JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

Our ref: A656808

19 December 2017

Professor Keith Evans
Chief Advisor, Public Policy
Silver Chain Group
Email:

Dear Professor Evans

Draft transcript and questions on notice from public hearing

Thank you for appearing before the Joint Select Committee on End of Life Choices on Thursday, 14 December 2017.

Regarding the draft transcript

Please find attached for your perusal the draft transcript of oral evidence you gave to the Committee.

If you have any corrections to make to the transcript there are several ways you can do this:

1) **Hard copy and post**

   Print out a hard copy and clearly mark any transcription errors in the margin (preferably in red or blue ink), and post to:

   Dr Jeannine Purdy
   Principal Research Officer
   Joint Select Committee on End of Life Choices
   Parliament House
   Perth WA 6000

   or deliver by hand to Level 1, 11 Harvest Terrace, West Perth.

2) **Hard copy, scan and email**

   Print out a hard copy and clearly mark any transcription errors in the margin (preferably in red or blue ink), scan the corrected document and email as an attachment to eolcc@parliament.wa.gov.au

3) **Electronically**

   Mark any transcription errors electronically using the Track Changes feature under the Review tab (if using Microsoft Word) and email as an attachment to eolcc@parliament.wa.gov.au

If you would like a copy of the transcript posted to you, please let me know.

If you wish to clarify any aspect of your evidence, or provide any supplementary material to your evidence, please forward this to me in writing at the same time.

If the transcript is not returned within 10 working days from the date of this email, the attached transcript will be deemed to be correct. Please note, due to the Parliamentary Christmas shutdown, the deadline will be **9 January 2018**.

Regarding Questions taken on notice

At the hearing, you undertook to provide information in relation to several questions taken on notice (page references are to the draft transcript).

1. What is the number of Silver Chain nurses and social workers with specific training and/or qualifications in palliative care? (p 4)
2. What is the Silver Chain in-home care data on the numbers of people who have been assessed as eligible for home-care packages in comparison to the number who is able to access those packages? (p 8)
3. How many hours or days you are able to service Jigalong? (p 10)
4. What are the details of Silver Chain's research which provides some support for the figure of about 2% for whom symptoms cannot be controlled by palliative care? (p 11)

In addition, the Committee requests that you provide a response to the following questions provided to you before the hearing but not answered due to time constraints.

Advanced Care Planning

1.(d) Are staff and contractors aware that both statutory and common law AHDs are valid in WA? (Note: common law AHDs can be oral or written and can be given for any reason – religious, social, moral or any other reason).

Palliative care in Western Australia

4. From your experience, is the role and availability of palliative care well understood by the community in Western Australia?
    a. If not, why?
5. Do you think current palliative care services in Western Australia are adequate?
    a. Where are the shortfalls, if any?
6. Do you think current palliative care services are sufficient to accommodate the preferences of patients in Western Australia?
    a. What are the obstacles to patients being cared for and dying in their place of choice?
7. Do you believe current palliative care services in Western Australia meet the needs of the following groups, and on what basis have you come to this view?
    a. CALD communities
    b. people living in aged care facilities and disability residential care
    c. people living in rural and remote areas
    d. Aboriginal and Torres Strait Islanders
    e. children and young people
    f. patients suffering non-malignant/chronic illnesses
    g. patients with intellectual and developmental disabilities
    h. people with mental illness, generally, and people detained involuntarily under the MHA, specifically;

i. Prisoners and others in detention.

8. Do you think cancer sufferers generally have better access to palliative care compared to patients with other chronic or life-threatening diseases?
9. How do you feel Western Australia's palliative care services compare to other Australian jurisdictions?
10. In what ways do you think palliative care could be better integrated across the WA health services?
11. Is the WA health system responsive to consumer demand for palliative care?
12. Can you comment on the adequacy of the palliative care system both within and outside the metropolitan area?

Silver Chain's provision of palliative care in Western Australia

19 Are there protocols for prescribing opiate, or derivative, or any other sedating, or pain relieving, medications for the purpose of palliative care?

Limitations of Palliative Care

23.(c) Are the current laws too constraining on health professionals providing palliative care?

i. What could be improved?

24. Can you explain why the national PCOC (Palliative Care Outcomes Collaboration) benchmark for community palliative care providers is 60% relief of pain and suffering compared to the 90% benchmark for those in hospital?

25. The Committee has received a number of submissions supporting the right of medical practitioners to not treat patients if it is contrary to their personal moral views. In your opinion do nurses have the same right to decline to treat patients if it is not in accordance with their conscience?

End of life care – Refusal of Medical Treatment

26. What is the refusal of medical treatment?
    a. When is a patient or the person authorised to make a treatment decision on their behalf entitled to refuse medical treatment?
27. Would you say the arrangements relating to refusal of medical treatment well understood and respected by Silver Chain employees and contractors?
    a. On what basis is this distinguished from conduct which might otherwise be a suicide attempt?
    b. Do you think permitting the refusal of medical treatment compromises efforts to reduce suicide generally in the community?
    c. Do you believe the relationship between health professionals and patients is compromised by permitting the refusal of medical treatment?
    d. Are you aware of any concerns that vulnerable people are being influenced or coerced into refusing medical treatment?
    e. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to refuse medical treatment or are exploiting their position in their own interests?
28. The refusal of medical treatment can include refusing artificial hydration and nourishment, as in the Rossiter case.

a. In your assessment, is this issue now clear for Silver Chain employees and contractors?

b. Would you say the practice is implemented consistently WA?

29. Does Silver Chain report incidents where medical treatment is refused?

End of life care – Palliated starvation and dehydration

30. Apart from individuals with anorexia, does the HCS treat patients at home who have refused nourishment and hydration?

31. Are you aware of the basis upon which the refusal of nourishment and hydration is distinguished from conduct that might otherwise be a suicide attempt?

32. Can patients be treated with pain relieving or sedating medications until they die?

33. Would you say the bond of trust between a Silver Chain health professional and a patient is compromised by being involved in a palliated starvation?

34. Are you aware of any concerns that vulnerable people are being influenced or coerced into agreeing to palliated starvation?

35. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to agree to palliated starvation or are exploiting their position in their own interests?

End of life care – Terminal Sedation

39.(a) In cases of terminal sedation, what is recorded as cause of death on the patient's death certificate?

42. Do Silver Chain staff report incidents when they administer terminal sedation?

    a. If yes, can you provide statistics over the past five years?

43. Do you think the bond of trust between Silver Chain health professionals and their patients compromised by the practice of terminal sedation?

44. Are you aware of any concerns that vulnerable people are being influenced or coerced into agreeing to terminal sedation?

45. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to agree to terminal sedation or are exploiting their position in their own interests?

End of life care – the Doctrine of Double-effect

49. In what circumstances are such medications increasingly administered?

50. Is this recognised as good end-of-life care practice?

    a. Is the consent of the patient required? (Or the consent of their authorised person for medical treatment decisions).

    b. Are there circumstances in which the HCS can decide to administer such medications on the patient's behalf?

51. Would you say increasing the amounts of such medication(s) in these circumstances risks compromising the relationship between Silver Chain and its clients?

52. Are you aware of any concerns that vulnerable people are being influenced or coerced into consenting to dangerous levels of pain relief?

53. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to consent to dangerous level of pain relief or are exploiting their position in their own interests?

End of life care – Legal issues and end of life choices

54. In your submission you stated that palliative care providers become a key source of information about the law for palliative care patients. Do you consider this area of law to be complex and difficult to understand?
55. What does Silver Chain do to assist its health professionals become fully informed of any legal complexities in this area?
56. Would you say the protections under the Criminal Code for Silver Chain health professionals in relation to treating patients at the end of their lives sufficient?
    a. If not, how could it be improved?

It would be appreciated if you could provide this information to the Committee by **Monday 29 January 2018**.

Unless otherwise directed by the Committee, your evidence is public and will be published on the WA Parliament website.

If you require any further information, please contact me on (08) 9222 7442.

Yours sincerely

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15 February 2018

Ms Jeannine Purdy
Principal Research Officer
Joint Select Committee on End of Life Choices
Legislative Assembly of Western Australia
Parliament House
4 Harvest Terrace
WEST PERTH WA 6004

Dear Ms Purdy

Joint Select Committee on End of Life Choices – Response

Questions on Notice

1. There are currently 94 number of nurses and social workers working in the palliative care program all of whom have received palliative care specific training.
2. Silver Chain Group does not collect specific data on the numbers of people waiting for home care packages. It has however been widely publicised lately that there are somewhere in the region of 100,000 Australians nationally currently sitting on the waitlist for packages.
3. Whilst Silver Chain is providing services in a number of remote communities it is no longer providing services in Jigalong.
4. The data in support of this proposition is sourced from the Palliative Care Outcomes Collaborative (PCOC).

Original Questions still to be answered

1.
    d. Yes, our staff are aware of this.

4. There is always more to do in promoting and educating the community about palliative care. There are misconceptions that palliative care is only required at the very end of life. It remains apparent that the principle provision of palliative care services is in support of people who have a cancer diagnosis (80:20) in our community setting, and support for people with complex and chronic conditions/neurological conditions needs improvement. Availability of palliative care differs markedly across the state; however, it is fair to say that resourcing does not meet demand even where service provision is good, and there is especially a significant resourcing issue outside the metropolitan area.

5. The principle shortfall is in relation to community based service provision, both in home and on a consultative services bases. In metropolitan Perth, palliative care consultative services in outer lying public hospitals (Joondalup, Midland and Peel Health Campus) could be improved. Outside of Perth there are significant shortfalls in relation to in-home service provision – this is a challenge given the geography and requires greater integration and implementation of innovative technologies.

If we take the basic premise that most people want to be cared for and die at home, and we couple this with the known number of people for whom this is a reality, we know that there is a deficiency in resourcing the supports required by people to feel safe to be cared in their home.

6. Our perspective would be that there is sufficient evidence to say that most people wish to be cared for and to die at home. If this is the case then the palliative care service framework should be orientated toward that principle intent. It must however be recognised that many people wish to receive care and die somewhere other than home and that for many people treatment and support in an in-patient setting is an inevitable and desired part of their care journey. The principle obstacles to people being cared for at home currently are inadequate service resourcing, together with a systemic issue of failing to recognise that the person would benefit from palliative care; availability of carers and carer fatigue; after hours supports (General Practitioner (GP) and nurse); medications particularly in country settings; and the increasing unavailability of Home Care Packages.

7. All of the groups cited here are typically under-represented in all areas of healthcare service provision and palliative care is no different. Recent work by Rosenwax et al (2016), *A retrospective population cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on,* BMC Palliative Care, serves to highlight some of the gaps that exist. For Silver Chain, our data shows that approximately 78% of clients referred to the palliative care service has a cancer diagnosis. Further research is required to provide on-going evidence to identify gaps in access and service provision.

8. Yes, this is true both for WA, and is also the case in every other jurisdiction.

9. Western Australia (WA) compares well both in terms of the quality of care and outcomes achieved in the community setting, as well as in terms of the numbers of people receiving care at home.

10. Palliative care education and training should be integrated into all junior doctor training and should include exposure to community based care delivery. In addition, specialist training should include palliative care training where the disease is one that is amenable to palliative care (for example Respiratory Medicine). The adoption of a systematic approach to identifying those that may benefit from palliative care would be a significant enhancement – the use, for example, of a prognostication tool (for example the Supportive and Palliative Care Indicators Tool - SPICT) across all public hospitals and in general practice could result in a "step change" in the way that care is approached with greater numbers of people being identified as possibly benefitting from palliative care and would increase the number of "conversations" had about goals of care.

11. There is significant room for improvement and additional resources will be required to support demand into the future – with the constraints as identified above.

12. Metropolitan Perth is well served with a comprehensive network of palliative care service provision however it is struggling to keep up with demand, and to adapt to contemporary practice which suggests that palliative care offers benefit over a longer term than has historically been the case. There are pockets where services could be enhanced in metropolitan hospitals. Overall resources are stretched in the

metropolitan area. Outside of metropolitan Perth the challenge is far more significant, perhaps understandably so given the geography and population, where in-home support is lacking.

19. Yes, there are Clinical Guidelines in support of symptom management for all medications used.

23. There is always a tension between overall public safety and what may support a better outcome in palliative care. In relation to the prescribing of Schedule 8 medication we would urge that the needs of palliative care patients not be lost when considering overall safety and that systemic approaches be taken to find solutions, such as live electronic monitoring of prescribing and dispensing, that allows for appropriate medication use to be supported rather than constrained.

24. The benchmarks for PCOC are the same irrespective of care setting.

25. Yes, any healthcare practitioner should be afforded the same rights.

26. Refusal of medical treatment occurs when a competent person refuses to give informed consent for that treatment. This may occur at any time.

27. Yes, the principles relating to refusal to medical treatment are well understood and respected by Silver Chain employees and contractors.
    a. Suicide is usually distinguished by the taking of an action explicitly with the intent to end life.
    b. No, we do not.
    c. Absolutely not. This is about supporting a person with information to enable them to make their own decision.
    d. We are not aware of any such concerns.
    e. We are not aware of any such concerns.

28.
    a. Yes, it is clear.
    b. The practice occurs extremely infrequently. We could not comment on its implementation across WA.

29. Where medical treatment is refused, this is reported and managed through the clinical treating team and escalated to the relevant medical governor where required.

30. Yes. It is however important to remember that cessation of nourishment and hydration is a part of the dying process for many people – there is a reduced feeling of hunger and thirst.

31. As detailed above in Q. 27 the two acts are very distinct.

32. Yes, it is possible to continue to treat patient's symptoms with pain relieving or sedating medications until they die.

33. No. The bond of trust is built over time and is an essential element of the therapeutic relationship which is founded on good communication, the sharing of information and respecting patient's choices in making informed decisions.

34. We are not aware of any such concerns.

35. We are not aware of any such concerns.

39.
    a. The cause of death is recorded as the underlying disease process, for example Chronic Obstructive Airways Disease or Lung Cancer.

42. No, we do not report on the provision of terminal sedation as it is not considered to be an incident.

43. No, we do not – this is underpinned by informed consent.

44. We are not aware of any such concerns.

45. We are not aware of any such concerns.

49. The most common occasion, albeit very infrequent, are in the management of delirium a symptom which causes very significant distress for the person and their loved one.

50. Yes, it is recognised as good end-of life care.
    a. And is supported by an appropriate evidence base. Consent is always sought from the person of the substitute decision maker.
    b. No, we would not administer such medications in the absence of consent.

51. No, we would not. Any such decision is taken only after thorough consultation.

52. We are not aware of any such concerns.

53. We are not aware of any such concerns.

54. The law is as complex as it needs to be to ensure that it is workable to provide for safety of the community. It also needs to be recognised that there is state based legislation which can have an impact.

55. Silver Chain policy is constantly reviewed and updated to reflect legislation and current best practice. This in turn is reflected in the education that is provided to staff.

56. Yes, the protections are adequate.

Yours sincerely

Mark Cockayne
General Manager Western Australia Health Care