

TO: The Secretary
The Senate Community Affairs
Reference Committee

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PART 2: SUPPLEMENTARY SUBMISSION BY:

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(Refer to original submission No. 149, 149a & 149b)

INQUIRY INTO AGED CARE

PART (C)

“The appropriateness of young people with disabilities being accommodated in residential care facilities (nursing homes) and the extent to which residents with special needs, such as dementia, mental illness or specific conditions (e.g. Acquired Brain Injury) are met under current funding arrangements.”

28th February 2005

The situation of Fiona Way and Family Feb 2005:

Recalling briefly events leading to Fiona's placement in a nursing home.

Jan 2001: Fiona visited at Brain Injury Unit Ryde by Director of Nursing (DON) of Leighton Lodge. DON had previous training in rehabilitation, and a close relative who had had a brain injury. While placement in a nursing home undesirable as only alternative, placement was in a single room enabling family to provide ongoing rehabilitation.

Fiona transferred to nursing home Jan 22, 2001.

On Fiona's arrival at the nursing home, she was confined to bed and wheelchair, had right hemiplegia, continuing post traumatic amnesia, was tube fed (via PEG), yes/no communication, short-term memory less than 5 minutes, long term memory reasonably intact, very good 'emotional memory' and confusion.

Family employed a neurophysiotherapist and speech therapist trained in brain injury, to work with Fiona as nursing home could not provide specialist therapists. DON and therapists assessed Fiona was capable of considerable recovery such that her nursing home stay would be a year or so only.

In May 2001 family organised a case conference for June 2001. Postponed to August in view of DON on leave. Case conference agenda sent to all parties and accepted.

Aug 6, 2001 case conference:

Present: From nursing home – DON, Senior RN's, and social worker; From BIU Ryde – medical specialist/rehab, social worker, outreach team; Fiona's GP, speech therapist; family – mother, stepfather, brother.

Aim: To discuss Fiona's care and work out a team plan for a win/win situation for Fiona, nursing home staff, medicos, therapists and family.

To the amazement and disgust of the attending professionals, and family the meeting was sabotaged by the nursing home representatives, the agenda ignored, and family threatened.

From August 2001: A continuous range of deliberate, unnecessary, inappropriate, at times threatening behaviour and abuse towards Fiona and family by senior nursing staff, nurses, CEO (since replaced), the acting DON (since replaced by Director of Care, DOC), and certain members of the Board. Please see previous submission 149, 149a, 149b.

Over this time family made repeated and extensive efforts to provide solutions to the problems raised by the nursing home. All were repeatedly obstructed.

Repercussions of this behaviour to 1. Fiona and 2. Family:

1. Fiona:

- Delayed rehabilitation (more than one year – neurophysio) due to chemical restraint insisted upon by nursing home (“NO chemical restraint, NO nursing care” - Acting DON) against the wishes of family, GP, consultant psychiatrist, and contrary to external assessment.
- Fear, panic, hyper-vigilance towards many nursing staff. This behaviour has NOT been experienced by visiting professionals, friends, family, nor when Fiona was taken out eg church, shopping centre, private functions, medical/dental assessments. Indicates inability of nursing home to provide proper care.
- Physical and psychological abuse by some nursing staff – witnessed by other nursing staff too afraid to be ‘whistle-blowers’ – eg bruising, pinch marks, physical threat, “I hate you. I hope you die”.
- Total disregard to continence management (not even a wet bed sensor).
- After PEG tube removed, meals often only partially given, or sometimes not at all. Fiona admitted to Hornsby hospital by family (not nursing home) for signs of starvation and weight loss in view of lack of food.
- Transferred by family (not nursing home) with breathing difficulties. Ambulance officer immediately placing her on oxygen. Diagnosed as pneumonia. No notification by nursing home to family of possible life threatening condition
- Institutionalisation of Fiona.

2. Family.

Huge stress due to attitude and behaviour of nursing home to Fiona, family, and visitors after August 2001. It is hard to describe the extent of the harm from this enduring situation physically, emotionally and financially.

A. Mother - Margaret:

- Return of chronic illness after more than 12 years of good health, stress related cardiac problems and other physical ailments.

- Psychology/counselling practice abandoned. This was necessary in view of the Commonwealth complaint process taking 12 months and two Guardianship Hearings, on top of the daily crises and normal care needs of Fiona.
- Attempts by nursing home to try and evict and inappropriately relocate Fiona.
- Loss of mothers work income to provide further rehabilitation for Fiona's needs.

B. Step Father - Gordon:

- With ongoing crises, and no stability of nursing care at nursing home, future plans following recent marriage as well as pending retirement, put on hold.
- Monumental effort to balance a private architectural practice with the demands of complaint processes, Fiona's daily needs and long term rehabilitation goals.
- The combination of non-compensable car accident, lack of appropriate accommodation options for young people, and a lack of other services for young adults creates a need for significant provision by family. The additional lack of even basic care in a nursing home results in an excessive burden on family.

C. Brother - Cameron:

- Increasingly involved as guardian, advocate, case manager compelled by increasing suffering of sister.
- Huge stress, increased symptoms of chronic illness.
- Delay and possible loss of self employment initiatives invested in over previous decade.
- Further severe emotional loss with break up of relationship and related concerns (ongoing), in view of disregard of Commonwealth complaint agency.

In Summary:

To this date no government body, Commonwealth or State, has taken any effective action. Fiona still remains at high risk.

Failure of any effective response to Fiona's mistreatment and abuse as a Commonwealth placement in a nursing home is outrageous.

KEY POINT:

The majority of the above harm is not a consequence of Fiona's initial injuries.

It has been the victimisation and subsequent failure of complaint processes that has resulted in Fiona not progressing by this time to be ready for semi-independent living in the community. This situation has not been a product of her capacity for recovery.

Similarly, the majority of stress trauma and compromise of family is also the consequence of the victimisation, followed by the demands and failure of complaint processes.

Margaret Way-Fuller.