**Canterbury's Dementia Care Pathway -it is time to develop it further.**

**Briefing paper for CCN's Aged Care Workstream**

**Matthew Croucher 20th June 2013**

Background

The CDHB has had a Cognitive Impairment Clinical Pathway aimed at facilitating GP-based primary care assessment and diagnosis of dementia for two years, hosted by the Healthpathways internet resource. See: www.canterburyinitiative.org.nz or access it via the CDHB intranet

This is the most accessed clinical pathway on the network and has been associated with more use of recommended assessment tools such as standardised blood screening, CT Head scans, and formal cognitive testing; higher GP engagement with the process of diagnosing dementia from some practices; more referrals to Alzheimer's Canterbury; and more prescribing of the cognition enhancing medication Donepezil.

The main problems with the system that have been thrown into sharper relief by this pathway are that there are limits to the capacity of GP practices to manage the relatively challenging aspects of the assessment of dementia, especially relating to time and staff pressures, and to fee-for service funding; there is a particular lack of understanding about the clinical utility of the CT Head scan in the assessment process; and there continue to be barriers to diagnosing dementia that appear to rest in part on stigmatising attitudes and beliefs. Of these, the most important appears to be the false belief that there are no effective treatment or management strategies to be offered to people with dementia. There are also some signals that health practitioners may also fear damaging effects of making a diagnosis upon the therapeutic relationship.

Meanwhile, the Ministry of Health and the National Dementia Cooperative have collaborated to write a National Dementia Care Framework. The final version of this is soon to be released but in essence it highlights that diagnosis is but one part of the journey that people living with dementia and those that care about them must negotiate. It also discusses the potential for a "health navigator" role to assist people with dementia and their supports to negotiate what is available to help them. The Ministry has required that all DHBs have an overarching dementia care pathway which must incrementally develop until they approach the coverage outlined below:



It is untrue that there is nothing available for people newly diagnosed with dementia in Canterbury - access to formal needs assessment, specialised psychiatric review, social work review and specific educational and supportive interventions (mainly via OPH&RS and Alzheimer's Canterbury) augment the Cognitive Impairment Clinical Pathways' support of cholinesterase inhibitor trialling and assessment of driving capability directly from GP-based primary care. In addition to this, health navigation is shared between GP-based primary care (in a relatively informal sense) and ALzheimer's Canterbury (in a more formal sense), although both rely primarily on client-initiated contacts.

However, there are significant gaps in what is available including many elements of comprehensive services that are discussed in the National Framework. These include the lack of availability of Cognitive Stimulation Therapy (except from a small private sector); the lack of availability of structured support to engage in healthier eating, healthier alcohol and other drug use, dementia-friendly exercise, dementia-friendly falls prevention, enhanced socialisation, enhanced preventative and opportunistic general health care, and improved medication management including adherence strategies and dementia-friendly polypharmacy reviews. Services exist to support several of these aims generally, but the community of people living with dementia, especially those newly diagnosed, represent a high-risk group that would benefit from tailored approaches.

The Minister announced via the 2012 budget that savings made from the National Pharmaceutical budget must be spent on dementia care pathways work, which for the CDHB amounts to a sum of $276K. Although this is a notional sum, the Ministry has nonetheless signalled its interest in receiving information about how it has been spent appropriately. The Ministry is also currently laying out how extra funds announced in the 2013 budget for dementia education and dementia services are to be spent - these are not yet clear enough to be itemised or given a dollar value.

The MoH and the South Island's Health of Older People Service Level Alliance hosted a regional workshop on 7th March to share ideas and encourage each DHB in its work to take their local dementia care pathways to the next level. Initial discussions among Canterbury stakeholders began then. This local group met again on 24th April to discuss our CDHB response in more detail. This briefing paper draws this work together as well as audits of components of the existing pathway to generate proposals for Canterbury's response to this challenge. These are presented for approval by the CCN's Aged Care Workstream.



**Leader, South Island Dementia Initiative (for HOPSLA)**Canterbury Dementia Care Pathway: Proposals for 2013/2014 year

1. Tweaking the existing cognitive impairment pathway.

* Organised education for doctors about the clinical utility and interpretation of the CT Head in the assessment of dementia, coupled with standardising CT Head reports obtained under the cognitive impairment pathway and with prompts in the pathway itself. (Suggest joint work by CRG, OPH&RS & Healthpathways)
* Organised education for health professionals about the clinical utility and interpretation of the MoCA as Canterbury's primary cognitive screening and outcomes monitoring test. (Suggest joint work by PSE, Pegasus and tertiary providers)
* Renewed information and education for prescribers about the clinical utility and monitoring of cholinesterase inhibitor trials. (Suggest joint work by PSE & Healthpathways)
* Improving the liaison between the specialist "Memory Assessment Clinic" based at the Princess Margaret Hospital at referring clinicians so that there continues to be a shift from secondary to primary care as the primary site for the assessment and diagnosis of dementia but without putting up barriers - aiming for a facilitative approach. (Suggest MAC to work with referrers)
* Improving the information and education for clinicians about the resources and supports available in Canterbury for people living with dementia and those that care about them once a diagnosis has been made. (Proposed work for the dementia care pathway stakeholders group)
* Education for health professionals about "how to break bad news" in the context of dementia and dementia-related losses of privileges such as driving. (Proposed work for PSE, CDHB clinicians and Pegasus.
* Strengthen the expectation that all people with newly diagnosed dementia are referred to Alzheimer's Canterbury for their easiest access to services including health navigation during the initial post-diagnosis phase. (Suggest joint work by Alzheimer's Canterbury and Healthpathways)

**The Aged Care Workstream is asked to endorse the work described above by the listed groups to improve upon the existing Cognitive Impairment Clinical Pathway.**

Canterbury Dementia Care Pathway: Proposals for 2013/2014 year

2. Enhancing the suite of early interventions available for people newly diagnosed with dementia

Planning and Funding should be asked to work with Alzheimer's Canterbury and other providers to begin developing a one-stop post-diagnosis community service that can engage in therapeutic work to attempt to engage people with dementia and those that care about them in the list of health promotion post-diagnosis interventions listed above. This could be coupled with the social-work mediated health navigator work Alz Canterbury is already carrying out. It should be a time-limited day-treatment type intervention (say, 8 facilitated weekly sessions over 2 months). It should link in with every relevant general older persons health promotion endeavour already being provided in Canterbury, such as the Medications Management Service or the Falls Prevention Service. Parallel streams could run, including a stream for the important group of younger people diagnosed with dementia, and indeed any of the less 'core' populations living with dementia as sufficient need arises (Maori, Pasifika, Intellectual Disability, Substance-related, Refugee & Migrant etc), and a range of times and possibly venues around the city to suit could also be envisaged. Encouraging participants to continue together with health-living activities such as socialising and exercise after the end of the intervention should be encouraged as one means of prolonging benefits and increasing social capital generally.

NB: As a personal view, I see this as a first step towards building a continuum of community-based day therapy and care for Canterbury people living with dementia, the next step towards which would be altering expectations of dementia day care providers to be providing similar services for people with more advanced dementia so as to improve quality of life, postpone context-driven disability, and prolong the capacity of people to live at home with community care. In addition to increasing the availability of what has until now been known as 'day care' for people with dementia in Canterbury, I would like to see a shift in focus towards treatment planning to meet restorative / rehabilitative, palliative and health promotion / illness prevention goals in addition to enhancing home-provided care and providing respite.

**The Aged Care Workstream is asked to endorse Planning and Funding's engagement with the Dementia Care Pathway stakeholders group and relevant providers over the 2013/2014 year to prepare a business case for an initial post-diagnosis dementia intervention as outlined above, and to explore options for moving towards a more comprehensive 'day care'-based continuum of therapy and care for people living with dementia in subsequent years.**

Canterbury Dementia Care Pathway: Proposals for beyond the 2013/2014 year

1. Beginning to focus on the end of life for people living with dementia

The scope of the National Dementia Framework in respect of the "end of life" phase is consistent with the CDHB's existing moves toward supporting formal Advance Care Planning and the recently published Framework for New Zealand Palliative Care: www.health.govt.nz/publication/resource-and-capability-framework-integrated-adult-palliative-care-services-new-zealand

A next step for people with dementia might be to work with palliative care services and primary care GP and ARC services in Canterbury to see how existing service pathways can better be used to meet the needs of people with dementia, with a main eye to how improved education and provision of consultation and/or liaison from palliative into primary care settings can enhance what is already available and already able to happen.

Key goals secondary to improving quality of life for people who are dying with dementia would be:

* to improve the competence and confidence of carers (formal and informal) looking after them
* to reduce the rate of their admission from private residences to ARC and to public hospitals
* to reduce the rate of their admissions from ARC to public hospitals
* to increase the proportion of people who had engaged with an Advanced Care Planning process prior to reaching the end stage of their life

**The Aged Care Workstream is asked to endorse this focus as the likely next Dementia Care Pathway step for the 2014/2015 year.**

2. Continuing the CDHB's investment in dementia workforce education

Following the Age Care Workstream's endorsement last year, the Walking in Another's Shoes dementia education programme is currently supporting the HBSS/CREST workforce in addition to the dementia-specialty ARC workforces at the R/N level and the carer/health care assistant/diversional therapist levels. The programme has variously been asked to extend this to general ARC and to hospital provider arm services for older people. It has also identified the importance of extending this to managers of the services it is already reaching out to. The South Island SLA has endorsed a general move in this direction and a manager's intervention is proposed for Canterbury prior to extensions into any other direction. However, the programme would require more resource in terms of training facilitators to be able to achieve these goals - approximately 0.5FTE for a Manager's intervention, 1.0 FTE for a non-dementia ARC intervention, and 0.5FTE for a CDHB provider-arm intervention on an ongoing basis.

**The Aged Care Workstream is asked to consider what it would like to recommend to the CDHB's Planning and Funding division for a potential 2014 expansion of Walking in Another's Shoes.**