NSW GOVERNMENT | Health

Submission No. 095
(Dementia)
Date: 15/06/2012

NSW Health
Submission to the Parliament of Australia

Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

June 2012

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Summary

NSW Health has invested significant energy in the development of the NSW Dementia Services Framework 2010-2015. A copy of the Framework is available on the NSW Health website: http://www.health.nsw.gov.au/policies/gl/2011/GL2011_004.html.

This Framework sets the vision and direction for improving the quality of life for people with dementia, carers and families in NSW. It is underpinned by a set of principles that emphasise quality dementia care and is contingent on being responsive to the needs and experiences of people with dementia, carers and families.

The House of Representatives Standing Committee on Health and Ageing has been set the task of investigating dementia, its early diagnosis and interventions, with a particular focus on how early diagnosis and intervention can improve quality of life.

NSW Health is using early diagnosis in this context to refer to diagnosis when concerns are raised or symptoms appear, not to preclinical diagnosis using cerebrospinal fluids and imaging biomarkers. These biomarkers are relevant in research rather than clinical settings, except where there are genetic issues involved.

NSW Health does not support population-level universal dementia screening of older individuals as the sensitivity and specificity the screening tools available would lead to many false positives, causing undue distress and unnecessary follow-up assessment costs. Instead, a "case-finding approach" is recommended where the General Practitioner acts on concerns raised or on symptom presentation.[1]

NSW Health does support the screening for cognitive impairment of people over 70 on admission to hospital due to the high risk of dementia and/or delirium in this group.

Early response to concerns regarding an individual's cognitive status through diagnosis and follow-up support is important and can improve quality of life for people with dementia, as well as for family members and carers.

As described in the NSW Dementia Services Framework Principles, NSW Health supports that the NSW population should have **equal** access to '*competent and timely, multidisciplinary assessment, diagnosis, care management and support services.*'

While significant barriers exist to early diagnosis[2] and support, there are a number of strategies that can be implemented at National, State and local levels.

Initiatives currently exist in NSW that provide access to diagnostic and intervention services that assist people with dementia to remain independent, socially engaged and active participants in community life. However, there is limited coverage across NSW with existing services reporting overwhelming demand and access issues for specific population groups.

NSW Health recommends the Standing Committee endorse reform strategies which provide every Australian experiencing symptoms of cognitive decline with equitable access to

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[1] Timely Diagnosis of Dementia: Can we do better? by Dr Jill Phillips, Professor Dimity Pond and Ms Susan Goode. A report for Alzheimer's Australia Paper 24 September 2011

[2] "Early diagnosis" is being used in this context to refer to diagnosis when concerns are raised or symptoms appear, not to preclinical diagnosis using cerebrospinal fluids and imaging biomarkers. These biomarkers are relevant in research rather than clinical settings except where there are genetic issues involved.

competent and timely, multidisciplinary assessment, diagnosis, care management and support services.

Introduction

When people or family members seek help with symptoms of dementia they usually consult their General Practitioner (GP). Current Australian research has confirmed that GPs under-diagnose dementia and do not refer to community support services.[1] There are numerous reasons for this including lack of time, remuneration or confidence, or uncertainty of the benefits for their patients.

It is important to remember that there is no definitive test for diagnosing Alzheimer's disease or any of the other causes of dementia. Findings from a variety of sources and tests must be pooled before a diagnosis can be made, and the process can be complex and time consuming.

Referral pathways for specialist diagnosis and assessment may not be available or poor communication experiences may discourage referral.

In NSW there is considerable regional variation with some areas well resourced with specialist memory clinics, while in other areas people may struggle with timely access to a GP with ad hoc specialist outreach to their area.

Lack of diagnosis and referral can prevent access for a person with dementia and carer to important information regarding planning ahead in terms of future financial and care arrangements, to early support programs such as living with Memory Loss Programs, and to carer education, counselling, behavioural advice and community support services.

A diagnosis should be the beginning of a process that leads to assistance to adjust to living with dementia and to good clinical management of dementia as a chronic, complex condition. It allows compensatory measures to be introduced in a planned and orderly manner.

Memory problems may interfere with a person remembering to take important medications for diabetes, heart disease or high blood pressure. Early diagnosis can alert carers and health professionals to review current medication taking and implement systems to address issues before problems arise due to medication omission, which is critical to chronic disease management.

There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process. These medications may assist to maintain daily function and quality of life, in addition to stabilise cognitive decline in several people. However, they are not suitable for everyone and they are not a cure. Early diagnosis allows for prompt access to medications and medical attention.

Early diagnosis can also help in the management of other symptoms which often accompany the early stage of dementia, such as depression or irritability.

A diagnosis is an important trigger for GPs and other health professionals to undertake Advance Care Planning and provide people with the opportunity to communicate their wishes. Advance Care Planning can reduce potential conflict in future end of life management decisions and enable decisions to be made based on a person's values and preferences.

Planning ahead for a time of future incapacity to make one's own decisions about medical treatment and care should be a high priority for improving care for people with dementia, given that loss of decision-making capacity is an inevitable aspect of this disease. Advance

Care Planning is a key early intervention strategy to support people with dementia, their families and carers to plan ahead for healthcare decisions.

Proactive follow-up after diagnosis provides an opportunity to involve the extended family in discussion on how they can support the person and carer to optimise their quality of life and to help make decisions, such as moving closer to children while a person can still adjust to a new environment.

People with dementia may experience a range of behavioural symptoms, referred to as Behavioural and Psychological Symptoms of Dementia. Early intervention through carer and worker education and referral to specialist services, when required, can improve quality of life.
Lack of early intervention increases the likelihood of the use of more intensive and costly services such as unplanned crisis admissions to hospital and/or premature placement in residential care.

People with younger onset dementia (YOD) before the age of 65 experience greater difficulty and delay in obtaining a diagnosis. Some dementias are more difficult to diagnose, such as fronto-temporal dementia because they can present with prominent behavioural symptoms that are out of proportion to the cognitive signs and without memory deficits. The lack of affordable neuropsychological services is particularly relevant for people with YOD.

People with dementia, their families and carers report the benefits of a diagnosis; the relief in knowing what is wrong; the trigger it provides for referral to support services; and the opportunity to plan ahead and sort out legal financial and future care arrangements. It also allows for consideration of medication and an opportunity to address issues such as transition from driving or future work responsibilities, if a person has younger onset dementia and is still working.

However, if a person communicates a preference not to know of a diagnosis, this should be respected.

Consultations for the NSW Dementia Service Framework 2010 – 2015 confirmed lack of and delay in diagnosis, resulting in missed opportunities to plan ahead for care requirements and the subsequent late presentation to services, often in crisis.

Service providers reported the difficulties that families face if financial arrangements such as Enduring Power of Attorney are not in place and the person no longer has capacity to manage their affairs.

In the consultations for the Framework, carers valued proactive follow-up after diagnosis when it occurred, while other carers reported they usually made contact only when desperate or in a crisis. Carers consistently report the importance of a key worker - a person with whom they can establish a continuing relationship, who can counsel, problem solve and sort through the myriad of issues that arise. Key workers are also influential in encouraging carers to join in education and support opportunities. Support of this kind can delay residential care placement.

Key priorities identified in the development of the Framework relevant to this Inquiry included:

- Creating greater community awareness of dementia that reduces stigma;
- Strengthening access to skilled dementia health experts to improve assessment, diagnosis and management; and
- Providing a key worker to support people with dementia, carers and families to enable continuity of care over the "long haul".

Supporting people with dementia, carers and families requires a co-ordinated and planned approach across health services (primary care, specialist health and mental health services for older people) and community care services, that also considers the important interface with residential aged care.

Funding and policy responsibility for health, community and residential services extends across both Commonwealth and State Governments, with considerable investment in supporting carers and the delivery of these services in collaboration with non-government organisations (NGOs).

The NSW Dementia Services Framework, jointly developed by NSW Health and Ageing Disability and Home Care, sets the directions for developing quality dementia care and outlines outcomes, service requirements and actions that span across both National and State areas of responsibility. The outcomes sought relevant to the Inquiry are at **Tab A**.

The challenge is to find solutions within the context of the significant, expected increase in dementia and potential improvements resulting from the implementation of the health and aged care reforms.

The following strategies are extracted from the NSW Dementia Services Framework 2010 – 2015.

Suggested strategies for improved diagnosis in relation to Commonwealth responsibilities for primary care:

1. Easier access to guidelines, screening instruments and referral forms in software used by GPs.

2. Effective use of Medicare Benefit Scheme items such as health assessments, management plans and team care arrangements.

3. For the minority of GPs who choose to take the lead and be actively involved in dementia diagnosis, greater incentives to undertake dementia assessment, diagnosis, ongoing management and referral to support services through:
   - Enhanced status subsequent to training.
   - Adequate remuneration for assessment, diagnosis, carer consultation, referral and joint care planning time and for Advance Care Planning discussions.
   - In group practices with practice nurses and GPs may delegate assessment and referral to practice nurses who could be upskilled and supported in this role.

4. Alternatively, expansion of Dementia/Aged Care Dementia Nurse Practitioner models.

Other potential National strategies include public awareness of Advance Care Planning, use of the patient controlled electronic health record and liaison with NGOs to support people with dementia, their family and carers to communicate early with health care professionals about planning ahead.

Strategies for consideration involving joint partnerships between Commonwealth and State Health Services, with potential involvement of Medicare Locals:

1. GPs and practice nurses could be supported through integrated multidisciplinary care models where dementia health experts, such as community dementia nurses and/or allied health professionals, can undertake a comprehensive assessment and have

access to consultation with medical specialists, such as geriatricians, if diagnosis is unusual or difficult, or psychogeriatricians for psychotic or severe behavioural issues.

2. Ideally GPs/practice nurses and Aboriginal Medical Services could link with a multidisciplinary team that could include:
   - Dementia Community Clinical Nurse Consultant who provides education and consultation.
   - Dementia community nurses to undertake comprehensive assessment and diagnosis for straight-forward cases.
   - Allied health professionals.
   - Behavioural specialists eg., Dementia Behavioural Management Advisory Services, Behavioural Assessment and Intervention Service.
   - Access to geriatric and psychogeriatric Medical Specialists who can review cases with the community dementia nurse to confirm diagnoses and see people where the diagnosis is uncertain, or difficult, where medications are being considered and if there are psychotic or severe behavioural symptoms. The community dementia nurses and where required other team members, would undertake a comprehensive assessment prior to the Medical Specialist, outpatient or home visit appointment.

3. Integrated models would need to be appropriate for rural settings and provide access for culturally and linguistically diverse and Aboriginal populations through interpreter time, outreach and liaison. In rural areas, the model would be dependent on improved access to these Medical Specialist positions, either through increasing the number of positions particularly in rural areas or improving access through recent tele-health initiatives.

4. Development of the key worker model. A key worker is a person with a nursing or allied health[2] qualification, skilled in dementia care, works closely with the person's GP/ Aboriginal Medical Service, proactively follows up after diagnosis and builds a continuing relationship. The key worker case manages care needs as they increase and/or become complex.

   As mentioned previously key workers can counsel, problem solve and sort through the myriad of issues that arise. An important aspect of the role is to assist people with dementia to remain independent for as long as possible. This may involve educating carers and family members to recognise the person's capabilities, to break down tasks into manageable chunks and not take over, to assess risks and to create a supportive environment as outlined in *At Home with Dementia* (http://www.adhc.nsw.gov.au/__data/assets/file/0011/228746/at_home_with_dementia_web.pdf). Key workers can also educate carers on how to respond appropriately to behavioural difficulties that commonly arise.

5. Generic health and community care workers, including Transitional Aged Care workers are trained to recognise symptoms of possible cognitive impairment, consult experts and refer (with consent).

6. GPs, health and community care staff are trained in Advance Care Planning and know the legal requirements.

7. Advance Care Planning is a key early intervention strategy to support people with dementia, their families and carers to plan ahead for healthcare decisions. NSW Health has developed a 5 year strategic and implementation plan (draft *Advance Planning for Quality Care at End of Life: Strategic and Implementation Framework)* that provides the policy context in which Advance Care Planning will be implemented in NSW, including the dementia sub-group.

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[2] "Allied health" includes positions such as social work, psychologist, occupational therapist in the community care sector

Strategies relevant to Local Health Districts (LHDs):

1. Establishment or strengthening of existing local Dementia Services Networks to include representation of primary care, Medicare Locals, National and jointly funded aged care services, State specialist health services and State community and disability services to enhance more timely referral, local service coordination and planning.
2. Development of local dementia plans.
3. The development of local dementia diagnosis, assessment and referral pathways agreed to, promoted and implemented at a Local Health District level.
4. Initiatives with Medicare Locals to improve diagnosis and dementia care at local level.

These strategies for LHDs are included in the draft implementation plan and are already underway in a number of LHDs.

For example, local dementia networks are in existence in Bega Valley, Eurobodalla and Goulburn and an Aged Care Network exists in Queanbeyan. Resources such as information brochures and the running of dementia community awareness events have evolved through these networks. A regional network meeting is held six monthly.

Current practices in NSW Health that support early diagnosis and intervention

- Many LHDs deliver regular public education forums to educate the concerned public about normal ageing and memory loss and how to access assistance if required. LHDs also partner with Alzheimer's NSW for Dementia Awareness Week and staff of specialist health services for older people also partner with Alzheimer's NSW to facilitate Living with Memory Loss Programs.
- A range of multidisciplinary clinical teams and services, which can include experienced medical clinicians (with expertise in both cognition assessment and general medical skills), psychologists, social workers, occupational therapists and nurses with access to imaging, neuropsychologists and old age psychiatrists. This expertise and these structures are found within specialist health services for older people. Access to comprehensive multidisciplinary teams is limited to metropolitan and regional areas. For example:
  - The Central Coast Dementia Care Service provides a comprehensive assessment in the client's home. A copy of the report is sent to the GP to assist in diagnosis and referral to specialists services. The health professional is also able to support the client and carer through the journey ahead.
  - At Nepean Hospital the Virtual Age Care Service (VACS) is a specialist service with a multidisciplinary team supporting patient and carers at home (either in the community or Age Care Facilities). If patients with dementia require hospital admission they are admitted via the Emergency Department Medical Assessment Unit (EDMAU), bypassing the Emergency Department. In EDMAU dementia patients are assessed, managed and then sent back to their home as soon as possible.
- Specialist outpatient and memory clinics, for example:
  - The Concord Cognitive Disorders Clinic (CCDC). In addition to medical and neuropsychology expertise, dedicated social worker support and access to other allied health, the CCDC has strong links to the in-home and centre based respite

  services and the education and support provided by the Sydney LHD dementia advisory services and Aged Care Assessment Team, and home therapy teams.
  - Geriatric Memory Clinic with a dementia nurse specialist and Geriatrician in the Wyong Shire.
  - Joint Geriatric/Neurological Outpatient Clinic targeting early diagnosis. Access to Geriatrician, Neurologist, Neuropsychological testing, counselling and advice from a dementia nurse specialist (Gosford Shire).

- Limited specialist outreach to rural areas. An example is the sessional Geriatrician clinics held in Southern NSW in Bega Valley, Eurobodalla, Cooma, Bombala, Braidwood, Queanbeyan and Goulburn which support early diagnosis and intervention. These occur monthly to three monthly.

- Integrated care models such as the Newcastle model consisting of Registered Nurses called Community Dementia Nurses (CDNs) supported one Clinical Nurse Consultant (CNC) Dementia. The CDNs work from their local Community Health Centres with close connections with Practice Nurses. There are geriatric clinics held weekly to correspond to the geographical location of the CDNs.

- Effective service models being implemented in NSW which contribute to improving the quality of life for people experiencing Behavioural and Psychological Symptoms of Dementia, their families and carers, as well as support longer term or intensive care requirements. These include Behavioural Assessment and Intervention Services, the Dementia Behaviour Management Advisory Services Program and the Mental Health Aged Care Partnership Initiative.

- Recently established Community Dementia CNC positions. The role of the Community Dementia CNC is to improve outcomes for people with dementia, their families and carers through leadership, clinical advice, consultation, education and support of other professionals in the provision of evidence based dementia care.

  This will be achieved through supporting the provision of comprehensive assessment, timely diagnosis, appropriate case management, timely referral and provision of support services that can prevent escalation of crises, reduce carer stress and enable a person to remain in the community for longer. CNC positions will stress the importance of early carer support, early consideration of future care planning and legal issues and general health monitoring, medication review and appropriate treatment of co-morbidities.

- Dementia/Delirium Acute CNCs in some rural areas have established links with GPs and Practice Nurses in supporting early diagnosis and intervention and to provide education and community awareness regarding dementia, early diagnosis and intervention.

- Limited neuropsychology services working collaboratively with geriatricians and psychogeriatricians and local mental health and aged care teams to assist in differentiating between cognitive, physical and mental health issues (For example, positions within Specialist Mental Health Services for Older People in Southern NSW and Murrumbidgee; and a position funded through COAG Sub Acute psychogeriatric funding in New England).

- Employment of Nurse Practitioners in Aged and Chronic Care.

- Early intervention initiatives such as 'Early Intervention Focus Talks' for clients with memory loss/dementia and their carers on the Central Coast. These talks provide information on normal aging, memory changes; mind your mind, an introduction to resources and future planning.

- Regular carer support groups providing education, information, guidance and support.
- Hunter New England LHD has created nine part time Dementia Support Worker positions, funded through COAG Sub Acute psychogeriatric funding distributed across the Hunter New England and aligned either with Aged Care Assessment Team or Community Health Services.
- NSW Health has recently conducted an End of Life Decisions Policy Review. This has taken into account the standards imposed by the Australian Health Ministers' Advisory Council *National Framework for Advance Care Directives*, while also taking account of broader concerns around Advance Care Planning and its implementation. The Review has been completed and the (draft) NSW Health Advance Planning for Quality Care at End of Life: Strategic and Implementation Framework finalised. The associated implementation plan currently being with the Pillar agencies. This Framework aims to strengthen Advance Care Planning as a standard component in the management of chronic life limiting illness. The dementia cohort or sub-population is one of the groups to whom this Framework's implementation will be targeted. This draft document can be found at: http://www.health.nsw.gov.au/ pubs/2011/pdf/endoflife_care_fw.pdf. Relevant themes and issues are summarised at **Tab B**. NSW Health has also developed Advance Care Planning resources.

Other practices in NSW that support early diagnosis and intervention

- Dementia Advisory Services funded under the Home and Community Care (HACC) Program provide an important role in:
  - promoting local awareness of dementia;
  - providing information, education and support; and
  - linking people to assessment and support services.
- Alzheimer's NSW also receives HACC funding to undertake dementia awareness activities across NSW.
- The key worker model is performed by a number of HACC funded dementia community nursing positions and by Dementia Advisory services to varying degrees. However, demand vastly outweighs supply, limiting capacity for proactive follow-up and ongoing case management role.

Interventions to assist people with dementia to remain independent for as long as possible and to increase opportunities for continued social engagement and community participation for people with dementia.

Points to consider:

- Inclusion of carers and families in assessment and diagnosis and ongoing management.
- Practical support strategies to assist people with early diagnosis of dementia to prepare Wills, Enduring Power of Attorney, Enduring Guardianship, Advance Care Plans.
- Information/education and support services for carers/families to assist them to care for their family member or friend with dementia. *(Currently many regions have long waiting lists for community care packages and respite care. Current resources are not able to*

meet the needs of the existing population with a known diagnosis of dementia. Early diagnosis alone will not improve the situation).

- The importance of the outdoor and community environment and the proximity to shops and health care.

- Community care that is flexible and person centred. Note Ageing, Disability and Home Care's Younger Onset Dementia Person Centred Packages. Maintaining social connections and supporting family members are key objectives through a packaged approach with a case management and brokerage model.

- There are also an increasing number of models within the HACC program aimed at meeting diverse needs and providing opportunities for social engagement, such as cafes and continued leisure activities. For example, the On-Track Dementia Café held at the Kokoda Track Café at Concord (co-ordinated by the Sydney LHD Dementia Advisor) is an established, effective and highly regarded model.

- Access to affordable safe transport options when a person can no longer drive.

- Education of front line staff such as bus drivers and police and staff in banks, pharmacies.

- Education for friends and community members on how to support a person with dementia to continue to participate in activities they enjoy, recognition of limitations and strategies to compensate so the person with dementia can participate.

- Partnerships between aged care and mental health services are particularly important in the care of older people with Behavioural and Psychological Symptoms of Dementia and people with co-morbid physical and mental health issues.

- Stratified delivery of education for health professionals according to the level of involvement in Advance Care Planning.

How best to deliver awareness and communication on dementia and dementia-related services into the community.

- The NSW Dementia Services Framework recommends an evidence based, positive national dementia awareness campaign that informs people that there are interventions that can make a difference and to see their GP if concerned. Any campaign needs to be balanced by an understanding that most older people do not develop dementia.

- Planning for the future and putting mechanisms in place should be encouraged as a normal practice as we grow older. The NSW Government has launched a planning ahead toolkit (website: http://www.planningaheadtools.com.au/) that provides information and tools on wills, advance care plans, Power of Attorney and Enduring Guardianship.

- Commonwealth Community Dementia Grants have funded local awareness strategies for specific population groups that include resources that may be of benefit to other groups. Evaluation of the grants program could ascertain the sustainability of these strategies and effectiveness in increasing awareness for specific population groups.

- In NSW the HACC funded Koori Dementia Care Project has commenced to build capacity in six urban and regional Aboriginal communities to respond to dementia.

Tab A

NSW Dementia Services Framework 2010 – 2015 Outcomes

Outcomes relevant to the Inquiry include:

- The public understands memory loss (normal ageing versus early dementia), knows help is available and consults their GP/Aboriginal Medical Services (AMS) when concerned.
- Any public awareness campaign is balanced by an understanding that most older people do not develop dementia. However, people are encouraged to plan ahead and put mechanisms in place in case they lose capacity including Advance Care Planning.
- Regardless of age, when a person, their family, or carer raises concerns with a GP, AMS or other professionals their concerns are taken seriously and investigated.
- A person experiencing cognitive impairment has timely access to a GP who can investigate, assess, and diagnose. For many GPs, practice nurses may conduct some of the initial assessments **or** the GP refers the person to an accessible dementia health expert who can conduct a culturally sensitive comprehensive assessment and diagnose in a timely manner whether the person has dementia and if so what type. The dementia health expert liaises with GPs regarding appropriate investigations, undertakes a culturally sensitive comprehensive assessment and determines the type of dementia.
- A person's carer is interviewed as part of the assessment and the carer's own physical and emotional wellbeing is assessed. Strategies are identified to maintain a person's health and wellbeing.
- Once the diagnosis is made, the person, carer and/or key family members are informed sensitively through a case conference. However, if the person communicates preference not to know of a diagnosis, this is respected.
- There is efficient and clear communication between the GP and the dementia health expert.
- Persons with dementia, carers and/or key family members are included in the development of the multidisciplinary care plan, are given a key person for further contact when issues arise and are advised when to expect a review of their care plan. They are provided with timely and culturally sensitive information.
- People with dementia, carers and/or family members are proactively followed up after diagnosis by a key worker with whom they can build a continuing relationship. The key worker is a person who has a nursing or allied health qualification, is skilled in dementia care and works closely with the person's GP.
- As care needs increase and/or become complex, the key worker provides assistance and is a case manager who negotiates an individualised appropriate package of care that is monitored, reviewed and includes access to health care.
- People with dementia, carers and/or family members are given culturally-appropriate verbal and written information on diagnosis. They are given adequate time and ongoing opportunity to discuss the information that includes:
    - Signs and symptoms of dementia, the anticipated course and prognosis, treatments, management of co-morbidities.

  - Specific information on wills, Enduring Power of Attorney, Enduring Guardianship and Advance Care Planning.
  - Capacity to drive and, if relevant, to work (especially for YOD).
  - An emphasis on maintaining quality of life, social engagement, independence and function.
  - Local community support services.
  - Financial assistance.
  - Needs of children for people with YOD.

- People with dementia, carers and/or family members may experience grief, loss, conflict and/or relationship breakdown. They are informed of and if they choose, referred for telephone, face-to-face, individual or group-based counselling and this is available for both people with dementia and their carers.

- Carers are encouraged to think about their own physical and emotional wellbeing, to involve other family members, to maintain friendships, to make use of respite and other support services and take up available educational opportunities.

- People with dementia, carers and/or family members have the opportunity to meet other people with dementia and their families following diagnosis.

- Carers are provided with support to enable them to maintain their own health, and physical, emotional and social well being.

- People with dementia, carers and/or family members are told whom to contact when issues arise and are proactively followed up after diagnosis. The key worker is a person with a nursing or allied health qualification, skilled in dementia care and who works closely with the person's GP.

- If competent, people with dementia appoint one or more Enduring Power of Attorney and Enduring Guardians, complete an Advance Care Directive and/or discuss their future preferences for health care treatment with their family/GP. People understand their legal right to accept or refuse treatment.

- People with dementia, carers and/or family members are provided with practical support, financial assistance if eligible, information and counselling along the pathway, as needed. For example, carers have access to support services, counselling and support to cope with guilt, grief and loss associated with residential care placement.

Tab B

Themes and lessons from the End of Life Decisions Policy Review

The End of Life Decisions Policy Review has developed through three phases of consultation. Feedback from community organisations and individuals may be of particular interest to this Inquiry. The themes outlined below have informed how a range of activities will be prioritised in implementing the Framework in NSW. These themes include that:

- Death is an inevitable part of life and this awareness needs to be gently brought back into managing chronic life-limiting illness.
- More awareness about the common clinical course of specific diseases would empower patients to be in a position to plan ahead for what may come.
- Starting conversations before the need for crisis care arises is necessary and helps families.
- Eliciting preferences about future care in the event they can no longer make decisions should be normalised as part of routine health checks. Consumers expect their health professionals to raise Advance Care Planning with them.
- Having effective conversations requires privacy; health professionals who are good listeners, willing to be honest, and empathic; and importantly enough time. A common theme was `heath care on the run' and how rushed clinical encounters were very common and not conducive to these conversations.
- Narrative is powerful. Ways need to be found to make personal stories more accessible to the public if cultural change around the taboo on 'death talk' is to change.
- Stories about planning ahead, how advance planning can help prepare and deal with illness and decline, and about dying 'well' are needed.

Some additional lessons that have emerged from this Review that may be of interest to the Inquiry include:

- Lack of clarity across populations of patients with chronic disease, including dementia, that they can plan ahead for a time of future incapacity and how.
- Insufficient understanding amongst health professionals and the public about the guardianship provisions in NSW (and probably elsewhere), and how families and other substitute decision-makers may be involved in making decisions.
- Health professionals' discomfort in having Advance Care Planning conversations and reluctance to discuss dying. Health professionals in NSW are seeking practical tools and resources to assist them in these conversations.
- Difficulties identifying 'approaching end of life' where death is likely in the next 6-12 months means that a model for activating Advance Care Planning should not be contingent on being able to do so.
- Low understanding amongst clinicians about how, in practice, to interpret and use an advance care directive or advance care plan when making clinical decisions.

- High level fear - largely unfounded - amongst clinicians of legal exposure and family complaints in discussing and documenting end of life concerns.
- Documentation problems, such as lack of standardisation, poor continuity and not recognising authoritative documents on patient transfer between care settings.
- Advance Care Planning and specialist palliative care are complementary. Increased uptake of Advance Care Planning is likely to lead to increased demand for palliative and community care and forward planning of services is needed to accommodate this likely trend.