Building on Strengths and Abilities: Update on the National Dementia Post-diagnostic Supports Programme

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Our vision is that people with dementia and their family carers receive the supports and services they need to fulfil their potential and to maintain their identity, resilience and dignity as valued and active citizens in society.
Objectives:

- To oversee the National Dementia Strategy’s implementation.
- Integrate different elements of the strategy into the wider health and social care system.
- To inform policy and practice on dementia care.
- Work in partnership and collaboration with key stakeholders, including people living with dementia and family carers.
The Health Service Executive will develop a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time.
Integrated dementia acute care pathway project

Diagnostic project

DEMENTIA POST-DIAGNOSTIC PROJECT

Care Pathways
Telling the person (Revez et al, 2018)

- Most people want to know their diagnosis;
- Experiences of diagnosis disclosure can be complex and emotional;
- Many healthcare professionals simply avoid disclosure altogether (at least to the person);
- The pathway of diagnosis-disclosure can be long and fraught;
- How the person is told has a significant impact on their experience of the condition;
- Tailoring information to the individual.

Adapted from findings of Lecouturier, 2008.
An Identified Care Gap following a Diagnosis

“Emotionally it is a hammer blow. It is a serious, it is a depressing thing, it just knocks you sideways. All I was left with was the sickening sense of loss” (person with dementia, PDS needs analysis)

“Following a diagnosis, the person with dementia will need considerable emotional and practical support. Local, well-coordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time” (National Dementia Strategy, 2014)

“Services offered may be fragmented, poorly coordinated, inflexible and inequitable” (Foley and Swannick, 2014)
Multi-disciplinary steering group

- Identify needs and explore current practice in Ireland
- Identify international best practice
- Negotiate implementation
- Support and increase capacity within the system
- Develop a framework

- Irish Dementia Working Group
- Dementia Carers Campaign Network
- Scoping
“To enable and assist people with dementia and their families to live a life of their choosing throughout the continuum of dementia. Post-diagnostic supports include interventions, therapeutic treatments and activities that build on strengths and abilities; helping to maintain and enhance quality of life”

(Dementia Post-diagnostic Steering Group, 2018)
Dementia Post-diagnostic Literature Review
(O’Shea, Keogh and Heneghan, 2018)

• PDS is crucial for contemporary and future decision-making;
• Can reduce anxiety and isolation; helping the person to work through the diagnosis and supports adjusting and coping;
• Can enable the person to plan for a life beyond diagnosis;
• Can reduce home-care placement (targeted carer programmes);
• Approaches can enhance self-efficacy, management of symptoms and maintaining independence;
• Timing of the intervention matters;
• Tiered approach to information provision;
• Responses tailored to the individual;
• Responses should address the needs of both the person with dementia and their supporters;
• Staying connected is very important.
4 key elements of post-diagnostic support:

**The Person**
- Understanding the condition
  - The right information, at the right time
  - Talking it through
  - Psycho-education

**Therapeutic interventions**
- Medications
- Cognitive therapies
- Assistive technologies
- Health promotion & risk reduction
- Psychosocial interventions
- Psychological & emotional support

**Planning for the future**
- Advanced healthcare directives
- Decision-making arrangements
- Financial management

**Staying connected**
- Dementia inclusive communities
- Peer support
- Public awareness and understanding
Initiative: Dementia Post-diagnostic Grant Scheme
• Focus on cognitive rehabilitation, cognitive stimulation and psycho-education programmes
• Call for applications April 2018
• €25,000 per grant to cover staff costs
• Open competition across Health Service Executive and section 38 and 39 organisation
• 18 sites
• Two per Community Health Organisation area
• 50+ applications received
• Independently reviewed
• Grants awarded in September 2018.

Funded by Dormant Accounts through the Department of Health
Grant Distribution
Intervention and Programme Areas

Cognitive Stimulation Therapy = 7 in total

Cognitive Rehabilitation = 6 in total

Psycho-educational Programmes = 8 in total
Tender process:
Awarded to Dr. Maria Pierce (independent researcher); Dr. Fiona Keogh and Prof. Eamon O’Shea (CESRD, NUI Galway).

WELLBEING FRAMEWORK

Purpose:
Assess the impact / effectiveness of interventions.

Primary objectives:
• Describe the programmes delivered and processes around their delivery.
• Assess the impact of the interventions for the person with dementia and their family members.

Secondary objective:
Assess if the PDS interventions have succeeded in addressing post-diagnostic support and care gaps.
NDO commissioned the Dementia Services Information and Development Centre to develop this psycho-education guidance; supported by a national multi-disciplinary group.

**Dementia Psycho-education Guidance Document (2019)**

- Offers suggestions on how to organise a programme;
- Outlines suggested content;
- Offers resource suggestions;
- It is not prescriptive;
- It is adaptable to suit local context

Available as an interactive pdf on [www.dementia.ie](http://www.dementia.ie) [www.understandtogether.ie](http://www.understandtogether.ie)
Initiative: Memory Technology Resource Rooms (MTRRs)
Memory Technology Resource Rooms

A network of MTRR established which aim to support independence and safety for people living with dementia and those with memory difficulties through the use of Assistive Technologies.

- Assistive technology libraries – Genio funded Community Consortia Projects;
- Older Persons Services applied for DoH Dormant Account funding.
Initiative: Cognitive Therapy Masterclasses
Cognitive Rehabilitation Therapy, where people with dementia and their supporters work together with a health professional over a number of sessions to identify **personally relevant goals** and devise and implement strategies for achieving them.

It generally refers to an individual approach to improving functioning in the everyday context rather than enhancing performance on general cognitive tasks (Baher-Fuchs et al, 2013)

- Four masterclasses health in November and December 2018.
- NDO partnered with Engaging Dementia.
- Mary McGrath, Advanced Specialist OT facilitated the workshops.
- **111 health and social care professionals** from across the Ireland attended.
Initiative: National Intellectual Disability Memory Service
National Intellectual Disability Memory Service

Centre of Excellence in proactive dementia assessment and diagnosis for people with an intellectual disability.

The service is led by Prof. Mary McCarron will:

- Operate a central coordinating national memory clinic, with a number of satellite clinics distributed nationally.
- Provide expert consultation which will include person-centred recommendations following a diagnosis of dementia to ensure that the person is in a position to live well and to die with comfort and dignity.
dementia

understand together

www.understandtogether.ie
Dementia: Understand Together campaign

I knew something was wrong

trying to hide it would have been worse

As he fell, people would be, "that's the man with Alzheimer's".
Survey results
A third of adults believe they have a reasonable understanding of dementia.
63% Saw TV CAMPAIGN (2.3 million)

59% Took some action (1.4m)

- Made a mental note to be empathetic (42%)
- Made a mental note to get in touch with someone with dementia (16%)
- Made a mental note to get in touch with carer of someone with dementia (15%)
- Called into someone with dementia (12%)
- Called in to see a carer of someone with dementia (9%)
- Went online or called helpline to find out more about dementia (2%)
We are growing a **movement** of people taking action
to create **understanding and inclusive communities**
where people with dementia and their families are **respected, supported and connected**.
See the person, not the dementia

Talk about dementia

Ask how you can help

Stay in touch

Support the person to keep up hobbies and interests

Make sure your service/space is easy to use
Partners

- Bloom
- Irish League of Credit Unions
- Banking & Payments Federation Ireland
- Elevator
- Healthy Ireland
- Ulster Bank
- Bank of Ireland
- Age Friendly Ireland
- POST
- Irish Pharmacy Union
- Friends of the Elderly Ireland
- Hello Brain
- Age & Opportunity
- Irish Rural Link
- Iarnród Éireann
- Irish Rail
- Dublin Airport
- Irish Gerontological Society
- NUI Galway
- ISME
- Dublin Bus
- The Irish Hospice Foundation
- IFA
Growing community of Champions
Initiative: Diagnostic and Post-diagnostic Framework
Post-Diagnostic Support Project

Dementia Diagnostic Project

- Identify Current Practice in Ireland
- Steering Group Established
- Identify International Best Practice
- Support & Increase Capacity in the System

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Develop Dementia Diagnostic and Post-Diagnostic Support Framework
Considerations

- **Stigma** may prevent people seeking support;
- Existing services may suit some more than others;
- Flexible, *individualised approaches* needed;
- What is a timely diagnosis?
- Different needs depending on where the person is in their dementia journey;
- Evidence on the effectiveness of various PDS interventions is weak;
- Different *local context* in which services are provided e.g. age-related care; mental health; neurology; primary care; secondary care etc.
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