

Robyn Kapp

30th July 2004

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Sir/Madam

Re: Inquiry into Aged Care

Please find attached a personal submission relating to the above inquiry.

If you require any further information please do not hesitate to contact me.

Yours sincerely

Robyn Kapp OAM

Senate Community Affairs References Committee

Inquiry into Aged Care

Young People with Huntington Disease and Residential Aged Care Facilities

Personal Submission – Robyn Kapp OAM

The lack of suitable long-term nursing home accommodation for people with HD who are under the age of 65 has affected me personally as well as professionally over the past 32 years.

In July 1972, my father who had Huntington Disease and aged 51 died in hospital, having been transferred from a nursing home for the frail aged.

In July 2004, my sister, who had Huntington Disease and aged 55 died in a nursing home for the frail aged.

In 32 years, how far have we come in providing appropriate long-term nursing home care for young people with advanced HD?

My sister was in nursing home care for 13 years. Initially she was a resident of the special HD Unit at Lidcombe Hospital (Lidcombe, NSW) and with the close of Lidcombe Hospital transferred to Huntington Lodge at Lottie Stewart Hospital (Dundas, NSW). But as she approached 50, we were asked to find alternative accommodation for her because the bed was required for younger people who could benefit from the specialised care at Huntington Lodge which has only 15 beds.

This proved very difficult for the family. How could we deny someone else the same special care that she had received for eight years? Yet she was only 50 and still a very young wife, mother, daughter and sister. Once she relocated to the nursing home all access to regular medical and health assessments including individual input from allied health professionals with HD experience ceased. Social activities and interaction with her peers also ceased.

I acknowledge that nursing homes who are willing to take young people with HD are endeavouring to provide the best possible care but they are having to do so with fewer resources, both financial and human. Unlike Huntington Lodge, they do not receive the extra funding that is required to give young people with HD the quality of care that they deserve. I also acknowledge that staff from the NSW Huntington Disease Service (Westmead Hospital and Lottie Stewart Hospital) provides very valuable in-service and education sessions to staff at those nursing homes.

However for my family and me there has been very little change in the past 32 years.

I implore both Commonwealth and State governments to give careful consideration as to how this situation should be changed and improved so that young people with advanced HD might receive appropriate age related care.