THE ALZHEIMER SOCIETY of IRELAND

- **Signposting and Support: The Alzheimer Society of Ireland Developing a Dementia Advisory Service**

Establish Advisory Service

- ASI Background
- Requirement for Advisory Services
- Initiatives in other Jurisdictions
- ASI Plan to develop Advisory Service
- What Dementia Advisory Service will look like
  - Knowledge Areas
  - Delivery

ASI Existing Services

- Home support, day care, respite care,
- Range of social supports including social clubs, Alzheimer cafes, support groups and other interventions including family carer training and assistive technology.
- Most of our services and supports are provided at a "point in time" on the dementia journey, have organically grown and are largely based on trying to meet people's needs who are living through the experience.
- Family advisory, Helpline, advice and information
- 4000 calls per annum. Powerful but limited communication
- Dementia adviser pilots

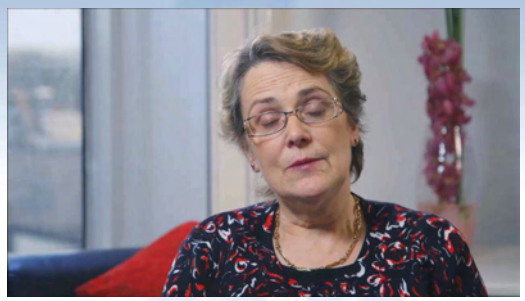
Requirement for Advisory service

- Dementia is a condition that people live with from diagnosis to the end of their lives.
- Challenges , not just at diagnosis but also at many of the key transition points on their journey with dementia.
- We have heard time and time again from families about the complete lack of information and supports at the time of diagnosis
- Consistent feedback around a lack of any direction, timely information or consistent support right across the whole lifecycle.
- These anecdotes are increasingly being documented in the international research literature to the point now where there is a compelling evidence base to find meaningful ways to support people with dementia and their families across the dementia lifecycle.

PWD Working Group quotes

- "We do not have the resources in the regions. When I was diagnosed I got zero."
- "It would have been crucial for me if someone gave me a little piece of paper saying that these are the things you need look into."
- There is a lack of general information about the illness and "the consultant has no other obligation other than to diagnose you"
- "Forget about Google – don't look it up, the internet tends to be quite negative and overwhelming".
- "I was on google reading very negative information."
- "It's important to be part of a group, being surrounded by other people and not feeling alone, you can share problems and experiences with them."
- "People need to be told about medication – that there can be side effects, and there are choices of different ones".
- "Lost, uncertain, you don't know what's to come. The person needs reassurance."

Helen Rochford Brennan- Chair, Irish Working Group for PLWD



Background

- In Ireland we have the 2012 Research Review for National Dementia Strategy report that has provides the evidence indicating that clearly our service system is inadequate and critical links are often missing in the chain of services to meet the need of people with dementia.
- (Cahill, O'Shea and Pierce) conclude that the individual experiencing the symptoms of AD along with family members confronting dementia need a key contact person whom they trust and who is knowledgeable about a whole range of pertinent dementia related issues.
- ASI has decided to try to fill some of the gaps by developing a dementia advisory service across 6 geographical areas in the country
- Not universal agreement on delivery: advisors, link worker, coordinator. case management
- ASI, plans to provide leadership in this area to demonstrate and evaluate the Adviser model

Experience in other Jurisdictions

- Variations of a theme are emerging in terms of dementia-advisory type services for e.g.
- France: Dementia Co-ordinators have been appointed as part of their strategy
- England: Dementia advisory services are emerging across the country
- Scotland: strategy is committed to developing link workers
- Netherlands, Norway and Sweden: we see the development of Specialist Dementia teams.
- They all vary in their roll out, with different levels of emphasis, but all share the core element of *signposting* and *supporting* people through the system.
- ASI have continually lobbied that the forthcoming Irish National Dementia Strategy will acknowledge this gap and make some recommendations to begin to address it in a systematic way.

UK Evaluation

Recent publication by the Dept. of Health Policy Research in England called the National Evaluation of Dementia Advisers in the implementation of the NDS in England.

Comprehensive report and certainly provides us an organisation with a renewed sense of energy and commitment to rolling out the Dementia Advisory Service.

1. The timing and flexibility of the support from the Dementia Adviser resulted in support that was tailored to the individual's needs and circumstances.

2. The Dementia Advisor, by sharing information and in signposting people with dementia and carers to appropriate other services and supports, has a significant role in enabling people with dementia and cares to re-narrate their lives and gave them control of their lives and their dementia.

3. The Dementia Advisor services filled a gap in support and had a positive impact upon well-being and quality of life.

ASI Pilot learnings

- Full Time Role- Activity management
- Need to avoid Role Definition drift
- Clear Role definition vital- (wriggle room)
- Set clear expectations for first engagement
- Empower PLWD/Family- don't do it to them or for them
- Agreed Action plan with PWD/Carer
- Quality, Timely Information with accurate records to understand trends, needs, gaps etc.

Pilot Learning

- Initial Meeting Key-Allow time and space
- Avoid Information Dumping- Right information at right time
- To date limited follow up requested- email/website
- Availability of service is reassurance of itself
- Small relevant interventions can have significant benefits to quality of life

ASI Plan

- We propose to develop a model that focuses on two main elements:
- (1) signposting the person through the system post diagnosis and at key transition times across the lifecycle and
- (2) providing on-going individual support to adjust to the diagnosis and to live well with dementia.
- Role definition is key- what, where and when will a DA deliver- and what not

Dementia Advisor Service

Free &Confidential service

Dementia Advisor Service
Information, Advice and Signposting Service

Who is this service for?

- People living with dementia
- Family members / carers

Who is the Service For?

•The service will concentrate on providing support to early stage / newly diagnosed people and their families who are not already in contact with our existing services.

•The Advisor will then be a named contact who can be available to the person/family at key times during their journey with dementia, where that may be needed.

Knowledge Areas

Brain Health	
What are risk factors for dementia	Be able to comfortably talk about risk factors
How to reduce risk	Be able to describe practical steps to reduce risk
Overview of evidence base	Have an overview and be able to sign post to evidence base

Knowledge Areas

Dementia	
What is dementia	To be able to describe dementia in plain english and in different circumstances
Types of dementia - AD, VD, DwL, FTD	Know and be able to explain the different types and characterics
Progression	In general how dementia can progress - an overview and differences between types
Medications and treatments	General overview of role of medication and management of symptoms
Health Care Professionals - GP, Consultants and memory clinics	Be able to explain role of GP, Geriatrician, Psych of Later Life and Neurologist. Know role of memory clinics in Ireland

Knowledge Areas

Early Signs and Diagnosis cont'd	
Tips to support a loved one with process	Suggest ways to prepare, diary, q's, accompanying person and calling or writing in ahead of an appointment
Who are health care professionals involved	Outline role of GP, Consultants and Memory clinics
When a person refuses to go to GP	Suggest approaches to begin a process
Risk factors for dementia	be able to list and talk through risk factors
Role of genetics	Be able to talk about genetics and dementia

Knowledge Areas

Impact of dementia	
Impact on person with dementia	Understand possible reactions and able to suggest approaches to coping, signpost to support
Impact on loved one	Understand possible reactions and able to suggest approaches to coping, signpost to support
anticipatory, ambiguous and hidden grief	understand ways grief may present - recognise it, signpost to appropriate support
Relationships - changes in roles	understand possible reactions to changes in roles and be able to signpost to support

Knowledge Areas

Day to Day Living	
Person with dementia	
Talking about dementia	Be able to offer space to talk about diagnosis and to be able to refer to people , supports for particular needs
Steps for living well	Be able to talk about diet, exercise, socialising, brain exercise, routines etc - to assist with day to day life

Knowledge Areas

Person with dementia cont'd	
Technology	Be able to refer to possible options / supports
Driving and dementia	Knowledge of and able to explain this area
Legal and financial Planning	Knowledge of and able to explain this area
Know your rights	Knowledge of and able to explain this area
Managment of symptoms and awareness of behaviours that may emerge	knowledge of symptoms and behaviours, able to suggest some coping mechanisms and sign post to possible medical and social supports

Knowledge Areas

Family Members	
in addition to knowledge areas for pwd	
Looking after yourself as a family carer	Why it is important and steps a person can take
Building a support network	How to build a support network - role of family, community and health and social care professionals

Knowledge Areas

Legal Areas	
Elder Abuse	Able to recognise EA in various forms and signpost person to correct supports.
EPA	knowledge of and able to explain this area
Ward of Court	knowledge of and able to explain this area
Capacity legislation	keep up to date with progress in the area

Knowledge Areas

Services and Supports	
ASI Services	be able to explain each of our services, locate local details and how person can access it
Role of HSE	Explain HSE, Role of PHN and PCT
Home Care Packages	Explain HCP, who to access etc
Other service providers	Carer's Association and private HC providers
Genio Projects	Explain and refer appropriately to each project
ASI PWD Working Group	Knowledge of and able to explain this area
Dementia Friendly Communities	Knowledge of and able to explain this area
Michelle Kelly and early intervention work	Knowledge of and able to explain this area
Financial Supports grants and entitlements	CA, CB, RCG, House adaptations etc, Role of CIC'S

Knowledge Areas

Transition to Nursing Homes	
NHSC	Knowledge of and able to explain this area
HIQA	Knowledge of and able to explain this area
Nursing Homes in Ireland	Knowledge of and able to explain this area
Impact on Person with Dementia	Knowledge of and able to explain this area
Impact on Family	Knowledge of and able to explain this area
Continuing to Care	Knowledge of and able to explain this area
Late Stage Dementia	
What happens generally at late stage	Knowledge of and able to explain this area
Possible care options and decisions	Knowledge of and able to explain this area
Bereveament	Knowledge of and able to explain this area

The key objectives

- Appoint 6 full time dedicated Dementia Advisors
- To provide an individualised, structured and responsive information, signposting and emotional support service.
- To provide a choice of face-to-face, phone and email support.
- To focus on the individual and their needs to live well with dementia.
- To seek to empower the person living with dementia to access the information they need, promoting self help, well-being, choice and control.

The key objectives

- To reach new people (not already receiving services) – the service will actively seek out those affected by dementia .
- To make connections and build relationships with other health and social care professionals and community based organisations / groups who may provide referrals into the DA service and to whom we may refer our service users to.

Service Delivery

- Monday to Friday between 9am and 5pm full time
- Available to meet the client at a venue and time convenient to them. (Within the service delivery hours)
- Follow up with another meeting, phone call or email if required.
- Create an individual action plan in consultation with the PLWD and their family based on their current needs.
- Leave the door open to the person living with dementia and their family to contact the DA at any stage during their journey with Dementia.

People who use the service can expect:

1. To receive factually correct and up-to-date information, tailored to their individual needs and communicated in a way that suits them
2. To be able to access, understand and use the information in a way that has helped and empowered
3. Support to access ASI and other services and to experience an integrated approach with health and social care professionals and with community groups & organisations.
4. To contribute to the service development through review and evaluation

What the DA service is not...

- Personal advocacy
- Counselling
- Case management service
- Clinical dementia 'expert' service

There is a need to identify these needs and then refer / signpost appropriately.

Key Challenges

- Partnership with Healthcare Professionals- Generate Referrals
- Avoid role definition drift and manage activity
- Organisation Fit within ASI- Complimentary to existing services
- Independent evaluation over a 3 year period

Thank you