

13 October 2020

Mr Peter Boshier
Chief Ombudsman
Office of the Ombudsman
Tari o te Kaitiaki Mana Tangata
70 The Terrace
Wellington

By email: info@ombudsman.parliament.nz

Tēnā koe Mr Boshier

Re: United Nations Optional Protocol to the Convention Against Torture (OPCAT) and Aged Care Residences

Thank you for meeting with The Royal Australian and New Zealand College of Psychiatrists (RANZCP). The New Zealand Committee of the Faculty of Psychiatry of Old Age (NZ FPOA) appreciated the opportunity to discuss the current challenges facing people living with dementia.

The purpose of this letter is to clarify our key concerns and suggest how we may work together in the future to improve the quality of life for people living with dementia.

Our Three Key Concerns

Context

In relation to your aged care inspection programme we raised three concerns regarding people with dementia. We maintain it is important to understand the context of dementia. While people with moderate to severe dementia are frequently cared for in dementia units or psychogeriatric hospitals, we reiterate that it is not the extent of the cognitive or functional deficit that determines need for these levels of care, but rather the **behavioural and psychological symptoms of dementia (BPSD)**. Old age psychiatrists are intimately involved in the management of BPSD and hence frequently see people who are in dementia units or psychogeriatric hospitals. Frequently old age psychiatrists are required to authorise placement in these levels of facility. The following is a list of some of the more common BPSD issues

- a. **Behavioural issues:** Aggression, agitation, appetite change, calling out, disinhibition, sleep disturbance and wandering
- b. **Psychological Issues:** Apathy, anxiety, depression, delusions, hallucinations and personality change.

Management of BPSD requires a thorough assessment of the person with dementia including their background, the type and extent of the dementia, comorbid medical conditions, mental health history, current mental state, as well as psychological, cultural, environmental, and social issues. Intervention is often difficult and can involve changes in carer behaviour, specific therapies, or the use of medication.

It is clearly established that medications have no role in some BPSD issues (such as wandering and apathy) whereas they can be of considerable assistance in others (such as depression and hallucinations). A good understanding of the types of dementia, the types of BPSD, the

medications available, medical comorbidities, and medicine side effects are needed to successfully manage BPSD with medication. It is also clearly established that there is a significant morbidity and mortality increase when some types of medication are used in the context of dementia. Examples of this include an increased risk of falls with some medications, and an increased rate of death with the use of other medications. It is important to note that the aim of using medications to treat BPSD is not simply to sedate the person with dementia.

It is the view of the Faculty of Psychiatry of Old Age that, in general, the options for managing BPSD should be thought of in declining preference:

- 1) Prevention of BPSD
- 2) Non-pharmacological management of BPSD
- 3) Pharmacological management of BPSD

Our concern about dementia units in psychogeriatric hospitals in New Zealand indicate a lack of priority given to the prevention and non-pharmacological management of BPSD. This will have the undesirable effect of increasing the utilisation of medication for management of BPSD. In addition, our concerns raise human rights and quality of care issues for the vulnerable individuals who find themselves in these facilities.

1. Outdoor space in dementia units

There has been considerable research about the physical design of dementia units and how this can assist in the prevention of BPSD issues. We support optimising the design of dementia units for the purpose of reducing and managing BPSD without resorting to medication. One aspect of the design of dementia units which requires considerably more attention in New Zealand is the provision of outdoor space. The Ministry of Health information resource entitled 'Secure Dementia Care Home Design' published in 2016 is an excellent overview of the important aspects of dementia unit design. Unfortunately, the recommendations in this document are not mandatory and therefore economic factors have come to outweigh quality of care factors. Concern about this issue has been increased with the advent of dementia units on the upper floors of multi-story buildings which have extremely limited outdoor space.

It is our view that unless there is a mandatory requirement for dementia unit outdoor space then the economic factors will continue to predominate, and new dementia units will continue to be built in a way that does not promote quality of care. In addition to the therapeutic benefits of appropriate outdoor space we believe there are human rights issues about compelling people to live essentially an indoor life. Without an associated outdoor area residents are entirely dependent on any friends or family to take them outside the unit as staffing levels are usually inadequate to provide supervision for outings.

2. Subtypes of the dementia population

Dementia is a group of different diseases which can have quite different characteristics. Dementia can affect people of a wide age range of any cultural, linguistic, or racial background. There is a tendency to view the population with dementia as a homogenous group when in fact there are sub-groups that have markedly different needs that are not met by a 'one-size-fits-all' approach. Examples of subgroups that we believe are not served well by the current arrangements include:

- Non-English speakers. There are an increasing number of older people in New Zealand who do not speak English and this becomes a major issue should they require placement in a facility where nobody else speaks their language. This would be difficult enough but with the added complication of dementia and BPSD there cannot possibly be adequate care if verbal communication is not possible with staff. We believe there are human rights issues as well as clinical issues in situations where individuals are unable to communicate. Resolving this issue would require planning and incentivizing to cluster staff and residents of linguistic groups.
- Early onset dementia. Dementia of any type, but particularly frontotemporal dementia, can occur at any stage from the late forties / early fifties and this group have very different

needs from the more common group with dementia in their seventies to nineties. Again, there would need to be some central planning to appropriately provide for this group.

- Cultural diversity. Although somewhat overlapping with the linguistically diverse issues we believe there is room for facilities to specialize cultural groups which would allow individuals with dementia to be immersed in their own culture. Other subculture groups such as the Rainbow community may also be better served by some specialization of facilities.
- Sexually disinhibited and forensic. Some types of dementia frequently result in inappropriate or dangerous sexual behaviour, and of course known sexual offenders can also develop dementia and require placement in facilities. In a similar fashion some individuals can become aggressive with dementia and known violent offenders can also develop dementia. These people, usually men, require secure care in a male only environment with specially trained staff. There is a lack of facilities catering to this group. Potentially these individuals pose a risk to other residents if they are placed in general dementia units.

3. Overall level of funding of dementia units and psychogeriatric hospitals

It is our view that the current level of funding for dementia units and psychogeriatric hospitals does not allow the provision of optimal care for the residents of these facilities. This is reflected in the number of care staff and in the provision of allied staff such as activity coordinators and occupational therapists. There are research based non-pharmacological interventions that would be of benefit to people with dementia if there were resources available allowing these interventions to occur. These are complex political and economic matters but we would like to clearly state our position on these issues.

Conclusion

The New Zealand Committee for the Faculty of Psychiatry of Old Age agree that your inspections of aged care facilities, under OPCAT, are an appropriate response and have a broader role in improving the quality of care provided in these facilities.

We trust that the concerns we have raised may be considered during your programme of inspections. We look forward to providing additional advice to progress your kaupapa.

We suggest you contact Dr Richard Worrall, a psychogeriatrician in Auckland, regarding adequate space for people living with dementia. He has a good understanding of this issue and has agreed he can be contacted for further information RWorrall@adhb.govt.nz

Meanwhile, if you have any questions regarding this letter, please contact Rosemary Matthews, National Manager, New Zealand, on 04 472 7265 or by email Rosemary.Matthews@ranzcp.org.

Nāku, na



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