DEMENTIA SERVICES
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promoting excellence in dementia care

MERCER'S INSTITUTE FOR SUCCESSFUL AGEING
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Report on the Memory Clinic Working Group Meeting

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Radisson Blu
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Introduction

The idea of formulating a Memory Clinic Working Group was born out of the success of the 1st Irish Memory Clinic Conference held in March 2011. The interest shown by participants in what other 'memory clinics' were doing across the country was very encouraging and this was reinforced by the formal feedback that was received. There was a general endorsement of the idea to form a community of professionals working in the field of memory and cognitive assessment both on-line, via a dedicated Memory Clinic website, and through regular meetings such as the national conference.

The proposal to hold a 'working group' meeting in November was driven in the main by the work being done by the Dementia Advisory Committee that resulted in the publishing in January 2012 of 'Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy' (Cahill, O'Shea, Pierce, 2012). It is hoped that this report will provide the evidence base for the proposed new strategy for Dementia in Ireland.

This review points to the fact that both the English and Welsh National Dementia Strategies and the French National Plan for Alzheimer and related diseases have championed the role of Memory Clinics as essential in the drive for early diagnosis of dementia. The belief being that early intervention will allow people to live independently for longer. These national strategies go on to suggest the primary (GPs), secondary (geriatrician, psychiatrist) and tertiary (multi-disciplinary memory clinics) elements be involved in a preferred diagnostic pathway.

In Ireland we are at a critical juncture in relation to how we diagnose people with dementia. In 2011 the Irish Government committed itself to develop and implement a National Dementia Strategy. In the Programme for Government 2011-16 they have promised to:

> "develop a national Alzheimer's and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years." (Cahill, O'Shea, Pierce, 2012)

It is vital that we decide on the best way forward for Memory Clinics in Ireland so that we can promote this vision and ensure not only that it is reflected in any dementia strategy but that adequate resources are made available to make this vision a reality.

Report on Working Group meeting

The meeting was formally opened by Professor Brian Lawlor. He gave a brief overview of the evolution of Memory Clinics since the1980's and asked what the future for Memory Clinics in Ireland would be?

The goals of the meeting were outlined as:

To discuss the status of Memory Clinics

Debate the function and purpose of Memory Clinics

To outline:

The type of staff working in Memory Clinics

Will it be part of integrated care service or on its own?

What will a Memory Clinic look like?

Dr Robert Coen was asked to deliver a short presentation on the differing definitions of a memory clinic. He opened by explaining that there is no clear definition of a Memory Clinic. There is a lack of specific standards or set models. He argued that every specialist service for older people should have a Memory Clinic but there are no specific guidelines on how to establish one.

In the UK Memory Clinics have received prominence because early diagnosis is seen as key to improving quality of life. The Department of Health declared their aim that there would be a Memory Clinic in every town. However others disagreed. Professor Roy Jones said "I think what we need is a memory assessment service in every major town linked to specialist centres like ours, because diagnosis for something like Alzheimer's isn't the easiest. It is not just doing a simple test and saying you have or haven't got it. All of these things cost money and that is the real issue. Is the money going to come in with the strategy to support what we need to see?"

There are several definitions of Memory Clinics in the literature. For example:

Wilcock GK et al. Diagnosis and management of dementia. A Manual for Memory Disorders Teams. Unipress. 1999.

Bullock and Qizilbash. Memory Clinic – A Guide to Implementation and Evaluation. 2002.

BPS survey (PSIGE MC)

Cahill and Maher in the booklet 'Memory Clinics in Ireland. A Guide for Family Caregivers and Health Service Professionals' give a very good definition:

"Memory Clinics have been defined as independent clinics primarily aimed at improving practice in the identification, investigation and treatment of memory disorders, including dementia (Jolley, Benbow and Grizzell, 2006). Memory Clinics are primarily concerned with the early diagnosis and treatment of memory problems (Lindesay, Marudkar, Van Diepen and Wilcock, 2008). Early diagnosis of Alzheimer's Disease or any of the related dementias is critical to appropriate treatments, to managing one's financial and legal affairs (including making an Enduring Power of Attorney), to planning services and to accessing supports. It is noted that the focus on the individual needs of the person with early stage dementia is a characteristic that differentiates Memory Clinics from other dementia care services".

Dr Coen went on to discuss how different authors have addressed the issue of staffing a memory clinic. There are differences of opinion from one author to the next. However Bullock and Qizilbash (2002) have a useful classification system where they break the staff down into:

essential - medical doctor, (neurologist, etc.),

desirable - psychologist, nurse, etc.

optional - social worker, OT, etc.

The issue of staffing caused a degree of debate amongst the participants especially in relation to access neuropsychologists. Their importance to interpret the tests carried out was recognised but it was not clear how easy it was to access neuropsychological services. Are they avaiable at Primary Care level for example and would it be possible to train others in the team to interpret tests?

It was pointed out that there are localy based psychologists available and that some of these clinical psychologists could be interested and/or have the expertise of working with older people. It would be down to us to find them and get them involved.

To sum up Dr Coen highlighted some key issues that need to be considered:

Referral criteria

Referral process

Assessment process

Carer/family assessment

Recording?

Feeding back/diagnosis to the referrer, the patient, family

Will follow-up be offered from the clinic?

Relationship between clinic & referrer

A discussion covering a range of interconnected topics followed Dr Coen's presentation and resulted in the following conclusions on the shape of a memory clinic:

Memory Clinics should offer assessment, diagnostic treatment and information services

Memory Clinics should have access to diagnostic tests/tools.

Memory Clinics should be multidisciplinary.

Memory Clinics are not in the position to offer follow-up care beyond (i) above

GPs and Primary Care have to be integrated into the system with Memory Clinics available to offer advice, training and information

Dr. Conal Cunningham gave a brief presentation Cost Benefit Analysis of Memory Clinics.

The cost of Dementia care in Ireland is estimated to be around ?400 million (10% of which is spent in primary care with 90% going on nursing home care and medication).

What would be the cost of a Memory Clinic approach in Ireland, ideally as part of a national strategy? This would depend on the number and type of Memory Clinic and how many patients per year it would see. There are the direct costs to consider (staff, time, etc.) and the consumables such as neuroimaging and neuropsychological testing which can be expensive.

There is research evidence to support the benefits of a Memory Clinic:

Logiudice D et al. 1999. Int J Geriatr Psych 14(8) p:626-32

Graff MJ et al. Community based occupational therapy…
BMJ 2006. 333 (7580): p. 1196

Wolfs. Arch Gen Psychiatry. 2009. 66(3): 313-23

There is also some ongoing research:

Holle R. (Usual care vs. GP) BMC Health Service 2009 9: p.91

Meeuwseen (MC vs. GP) J Nutr Health Aging 2009 13 (3) p.242-8

The final discussion of the morning was on how Memory Clinics in Ireland could be structured. It was questioned whether it would be possible to follow the example of cancer or diabetes management where they have specialist teams integrated with the primary care teams. Everybody agreed that we have to try to integrate specialists and primary care but that it would be difficult to emulate cancer care for example, as the outcome measures for Memory Clinics are not as obvious or tangible.

Conclusion

In order to draw the debates to a close it is necessary to return to the original goals of the meeting as stated at the outset namely to: a) discuss the status of Memory Clinics;

b) debate the function and purpose of Memory Clinics; c) to outline the type of staff working in Memory Clinics and finally answer the questions what will a Memory Clinic look like and will it be part of an integrated care service or on its own?

Everybody present agreed that Memory Clinics provide high quality early intervention, treatment, support and research. There is also research evidence backing up this claim (Jolley, Benbow and Grizzell, 2006; Lindesay, Marudkar, Van Diepen and Wilcock, 2008) plus "emerging evidence that these specialist services are highly valued by both patients and family caregivers because of the opportunities they afford for in-depth discussion about the illness and prognosis". (Cahill, Gibb et al, 2006).

The primary function of a Memory Clinic is assessment, diagnosis and the provision of information. They are not in a position to provide ongoing care and support to their clients.

Memory Clinics require a medical doctor with experience of working with older people in order to fulfill their basic function. Ideally they should also have neuropsychological input or access to psychological services. In the best case scenario a Memory Clinic would have a full multidisciplinary team that also included allied health professionals such as social workers and OT's.

What will an Irish Memory Clinic look like within the context of a National Dementia Strategy? It would be possible to argue for a clinic within every town but in the present financial climate this is highly unlikely. However, it is important that local assessment and diagnostic facilities are fostered as these are ideally placed to offer advice and support to people with dementia, their caregivers, GPs and Public Health Nurses amongst others. The difficulty for localised assessment services is lack of access to neuropsychological services and other specialist services such as scanning (PET, DAT, MRI etc). In the future this may also include access to bio-marking services. If this is the case then should we be arguing, as Professor Roy Jones does in the UK, for regionalised centres that are linked to the local assessment services?

It would be easier to argue for these centres to be adequately resourced with multidisciplinary teams that have access to the specialist services required for earlier diagnosis. They would also provide valuable and badly needed research hubs. These centres would need to be located in areas that made sense both geographically and in population density terms. This would improve the situation in areas like the west of Ireland that, until recently, have had no formal memory assessment services.

One of the important areas that needs to be addressed is the evidence base. We all acknowledge that we believe Memory Clinics to be of value. We strongly suspect that an early diagnosis from a Memory Clinic probably reduces caregiver burden and possibly delays nursing home admission. If these assumptions are correct then Memory Clinics are cost effective and therefore attractive to government. In the UK the impetus for the National Dementia Strategy was partly derived from the fact that dementia cost more to manage than heart disease and cancer combined. It is likely that the same is true in Ireland but where is the evidence?

Over the next year the Department of Health will be commencing a direct consultation process with all the key stakeholders in the next phase of the development of a National Dementia Strategy. It is important that Memory Clinics are an integral part of this discussion or risk being sidelined as an afterthought.