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14 July 2020

Joint Select Committee on Palliative Care in Western Australia
Legislative Council
Parliament House
PERTH WA 6000

Dear Mr Tallentire

SILVER CHAIN'S SUBMISSION TO THE JOINT SELECT COMMITTEE'S INQUIRY INTO PALLIATIVE CARE IN WESTERN AUSTRALIA

Silver Chain Group appreciates the opportunity afforded by the Joint Select Committee on Palliative Care to make a submission on the Terms of Reference for the *Inquiry into Palliative Care in Western Australia*. Silver Chain has worked in partnership with WA Health to deliver comprehensive palliative care services across metropolitan WA for more than 40 years. Our strengths reside in delivering, navigating and coordinating home care, particularly at the higher levels of acuity, with a focus on quality and wellbeing. We are renowned for driving innovation and providing evidence-based care and services that deliver measurable value to clients, carers, communities and funders.

Our services have enabled people to live out their lives in their home and community with their loved ones. Having seen the benefits that arise from the provision of high-quality palliative care, Silver Chain advocates strongly for equal access to quality palliative care for all people nearing the end of their life. We believe that access to palliative care is a human right and that our focus is to support people to live as well as they can for as long as they can at home. We provide the support needed to allow people of all ages to die in dignity in the place of their choice.

Silver Chain has long been a leading care provider in WA and during the past decade our service has grown and expanded nationally. In 2019, Silver Chain cared for more than 100,000 health and aged care clients in their homes. 3000+ individuals were supported in their right to die in the place of their choice. We expect this number to continue to increase as greater access to palliative care is delivered across the metropolitan area, and as we seek new opportunities to assist regional and remote communities.

Our Submission focusses on Recommendation Two of the Terms of Reference. We have provided our views on the progress of palliative care services in WA in relation to the 2017 Inquiry recommendations, and the relevant issues that we believe should be addressed to ensure that equitable, consistent and dignified care continues to be provided to vulnerable members of our community.

As an essential provider of home care, the nature of our work has never been more important. Above all, we remain committed to protecting the health and wellbeing of our community, our 100,000 clients and our 4,000 health and aged care workers. We are eager to work collaboratively with governments, our health and business partners and other peer organisations to continue to ensure the highest standards of palliative care services are delivered to our community.

Yours sincerely

Michelle Noort
Executive Director Health Care

Terms of Reference Point Two:

In consideration of its review of the progress of palliative care in Western Australia, Silver Chain believes it is critical to consider the ongoing challenges presented to the healthcare industry by the Coronavirus (COVID-19) pandemic. While there has been a consistently declining number of coronavirus cases reported across Western Australia in recent weeks, we need to avoid complacency. Social-distancing measures and restrictions will be the new normal for some time and the threat of an outbreak will be constantly present in the absence of a vaccine.

Silver Chain and other care providers need to maintain a latent operational capability which is able to provide an immediate response to any future waves of infection. Close collaboration with the government, organisational flexibility and the ongoing adherence to preventative measures by the community will be essential to protect all Western Australians during these volatile and uncertain times.

2a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;

Silver Chain has reviewed the recommendations made by the Joint Select Committee into End of Life Choices and assessed the progression based on extensive consultation with our key stakeholders and our experiences in delivering palliative care to Western Australians. A detailed response to these recommendations is provided below.

As noted in response to the previous inquiry, some recommendations are not applicable to Silver Chain, therefore it was not deemed appropriate to respond. However overall, we note that there has been significant progress on a number of recommendations. Silver Chain continues to support the implementation of all recommendations.

2b) the delivery of the services associated with palliative care funding announcements in 2019–2020;

Silver Chain welcomed the announcement in the 2019-20 May State Budget of an additional \$41 million for palliative care over the next four years. This additional funding commitment is an important first step and will go some way to ensuring that all Western Australians who need it, have access to quality palliative care at end of life.

We are still awaiting advice on the next steps for the delivery of these services.

2c) the delivery of palliative care into regional and remote areas; and

Silver Chain has been a trusted provider of palliative care services in partnership with WA Health for more than 35 years. To date, our services have been provided across metropolitan WA, however we continue to look for opportunities to provide these services into regional and remote communities.

Silver Chain has extended this offer of support to the WA Country Health Service, which received an allocation of the funding in the 2019-20 Budget, and we stand ready to discuss capabilities and explore partnerships to support its activity in regional WA. We are currently awaiting advice on the next steps.

2d) the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas.

Silver Chain advocates strongly for equal access to quality palliative care for all people nearing the end of their life, regardless of their location in Western Australia.

We believe that access to palliative care is a human right. Our focus is on supporting people to live as well as they can, for as long as they can, at home and with support to die with dignity in the place of their choice.

We continue to offer our support to the WA Government to ensure equity of access to palliative care services between metropolitan and regional areas. Silver Chain operate from 26 locations across a vast geography in non-metropolitan WA. As an integrated health and aged care provider we are able to expand the capability of our workforce and develop models of care which will assist rural communities.

Further Information (2a)

Recommendation 1

The Attorney General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice – and provide recommendations in relation to the following matters:

- The establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a mechanism for reporting to Parliament annually the number of advance health directives in Western Australia.
- A requirement that health professionals must search the register for a patient's advance health directives, except in cases of emergency where it is not practicable to do so.
- Amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7 (see page 48).
- Consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity.

Silver Chain's response:

Silver Chain continues to support the use of Advanced Health Directives (AHDs) and ongoing development of the "Goals of Care" framework and its application across both the health and aged care systems. These are important tools and resources for clients, families and professionals. They enable Australians to have meaningful conversations and plan for their death. These tools also help families and professionals understand and enact an individual's choices.

Silver Chain continues to support the establishment of a centralised register for storage of AHDs, that is accessible by all health professionals across public, private, not-for-profit health and aged care providers.

Importantly, Silver Chain supports efforts to increase adoption of AHDs, noting many Australians with terminal illnesses and older Australians do not have an AHD in place.

Dementia may affect decision making capacity and is a crucial consideration as the end of life approaches. People with dementia may not have determined their end of life choices, which limits the ability of health professionals and care providers to tailor individualised care.

We recognise there is significant need for greater understanding in relation to end of life care for dementia patients. Silver Chain has recently employed two Nurse Practitioners who will specifically focus on providing specialist support and health navigation for clients with dementia, their families and carers.

To date, these specialists have established practice guidelines, built networks, provided education within the healthcare sector and delivered care to clients who live with dementia in their own home. One of the key insights has been the limitations of “episodic care” and the need for a care solution that will support these people across a lengthy illness.

Recommendation 2

The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:

- The nature, purpose and effect of advance health directives and enduring powers of guardianship;
- How to identify a valid advance health directive; and
- How to identify the lawful substitute treatment decision-maker.

Silver Chain’s response:

Silver Chain understands that work on this recommendation is ongoing. The organisation supports the need for an extensive program to educate health professionals with regards to AHDs and Enduring Power of Guardianship. There are complex issues in relation to consent and autonomous decision making which require thoughtful and engaged education programs to ensure participants are fully equipped to deal with a broad range of scenarios.

We look forward to working in conjunction with WA Health in the development of training materials and in the implementation of education for care providers. It is acknowledged that development of greater capacity within our healthcare teams across the sector will support better client experiences and improved client outcomes.

Recommendation 3

The Attorney General, in consultation with WA Health, provide greater education for the wider community about:

- Advance health directives;
- Enduring guardians; and
- The hierarchy of medical treatment decision-makers.

Silver Chain’s response:

Silver Chain strongly supports the recommendation for greater education in the community. Our care providers regularly deal with families supporting individuals to make end of life choices. Equally, some clients do not have extended support networks and may be vulnerable without a clear understanding of the options available to them.

Recommendation 4

WA Health immediately develop a strategy to ensure that when an AHD is provided by a patient to a hospital, it is easily accessible and stored prominently on the medical record – until there is a central database.

Silver Chain's response:

In line with Silver Chain's current procedures, the original copy of the AHD is kept by the client in their home. Silver Chain keeps an electronic copy of this record, which is available to all staff via our electronic client record.

Recommendation 5

The Minister for Health recommends to the Council of Australian Governments an amendment to the Medicare rebate schedule to include preparation of advance health directives with general practitioners.

Silver Chain's response:

This recommendation is not applicable to Silver Chain because our Medical Consultants at times will prepare AHDs through the existing Palliative Care Service, which is funded through the WA Health contract, not Medicare. Nevertheless, Silver Chain supports an amendment to the Medicare rebate schedule to include preparation of advance health directives as it will enable GPs to better support AHDs, which may also enable more people to choose to be cared for at home.

Recommendation 6

The Minister for Health report to Parliament annually on the number of advance health directives held on hospital medical records in Western Australia.

Silver Chain's response:

This recommendation is focused on hospital medical records and is not applicable to Silver Chain. However, our organisation acknowledges the critical role of monitoring and reporting in relation to the implementation of the new legislation.

Recommendation 7

The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.

Silver Chain's response:

Silver Chain understands that this recommendation is underway. An increase in the number of publicly funded inpatient beds will enable better access to palliative care. However, in assessing the progress of this recommendation it is equally important to ensure that we continue to consider patient choice to be cared for in the community.

Recommendation 8

The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

Silver Chain's response:

Current funding for Silver Chain demonstrates this recommendation is yet to be delivered.

Silver Chain currently provides the largest community-based specialist palliative care services in Western Australia. Our service provides care for home-based residents around the clock and in locations across the breadth of the metropolitan area, from Two Rocks in the north to Waroona in the south.

Our staff deliver more palliative care services than the organisation is currently funded to deliver. At present, Silver Chain is delivering services for an average of 600 clients per day, well above the average of 563 clients per day that it is funded for under the WA Health contract.

In accordance with our values, Silver Chain does not decline additional referrals. However, we are not being reimbursed for the additional services provided.

To date, Silver Chain has not received any additional funding to meet this increased demand. It is noted however, that other community providers such as MPaCCs and Residential Care Line have received increased funding resulting in increased services. WACHS has also received substantial increases to its funding.

As previously stated, the average length of stay (LOS) is 76 days, however, this LOS is skewed by some diagnostic groups where there is a long trajectory, such as Motor Neurone Disease (MND). Silver Chain believes that with additional funding, there is an opportunity to enhance our current programme by establishing a Specialist Consultancy Programme which would enable us to support the needs of people with progressive life-limiting illness earlier in their disease trajectory. This would align with contemporary palliative care practice and it would also enhance the connections between GP and Specialist Palliative Care in the Community and reduce the need for people with life-limiting illness returning to Hospital Outpatient Departments. This service would facilitate improved symptom management at an earlier stage. Improved access to Palliative care services has been linked to improved quality and quantity of life, this may reduce distress associated with symptom burden and alleviate fears associated with dying. Improved access to timely palliative care may also reduce the number of requests for VAD or ensure that VAD is an informed choice.

Recommendation 9

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).

Silver Chain's response:

This recommendation has been delivered. The independent review has commenced and Silver Chain's Director of Clinical Operations for Palliative Care in WA is on the Advisory Committee.

Recommendation 10

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.

Silver Chain's response:

Silver Chain understands that this recommendation is ongoing.

WA Health has undertaken a process to explore the unmet needs for palliative care. Silver Chain has been part of the consultation process.

Silver Chain looks forward to the findings of the project and hopes that consideration is given to the percentage of “unmet demand for palliative care” is not just measured by the number of people who accessed palliative care, but also the number of those accessing palliative care very late in the trajectory of their illness and therefore not receiving timely referrals.

Some people who may already be receiving home care packages or other clinical services are admitted and die in hospital as a result of failing to recognise the irreversibility of their condition.

More timely referrals can mean better symptom management and quality of life for those with terminal illnesses.

Recommendation 11

To improve understanding of palliative care in Western Australia, WA health should:

- Establish a consistent definition of palliative care to be adopted by all health professionals;
- Provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community;
- Encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- Establish a palliative care information and community hotline.

Silver Chain’s response:

This recommendation has not been delivered. Silver Chain looks forward to the development of consistent definitions to describe palliative care services and improved information resources to support people to better access palliative care in the community.

Recommendation 12

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.

Silver Chain’s response:

This recommendation has been delivered.

Recommendation 13

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.

Silver Chain’s response:

This recommendation has been delivered. Silver Chain supports the Minister’s recommendation on addressing the needs for palliative care for people living outside metropolitan Perth. Silver Chain looks forward to supporting service development as required.

Recommendation 14

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.

Silver Chain's response:

This recommendation has not been delivered. Silver Chain would be supportive of the Minister appointing an independent review and an audit process to create transparency and equity across all aspects of palliative care service provision.

Recommendation 15

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

Silver Chain's response:

Silver Chain understands that this recommendation is ongoing. WA Health has developed a Capability Framework that has been endorsed and will be adopted across metropolitan health services and WACHS.

Silver Chain continues to be committed to the ongoing development of our staff who provide care to people living with life limiting illness while living at home. We manage these clients in a number of our programmes, and we would look to further invest in growing capability that aligns with the newly developed capability framework. We would seek similar investment to the public health system by the State government to support implementation of this training within our community.

Recommendation 16

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.

Silver Chain's response:

Silver Chain understands that this recommendation is ongoing.

Silver Chain continues to support the need for ongoing professional development across all of our programmes caring for people with progressive, life-limiting illness and we are keen to align to the State Capability Framework.

However, we note that enhancing our existing training solutions will require additional resourcing.

Recommendation 17

WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments.

WA Health should consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area.

Silver Chain's response:

Silver Chain understands that this recommendation is ongoing.

We support the need for further professional development which aligns to the changing needs and wishes of people with progressive, life limiting illness. Silver Chain works collaboratively across the healthcare sector to provide client-centred care. We look forward to improved communication systems that are easily accessible and provide a contemporary view of the agreed goals of care. Educated community members, empowered to make informed and timely choices, will result in better palliative care outcomes.

Recommendation 18

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment. As per any other medical treatment, the requirement for informed consent must be clear. The treatment must be specifically noted in the medical record as 'terminal sedation'.

Silver Chain's response:

Silver Chain understands that this recommendation is ongoing.

Symptom management and psychosocial care are central to the delivery of care within our community-based specialist palliative care service. Clients who experience intractable symptoms during their final days of life are managed in accordance with guidelines that reflect State and National approaches.

Recommendation 19

The Minister for Health should ensure that any bill to introduce a legislative framework for voluntary assisted dying is introduced by the government.

Silver Chain's response:

This recommendation has been delivered.

Recommendation 20

The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.

Silver Chain's response:

This recommendation is ongoing.

Silver Chain's position is that the Palliative Care Service will not provide VAD but will support referral. We believe that access to palliative care is a human right. Our focus is on supporting people to live as well as they can, for as long as they can, at home and with support to die with dignity in the place of their choice.

Silver Chain developed its position on VAD through consultation with key stakeholders within our organisation. Our consultation process resulted in the recognition that for some people in our community, there is a myth that palliative care is VAD. Our organisation feels strongly that palliative care and VAD are very separate interventions and to reduce any risk of clients declining referral to palliative care because of misconceptions, VAD would not be a service that we offer. This approach mirrors that of other palliative care services internationally, in countries where VAD is legal.

Silver Chain will support all clients who meet our eligibility criteria and will refer people who request VAD to the appropriate services.

VAD services are yet to be established and referral pathways are still to be developed. However, it is likely that there will be a "Navigation Service" developed. The purpose of this service will be to screen clients, support decision-making, provide education and advice to healthcare professionals and connect clients to VAD service providers.

Recommendation 21

The Minister for Health establish an expert panel including health and legal practitioners and health consumers to undertake consultation and develop legislation for voluntary assisted dying in Western Australia, and that this report, together with the Framework contained at the end of Chapter 7, be considered by that Panel.

Silver Chain's response:

This recommendation has been delivered. Silver Chain had representation on this expert committee.

Recommendation 22

The Minister for Health should ensure that legislation require that death be *reasonably foreseeable* as a consequence of the condition.

Silver Chain's response:

This recommendation has been delivered

Recommendation 23

That the Minister for Health ensure the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.

Silver Chain's response:

This recommendation has been delivered.

Recommendation 24

The Western Australian Government develop and introduce legislation for voluntary assisted dying having regard to the recommended framework and following consultation with the Panel established under Recommendation 21.

Silver Chain's response:

This recommendation has been delivered. Silver Chain will continue to care for people with progressive life limiting illness through expert symptom management and by promoting choice in relation to end of life.

Tish Morrison

Director Clinical Operations – Palliative Care & End of Life Care, WA