MEMORY CLINICS ON THE FAR NORTH COAST OF NEW SOUTH WALES: Balancing the community’s interest in memory assessment with limited resources

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Organised services for people with dementia and their carers are increasing. This growth has been stimulated by a rise in the numbers of people with memory problems and by an increased appreciation of the issues faced by this client group. The need and demand for early assessment and diagnosis of dementia is growing now that medical science appears to have crossed the threshold of effective treatment for many people with dementia (1).

This paper describes how the Dementia Outreach Service (DOS) is working towards meeting the need for timely assessment and diagnosis of early dementia by offering a model of memory clinics that reflects the limited health resources of our regional area.

The Dementia Outreach Service was established in March 2001 under the Dementia Advisory Service initiative of the New South Wales Department of Ageing, Disability and Home Care. DOS is auspiced by the North Coast Area Health Service and based at St. Vincent’s Hospital Lismore. There are now more than twenty Dementia Advisory Services in NSW. DOS is the only one that provides services exclusively for people who have mild stage dementia and their families and carers. The Dementia Outreach Service allocates 50% of its time to providing ongoing support and monitoring to people with mild stage dementia and their families and carers. Included in the time allocated to this clinical work is the assessment of members of the community who have memory impairments that may indicate the presence of mild stage dementia. DOS allocates 25% of its time to delivering educational activities to people who have mild stage dementia, their families and carers, and to professionals who work with this group of clients. We also give talks to community groups about the normal memory changes that come with ageing. The remaining 25% of our time is spent on facilitating the development of dementia care services that are appropriate for people who have mild stage dementia and their families and carers.

The Dementia Outreach Service is based in the far north coast region of NSW, covering an area of 24,555 square kilometres with 41,966 residents aged over 65 years (based on the 2001 census). The region has three valleys, each of which has an Aged Care Assessment Team. There is one geriatrician in the region whose work is confined to one of the valleys only. DOS is staffed by a full-time social worker, a part-time registered nurse and a part-time gero-psychologist. Our gero-psychologist had worked in memory clinics in Western Australia and the UK before his current position and was keen for the Dementia Outreach Service to provide a regional memory clinic service.
Early assessment and diagnosis of dementia benefits the person with dementia and their family and carer. Early diagnosis facilitates appropriate treatment, support, planning and timely entry to dementia care services. It provides people with an opportunity to learn about dementia, to understand the changes as they occur and to deal with the everyday issues of living with cognitive impairment. General practitioners recognise only between 15% and 42% of cases of dementia, with better recognition in more severe cases (2, 3, 4) and treat only 7.6% of cases (4, 5).

Memory clinics began in the USA in the 1970s as a part of research initiatives looking into Alzheimer’s disease and were often associated with drug trials. These clinics aimed to identify memory impairment and to provide diagnosis, treatment and support for the person at an earlier stage than they would have otherwise presented themselves to standard services. Memory clinics in the UK were established in the 1980s and took the initiative to develop themselves as accessible services for patients, rather than academic centres, whilst retaining close links to research development (6). Memory clinics, in metropolitan areas of Australia, offer an opportunity to attend a centre-based service to gain early assessment and diagnosis of dementia, prompt referral to specialist services, access to new treatments and good information about dementia and support services. Memory clinics, based on models that are appropriate for local needs, are offered elsewhere in Australia. There is no ‘set’ way of developing a memory clinic.

The Dementia Outreach Service has developed a model of memory clinics that suits the particular circumstances in our regional area – these circumstances include a lack of geriatrician hours, the unavailability of a centre-based memory clinic, the large geographical area and the early dementia specific services offered by DOS. Our model of memory clinics is focussed on identifying those people who are showing signs of a possible mild stage dementia and giving them a pathway for gaining diagnosis. Our memory clinics are complemented by the three aspects of service delivered by DOS i.e. ongoing support and monitoring, education, and service development. The DOS memory clinic model is similar to that of the Community Memory Screening Clinics that are auspiced by The Research Institute for the Care of the Elderly (RICE) at St. Martin’s Hospital in Bath, UK (7). DOS has run memory clinics in major towns across the far north coast of NSW since 2002 and will be running eight clinics in 2005. Our memory clinics do not provide dementia diagnosis. The purpose of the memory clinics is: (a) to distinguish between a possible early dementia and memory problems due to other causes such as physical ill-health, stress and depression; and (b) to offer advice on gaining diagnostic services. The memory clinic procedures are: brief history of memory problems, general health questionnaire, and neuropsychological tests.

The memory clinic to be held in any particular town is advertised via the community notices segments of the local press and radio stations and people are asked to phone the Dementia Outreach Service to make an appointment to attend the clinic. A GP’s referral is not required. Each general practitioner
who covers the particular town and its surrounding area is posted information about the memory clinic and is invited to refer patients to the clinic.

A screening interview is conducted, by phone, with those people who make an enquiry. We usually have between 20 and 30 enquiries for each clinic and cannot accommodate this number of assessments. The phone interview covers the topics of: rate of onset; short-term memory abilities; memory for names of familiar people; misplacing of objects; word-finding difficulties; repetition in conversation; losing track in conversation; praxis; planning and concentration skills; driving; psychological issues; changes in personality; recent stress; general health; and family history of dementia. At the start of the phone interview, the DOS staff member emphasises that everyone has difficulties in some of these areas of memory some of the time and that the interview is looking for problems in these areas that are happening significantly more than usual for the person concerned and that may even be interfering with the person’s ability to be independent.

Our experience has been that we can categorise enquiries into four groups: a) those people who have a general interest in memory changes but are not concerned that they may be developing dementia; b) those people who are experiencing the normal slowing of memory that comes with age and are concerned that they may be developing dementia (many of these people are quite anxious); c) those people who have significant changes in many of the areas covered by the screening interview; d) those people who the staff member is just not sure about. The DOS staff member offers to post an information package, to people in categories (a) and (b), comprised of handouts that describe the normal changes in memory that come with ageing and give some tips on how to deal with these changes. The package also includes a letter encouraging the person to contact DOS if they are not reassured after reading the information. People in categories (c) and (d) are offered a memory assessment. It often happens that we have more people to assess than can be fitted into the one day clinic. We prioritise those people who are displaying significant changes in the areas covered by the phone screening and offer them a place at the memory clinic. Other people are offered a home based assessment by one of the DOS staff members.

A clinic lasts one full day and a maximum of six people can be assessed – three in the morning and three in the afternoon. Participants attend for approximately two hours. Each attendee is encouraged to bring along a relative or friend, to provide their perspective of the memory changes. The attendee is assessed by each of the three DOS team members.

The social worker meets with the clinic participant and their support person. She administers the MMSE and clockface assessment. She also confirms the history of memory changes, gathered during the phone interview.

The registered nurse meets with the participant and their support person to elicit information regarding the person’s past and present health status, medications and level of ability in activities of daily living.
The gero-psychologist sees the participant alone and administers the Repeatable Battery for the Assessment of Neuropsychological Status or RBANS. The RBANS is ‘a test measuring attention, language, visuospatial/constructional abilities, and immediate and delayed memory’ (8). The gero-psychologist has chosen to use RBANS as it covers all the domains that need to be assessed when screening older people for dementia. It is a concise instrument and has normative data available for adults between 20 and 89 years of age. The Frontal Systems Behaviour Scale (9) is used when there is evidence of dysexecutive function.

When all participants have been interviewed by each of the DOS team, the clinic staff meet to compare their findings. The participants and their support persons are given individual feedback at the end of the clinic session they attend, regarding the findings and recommendations from the memory clinic assessment. Those participants who are considered to be showing the signs of a possible early dementia are advised that the memory clinic staff are not making a diagnosis as to the cause of their memory impairment but are suggesting that they seek further medical investigations. The clinic staff give details of how to access these investigations. The participant and their support person are also advised that, should a diagnosis of early stage dementia be made following these investigations, the Dementia Outreach Service will be able to provide an ongoing support and monitoring service.

In the two weeks following the memory clinic a DOS staff member posts, to each participant’s GP, a summary of the clinic assessment findings plus a letter giving recommendations. For those clinic participants who were assessed as showing signs of a possible early dementia, the GP is asked to consider authorising a full blood screen, a CT scan of the brain and a referral to a specialist for diagnosis.

On the far north coast of NSW, we do not have access to a diagnostic memory clinic and we have limited access to a geriatrician. So, what happens to those people who are identified as showing signs of a possible early dementia by the memory clinics run by the Dementia Outreach Service?

In the Richmond Valley, it is easy as this is where our sole geriatrician is based. Clinic participants who live in the northern end of the Clarence Valley are encouraged to drive to the Richmond Valley for an appointment with the geriatrician. Those participants who live in the southern end of the Clarence Valley are encouraged to drive to Coffs Harbour for an appointment with the geriatrician based there.

Clinic participants who live in the Tweed Valley may be in a position to access a private geriatrician on the Gold Coast or in Brisbane. DOS has recently negotiated with a physician, who practices in the Tweed Valley, to gain his approval to be a referral destination for memory clinic participants in that area. Gaining access to a specialist, for diagnosis, is no easier than before the regional memory clinics were started and this issue is an ongoing one for many regional areas. But since the clinics commenced, more people are
being assessed, in the early stage of dementia, than previously and are gaining timely referral for diagnosis and follow-up.

An editorial, in the International Journal of Geriatric Psychiatry (10), suggests that memory clinics have ‘great potential for developing psychosocial intervention strategies’. The Dementia Outreach Service is striving to meet this potential through the ongoing support and monitoring it offers to people with a diagnosis of mild dementia and their families and carers. The same editorial suggests that memory clinics provide a potential setting for developing psychoeducation strategies for this client group. The Dementia Outreach Service is striving to meet this potential by facilitating the delivery of the Living With Memory Loss program across the far north coast. We are funding the development of a Certificate IV course which will train dementia service staff to deliver what we have called the Positive Approach program. Positive Approach is based on cognitive behavioural therapy and is designed to provide interventions to address depression in the carers of people who have mild dementia. If funding becomes available, we hope to be involved in the development and delivery of cognitive rehabilitation programs which will directly benefit people who have mild dementia.

‘One salient and valued outcome for persons in early stages (of dementia) is access to knowledgeable and sensitive health professionals who take their complaints or those of their families seriously’ (11). It frequently happens that people’s concerns about memory changes are dismissed, or they are presumed to have dementia without the benefit of a comprehensive evaluation. The Dementia Outreach Service does not claim to offer the same level of service as a metropolitan based memory clinic but we believe that we are enhancing the timely assessment of early dementia, within the parameters of a regionally based service.


7. The Research Institute for the Care of the Elderly, Bath, UK. www.rice.org.uk/memory


