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Dear Ms Alexander

**Alzheimers New Zealand: draft National Dementia Strategy**

Thank you for the opportunity to comment on your proposed National Dementia Strategy. As you highlight, this is an important and timely issue that requires advanced planning, given that the prevalence of dementia is projected to increase as the population ages.

**Public education/awareness campaign**

We welcome and fully support your aim to conduct an extensive public education campaign to raise awareness of dementia issues and reduce its associated stigma. A suggestion for your campaign is that it would be helpful to have parallel campaigns targeted at specific communities where dementia is a particularly difficult issue i.e. Asian culture.

Within the campaign, it would also be helpful to raise the issue of the importance of putting into place appropriate legal arrangements, such as enduring power of attorney, for the possible time when that person is not competent to make their own decisions. Unfortunately, family courts are often left to deal with such issues when no direction is available, adding another stressor at an already difficult time for the family/whanau.

The promotion of self help strategies aimed at delaying the conditions debilitating effects should also be advocated, such as the use of brain training games, cross words etc,.

### **Access to care options.**

In relation to accessing residential care for dementia sufferers, we urge a note of caution. In supporting your reflections about the potential cost efficiencies from sufferers remaining in their own homes for longer, ANZASW would not wish to see, as a result of this policy, access to residential care being made difficult with the introduction of strident gatekeeper criteria for such care, for example. Family situations and the provision of local community based support services for dementia sufferers and their families is varied, therefore flexible options must be assured for them and their carers.

### **Medication**

Funding support for the appropriate medications to slow the progress of the early stage dementia is essential; alongside the education initiatives to ensure early symptoms are detected. The importance of self help strategies as mentioned before also have relevance in strategies for slowing the progression of the disease.

### **Residential care providers**

There has been much publicity around care issues in residential care and the deficits within the current system (Consumer NZ, August issue 2009). These include poor regulation, inadequate staffing ratios of registered qualified staff to unqualified staff. We are in support of your strategy to have in place effective monitoring and enforcement procedures in the residential care industry. It is essential that monitoring is relevant - it needs to be designed to have a balance of compliance with both contractual and statutory requirements as well as a thorough quality assessment of service delivery – for example whether the care plan in place is appropriate and is being implemented.

Monitoring and quality auditing should be undertaken on a regular basis, be transparent and that necessary sanctions for failed inspections have an impact on the service provider. The model used by the Education Review Office in posting audit reports on their web site would assist ensuring greater transparency of the audit process and enable families to have access to audit reports.

### **Funding and workforce issues**

With the projected increase in the prevalence of dementia sufferers along with the desire to enable dementia sufferers to remain in their homes for longer, an additional challenge will be

to ensure that adequate numbers of appropriately qualified and skilled workforce are available, both in health and within the community. This implies an exponential increase in appropriately qualified workforce will be required. Research and workforce planning needs to be undertaken to identify future models of service delivery and the associated workforce requirements.

Discussion of the issues relating to the recruitment and retention for staff in the residential care and community sectors is urgently required, particularly current comparative remuneration and conditions of employment of workers.

Currently, reported reductions in funding for home support by DHBs work against the 'aging in place' policy and supporting in home dementia care. It is imperative that this approach is reversed with a call for realistic central funding to support these care sectors. Funding formula should reflect the true cost of providing home based care, which should have trickle down effect to the salaries of appropriately qualified home care staff.

Given that some cases will require a complex and unique package of care, mechanisms must be put in place to allow funding to be vied across sector budgets to ensure the appropriate care is provide.

We support your aim for the workforce to be appropriately trained and minimum standards be in place relating to community based care and particularly residential care. Specific educational standards and training in this area, both for clinicians and support staff, is a necessity. Discussions are currently taking place within the Ministry of Social Development regarding a competency programme for the age care sector. It would be appropriate to be involved in such discussions to include dementia care within these forums.

The development of a nationally accepted recommended pathway of care for all stages i.e. early, moderate late and end stage dementia may assist professional recognition across all health sectors.

### **Support for carers**

The provision of support for informal and formal carers is inequitable. The missed opportunity of work by stay at home family carers is not reflected in the reimbursements available to them. The current threshold for financial reimbursement for family carers is such that very few currently qualify and offers little incentive for a family member to provide care. Rectifying this issue must be a priority if increased home care is to be a reality. Greater availability of quality respite and day care services, along with a guaranteed level of annual access to such care (we recommend the same period as the statutory annual leave requirements - 4 weeks) will also need to be factored in.

## **Ethics relating to the care treatment of dementia sufferers**

In relation to the proposal to develop a code of ethics for the care and treatment of dementia sufferers, dialogue should also include local DHB specialist services as they may already have policy in this area. We are aware Canterbury DHB Psychiatric Services for the Elderly do have such policies in place.

## **Needs of special needs groups**

We concur that there is an urgent need to have a strategy to enable those people with early on-set dementia, have age-appropriate care and facilities. The placement in aged care sector is inappropriate.

However, this could be broadened to ensure the widespread availability of dementia specific care facilities.

I wish you every success with your national strategy.

Yours sincerely

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