

Name: Marina Re
I wish to appear in person to present my case.

Position: Chief Executive Officer Identitywa

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WA Parliament Joint Select Committee on End of Life Choices Submission

Background

1. Identitywa has been operating for over 40 years and is one of the largest disability service providers in Western Australia. We provide accommodation to over 150 people who live in our homes across the Perth metropolitan area. The majority of these people have significant needs and require 24/7 care and support. Many of these people are aged over 50 years and experience a range of conditions relating to their disability which results in shortened lifespans.
2. We have instituted a range of initiatives including Advance Care Planning which supports individuals and families through the end of life stages and ensures that we (often as the final provider of care) work within the directions and wishes of the individual and family. We believe this approach together with our commitment to supporting people to die within their own homes and (with) the involvement of palliative care services makes the experience of a good death more likely. For each individual who lives in an Identitywa home this is their home and they have the same rights to continue to live there as they wish.

An example

3. Charissa was 41 years of age when she passed away at her Identitywa home of over 10 years in a Perth northern suburb. She had been unwell with aspirative pneumonia and had been admitted to Joondalup Hospital. Her family sensed that although she had been a fighter over many episodes of ill health this time she may not be able to overcome it.
4. Identitywa staff stayed with Charissa during the 14 days in hospital and in due course it became evident that she required palliative care. The family felt strongly that Charissa would want to live out her last days in her own home surrounded by her family, her staff and her housemates.

5. This is exactly what we were able to achieve for Charissa. With support from Silver Chain and the strong commitment from staff to continue to care for her for as long as possible. Charissa's mother Gaye wrote "*Charissa's end of life was one each of us would wish for ourselves and we are eternally grateful to the wonderful carers and senior management for giving such dignity and love to Charissa at the end of her life.*"
6. Within Identitywa end of life care has been offered and provided to a number of people and their families unanimously view this as an important part of the continuum of care we offer. (TOR 1)
7. It would be absolutely unacceptable that as a consequence of Assisted Dying legislation being passed that palliative care be less available or accessible to people with disabilities like Charissa.

Comment

8. We believe that people with disabilities have the most to fear from the move to assisted dying. For many people supported by Identitywa the decision would rest in the hands of others and in some cases those others may have limited exposure to people with disabilities or understanding of the health complexities faced on a daily basis by many.
 9. We believe that high quality advance care planning and excellent palliative care is the best mitigation against subtle pressures which view the lives of people with disabilities as less worthy. These pressures may be financial, emotional and/or may come from a support system which is still rationed with uneven access.(TOR 2)
 10. A compassionate and skilled workforce who value life can make a good death possible for people with disabilities and remove the desire for a hastening of the dying process.
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