.gen-agedcaredata.gov.au/Topics/People-leaving-aged-care>

¹³ https://www.justice.qld.gov.au/data/assets/pdf_file/0006/545550/opa-submission-future-integrated-aged-care-at-home-program.pdf

¹⁴ https://www.gen-agedcaredata.gov.au/www.aihwgen/media/Home_care_report/HCP-Data-Report-2017%E2%80%933rd-Qtr.pdf

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- ii. The quality of care received is dependent on the service provider, and the recipient's ability to negotiate.¹⁵

3. Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?

a. Residential:

The quality of services received are inconsistent, despite quality inspections and accreditations. This is impacted by several issues, including quality of staff, staff numbers, staff experience and training. Clients often request specific staff members based on their compassion and ability to care appropriately. Clients regularly report continuing falls, neglect of personal care needs, and limited to no flexibility within a facility's routine. Expectations of '24/7 care' is unrealistic and falsely used to justify a premature placement in a RACF. Restrictive practices in aged care are unregulated and unreported.¹⁶ We again note that the federal government has recently released guidelines for chemical and physical restraint use in aged care.

The recent federal government budget announcement of \$185 million over 10 years to be spent on dementia, ageing and aged care research, is very welcome. Also announced was funding for quality reform, including the implementation of mandatory national quality indicators (which will provide insights into patient conditions such as the prevalence and context of the development of pressure sores, drastic weight loss, etc.).

- i. Home Care packages are generally adequate for an adult with aged care needs commencing in Level 1 or 2, however Level 3 and 4 packages often do not meet the real needs of the adult, such as nursing support services. Quality of the staff is variable and there are insufficient regulated requirements for staff training, or qualifications.
- ii. Transition Care – The ambition of transition care is to reinstate the patient to how and where they were, prior to a hospital admission. Access to transition care is reliant on the hospital discharge plan providing and organising the necessary requirements for a particular patient. We understand that it is often overlooked and discharge without care forfeits this opportunity. It is reportedly of a good quality and quantity of additional short-term (12 weeks) care. As mentioned, it is not always made available to eligible patients, based on perceptions of long term viability and other discernments by the hospital staff.
- iii. Respite Care – this category of care is difficult to access with only limited availability provided through Commonwealth Respite Carelink Centre (CRCC).

¹⁵ https://www.gen-agedcaredata.gov.au/www/aihwgen/media/Home_care_report/HCP-Data-Report-2017%E2%80%933rd-Qtr.pdf Table 6, 7

¹⁶ https://www.justice.qld.gov.au/data/assets/pdf_file/0003/584931/opa-qld-submission.pdf;
https://www.justice.qld.gov.au/data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf;
https://www.justice.qld.gov.au/data/assets/pdf_file/0003/564429/opa-submission-inquiry-into-quality-of-residential-aged-care-final-revised.pdf.

4. How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?

With the forecast ageing population and considering the deficiencies within the current system which is already failing to meet needs, evidence suggests that it will become more difficult to provide appropriate, expected, quality care, in spite of the aforementioned recent budget commitments. In addition to the resourcing and funding challenges mentioned, a cultural evolution of community attitudes towards bodily autonomy, respect for mental capacity and notions of supported decision-making, and doctor-patient collaboration in health care decision-making may also have an impact. Previous generations have been more compliant with medical opinion and were less likely to complain or challenge authority. The next generation to move into aged care - the 'Baby Boomers' - will be more demanding. Care services will be driven by a 'rights focussed' cohort, unwilling to be passive and overlooked.¹⁷

This will drive a demand for responsive and adaptive high quality staff and facilities, and a true 'client-centred' care model will be sought. Service providers will need to be flexible in order to meet the demands of their clients and there will need to be significant investments in additional systems and infrastructure, such as technology and other accessibility and service mechanisms. We can expect that Wi-Fi will become mainstream in all RACFs, high quality food provided, and activities offered that are more tailored and relevant. There has been a significant shift from paternalism to autonomy through this generation, and there will be a demand for the recognition of continued independence.

With an increasing ageing population comes a proliferation in the numbers of chronic illness and disease, including the impact of co-morbidities. We refer to our response to question 1, in which we raised the need for both appropriate ratios and skillset – this is needed to ensure adequate care is given for specific issues, such as dementia. Significant investment will be required in health and care management to govern this increase.

Significantly increased attention, upskilling and resources are required to facilitate palliative care provisions in aged care. Only 2% of Australians living in aged care were referred to palliative care specialist teams, which is in considerable contrast to the 71% of aged care 'exits' attributable to death of the resident.¹⁸ It is reasonable to presume that a sizeable number of these deaths could have been supported with palliative care, if adequate services were available.

5. Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?

QLS awaits the outcome of the Royal Commission to determine this. However we note that there are generally longer waiting periods in regional and remote areas, than in metropolitan areas. The recent federal budget commitments do not address this existing concern in any real way.

¹⁷ Purser, Kelly & Sullivan, Karen (2019) [Capacity assessment and estate planning - the therapeutic importance of the individual](#). *International Journal of Law and Psychiatry*, 64, pp. 88-98.

¹⁸ <https://www.gen-agedcaredata.gov.au/Topics/People-leaving-aged-care>

6. Are adequate numbers of home care packages available in areas at the levels required?

The Society awaits the outcomes from the Royal Commission, however there are generally noted longer waiting periods in regional and remote areas, than cities. As addressed in question 2, level 3 and 4 packages are severely undersupplied across Queensland. Again, the recent federal budget commitments do not address this existing concern in any real way.

7. Are there sufficient staff in the aged care sector to meet current and future workloads?

We refer to our response to question 1. We note the consistent feedback provided by staff and consumers that numbers of staff are insufficient across the sector to meet the current, let alone future demands.

In 2016, 28.5% of full time equivalent direct care staff at aged care homes were either nurses or allied health professionals, down from 31.8% in 2012 (Department of Health 2017)¹⁹

8. Is the mix of staff appropriate for different settings within the aged care sector?

We refer to our response to question 1.

9. Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

We refer to our response to question 1, set out under (d). Staff training is an integral element to operational success and provision of appropriate care is reportedly grossly insufficient for both PCWs and Assistants in Nursing, as well as for RNs and ENs in the sector.

10. What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?

Although fulsome data was not available, in recent research papers²⁰ the Productivity Commission carried out an assessment of the impact of aged care across Australia.²¹ There remains a cohort who spend time in hospital, awaiting aged care accommodation. Further research, data collation and understanding is needed, including the reasons which are attributed to or obligating an extended hospital stay. Anecdotally, we are informed regularly that patients are held in hospitals because they refuse to agree to an aged care placement, instead preferring to return home. For a variety of factors the hospital may be unwilling to accept this view and instead instigate tribunal proceedings, seeking substitute decision

¹⁹ <https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/aged-care-services/rogs-2018-partf-chapter14.pdf>, p7.

²⁰ See for example: <https://www.pc.gov.au/research/completed/ageing-australia/ageing-australia-overview.pdf> and <https://www.pc.gov.au/research/completed/ageing-australia/ageing-australia-overview.pdf>

²¹ <https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/aged-care-services/rogs-2018-partf-chapter14.pdf>

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makers for accommodation. Often these patients report they were not offered transition care or an opportunity to trial returning home with services to assist.

11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?

We refer to our response to question 1, in particular under (e).

12. Is the current aged care system making an appropriate contribution to the health of older Queenslanders, within the context of the broader health system in Queensland?

There is no comparative statistical evidence regarding this issue. It is known and understood that generally Australians are living longer, however there has been no increase in longevity while residing in aged care facilities, which remains at an average of 30 months (see response to question 1(g)).

13. How can the delivery of aged care services in Queensland be improved?

A significant increase in home care packages, including appropriate initial and on-going training and resourcing, including for culturally and linguistically diverse communities is required – for example, transitional and short-term restorative care (as explained below).

14. Are there alternative models for the delivery of aged care services that should be considered for Queensland?

We refer to our response to question 13 and to the findings of the Productivity Commission's 2018 report on Government Services:

'Short-term restorative care (STRC) is similar to transition care but is provided to people who have had a setback or decline in function without having been in hospital. On 23 February 2017, the first 400 STRC places were allocated across Australia. Since 23 February, 110 people have received STRC services, with 90 people receiving care at 30 June 2017 (Department of Health, unpublished).'²²

15. How will the model of aged care develop with evolving technology and medical practices?

We refer to our response to question 4. Considerable investments in new and ongoing technology are required but should be carefully implemented so as not to be achieved at the loss of individual care, as reliance solely upon a technologically-based solution runs the risk of increasing isolation and risk of abuse to vulnerable older people. Additionally, a greater focus

²² <https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/aged-care-services/rogs-2018-partf-chapter14.pdf>

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on provision of services such as adequate palliative care, staff training, investment and development will be required.

16. What are the key priorities for the future?

It is critical that the care model recognise and support values including individual independence in decision-making, choice and control – in relation to accommodation, services and healthcare options.

Significant financial investment in home care packages – both in terms of quantity and options will facilitate better support for older individuals requiring care and will ease the burden placed on facility staff as the care requirements are better disbursed.

Implementation of minimum ratios for aged care staffing will increase quality of care and reduce burnout amongst experienced staff.

Increased and ongoing education and programs for staff in aged care and complementary hospital staff, such as discharge planners, social workers, geriatricians and others across the aged care sector will positively affect outcomes for residents, patients and staff.

End-of-life and palliative care

17. What are the palliative care services offered in Queensland?

We note two models:

- a) Hospital based (in-patient care in designated palliative care beds (e.g. palliative care ward), in-patient care in other beds (e.g. a single room in a surgical ward), outpatient services, and care provided in intensive care or in the emergency department.
- b) Community based (own home), aged care facility, retirement village, manufactured home, caravan, specialist housing (which may be available in some circumstances for persons with a disability or mental illness).

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

Statistics set out in the 'Palliative Care Service Development Guidelines 2018', developed by Palliative Care Australia (the **Palliative Care Service Development Guidelines**), suggest that almost 160,000 people die each year in Australia. About 75% of all deaths are expected (for example associated with cancer, or chronic illness such as end stage renal disease). Of these, it is reported, approximately 120,000 people each year could benefit from palliative care. QLS notes that it is difficult to reconcile statistics on a per year basis as people may live with a life limiting illness for a number of years, requiring on-going palliative care.

The evidence suggests there are issues with access to specialist palliative care services and a lack of specialist palliative care resources to enable a person receiving palliative care in their environment of choice. For example, a lack of beds in a designated palliative care ward may result in a person receiving palliative care in a bed in another ward, where the staff may not

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have adequate palliative care training and experience. Similarly, this lack of resourcing will often mean that a person may not be able to pass away at home, if that is their choice.

The National Palliative Care Standards²³ also emphasises the need for a holistic approach, and a particular focus on the family and carers of persons with a life limiting illness. The reported lack of resources to care for the patient suggests that there is a lack of resources to care for families and carers as well.

19. Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?

Statistics drawn from the Palliative Care Service Development Guidelines state that 50% of people die in hospital, and 50% die in non-hospital settings (such as aged care facilities, in their home).

Community expectations are likely to be about 'choice'. The presence of significant limitations in resourcing restricting access to specialised palliative care services that prevent a person from being able to choose the environment where they receive palliative care and ultimately pass away, are unlikely to meet community expectations.

20. How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

The Palliative Care Service Development Guidelines suggest that the illness trajectory for those with life limiting illnesses can be divided into three categories:

- i) Short period of evident decline – person is able to function well for a long period of time followed by a few weeks/months of rapid decline prior to death;
- ii) Long term limitations with intermittent serious episodes – gradual decline in function interrupted by acute episodes where the person may receive treatment and survive but will still continue to decline; and
- iii) Prolonged dwindling – long term progressive disability where the person may ultimately pass away from other events such as infection, falls or fractures.

An aging population will increase the demand for palliative and end of life services. This will be seen particularly in relation to persons who are in categories 2 and 3, where access to a number of different health practitioners over a potentially long period of time will be required. With the increase in the number of Home Care packages and people wishing to receive care in home, the delivery of palliative and end of life services may need to increase the focus on community based care with specialist palliative care services providing in home care (whether that be in the home, retirement village, aged care facility).

Community education programs on the importance of advance care planning to expressly address a person's choice concerning palliative care would be beneficial.

²³ https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-National-Standards-2018_web-3.pdf

21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

By ensuring sufficient resources to enable people to choose where they receive palliative care and by ensuring there are enough specialist palliative care health practitioners to meet demands of patient care and also care for families and carers.

This may include a significant funding increase and development of a plan to install designated palliative care services, including increased palliative care beds, for each Health and Hospital Service area (HHS) across Queensland. We note the question asked by Mr Michael Crandon MP to the Minister for Health and Minister for Ambulance Services, the Hon. Dr Steven Miles on 28 February 2019, regarding the current number of palliative care beds available per region.²⁴ Alarming, in several areas across the State it was reported that there are 0, or sometimes only 1 or 2 palliative care beds allocated. We note that the Metro South region which registered by far the most palliative care beds, reported only 46 beds. Data taken from the Palliative Care Service Guidelines would suggest these allocations are inadequate. We note however that the question may not consider the number of persons who are provided palliative care in a non-hospital setting.

22. What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

We refer to our response to question 21, noting that palliative care services are inadequate in metropolitan areas. This inadequacy is acutely increased in regional, rural and remote areas, where access to specialist palliative care services and delivery of consistent quality care across different health services is severely underfunded, under resourced, and results in general unavailability for those in need.

23. What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

Significantly increased access to specialist palliative care services and ensuring that those providing the services are appropriately trained in acknowledging different models of delivery that may be required (for example, not only in provision of proper palliative care services but also in relation to customary practices and cultural beliefs).

For portions of Australia's First Nations people who are located in rural, regional or remote areas, the increased challenges in relation to access and availability of currently limited services will apply (see response to question 22).

QLS suggests that significant and thorough consultation with Aboriginal and Torres Strait Islander communities is urgently required to facilitate the collaborative development of a palliative care model that appropriately caters for provision of care for these communities.

²⁴ <https://www.parliament.qld.gov.au/documents/tableOffice/questionsAnswers/2019/246-2019.pdf>

24. What are the key priorities for the future?

QLS suggests that the development and commencement of an action plan to improve palliative care services is required, including thorough and appropriate consultation with key groups and considering:

- a) an objective to ensuring timely access to specialist palliative care services for all Queenslanders;
- b) funding and implementation of an appropriate education and training for specialist care service staff, and for other healthcare staff and support workers who assist in or are associated with the provision of palliative care;
- c) ensuring sufficient resources to meet growing demand in both hospital and community settings;
- d) the implementation of a designated and specialist palliative care team at every hospital in Queensland, adequately resourced and funded to appropriately provide healthcare and case management services for each palliative care patient. This should include the installation of a dedicated case manager who can assist each patient as a liaison in their interactions with other specialists, health services, and accommodation providers; and
- e) community education to inform the public about the benefits and challenges of palliative care, as well as clarifying the distinctions between palliative care and voluntary assisted dying.

Voluntary assisted dying

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

QLS recognises that this issue is one of great focus for many Queenslanders. In forming a response on the issues raised in the issues paper in relation to VAD, QLS had regard to the significant amount of feedback received from members and key stakeholders.

The Society acknowledges that our members have divergent views, and in some cases, hold strong and personal convictions that may be strongly in support of, or against, the introduction of VAD laws in Queensland.

In this subject there is a convergence of issues which must be considered: the fundamental legal principles to be upheld, the importance of laws which serve and are in the public's interest, and the acknowledgement of diverse views and values wherein some will consider the legalisation of VAD to be a matter of public concern and others will consider it to be a personal matter to be accordingly treated within a legal and health framework.

Fundamentally, the decision to introduce laws enabling VAD in Queensland is a matter for the Parliament. However, as the Society has previously advised, when the prohibition of private conduct originated from social values and expectations of a particular time, it is possible for a disconnect to emerge between the contemporary public interest, and the state of the law. Where this is demonstrated, it is an exercise of promoting good law to align legislation with changed public expectations. A recent example of this can be seen in the expungement of historical homosexual offence convictions. In 2017, laws were passed to establish an administrative scheme to expunge previous convictions, and drew reference to the point that

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the private and voluntary acts of adults is not a matter for concern of the criminal justice system.

For some years now, a number of surveys seeking community attitudes in relation to legalisation of VAD, or physician assisted dying (PAD) have illustrated a trend of strong public support for legalisation in certain circumstances.²⁵

Acceptance of community attitudes are recognised in other sources, including by academia,²⁶ and by various state and territory parliamentary or select committees tasked with undertaking a review into VAD, PAD and euthanasia.

For example, the report by the Western Australian Joint Select Committee on end of life choices tabled on 23 August 2018 accepted that community attitudes had shifted demonstrably in support for legalisation of assisted dying including that, *"Polling suggests there is widespread community support for changing the law to allow for assisted dying, and political debate to legislate for such change has become more common since the mid-90s."*²⁷

The report surmised: *"The report reflects community sentiment that people should have a greater range of options at end of life. Indeed, Australians have long accepted that people should be free to chart their own course, and make their own decisions, such that they can lead a good life, and one of their own making. Significant numbers of Australians have adopted similar attitudes regarding death and dying."*²⁸

QLS has reviewed the survey and written submissions published to date on the Queensland Parliament's website in relation to the Inquiry, and consider that the responses can be categorised as follows:

(As at 18 April 2019)

Views: Voluntary Assisted Dying	Submissions
Support	361
Against	51
Unsure / Not disclosed	50
TOTAL	462

²⁵ See for example: 2016 survey by ABC Corporation 'Vote Compass', which published findings that 75% of 201,404 respondents who participated in Vote Compass from May 8 to May 19, 2016 agreed that terminally ill patients should be able to legally end their own lives with medical assistance. Vote Compass reports that the data has been weighted to ensure the sample reflects the Australian population, <<https://www.abc.net.au/news/2016-05-25/vote-compass-euthanasia/7441176>> viewed 10 April 2019; Survey by The Australia Institute 'Survey Results – Attitudes to Voluntary Euthanasia' (2011), <<http://www.tai.org.au/sites/default/files/MR%20Survey%20results%20attitudes%20to%20voluntary%20euthanasia.8.pdf>>, viewed 10 April 2019; see also results of surveys conducted by Newspoll (2012), ABC Vote Compass (2013), Essential Media Communications (2014 and again in 2015).

²⁶ See for example: White B and Willmott L, "How should Australia regulate voluntary euthanasia and assisted suicide?" (2012) 20 *Journal of Law and Medicine* 410.

²⁷ Joint Select Committee on End of Life Choices, 'My Life, My Choice', Report 1, The Parliament of Western Australia (August 2018) <[http://www.parliament.wa.gov.au/Parliament/commit.nsf/\(Report+Lookup+by+Com+ID\)/71C9AFECDD0FAEE6E482582F200037B37/\\$file/Joint%20Select%20Committee%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/71C9AFECDD0FAEE6E482582F200037B37/$file/Joint%20Select%20Committee%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf)> [1.13]. See also report issued by parliamentary committee in Victoria: Legislative Council Legal and Social Issues Committee, *Inquiry into end of life choices, final report*, Melbourne, Vic, Parliament of Victoria, 2016.

²⁸ Ibid, [1.5].

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QLS acknowledges the view of some that consider and interpret sanctity of life to be paramount, and not malleable to changing public opinion. Whilst those who hold this view may perceive the introduction of VAD laws to impose the 'tyranny of the majority', we must remember that a VAD scheme is, by definition, voluntary in nature and will serve only to permit, not mandate, access to VAD. As such, the majority view is not imposing an obligation on those with personal beliefs against VAD to access the scheme. In contrast, the prohibition of VAD ensures that those who do not hold the same personal beliefs and concerns remain unable to exercise a choice to access VAD.

Care and treatment at the end of life is a community and government responsibility. The Society has received feedback that, in order to align with values that are based on Australian existing legal principle and which are reflected in the common law – for example, life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering – in the event of legalisation a values-based model should be introduced to align with these values. QLS has also received feedback that, as such, in upholding the values of autonomy, freedom of conscience and reducing suffering, legalisation should be brought in to allow some people to access VAD in accordance with their own conscience.

In contemplating these issues and in formulating responses to questions 25 to 38 herein, QLS has had regard to the models of legalised assisted dying which are in place in Victoria and internationally, including Belgium, Canada and in an increasing number of US jurisdictions. In particular, we note the Belgian model which is built on a system of determined values that are embedded in the legislation, and in particular the outcomes of this model which have resulted in significantly increased palliative care spending and attention since VAD commencement.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

VAD should be appropriately defined to clearly demonstrate the parameters of the legalised approach and method.

The definition should include a description of how VAD may legally occur, for example by a registered and appropriately qualified medical practitioner administering approved medication to a person to bring about the person's death, or the self-administration by a person of approved medication to bring about their own death under supervision of a registered and appropriately qualified medical practitioner.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

This question is not applicable to QLS.

28. If there is to be a VAD scheme, what features should it have?

A legal framework legalising VAD must be appropriately robust to uphold the values of the community underpinning the law, including for example autonomy, self-determination and

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reducing suffering whilst also being supported by adequate protections to prevent its misuse and safeguard vulnerable persons.

Eligibility requirements, including in relation to the age of a person, capacity considerations, and the degree of seriousness or terminal nature of their medical condition ought to be set out in the framework.

An appropriate test to decipher the capacity of an individual to make an informed and voluntary decision to elect to undergo a process for VAD, and to communicate (in some way) their understanding of the implications of the decision should be set out.

QLS acknowledges that, if a model were to be adopted where capacity is to be demonstrated repeatedly and consistently throughout the process, certain persons who meet all other eligibility criteria may be ultimately excluded from accessing VAD due to diminished capacity, which may be a result of their medical condition.

Clear and mandatory reporting requirements must be implemented, and an independent oversight body established to oversee the framework.

An option for a medical practitioner to 'opt out' of participation of advising on or administering VAD ought to be included.

Access to the scheme must be carefully considered in the context of persons who are in rural, regional and remote locations to ensure that these persons are provided with reasonable mechanisms to facilitate access and are not excluded as a consequence of their location.

29. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

QLS has received feedback from members expressing concern with respect to the position in the Victorian legislation that the self-administration of medication to bring about death, as opposed to administration by a physician. It has been suggested that the framework should not contain a default position so that the most appropriate method can be determined in the context of the individual, their family and support persons.

30. Who should be eligible to access VAD and who should be excluded?

We refer to our response to question 28.

31. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

We refer to our response to question 28, and reiterate the importance of the inclusion of a clear and appropriate test to determine the capacity of the individual to understand and make an informed and voluntary decision in relation to accessing VAD.

32. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

We refer to our response to question 28.

In relation to conditions of terminal illness, and/or unbearable pain and suffering, it has been suggested that it should include both those who are terminally ill and those with neurodegenerative diseases or other conditions likely to result in death, in accordance with prognosis.

33. What features should be included in a process to allow a person to legally access VAD?

We refer to our response to question 28.

34. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

It is critical that any framework for VAD only permit access to persons who make the decision voluntarily. Guidelines and regulations ought to be developed, setting out procedures which are designed to assist a decision-maker in determining if a request for VAD is made freely and without coercion. For example, this would include excluding all other persons whilst assessing a patient.

35. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

The availability of counselling is supported. Appropriate clinical guidelines should include information on unbiased counselling options, as well as any associate protocols.

36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

If a VAD scheme is introduced, each aspect and any underpinning guidelines or regulations must be carefully considered and the necessity of each step clarified so as to reduce any unnecessary delays or duplication, which may cause further distress to the patient.

37. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

We refer to our responses to question 28 and question 38.

38. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

We refer to existing guidelines with respect to conscientious objection in Australian codes of conduct and ethical standards for medical and healthcare practitioners, which require an objecting practitioner to ensure that a patient's health care is not impeded.

A conscientious objection, by definition, is a personal objection in principle to VAD on grounds of personal belief, or 'personal conscience', that the patient may not share. The patient is therefore entitled to be made aware of the options open to them, including the option of consulting with another practitioner.

We note an additional distinguishing point which is relevant to these issues and which can be seen between those medical practitioners with a conscientious objection, and those who may not hold strong personal beliefs in support of, or against VAD, yet who may elect to not be registered or licensed to carry out VAD.

If you have any queries regarding the contents of this letter, please do not hesitate to contact our Legal Policy team by phone on (07) 3842 5930 or by email to policy@qls.com.au.

Yours faithfully



Bill Potts
President