

Memory Assessment Services Ireland

A REPORT ON PROCEEDINGS OF THE MEETING ON 30.5.19



Organised by

DEMENTIA SERVICES
INFORMATION & DEVELOPMENT
CENTRE

Note regarding terminology

Introduction

Memory clinics were first described in the US in the 1980's and the first clinic opened in Ireland in 1991. Their purpose is the "identification, investigation and treatment of memory disorders including dementia" (Jolley et al, 2006).

In Ireland, there is a lack of uniformity in memory clinic services and of the specialisms of the health professionals involved. Consequently, memory clinics can vary widely in both their composition and the type of services provided. In order to cover this variance between the memory clinics it has been decided, for the purpose of this report, to refer to them using the general term of 'memory assessment service'.

The Dementia Services Information & Development Centre organised a meeting to provide a forum for the memory assessment services of Ireland to discuss their future direction and to possibly find common ground in the areas of diagnostics, disclosure of diagnosis, post-diagnostic support and people with a young onset of dementia.

An invitation to attend the meeting was sent out to the clinical leads of all the memory assessment services in Ireland and relevant staff. The response was overwhelmingly positive leading to the attendance of fifty individuals, including over 90% of the clinical leads. Other attendees included psychologists, senior nurses, an occupational therapist and three neurologists who are involved in the diagnosis of people with young onset dementia and other rarer sub-types of dementia.

Observers from the HSE's National Dementia Office, the Global Brain Health Institute and the Dementia and Neurodegeneration Network Ireland were also in attendance.

The following is a report on the day's proceedings and attempts to summarise the discussions that took place. It does not reach a consensus but draws out conclusions which add to the current narrative around memory assessment services in Ireland. The report captures the perspectives of clinicians and allied health professionals and does not capture the views of people living with dementia and their families.

Purpose



The primary purpose of the day was to ask the attendees to consider four general topics that map on to the current national narrative. i.e.

1. A national structure for memory assessment services
2. Delivering a diagnosis of dementia - best practice
3. Post-diagnostic supports
4. Young onset dementia

Meeting structure



There were three short presentations made on the day to update attendees on the following work:

- Memory Assessment Services - the national viewpoint (Dr Suzanne Timmons, on behalf of the National Dementia Office)
- A National Dementia Registry for Ireland (Dr Louise Hopper, Dublin City University)
- Update on the National Memory Clinic eReferral (Dr Chris Soraghan, St James's Hospital)

There were two additional presentations:

- St Patrick's Hospital, Cashel Memory Clinic & South Tipperary Dementia Services, Living Well with Dementia (Elaine Wilkinson, St Patrick's Hospital, Cashel)
- Post-diagnostic supports, Kilkenny Memory Clinic (Joan McDonald & Mary Hickey, St Columba's Hospital)

During the morning sessions a brief introduction to each topic was given. The attendees were then divided into three groups in order to facilitate discussion. Each group comprised of geriatricians, psychiatrists, nurses etc. to try and ensure a balanced skill mix. A note taker was provided and each group appointed an individual to record the main discussion points on a flipchart.

In the afternoon sessions the group remained together to discuss the topic of young onset dementia.

A national model for memory assessment services?

A model of care is better than a structure of care - a structure is geographically based, like cancer or stroke care, a model is not geographical but a set of determinants to be followed, and depending on the resources, you have you try and fit a model. Sean Kennelly, participant

The prevailing opinion from all the attendees was that there needs to be a national model for memory assessment services in Ireland and that this would be beneficial for both patients and practitioners alike. There were some difference of opinions relating to how this model might look at primary, secondary and tertiary levels and these are summarised below. There was a call for a 'pathology-based' approach to diagnosis to lessen the difficulties that people with a young onset dementia face when presenting to a doctor.

Primary Care level

Feedback from the groups regarding the provision of a national structure at the primary care level was mixed. The prevailing opinion was that primary care was too diverse and GP skill levels and interests too mixed to facilitate a fully standardised memory assessment service at this level. There was also a feeling that many GPs are reluctant to give a diagnosis of dementia.

However, there was a degree of consensus that GPs should be able to diagnose straightforward presentations of dementia and in other cases should be able to complete a basic screening of patients before referring them on. This screening test should be standardised and include a basic cognitive assessment tool such as the MMSE or MOCA, a full blood screen and an ECG. The staff involved or available at primary care level varies from location to location but it should include the GP and a public health or practice nurse as a minimum. It was accepted that brain imaging would not form part of the diagnostic process at primary care level but GPs may help reduce waiting times by ordering brain imaging especially for those patients who have private medical insurance cover.

A national model for memory assessment services?

Secondary Care Level



There was a greater degree of consensus of opinion regarding what should happen at a secondary care level. All attendees felt that an agreed national model could be developed for the secondary (and tertiary) care levels. This is where the bulk of diagnosing will take place and not at the primary care level. Equity of access to a diagnostic service also emerged from the discussions with concern that there should be no 'post-code' or geographical discrimination.

Some felt that it would be possible to follow the UK's NICE guidelines on diagnosing dementia (<https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#diagnosis>) by adopting the procedures that they recommend for assessment in the non-specialist setting. However, if there is an assumption that this is where most people will receive a diagnosis of dementia, then more input than suggested by the NICE guidance would be required including brain imaging and some degree of psychology input.

All the groups stated that multidisciplinary input (medical doctor, nurse, psychology, plus or minus occupational therapy, speech and language therapy, social worker) was essential. These multi-disciplinary teams would have the ability to undertake comprehensive assessments with the more straightforward cases. All groups wanted access to brain imaging and, in some instances, functional imaging and CSF biomarkers.

A national model for memory assessment services?

Secondary Care Level



Several mentions were made of replicating existing models of other services specifically the stroke service where the goal is a Stroke Unit to be available in every hospital in Ireland. There is much to be learned from this model with the development of care pathways, protocols and care bundles that would be advantageous to those experiencing memory and cognition difficulties and those receiving a diagnosis of dementia. The focus on prevention would also be welcome as we become more aware of the potential risk factors for developing dementia later in life.

The number of clinics required at the secondary care level was addressed with the suggestion of a 'skilled' multi-disciplinary centre in each county. Another suggestion was a minimum of 16 skilled centres each seeing a minimum of 10 patients per week. Others were less specific on numbers but would like to have stronger links to existing services with the view of holding regional memory assessment service meetings to discuss complex cases.

There was a call to consider using telemedicine to diagnose patients in remote areas.

There was also a recognition that more time and resources need to be given when diagnosing at this secondary level. This would be especially true in out-patient department scenarios where very little time might be afforded for the disclosure process.

A national model for memory assessment services?

Tertiary level (specialised services)



There was a good deal of agreement over what tertiary level clinics should look like, the resources at their disposal and what type of referral they should accept.

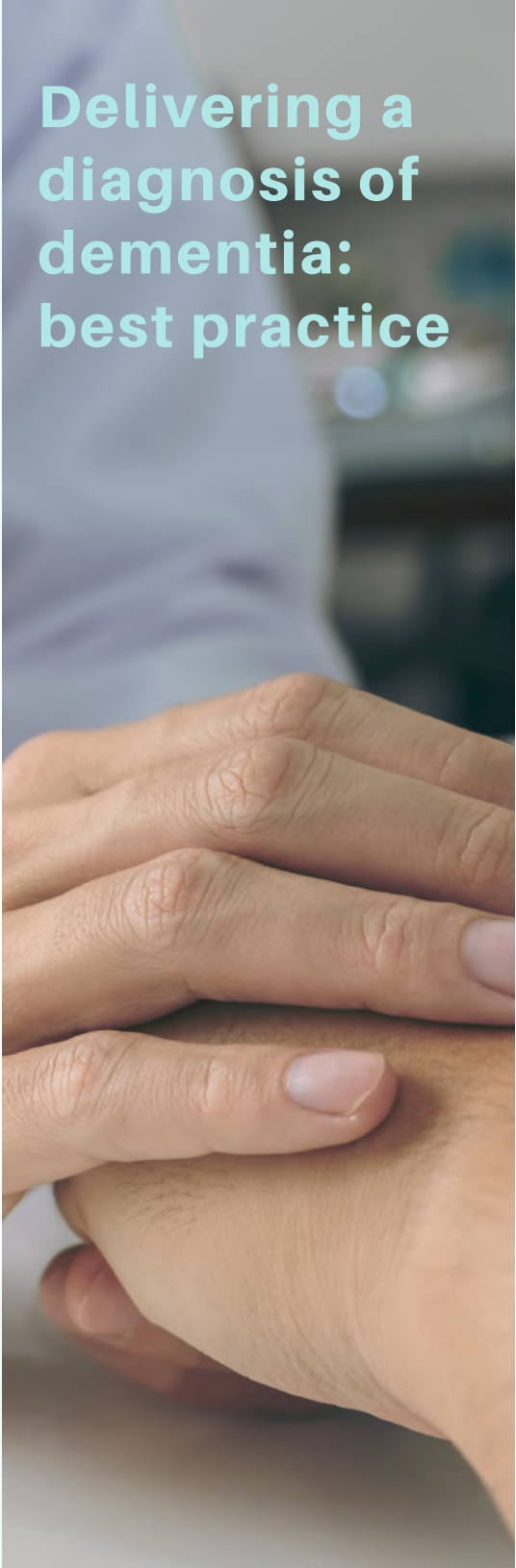
It was envisaged that there would be three or four of these tertiary centres located at appropriate sites around the country.

Ideally these multi-disciplinary services, under strong leadership, would be staffed by specialists - medical doctors, neuropsychologists, nurses, occupational therapists, speech and language therapists and social workers. Radiologists with a specialist interest in the interpretation of brain imaging should also be available.

These teams, primarily offering bespoke assessments to complex, atypical and young onset cases, would routinely have access to brain imaging (MRI, PET) and CSF biomarkers and full neuropsychological input.

There were mixed views as to whether these centres would cater for patients with an Intellectual Disability or whether these patients should be seen by an alternative specialist service.

A hub and spoke model was suggested with the hub responsible for diagnosis and the spoke for post-diagnostic support and ongoing medical management.



Delivering a diagnosis of dementia: best practice

Many common themes emerged from the discussions around best practice in relation to delivering a diagnosis of dementia. Most of the services felt that their approaches to disclosure were closely aligned to current best practice. However, they recognise that the majority of disclosures are likely to happen at, for example, a geriatric outpatient clinic and it is suspected that approaches may be different depending on the environment.

There was a recognition of bad practice with examples such as: relatives being told the diagnosis before the patient; the use of medical jargon; doctors not clearly explaining the diagnosis (e.g. dementia v Alzheimer's disease); diagnosis with no follow-up support; and not enough time and space being given for the diagnosis.

Preparation for disclosure should include considering the venue in which the meeting will take place. A quiet, calm and private environment was recommended. To keep anxiety levels at a minimum it was suggested to avoid 'medical-style' posters on the walls or have information about dementia on show. Giving the diagnosis in the patient's own home, where they might feel more at ease, was also suggested as an option.

Clinicians should be accompanied by an experienced health and social care professional for the disclosure meeting so that as many of the patient's and family's questions can be answered and that appropriate emotional support can be given if needed.

Individualised disclosure

*...the issue is not “whether or not to disclose the diagnosis of dementia but rather how and when to do so.”
(Lee L, Weston W., 2011)*

Preparation for disclosure should begin before the start of the assessment process itself by sending the patient information about the memory assessment service its processes and what they might expect when they attend. This helps develop a relationship between the service and the patient. At the first meeting staff can then explore with the patient what their expectations are and how much information they would like to know about the results of the assessments. Initial conversations could include the benefits of knowing a possible diagnosis.

Attendees from all the memory assessment services felt that the style and pace of the disclosure of diagnosis should be matched to the individual's needs and wishes. The patient should remain in control of the process throughout and be able to decide who attends for both sharing collateral information and for support at the disclosure meeting. They should also be able to change their mind at any point.

The careful use of language was raised by two of the groups with attendees suggesting that clear, unambiguous terminology be used but in a gentle and considerate manner.

The content of the conversation was also raised. It is important to be empathic and to convey a feeling of hope. Patients should feel supported throughout the process.

Following on from this the provision of written information, including both the diagnosis and additional information, was viewed as being very important.



Allowing an adequate amount of time to deliver a diagnosis was seen as crucial

There were differing views on what information should be given at the point of disclosure. Some advocated a standard/generic pack of information leaflets and booklets from a variety of sources, whereas others suggested that any information given should be individualised to match the patient's experience and needs. For example, there is little point in giving detailed advice about driving licences, car insurance and on-road testing if the person does not drive.

Exploring the impact of the diagnosis with the patient was thought to be useful by some, especially with regards to discussing what the patient is still able to do well and how to best maintain their quality of life. A clear plan for the patient and their care partners going forward could help with this.

Crucial to a 'successful' disclosure of a diagnosis was the issue of time. It was acknowledged that a disclosure is a very delicate process and that clinicians and health and social care professionals need to allow an adequate amount of time to deliver it in a proper fashion. Some suggested that this should be a two appointment process with the first visit to disclose the diagnosis and the follow-up to offer emotional and practical support once the person has had an opportunity to absorb the information.

In the weeks following a diagnosis some form of follow-up contact, whether a phone call or home visit, was seen as important. This could help the patient and their care partners in accepting the diagnosis, give them an opportunity to clarify any issues that they identified and to offer post-diagnostic advice.

Post-diagnostic supports and memory assessment services

Memory assessment services should provide some level of post-diagnostic support



There was a general consensus amongst the attendees that they should provide some post-diagnostic support as part of their overall service package and it was acknowledged that most of the memory assessment services do provide some degree of automatic follow-up. There was a feeling that if the memory assessment service didn't fulfill this role then who would?

However, it is important to acknowledge that in the current climate this would be resource dependent and there was a danger that taking on too much in this regard could overload a memory assessment service.

The prevailing view was that post-diagnostic services had to be pro-active and that there should be follow-up phone calls or home visits in order to identify issues or problems at an early stage and attempt to resolve them. There was also an opinion that Primary care services needed to be involved here as well. It was felt that basic pharmacological management, for example, reviewing a prescribed acetylcholinesterase inhibitor, should be carried out by the patient's GP.

However, it was felt that when the diagnosis of dementia was being made in a memory assessment centre that was out of the patient's home region then leaving the post-diagnostic support work solely to the GP could be problematic. There was a suggestion that each CHO area should have a single point of contact such as a 'dementia co-ordinator' who could act as a key or link worker. The co-ordinator would need to be a skilled dementia specialist who could offer support on a number of different levels. This position was not envisaged as being the same as an Alzheimer Society of Ireland dementia advisor.

Post-diagnostic supports and memory assessment services

Community based supports utilising existing facilities

Post-diagnostic information and signposting was seen as the minimum level of intervention that should be on offer from a memory assessment service. A number of different topics that could be covered were suggested. These included: enduring power of attorney and other legal issues; driving; brain health advice; health and well-being (avoiding infections, delirium etc); advice on medication; home safety, memory aids (memory technology resource rooms); addressing any vision or hearing difficulties; information on dementia and its prognosis and progression; useful websites; dementia 'passports' or similar (in case of a hospital admission); and useful contact numbers such as the local dementia advisor, if available.

Others suggested a nurse led group support model that could address issues such as the titration of medications, tackling emerging difficulties, addressing any non-cognitive symptoms of dementia (BPSD) and quality of life. By using this combined medical and psychosocial approach and anticipating certain problems this could lead to a reduction in re-referral rates to some memory assessment services.

Home visits were seen as helpful for educating people on a one-to-one basis or as a family group.

Some wanted memory assessment services to offer more in the way of supports such as Cognitive Stimulation Therapy, Cognitive Rehabilitation, activity groups for those with a young onset of dementia and other psychosocial interventions.

Existing community resources could be utilised more effectively and used as post-diagnostic supports and memory assessment services could play a role in making them more dementia inclusive environments.

Young onset dementia (YOD)

A number of questions and statements were posed on powerpoint slides at the start of this session:

YOD: How do you see it?

- Do we need different pathways for diagnosis?
 1. Are you happy assessing YOD?
 2. Who should be involved? MedEl; PsychEl; Neurology; Psych; GP
 3. Access to neuropsychology, allied health and investigations?

- Do we need different post-diagnostic care?
 1. By whom and where should it be provided?
 2. What are the missing elements of post-diagnostic care in YOD?
 3. How should it be funded?

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- Different disorders needing different assessment?
 1. Prevalence less frequent: 98 to 168 per 100,000
 2. More complex - more atypical AD, FTD, atypical PD, MND
 3. Diagnostic assessment - longer and more investigations

- Different experience having YOD?
 1. Different Impact - working and supporting dependents; otherwise healthy, active and mobile
 2. Less support - to publicly funded services and to personal income; uncertain pathway to care and poor engagement: isolation

- Burden on more than person with YOD: partner and children

Young onset dementia

YOD: A Different Approach?

- Different disorders needing different assessment?
 - Prevalence less frequent: 98 to 168 per 100,000
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Young onset dementia: A different approach?

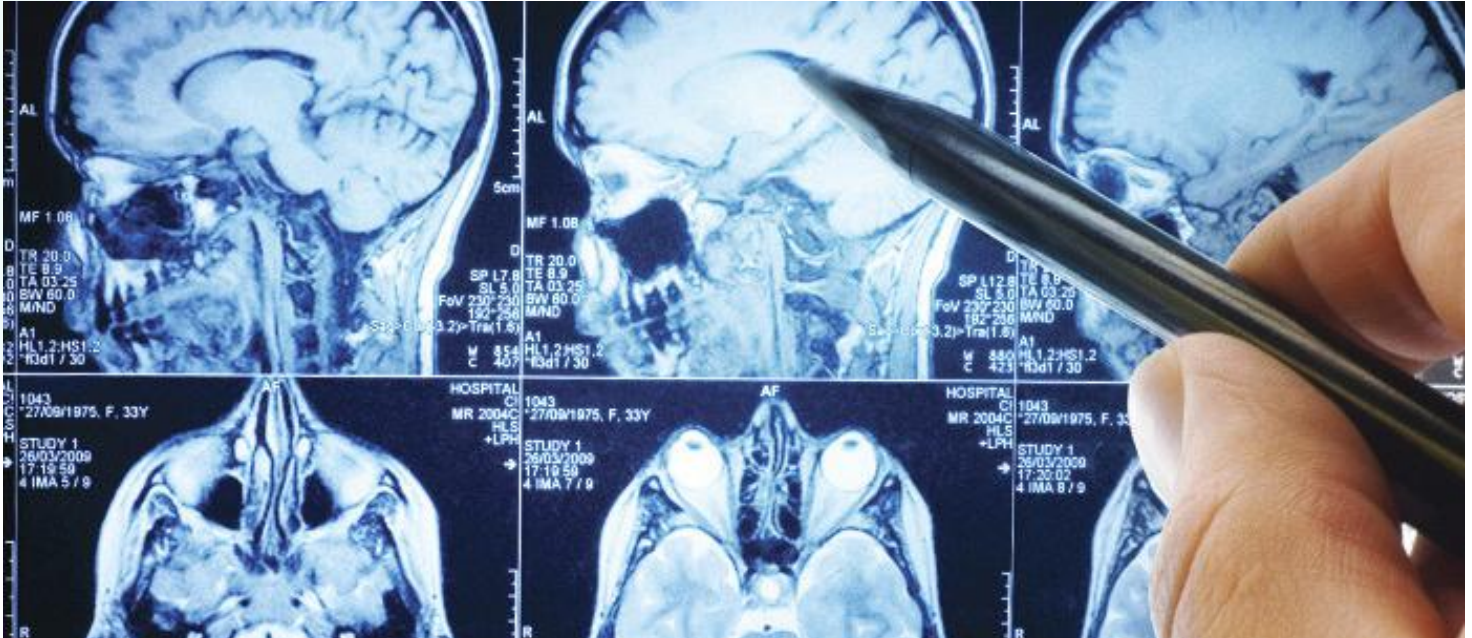
"The diagnosis of younger onset dementia is challenging, with symptoms often confused with other disorders and disabilities..." Irish National Dementia Strategy

The first issue raised within the group was the time delay in receiving a diagnosis of young onset dementia from the point where a person first started experiencing problems. Part of the difficulty here is that some young onset dementias first manifest themselves in a less than obvious manner. For example, a posterior cortical atrophy (PCA) might first be picked up by an optician. It was also pointed out that clinicians in primary care often don't think about the possibility of dementia when they see unusual presentations in younger adults. Age, in these instances, is not a good discriminator and the path to diagnoses should be driven by presenting symptoms.

The second main issue to come out of the discussion was the difficulty that people under the age of 65 can have in accessing physicians with the appropriate skill sets to diagnose young onset dementia. Some geriatric and psychiatry of old age services won't see people under the age of 65, yet they are often the very services with the necessary skills to carry out a complex diagnosis.

Young onset dementia

Younger patients often require more detailed investigations



It was noted that general adult psychiatry services, who cater for the mental health needs of the under 65 age cohort, often argue that they do not have the necessary skills or resources to diagnose people with a young onset dementia or to offer ongoing medical advice and support following a diagnosis.

Neurology services on the other hand do not have an age cut off for their services, however, neurologists tend to have areas of expertise and currently it is estimated that there are only six neurologists in Ireland with a particular interest in memory and cognition. Attendees were advised not to refer people with complex memory and cognition difficulties to general neurology services as they could, in some parts of the country, face years on a waiting list before being seen.

It was recognised that the confidence of doctors to assess younger people with memory and cognition concerns varies considerably. Matters can be further complicated when there are other comorbidities such as anxiety and low mood. Patients presenting like this will often require further, more detailed, investigations such as PET scans or lumbar punctures and hence tertiary level input[1].

[1] Re. tertiary level input: CT and MRI scans can be completed at local hospitals and most will be accessible via NIMIS.

Similarly, lumbar punctures can be performed locally and the CSF can be sent to St James's Hospital, Dublin for analysis at a charge of €200.

Young onset dementia: post-diagnosis

Concern was raised that people with a young onset of dementia and their caregivers/families don't receive adequate levels of support because they don't meet criteria for services, mainly because of their age. Attendees felt that many of these people were refused access to many aspects of Primary Care services - not just the Public Health Nurse. Many had come across patients who had been refused access to the PHN because they didn't qualify for a Medical Card. Similarly, other attendees were aware of patients who had been denied access to other health and social care services, such as Occupational Therapy, based on either their age or not having qualified for a medical card.

The experience of most of the participants at the meeting was that it takes a great deal of extra effort advocating for people with young onset dementia to be seen by the PHN and other health and social care professionals in primary care settings.

Isolated and lost to the support services that they need

It was suggested that people with a young onset dementia who had been refused a medical card (usually on financial grounds) should be encouraged to apply for a discretionary medical card. Help should be sought for this and other entitlements and appeals from the local Citizens Information Centre.

These difficulties can lead to individuals and families becoming isolated and lost to the support services that they need.

The inequity of service provision around the country was highlighted and all attendees were aware of areas of the country that are very poorly resourced.

The issue of shorter life expectancy was also broached as there was the risk that some patients might not be in contact with a specialist service again following their diagnosis. This could mean that their next contact with a health care professional occurs when they are admitted to a nursing home or a hospice. If they haven't registered their end-of-life preferences this can generate significant trauma for both the patient and the family. This is obviously a very delicate area and should be addressed at a much earlier stage of the illness.

A call was again made for a specialised service for dementia (such as dedicated Dementia Coordinators) at CHO level that was independent of the primary care structure.

Conclusion

Memory assessment services in Ireland:

A big thank you to:

- all who attended on the day
- the speakers - Prof Brian Lawlor, Dr Suzanne Timmons, Dr Louise Hopper, Dr Chris Soraghan, Dr Sean Kennelly, Dr Rory McGovern, Dr David Robinson, Anne Quinn, Joan McDonald, Elaine Wilkinson, Mary Hickey, Dr Siobhan Hutchinson

1. recommend a national model for memory assessment services involving primary, secondary and tertiary care levels
2. believe GPs are capable of diagnosing straightforward presentations of dementia and should follow a standardised format for referring on
3. need multi-disciplinary teams with access to brain imaging to assess and diagnose at secondary care level
4. need a small number of tertiary level centres to assess those with suspected young onset dementia and other complex presentations
5. believe that they follow best practice in disclosing a diagnosis of dementia
6. recognise that mainstream outpatient clinics may not be aware of or have the resources to implement best practice in relation to disclosure of diagnosis
7. know that it takes time and a high level of skill to disclose a diagnosis of dementia

Conclusion

Memory assessment services in Ireland:

Thanks also to Dr Emer Begley for her suggestions and editing advice and to the staff of the DSIDC - Lorraine Lovely, Diana Burgui, Cecilia Craig, Bernie McGovern for all their hard work before, during and after the event.

Matthew Gibb 01-08-19

8. want to provide post-diagnostic supports provided that they are adequately resourced
9. would like a single point of contact for patients and care partners to access post-diagnostic supports
10. recognise that it often takes people with a young onset dementia a long time to get a diagnosis
11. understand that, because of their age, people with a young onset dementia often have difficulty accessing the physicians with the skill sets to diagnose them in a timely fashion
12. are aware that people with a young onset dementia are often denied access to primary care services and have greater difficulty qualifying for medical cards because of their age
13. are aware that there are few adequate community resources for people with a young onset dementia
14. welcome the support of the small number of neurologists who are interested in young onset and other rare forms of dementia

References:

Lee, L. and Weston, W. 'Disclosing a diagnosis of dementia: Helping learners to break bad news', Canadian Family Physician, 2011 Jul; 57(7): 851–852.
Irish National Dementia Strategy, Department of Health, 2014