15 August 2024

Committee Secretariat
Health Committee
Parliament Buildings
Wellington

Tēnā koe

Inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders

Thank you for the opportunity to submit on the above Inquiry. The Kāpiti Coast District Council (the Council) supports the terms of reference and intention of the Inquiry. Our specific feedback on the Inquiry's terms of reference is provided here to help inform your approach to the Inquiry itself.

With an ageing population and increasing prevalence of such conditions, this is a huge challenge for our country, as well as for us at a local level. The negative impact of these conditions on the lives of those with them, and those around or supporting them, is often high and life changing.

The Kāpiti Coast district has one of the highest proportions of people over 65 across all local territorial authorities, and acutely feels the challenges in the provision of health care and services for this cohort. While this means we benefit from a number of care providers, we also suffer from the national challenges in staffing and limited higher level care for those with additional needs, such as neurological cognitive disorders. At a practical level, with some people actively supporting whanau to 'live in place' rather than in care, there is high impact on the day-to-day lives of people, such as more limited employment opportunities, and their overall wellbeing.

Our community has highlighted concerns around poor access to health services as a key issue on the coast, including the provision of health services for older people locally in our district.

The Council therefore considers it is essential that the Kāpiti community voice helps inform the important work of this Inquiry, the work of the Health Committee and wider work focused on improving health outcomes on the Kāpiti Coast.

1. **Appropriate services for people with neurological cognitive disorders across the care continuum including from home and community care to residential care, to palliative care.**

1.1. We support the breadth of this point. It is vital that the Inquiry assess all forms of relevant care services from in-home care (including support for caregivers) to palliative care. Council encourages you to include innovative, evidence based, approaches such as the social approach demonstrated in our district by providers like Home4All https://home4all.co.nz/.

1.2. Since August 2023, Council has embarked on a significant district community engagement exercise, *Vision Kāpiti,* to ask what matters to our people, and what they want to see for the future of our district. The gap in availability of health services has been a key theme that has come through in this work. This has been a consideration for our district for a number of years, and, for this triennium, has been a priority recognised by our Council. We note that:

- Brain Research New Zealand notes that by 2036 one in four New Zealanders over 65 will be affected by brain disorders like dementia (such as Alzheimer's and Lewy body dementia), Multiple Sclerosis, Huntington disease, Parkinson's, and the effects of stroke. By 2030, dementia alone will cost New Zealand $2.7 billion.

- The *Dementia Economic Impact Report 2020* estimated that by 2050 10% of over 65s will be living with dementia. The Council estimates the Kāpiti district's population will be around 64,000 in 2030 and around 80,000 by 2050. Kāpiti district's population has an older profile than the country's average with about 26% of the population over 65 years, compared to 15.3% nationally. The percentage over 65 years is expected to increase to 30% in the next twenty years.

- Using these metrics, Council expects for there to be around 2,400 persons within its district living with dementia by the year 2050 and around 6,000 with neurological cognitive brain disorders more widely.

- In consultation on a district-wide *Health Strategy* we have further evidence of Kāpiti's growing community concern around gaps in health services. In particular, Kāpiti has a significant shortfall of primary health services in the district and faces significant difficulty in accessing regional health services. In addition, our Kāpiti Health Advisory Group has considered health services for older people to be a priority for our district for some years.

1.3. Council is aware of five residential care homes in its district that offer dementia care. These tend to run in cycles of having some open capacity and then all being full. Some patients have to be moved out of their local community and away from support networks to access appropriate levels of care, especially palliative care. In addition, Council is aware that some in-home care needs can only be met by support services currently offered outside of our district.

1.4. The Inquiry should also be mindful of ensuring services have appropriate checks and balances in place to ensure those receiving services who are affected by neurological cognitive conditions are protected from elder abuse. These groups may be less able to speak out where conditions are progressed, and the design of services should take this into account.

2. Resources available and the ability for the health system to provide appropriate care and what support enables 'aging in place', including for priority populations.

2.1. **Lack of local services:** We understand that nationally only 13% of people living with dementia needing help, actually get it. While we do not have specific local statistics, we do know that Kāpiti's residents have to travel outside of the district for hospital secondary care and most specialist services, including diagnostic and neurological services and palliative care.

2.2. **Mechanism of service:** Our district's difficulty accessing health services would suggest that the Inquiry not only consider the funding and provision of neurological cognitive disorder services but also the question of their access: the where, when and how of getting to the services. Another question of access is how best to facilitate the in-home delivery of necessary services to those with neurological cognitive disorders 'aging in place'.

2.3. **Service Support:** For every person living with a long term neurological cognitive condition there is a primary carer, whānau and friends, all of whom need support to endure and cope daily as conditions progress. The impact of supporting a whānau member with a degenerative neurological cognitive condition can change the course of a person's life. Council knows that some take on care full time for their affected whānau, taking them out of their full-time careers, and putting them in a position of learning how to care for a person with these conditions without prior experience. This can take a huge toll, and Council has been concerned by the removal of respite funding options for those with disabilities announced by Whaikaha – the Ministry of Disabled People - earlier this year. The Inquiry should consider service support needs for caregivers as well as those 'with' neurological cognitive disorders. This should consider wrap around support for carers covering education, respite and specific funding. We would also like to see the Select Committee ensure the Inquiry is informed by the lived experience of carers. Council requests this as we support an 'aging in place' approach to keep people close to their support networks as much as possible.

2.4. **Priority for rural health areas:** The Ministry of Health has developed a Rural Health Strategy. This sets the direction for improving the health and wellbeing of New Zealand's rural communities over the next 10 years. Kāpiti meets the criteria for a Rural 1 district classification. The Ministry recognises that rural communities' health needs are often under-served, particularly in relation to accessing health services. Council submits that this Inquiry should give specific attention to the application of the five Rural Health Strategic priorities[1] within its assessment approach.

---

[1] Priority 1 – Considering rural communities as a priority group; Priority 2 – Prevention: Paving the path to a healthier future; Priority 3 – Services are available closer to home for rural communities; Priority 4 – Rural communities are supported to access services at a distance; Priority 5 – A valued and flexible rural health workforce.

2.5. **Consideration of disability in priority populations:** The terms of reference are not clear on the priority populations that will be considered in the Inquiry. We recommend that disabled people be included for consideration. Some younger people with disabilities can be placed in aged care facilities. While not meeting the criteria of being over 65. Disabled people can have other co-occurring conditions including neurological cognitive disorders and may require additional care. In addition some neurodevelopmental conditions such as Autism and Down syndrome are considered to be at an increased risk for some neurological cognitive disorders such as Alzheimer's or other dementia at a younger age. It is essential that workers in aged care facilities are equipped with the skills and tools to manage care for these people, to avoid risk of abuse or neglect.

3. The funding model, amount of funding available, including best practice. The process of applying for funding and care resources.

3.1. Council supports that the terms of reference include consideration of the funding model, amount of funding, and process for applying for funding. We also propose that the following considerations be formally stated as in scope:

- **Addressing variation and equity:** We expect that the Inquiry will also acknowledge the inherent difference in districts regarding such matters as demographic profile, levels of deprivation, rural vs urban etc to advance an equitable funding model. The funding model should differentiate appropriately to reflect the financial need of the various service providers, including addressing equity considerations. This should include consideration of equity for people with disabilities, many of whom experience increased financial challenges which can affect their levels of choice and control regarding remaining in their homes, or which facility they go to. This can increase the risk of isolation, and abuse or neglect.

- **Financial support:** The funding model should also address the financial support for the people with neurological cognitive disorders and their primary caregivers. This should be equitable and differentiated. For example, household income might be a determinant and any consideration of fixed assets should exclude the family home (as they do already for funding for rest home care). If ageing in place is to be encouraged, the funding model should support and not undermine this objective.

- **Incentives for living well in communities:** Council recognises that 'aging in place' with the support of whānau and friends is a more cost-effective way of managing a person with a neurological cognitive disorder. This includes the provision of appropriate local/community services, rather than through rest homes or other residential care options. We note that supporting people to live well in the community is a much more cost-effective option than residential care options. However, the transfer of 'cost' to whanau and those supporting people with neurological cognitive disorders in the home must also be considered – the impact can be high, as noted in an earlier point, to whanau and family, and the community more broadly. The cost could potentially be higher than that saved in relation to the noted residential care options, so we believe this should also be considered by the Inquiry.

- **Alignment to existing Action Plans:** We note the national Dementia Mate Wareware Action Plan and its focus areas of prevention (reduce the incidence of dementia) and

recognition of the impacts on care partners and whānau and the need for support. We encourage the Select Committee to consider this Action plan, jointly developed with stakeholders, in its Inquiry process, and how it can progress the aims of this work, as these will make a difference to those in the community affected by dementia/mate Wareware.

4. Projections for future needs for people with neurological cognitive disorders.

4.1. The Dementia Economic Impact Report 2020 states that evidence is emerging that up to 40% of dementia is preventable by reducing physical and psychosocial risk factors. This will vary by condition (for example the Stroke Foundation notes that over 75% of strokes are preventable), but Council considers that the Inquiry should report on any insights and learnings on relevant social determinants and prevention approaches that might help mitigate future service demand.

4.2. Council would be interested in these insights as it is a significant provider of population health infrastructure such as, green spaces, parks, walkways, cycleways and activity centres, and how it can contribute to supporting prevention of such conditions with the levers we have.

5. Kāpiti Coast District as a case-study

5.1. While it will be necessary for the Inquiry to proceed with a focus at the national level, the Kāpiti Coast is also well placed to be a local 'case study' to help central government understand the impacts of decisions at a local level.

5.2. Our challenges in primary health care services and dementia support services mapped against forecast demand for services for neurological cognitive conditions would provide a compelling insight into the localisation of the problems, options and solutions. We would also be very interested in a discussion of how local government's levers and tools can contribute to, including to prevention (through the provision of facilities and spaces to help people address modifiable risk factors) and supporting the development of an accepting community.

Council thanks the Health Committee for considering our submission on the scope of this important work. We would be happy to discuss the proposal noted in section 5 of this submission further with Select Committee.

Yours sincerely

Darren Edwards
Chief Executive
Kāpiti Coast District Council

Janet Holborow
Mayor
Kāpiti Coast District Council