Sue Pieters-Hawke
Speaker Writer Consultant

Dear Commissioners

I'm submitting this letter to your inquiry into "Aged Care for Older Australians" on the basis of the following:

- My personal journey as daughter, carer and advocate over about 13 years alongside my mother, who has dementia.
- As writer 6 years ago of a best-selling book about this journey, and subsequent opportunity to speak and listen to thousands of people living with dementia, their families and loved ones, carers, service providers, care-workers, nurses, researchers, GPs, educators and clinicians.
- Two and a half years as co-chair of the federal Minister's Dementia Advisory Group (MDAG).

Given this background I've had a privileged opportunity to gain a depth of insight into issues and practices surrounding dementia from a broad range of stakeholder perspectives. These perspectives lead me to the view that the prevailing societal attitudes to dementia, and too many of our personal and systemic responses to it, are dominated by the myth that dementia is a natural part of ageing, and also that dementia remains shrouded in negativity, stigma and lack of sound knowledge. Moreover, in my judgement there is a chasm between what we know is good dementia care practice, and most current practice, and that although some progress been achieved in recent years there are important priorities that remain to be addressed.

Several members of MDAG have submitted papers to you regarding their particular areas of expertise. Mine is more of general overview.

As regards your Inquiry, I have formed several conclusions, namely that –

- Dementia issues cannot be separated out from consideration of aged care reform, ie they interpenetrate so deeply that considering one necessitates considering the other;
- The need for dementia reform is not confined to aged care, and will not be sufficiently addressed if health care reforms do not play their part, for example in respect of primary care , community care, respite care, end of life care, acute care and dementia risk reduction;
- There is broad and deep concern across the community about dementia issues;
- Comprehensive dementia reform is essential if we are to eliminate much of the avoidable suffering it presently entails for people with it and the people who love them and care for them; and that
- The case for dementia and aged care reform is pressing, powerful and urgent for economic, ethical and social reasons.

Based on concerns and issues I consistently encounter across the sector, I strongly suggest that as a country we need urgently to commit to a two-pronged vision:

A) Ensuring systems which allow for equitable, affordable, best-practice dementia care, support and services for all Australians living with dementia, their families and carers (“a journey through the stages and impacts of dementia characterised by quality services, care and support, accessed easily and equitably by all Australians”) and

B) Striving to reduce future personal and taxpayer burden and costs, whilst ensuring that money spent accomplishes quality outcomes.

To help build towards this achievable vision I believe the Inquiry should address the following areas:

1. The **stigma** and ignorance attached to aging, and even more so to dementia. Effectively promote and protect values of ‘full personhood’, of respect, dignity, choice and human rights for all older Australians, including those living with dementia, across the whole Australian community. Clearly articulate the **intelligent self-interest** and responsibility of the **whole community** in embracing and participating in best-practice care and support of older Australians, where it is needed. Concentrate on abilities, capacities and humanity that persist in the face of age-associated disability, rather than reducing people to dehumanised, dis-abled statistics that need servicing. Highlight and promote opportunities for mutual responsibility and meaningful participation of all older Australians in the life of our community.

2. Revolutionising prevailing **attitudes, assumptions and behaviours** towards dementia by proactive campaigns to re-educate both the whole community and relevant professional and service sectors regarding current knowledge and best practice, attitudes to dementia, and to people with it. “Create a dementia literate and dementia friendly community”

3. Listen carefully to consumers and experts in the field as we build the reform process. Value government **partnership** with the peak sector consumer body, Alzheimer’s Australia, and with the federal Ministers Dementia Advisory Group, as rich sources of comprehensive consumer and sector representation, of service provision, research and innovation know-how, and of the intellectual capital required to inform meaningful reform planning. Involve stakeholders actively in the reform process.

4. Take **initiatives aimed at reducing prevalence and burden**: risk reduction, prevention, onset delay and symptom mitigation. These fall primarily into - educating and promoting for preventative body and brain health behaviours; funding research at levels proportionate to prevalence and projections; and distress reduction by a) adoption of best practice behaviours towards and care of people with dementia and b)proper carer support.

5. Implement reforms designed to ensure **timely diagnosis and effective integrated responses** as the condition progresses. Includes attending to issues including: availability and awareness of information; training and incentivisation of GPs and Practice Nurses; availability of specialists; multi-disciplinary team building in all relevant sectors; methods of diagnosis; communication of diagnosis; adequate pathways of appropriate referral; case management; carer and family support; support to identify needs and access services, supports and facilities as needs change; simplification and improvement of information provision and service pathways.

6. Take measures to **ensure hospitals that are safe and appropriate** for people with dementia, thereby reducing unnecessary danger, burden, distress and endemic waste. (Cognitive Impairment Identifier and training program implemented in some Victorian hospitals is a very good model that could be rolled out nationally).

7. The fact that we already rely enormously on the **unpaid care provided by families**, often at intolerable levels of personal burden and family stress, and often at significant health and workforce participation costs. This largely unsupported reliance is set to be strained further by demographic shifts re ratio of available carers to persons needing care.

8. The widespread dissatisfaction about the **configuration of respite options**. The need to build options that are appropriate and responsive to the circumstances and needs of carers and people with dementia, and that embed opportunities for constructive engagement for people with dementia into the respite care experience.

9. Vastly **unequal access to dementia services and iniquities in quality of services**. Attention to the specific needs of particular groups such as younger onset dementia, CALD and ATSI populations, people living alone, people with low or no income, remote and regional populations.

10. Create sufficient methods and **supply** of equitably available, quality community based care and supports based on a recognition that the various dementia journeys often require a **diverse and flexible suite of services** and supports as needs and capacities change.

11. Proactively generate **alternatives and choices in the domain of residential care** away from demeaning and often premature warehousing of people with dementia in outmoded models of residential care. Move towards ensuring sufficient supply of appropriate residential living and care facilities based on best-practice models here and overseas and on the diversity of consumer needs and preferences.

12. Get intelligent about **regulation!** The regulatory and risk-avoidant culture of Aged Care has become so pervasive, especially in residential care, as to mostly displace innovation, initiative, individuality, human relationships, individual attention – in fact, “Care”. Task completion and regulation fulfilment focii operate powerfully to displace the time and inclination to focus on people and their needs. ‘Person centred care’, initially conceived as a paradigm for orienting care to its real purpose, has unfortunately mostly devolved to another thing to do. As a leading educator in the field said recently – “You can’t ‘do’ person centred care. Either you’re person centred, or you’re not.” Despite the fashionable rhetoric and lip service, our systems and most facilities are not.

13. The need for an active process of **culture and practice change** throughout all areas of service provision relevant to dementia, aimed at achieving outcomes where all services achieve best-practice quality, which is now only sporadically available in a minority of settings. There are isolated instances in Australia of world best practice care, costing no more than the mediocre standard that prevails. We should be drawing heavily on the research, the evidence, the exemplars, and working to make best practice the norm.

14. Confront our attitudes and practices towards **people living and dying with late stage dementia**, including specifically the underprovision of palliative care for

dementia patients, and the wholesale neglect of opportunities for engagement and meaningful human connection which are desperately needed at this time.

15. Create a **workforce** adequately selected, trained and supported to provide appropriate aged and dementia care and services. Create career pathways for nurses, clinicians, careworkers, and allied health professionals in aged and dementia care, and work towards appropriate remuneration across the sector. To achieve quality of life for all older people (with or without dementia), and especially those in residential aged care, we need a workforce that is dementia friendly, dementia literate and dementia skilled. At the moment, the capacity of any aged care facility to provide good dementia care and therefore maintain a caring environment for all its residents is a matter of hit and miss. I have lost count of the cases of inadequate care and distress this has caused that have come to my own attention.

16. Fund appropriate levels of targeted **thinking and research**, valuing innovation and promoting concrete translation of **knowledge into practice**, especially regarding:
    i. Causes, prevention, risk reduction and management, onset delay, symptom management.

    ii. Psychosocial and multi-disciplinary models of intervention, care and support. Build on the evidence that they work!

    iii. Innovative models of care, supports and services and of innovative means of delivery and empowerment of such.

    iv. The level and mix of service supply sufficient to properly meet needs.

    v. Overcoming barriers to accessing care and services and to sustaining quality of life generally, and especially amongst particular sectors of the population with distinct or specific needs or circumstances eg CALD, ATTSI, remote and regional, Younger Onset Dementia, low income people with dementia, people living alone with dementia.

vi. Pro-actively maintaining the quality of life of people living with dementia, their families and carers throughout the dementia journey.

vii. Enabling the cultural and organisational change needed to underpin transition to an equitable best-practice systems.

viii. Models of future funding.

ix. Creation of “dementia friendly communities” (eg Japanese initiative)

The time is right to build on the best of what has been learnt within the sector and in the delivery of the Dementia Initiative – Making Dementia a National Health Priority; in the face of projections re future prevalence; and in the context of opportunities created by the Health reforms. I look forward hopefully to this Inquiry’s contribution to that process, and thank you for the opportunity to submit.

Warm regards,

Sue Pieters-Hawke