

Name: Mrs Gaye Matthews

Committee Name: West Australian Parliament Joint Select Committee on End of Life Choices.

Inquiry Title: Inquiry in to the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices.

My personal experiences:

1. The death of my mother in 2007
2. The death of my daughter in 2011

1. The death of my mother in 2007.

My mother, Valerie Booth, had been diagnosed with thyroid cancer in 2005, which metastasized to renal cancer in 2006. She had surgery for both these cancers. Her death certificate stated transitional cell carcinoma of the bladder was a contributory cause of death.

My mother lived in a retirement village and had enjoyed the care of a wonderful General Practitioner since her arrival at the village in 1989. She had broken her hip in 1992 and although my father was alive then the Dr quickly put in place a home care package which allowed them both to live independently. After the thyroid surgery the Dr engaged both Mum and I in a conversation about palliative care which we appreciated. We were both aware of this service but as mum was now widowed and fiercely wanted to remain independent it was important to have this conversation.

Silver Chain was the selected Palliative Care provider. This service was important to me also as I had a profoundly disabled daughter's care to oversee, and my husband's step mother who required much attention due to mental health issues. I rang my mother daily and visited her often and she came and spent time with us to enjoy the family life that she so treasured. Although requiring medication at various times for acute pain never did she express a wish to have her death hastened. She was a woman of incredible inner strength, of great religious faith and supported so many people whom she saw as needing care and love with her happy disposition, despite her own serious health issues.

One example of her strength was to discuss with an oncologist the possibility of an extensive radiation treatment. She openly questioned him about what quality of life that would afford her and more importantly how much more time it would give her which he answered openly and honestly. He said his professional opinion still did not allow him to play God. They laughed together before she thanked him graciously and declined the treatment. She had decided for herself that the quality of life she may gain would be outweighed by the negative side effects of the radiation which he had clearly explained.

Sadly in the August, while she was staying with us, she fell and broke her pubis. She was admitted to the Mount Hospital and from there to Glengarry Hospital's Hospice ward. She was soon recognized as not only a cancer patient but as an elderly lady who required rehabilitation to return home "as soon as possible" and was transferred to the Rehabilitation ward.

Obviously the wonderful Glengarry staff recognized her health issues and in retrospect the bladder cancer had developed but she worked hard at her rehabilitation programme for she was overjoyed at the anticipation of the arrival in early November of her first great grandchild.

I had begun to look for a residential placement which would allow her the continual care she required but infections delayed any discharge and her pain levels escalated until one morning at the beginning of October she told me she could no longer cope with the pain and needed to talk to the Doctor about more medication. Once more she was in complete control of her life and death and appropriate palliative pain control was introduced. The staff of the Rehabilitation ward requested that she remain there rather than move to the Hospice Ward as they had known her so well. She encouraged open discussion about her quality of life, her hopes to see her grandson's child but also her open acknowledgement that this may not be possible due to her illness and her choice for more intervention to control the pain.

She quietly and peacefully died in the early hours of the morning of October 7.

Terms of Reference addressed within this experience:-

- a) - Assisting a person to exercise how they manage their end of life when experiencing Chronic and /or terminal illness and the role of palliative care. It is important that patients who are severely ill are afforded open discussion with doctors about this valuable form of medicine. Sadly there is still not enough information available. As a society my experience has been that instead of death being a mystery it is so often seen by society, many in the medical professions and family members as a problem which is to be solved which leads to legislation rather than public and specific education.
- b) I am interested in the proposed Victorian model but it does not seem to have a requirement to first properly engage with palliative care.
- c) – No legislative changes would alter my mother's options, as her GP, surgeons and nursing staff understood fully what my mother was expressing and honoured her views and decisions.
- d) – I held an EPA for my mother and we were open in our discussions as to her wishes as to the quality of her life and especially her death. (EPG's were not available at that time but she would have approved)

2. The death of my daughter in 2011

My daughter Charissa died at her home as a result of respiration failure after being hospitalized with Aspiration Pneumonia eighteen days earlier. She was 41 years old and a profoundly disabled woman having been diagnosed with Rett Syndrome as a child.

She had moved from our family home in 2002 to a group accommodation option with 3 other people who had similar care needs. This accommodation option, developed by Identitywa, one of the largest disability agencies in Western Australia, soon became home to these 4 adults. Even with their own particular needs they acknowledged the needs of the others and it soon became a wonderful caring environment, overseen by a senior management and cared for by care staff who valued each resident's personality as well as care needs.

Charissa could not speak, feed herself or move herself and yet as people came to know, understand and love her there was no doubt that her life was valued. Without means of normal communication it was obviously clear to those who knew her what her needs were from her eye contact. She enjoyed her life with her housemates and the different staff and also the weekends when she came home.

Communication between her staff and us, her parents and extended family, was very important as we could talk to her about what she had been doing at home or at her day placement.

Sadly not everyone valued her. On two occasions when she had been admitted to hospital in emergency situations we were asked quite bluntly if we wanted her treated. We carefully explained that although Charissa had a disability she was also a person who expressed a joy in her quality of life for as long as it was available to her.

When Charissa was diagnosed with this serious illness we knew it was something from which she may not be able to recover. We requested the options for treatment from the consultant doctors and then went to speak with her own GP who knew her well as a patient and a person. From our knowledge of her and her past medical history the options held no guarantees other than extreme discomfort for Charissa, even if she survived the surgery which was not assured.

The Consultant suggested we “just take her home.” There was no mention of palliative care and after my mother’s experience of such dignity to the end of her life I was forced to insist on a much better end of life care for Charissa.

We were offered, finally after some distressing meetings, the option of palliative care and finally selected Silver Chain to assist the staff at Charissa’s own home. The understanding, care and support of the senior management of Identitywa, allowed us to take Charissa home on December 19th, where she was quietly and lovingly welcomed by her housemates and staff.

I shall never forget saying to her that morning as we waited for the ambulance “You are going home” and she gave me such a happy smile. I always knew that although she was profoundly disabled no one should ever assume she did not understand.

We, her parents, sat with Charissa at all times while staff attended to the needs of the other residents, or took breaks while staff sat with her. Staff who were off duty in both this house and the duplex next door were continual visitors to the room to speak to Charissa and let her know how loved and special she was. I would have liked some doctors who had questioned her right to life in the past to have witnessed those interactions!

Friends and family came to the house, the Silver Chain Chaplain made an offer to visit and pray which was accepted by staff. The Silver Chain Nurses reassured us constantly that Charissa was without pain.

Her life came to an end on the Friday afternoon five days after her hospital discharge leaving such sadness. While there are people to remember her and other disabled people like her it is important to remind people that such people have a right to a quality of life and death despite the views of those who have no, or limited interaction with people with disabilities.

There is, rather than a call for someone else’s decision as to when and why the lives of these people should be ended a greater need for an enhanced understanding of good palliative care and communication with those who really know and love people who cannot speak for themselves.

As her parents we were able to understand that Charissa had reached the end of her life. Rett syndrome occurs predominately in females who do not generally live to an old age. Of the six who died in 2011, 3 were 5 years old, 2 were in their twenties and Charissa was 41. We knew the statistics and had offered her much care, love and laughter for thirty one years before choosing a residence that became her home in every sense of the word. She deserved a quality of life and now at the end of it every consideration for a quality of care.

Sadly for some people with need for care they do not have family to continue to be part of their lives. We held an Administration Order for Charissa through the Office of Public Guardian from the time she was sixteen but as her parents did not, at that time, have to take out a Guardianship order although this is probably changing. Agencies such as Identitywa can be over ridden by The Public Advocate in circumstances of severe illness. The “Do not Resuscitate “ clause does not recognize that disabled

people get sick, need to go to hospital but can be treated and recover to continue a quality of life that they enjoy. More consideration needs to be given to the decisions made by the Public Guardian of uninformed distant relatives if legislation is to be considered.

Terms of reference considered in this experience:
a), c) and d)

Thank you for your consideration,

Gaye Matthews