

# Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways

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## FOREWORD

Having worked with people with Young Onset Dementia (YOD) for many years I want to thank the National Dementia Office for commissioning this work. Despite many highlighting the plight of people with YOD, it has not received the focus of policy makers and healthcare resources, until now.

Although people with YOD are a small number of all those living with dementia, the impact of having this disease at this time in their lives is so huge that it reverberates and causes such hardship and heart break, not only to the person with YOD, but also to their whole family.

There is no defined path for them to follow to access care and no one service that takes ownership to care for them. People with YOD have to fight every step of the way from recognition of their symptoms, access to assessment, finding support to live with the disease and endure the damage it wrecks on them and their families. One person with YOD in this report describes the experience so poignantly as the 'rollercoaster of sadness'.

The mixed-model approach employed by the researchers is an excellent one. The literature review is comprehensive, informative and directive. The case studies not only echo my experience but, as I think others will find, offer insight into others' experiences that is enlightening. As often noted, health care professionals often work in 'silos', rarely having the time or means to widen the view and look away from their own practice to what others are doing or what the people we care for want or need.

This report highlights the shortcomings of the Irish healthcare system in caring for people with YOD, reviews international experience and good practice and therefore formulates recommendations to improve the care and support of people with YOD in Ireland.

It has galvanized my resolve to improve my practice, as I am sure it will others. But most importantly it is the foundational step for the NDO in their mission to transform the dementia landscape and allow people with YOD and their families to live well.

Siobhan Hutchinson

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## ABBREVIATIONS

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YOD: Young Onset Dementia

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LOD: Late Onset Dementia

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AD: Alzheimer's disease

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HSCP: Health and Social Care Professionals

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WHO: World Health Organisation

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NDS: National Dementia Strategy

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NDO: National Dementia Office

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HSE: Health Service Executive

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PHN: Public Health Nurse

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PDS: Post-diagnostic Support

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ANP: Advanced Nurse Practitioner

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MDT: Multidisciplinary Team

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ASI: Alzheimer Society of Ireland

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FTD: Fronto-temporal Dementia

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GP: General Practitioner

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DA: Dementia Advisor

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ICP: Integrated Care Pathway

---

EEG: Electroencephalogram

---

DSiDC: Dementia Services Information and Development Centre

---

MTRR: Memory Technology Resource Room

---

CRT: Cognitive Rehabilitation Therapy

---

CST: Cognitive Stimulation Therapy

---

OT: Occupational Therapist

---

GPCOG: General Practitioner Assessment of Cognition

---

MCI: Mild Cognitive Impairment

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MMSE: Mini Mental State Examination

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## LAY SUMMARY

People who are diagnosed with any type of dementia before the age of 65, are said to have “Young Onset Dementia”. People who are affected by Young Onset Dementia can face different challenges to people who are affected by dementia at an older age, and may need different supports. However, in Ireland and in other countries we know anecdotally that mainstream dementia services are not always suitable for a younger person. Also, sometimes the service has an age cut-off and may not be available to the younger person. The National Dementia Office (NDO) commissioned this report to investigate the diagnostic and post-diagnostic support needs of people with Young Onset Dementia in Ireland.

This was a mixed-methods study, meaning that different research methods were used. A literature review was conducted to gather the evidence for I) diagnostic pathways and processes and II) post-diagnostic pathways and processes for people with Young Onset Dementia. Interviews were conducted with people living with Young Onset Dementia ( $n=10$ ) and their spouses and children ( $n=12$ ) about their experiences and preferences. Interviews were also conducted with healthcare professionals and healthcare managers ( $n=25$ ) working in dementia services to explore their experiences of current services, and their opinions on how these may be improved.

The findings from across the literature review and the interviews were consistent. Healthcare professionals felt that diagnosing Young Onset Dementia is complex as there are more unusual sub-types and also because dementia might not be suspected in a younger person. People thus experienced many delays in waiting for a diagnosis, which was a very anxious time for them and their families. Experiences of diagnosis disclosure varied, poor experiences included not being given written information, and being told the diagnosis in an inappropriate (not private) setting. Once a diagnosis was established, people with Young Onset Dementia found it difficult to access post-diagnostic supports. Those who had accessed supports found that many were inappropriate, such as respite or day centres. People with Young Onset Dementia and their families needed information about employment rights, and accessing financial supports. Younger children of people with Young Onset Dementia might have psychological and emotional distress and may benefit from counselling or additional support.

Overall, the findings from this report suggest that people with Young Onset Dementia in Ireland face many challenges, and their needs are not being met by current services. This report puts forward a number of recommendations to guide the development of policy and services in this area, which could lead to a better quality of life for all those affected by Young Onset Dementia.

## BACKGROUND

This report provides new Irish-based data to enable the development of models of care in relation to the diagnostic and post-diagnostic support needs for people with Young Onset Dementia (YOD). The current report presents the findings from a mixed-methods study, developed to comprehensively address the research aim and research questions.

The high level objectives of the research are to:

- (i) Identify international best practice and/or models for diagnosis and post-diagnostic support for people with YOD;
- (ii) Capture the experience of receiving a diagnosis of YOD in Ireland;
- (iii) Explore the current diagnostic and post-diagnostic pathways and processes for YOD in Ireland; and
- (iv) Make recommendations to support ongoing work on the development of diagnostic and post-diagnostic dementia care pathways.

## RECOMMENDATIONS

A consistent finding across the different elements of this report was the significant impact a diagnosis of YOD has on the individual and their families, and the particular difficulties they face experiencing dementia at a younger age. Findings highlight that people with YOD and their family members are significantly disadvantaged in the Irish health and social care system, where there is a dearth of age-appropriate services (Hutchinson, 2013). There are a number of specific priority areas informed by the results of this research project, along with actionable recommendations, as follows:

### ***Individualised approaches***

The individual and unique needs and experiences of every person with YOD must be a central consideration across all aspects of dementia care, from assessment and diagnosis, to the timing and planning of post-diagnostic models of supports in the community, to long term residential care and to end of life care.

### ***Streamlining diagnostic processes***

The current processes of assessment should be reviewed, and streamlined, with the specific needs of people with YOD in mind. All HSCPs including primary care staff, staff employed in secondary services, and those in the acute sector, need to be aware of YOD as a condition and assess and/or refer younger people with memory complaints appropriately. There are key resources available to GPs to aid with timely referral, for example, the new national e-referral facility for memory clinics (DSiDC, n.d.). Information about such resources should be widely disseminated. Pathways to specialist consultation, testing and imaging should be straightforward, easily and readily accessible and timely. At the point of diagnosis, the person making the diagnosis needs to make all relevant HSCPs aware of diagnosis confirmation (e.g. GP, local memory clinic if diagnosed elsewhere). Critically, the person must be kept informed about this process throughout. Wider awareness is required amongst community-based HSCPs regarding YOD assessment and diagnosis.

*1. Recommendation:* HSCPs (for example GPs) should have clear pathways to accessing assessment for patients in their area and nationally. HSCPs need to be fully informed as to where they can refer, which specialists in their local area are accepting referrals, and which have age restrictions.

*2. Recommendation:* All people, regardless of age, should have access to specialist services for assessment and diagnosis.

### ***Disclosure***

There should be greater consideration given to the process and impact of disclosure, including provision of protected time, space and personnel to support an optimum disclosure meeting. Only key HSCPs should be part of the disclosure meeting. The preferred contact for the person (such as a family member) should be encouraged to attend and included in the meeting, unless the person chooses otherwise.

*3. Recommendation:* The process of disclosure should be planned and cognisant of the time and privacy needed. HSCP should ascertain the individual's wishes vis-a-vis disclosure and only necessary personnel should be in attendance.

*4. Recommendation:* A nominated HSCP from the clinic should be available to provide early support post-disclosure (e.g. if required on the day, and a follow-up call in the following days).

### ***Information provision at disclosure***

People with YOD have specific, unique information needs. However too much information given at the same time may not be absorbed and may be harmful. At disclosure, key information should be provided in a readily accessible but staged format. Consideration should be given to what is discussed at disclosure, and what can await discussion at the next review meeting. The person should also be provided with written information to supplement what is discussed during a diagnosis meeting. Information relating to key first steps should be offered at this time e.g. contact details for dementia organisations, and information on how to access local supports.

*5. Recommendation:* Information provided on day of disclosure should focus on diagnosis, treatment and on that person's and family member's urgent information needs at the time. The person should be invited for a return visit 4-6 weeks post-disclosure, when additional, detailed conversations can be held.

*6. Recommendation:* Written information should be provided at time of diagnosis relating to YOD, the specific diagnosis sub-type and treatment. Written information should be supplied in the form of leaflets and/or information cards signposting the person to key dementia and community organisations and their contact details.

*7. Recommendation:* The person/family should be provided with specific guidance relating to financial and legal issues, at the appropriate time.

### ***Service level integration***

There must be clear, channels of communication between diagnostic and post-diagnostic services. There should be clear pathways for the person and for HSCPs to easily access and navigate services, facilitating early intervention. These pathways should be available at the time of diagnosis, and must be responsive to preferences and changing needs of the person (and family).

8. *Recommendation:* At diagnosis, families should be provided with a named point of contact from within the specialist services (e.g. a nurse, advanced nurse practitioner (ANP), Health and Social Care professional, or similar from within the clinic MDT).

9. *Recommendation:* If this is not possible, the specialist and GP should liaise to ensure clear channels of communication and information with the person with YOD.

#### ***Named point of contact- post diagnosis***

A person diagnosed with dementia should be given a named point of care within community settings, such as a key worker, for PDS. A dementia-specific HSCP would be optimal, as a point of contact to support them on an ongoing basis. It is important that community-based HSCPs (e.g. community and public health nurses) are aware of the specific issues experienced by people with YOD. They need to be aware of those living in their area with YOD, and who may potentially have young families and specific needs.

10. *Recommendation:* The person with dementia should be provided with a named point of contact for ongoing post-diagnostic support in the community, e.g. DA or Dementia care co-ordinator.

11. *Recommendation:* Community-based HSCPs should receive education and training and be aware of the specific issues relevant to YOD, models of care and key local and national services.

#### ***Post-diagnosis (outcomes-focused approaches)***

Post-diagnostic approaches and interventions should be planned with specific consideration to individual preference, pitched at the appropriate time and level. Outcomes-focused approaches to care planning and post-diagnostic service signposting should be adopted. These approaches will support and enable the person to maintain an optimal standard of living and engage outlets that are empowering and meaningful.

12. *Recommendation:* There should be a range of PDS options available to address the individual and their family members' needs. In addition to dedicated dementia models of care, consideration should be given to non-dementia supports that will facilitate people with YOD to live well, and to continue their own preferred and usual roles, occupation and interests.

13. *Recommendation:* Community HSCPs should utilise an outcomes-focused approach to care, guided by the person. Decisions about interventions, and timing of interventions, should be led by the person.

#### ***Legal and Financial advice/information***

Specific information and advice should be given to people with YOD and their family members on key areas such as employment rights, financial supports, welfare entitlements, driving and legal issues such as appointing assistant decision-makers and arranging Enduring Powers of Attorney. This is key not only for people experiencing the symptoms of dementia and others such as family members affected by dementia, but also for the HSCPs involved and relevant others such as state institutions, employers etc. Specific guidance documents should be prepared by key dementia organisations such as the NDO or the ASI.

*14. Recommendation:* Guidance should be available to employers highlighting the unique circumstances that YOD presents. Guidance and information should also be available to people with YOD on their rights and entitlements in the workplace.

*15. Recommendation:* Staff in key government agencies such as the Department of Employment Affairs and Social Protection and Disability Services should be made aware of the specific challenges confronting the individual and family members where a diagnosis of YOD is made.

### ***Family support***

There needs to be dedicated information and support services for families of people with YOD, including young children. These need to be provided in a timely manner and in a format that is accessible to families.

*16. Recommendation:* Specific information leaflets suitable for children of people with YOD should be developed by key dementia organisations such as the NDO or the ASI.

*17. Recommendation:* There should be dedicated support interventions for young families of people with YOD. Particularly valuable may be informal mentorship/peer support groups.

*18. Recommendation:* Counselling programmes should be made available as an option for the time after diagnosis and as part of PDS.

### ***Advanced care planning / Palliative care***

Information on palliative care and Advanced Care Planning should be made available at the appropriate time to the person with dementia and family carers by a HSCP who has the appropriate skills and expertise.

*19. Recommendation:* Conversations on advanced care planning including end of life decision-making must commence early and be reviewed and organised over time. HSCPs must document and facilitate care preferences as outlined by the person.

### ***Wider community approaches***

A whole-of-community approach should be taken to increase awareness and to address stigma experienced by people with YOD. A community that is knowledgeable and aware of YOD could potentially empower people with this condition to remain connected and socially engaged and ultimately enjoy a good quality of life

*20. Recommendation:* Existing community activation initiatives could be further extended to increase awareness of YOD and the unique issues experienced by the person and their families.



# Chapter One: Introduction

## 1.1 Policy Context

Approximately 50 million people are living with dementia worldwide (World Health Organisation (WHO), 2019). In Europe, the numbers are projected to increase from 9.8 million in 2019 to 18.8 million by 2050 (Alzheimer Europe, 2019). In Ireland, reliable epidemiological data are lacking, but recent estimates indicate that there are between 39,272 and 55,266 people living with dementia; the exact figure being dependant on the methods used to measure prevalence internationally (Pierse, O'Shea and Carney, 2019). Within this range it is estimated that between 2,906 and 4,311 people are living with Young Onset Dementia (henceforth YOD) (Pierse et al., 2019). Whether the precise figures are higher or lower than these estimates, the point remains that there is a low diagnosis rate in Ireland, and our health services and community supports are not sufficiently equipped to respond to even the lower estimates (Pierse et al., 2019).

Internationally, there is a lack of policy focus for people living with YOD, and this lack of focus has led to significant social and psychological stress for those impacted (Carter, Oyeboade and Koopmans, 2018). Supports and services are designed based on level of need (Pierse et al., 2019) and much of the research on YOD (including prevalence) is limited to persons already diagnosed, and already in contact with services (Prince et al., 2014). People with YOD have historically been excluded from active involvement and consultation in service and policy design (Mayrhofer et al., 2018; Rabanal et al., 2018). Legal frameworks and decision-making powers remain overlooked (WHO, 2018). This is important when we consider that the information needs of people with YOD are different, and warrant

dedicated approaches (Cahill, O'Shea and Pierce, 2012). For example, support relating to employment, legal and financial matters is under researched (Mayrhofer et al., 2018). Because access points to specialist services (e.g. neurology, memory clinics) for people with YOD are often very diverse (Withall et al., 2014), and service options limited, the provision of clear information, in addition to guidance and support, is vital.

After diagnosis, people with YOD experience numerous complex psychological processes and try to identify ways to cope with and adjust to the significance of their diagnosis (Spreadbury and Kipps, 2019). The Alzheimer Society of Ireland (ASI), one of the main service providers of dementia specific services in Ireland, does not restrict service access based on age. However, there remains a lack of specific dedicated services for people with YOD in Ireland (Pierce, Cahill and O'Shea, 2014). Traditional models of post-diagnosis support (e.g. day centres) are not designed for younger demographics (Rabanal et al., 2018). When dedicated services are developed, these are often geographically variable (Mayrhofer et al., 2018) and therefore not available to all who might need them.

## 1.2 Report Background

Since the publication of the Irish National Dementia Strategy (Department of Health, 2014), a number of instrumental priority actions and related projects have been implemented. One such priority action area aims to target 'Timely Diagnosis and Intervention', a commitment to develop national and local dementia care pathways that will plan and signpost optimal pathways through the system, from initial presentation with symptoms, to diagnosis, to enacting



appropriate levels of intervention. To advance this priority action, the NDO established two projects: the Dementia Diagnostic and Post-Diagnostic Projects, both supported by national multidisciplinary steering groups. The projects focussed on identifying current service provision and best practice in relation to dementia diagnosis and PDS. Over two years there has been a series of outputs from these projects including:

- A Guide to Memory Clinics in Ireland (Gibb and Begley, 2017)
- Literature Review of Diagnostic Processes in Ireland (Revez et al., 2018)
- Literature Review of Post-Diagnostic Support for People with Dementia and their Carers (O' Shea, Keogh and Heneghan, 2018)
- Next Steps Guidance on Post-Diagnostic Psychoeducation for People Living with Dementia (Gibb et al., 2019)
- Clinicians Survey: Dementia Diagnostic Processes and Practices in Ireland (NDO, 2019)
- Evaluation of Dementia Post-Diagnostic Support Grant Scheme (Pierce et al., 2019)

The provision of timely diagnosis and clear post-diagnosis pathways is particularly relevant to people who live with YOD, who will often *"experience greater difficulty accessing a diagnosis and fitting into existing dementia service provision, which is generally tailored to the needs of older people"* (Department of Health, 2014, p.11). While both the diagnostic and post-diagnostic projects include consideration of people with YOD, it was identified that further research was needed to examine current processes and pathways and to inform models of diagnostic and post-diagnostic services specific to this group.

Therefore, the aims of the current project were to:

- I) identify international best practice and/or models for diagnosis and PDS of people with YOD;
- II) capture the experience of receiving a diagnosis of YOD in Ireland;
- III) explore the current diagnostic and post-diagnostic pathways and processes for YOD in Ireland; and
- IV) make recommendations to support the ongoing development of diagnostic and post-diagnostic dementia care pathways.

### 1.3 Scope of the Report

This report was commissioned to provide an overview of YOD in the Irish context. In order to achieve this, and to meet the above aims, a mixed-methods study was planned with three elements, as follows:

- I) A structured literature review to identify national and international best practice models for (a) diagnosis and (b) PDS of people with YOD.
- II) A qualitative study to capture the lived experience of being diagnosed with, and living with, YOD in Ireland.
- III) A qualitative study to explore the current diagnostic and post-diagnostic pathways and processes for YOD in Ireland, from the perspectives of key HSCPs in Ireland.

This report is divided into seven chapters. Chapter one provides a brief overview of YOD in Ireland and outlines the background and context for the project. This chapter also reports on the project's key aims and objectives. Chapter two reports on the study methodology. Chapter three presents a review of the literature relating to diagnosis and discusses findings from the international and national literature on best practice models for diagnosis. Chapter four presents a review of the literature relating to post-

diagnostic supports for people with YOD and their family members and identifies models of best practice.

Chapter five presents the findings from the qualitative interviews with people with YOD in Ireland and their family members, providing insight into their experiences of receiving a diagnosis, and of navigating care pathways. Chapter six presents the findings from the qualitative interviews with HSCPs, providing an overview from their perspective of the

current practices and processes for diagnosis and post-diagnostic models of care for people with YOD in Ireland. Chapter seven draws together and synthesises key findings from the in-depth interviews and discusses these against the backdrop of the national and international literature. In this final chapter recommendations are presented regarding specific service development and reform in the area of YOD; these are also presented next.

02



# Chapter Two: Research Design and Methodology

A mixed-methods design was developed to comprehensively address the research aims and research questions. The design included a comprehensive literature review, and two qualitative elements, interviews with people with Young Onset Dementia (YOD) and their families, and interviews with health and social care professionals (HSCP). The methods for each of these three elements are outlined below.

## 2.1 Methods I. Literature Review

The broad aim of the literature review was to identify international best practice models in the diagnostic and post-diagnostic support (PDS) of persons with YOD. The search was conducted to provide the evidence base required to develop equitable and accessible service supports for this vulnerable group of people. Three key research questions outlined in the National Dementia Office's (NDO) commissioning document were used to guide and inform this literature search:

- I. What models are available nationally and globally for the diagnosis of people with YOD, and what evidence is available to support these models?
- II. What models are available nationally and globally for the PDS of people with YOD, and what evidence is available to support these models?
- III. Are there differences between diagnostic and post-diagnostic processes and pathways for people with YOD versus those with late onset dementia (LOD)?

At the outset a decision was made to exclude any literature relating to intellectual disability and dementia, since an independent workstream on this topic has been commissioned by the NDO. A structured

review was undertaken and the following databases were systematically searched: Pubmed/Medline, PsychInfo, Cinahl, Embase, The Cochrane library, Lenus and Google Scholar. In addition, grey literature such as conference proceedings, national dementia strategies, dissertations, World Alzheimer reports, Alzheimer Europe reports, Alzheimer Society reports, and institutional repositories as for example TARA and RIAN were also searched. The research strategy consisted of developing a systematic search-string that was later applied to all relevant databases, thereby ensuring exhaustive coverage and overall consistency. For Dementia/Alzheimer's disease, Mesh/Thesaurus search terms used were: (TI dementia OR pre-senile dementia OR Alzheimer's disease OR Pick's disease OR vascular dementia OR front temporal dementia OR Huntington's disease OR Parkinson's disease dementia OR Lewy bodies OR Lewy body dementia OR Korsakoff's syndrome OR Korsakoff's dementia). Search terms used for young onset were: (TI early-onset OR early onset OR young-onset OR young onset OR YOD or EOD). Search terms used for diagnostic pathways were: (TI/AB diagnosis OR assessment OR recognition OR detection OR disclosure) and for post-diagnostic pathways: (TI/AB support OR service OR intervention OR planning OR information OR advice OR programme).

The literature search was conducted in a staged manner between March and May

2019. In the initial phase, all bibliographic material was imported into EndNote, duplicates removed and abstracts perused by two reviewers. In relation to research question one, a total of 388 articles/publications were retrieved; most of which were extracted from either Medline/Pubmed or Embase. Regarding research question two, a total of 322 articles/publications were retrieved, most of which were retrieved from Medline/

Pubmed or Embase. As a large majority of the papers extracted addressed the topic of the difference between YOD and late onset, a further literature search was considered unnecessary to address research question three. Following the application of the agreed inclusion/exclusion criteria (see Table 2.1 below), two researchers worked together to review the identified papers using Covidence software.

**Table 2.1:** Inclusion and Exclusion Criteria Applied in Review

| Inclusion   | Exclusion   |
|---|---|
| Literature published since Jan 1 <sup>st</sup> 2005                           | Diagnostic services for people with Intellectual Disability (ID)^ |
| Aged between 18 to 64 at the time of diagnosis                                | Post-diagnostic services for people with ID                       |
| Any type of diagnostic service in any setting                                 | People aged 65 and over   |
| Any type of post-diagnostic service in any setting                            | Non-English language literature                                   |
| Any outcome measure   | Abstracts and conference proceedings                              |
| Any evaluation type   |   |
| Any type of scientific evidence-based on quantitative or qualitative research |   |

^Intellectual disability services were excluded from the current study as the NDO has commissioned a separate study specific to the needs of this population.

A narrative synthesis approach was used to evaluate and summarise materials selected in the review (Berrang-Ford, Pearce and Ford, 2015). The narrative analysis drew on texts to interpret and explain key findings derived from the review. This narrative synthesis has

also included a discussion of the similarities and differences between the findings of the selected studies, especially those pertaining to diagnostic and post-diagnostic pathways for people with YOD versus those with LOD.

## 2.2 Methods II. Exploring the Experiences of People with YOD and their Family Members

In chapter five we present the results of the qualitative interviews, which explores the perspectives of people living with YOD and family members, in relation to their experience of accessing and receiving a diagnosis, and of post-diagnosis supports and services. Three key research questions were used to guide and inform this element:

- I. What is the experience of receiving a diagnosis of YOD, from the person and the families' perspectives?
- II. What is the experience of living with YOD in Ireland?
- III. What extra (post-diagnostic) supports do people with YOD and their families feel they would benefit from?

### 2.2.1 Design

A qualitative design was used. Qualitative, in-depth interviews were conducted with people living with YOD and/or family members.

### 2.2.2 Data collection

All interviews were conducted face-to-face in a location most convenient for the participants (e.g. in their home, or a neutral location). The duration of interviews lasted between 32 minutes to two hours. Interviews were either individual ( $n=8$ ) or dyads (i.e. person with YOD and family member;  $n=7$ ). Family members were included in order to capture their unique experiences. The option of dyad interviews also gave the person with YOD the option of a supportive accompaniment during the interview. Themes to guide interview

topics were developed from the literature on YOD, as well as discussions with the project collaborator group comprised of clinical and topic area experts. The interview schedule is presented in Appendix I.

### 2.2.3 Recruitment

Participants were recruited using purposive sampling, via multiple channels. An email and information pack (information leaflet and a study poster with contact details) was sent to the Alzheimer Society of Ireland (ASI) service managers across three regions. The ASI regional contacts assisted recruitment by providing service users with the information leaflet and making the study posters visible. Further recruitment was made via the networks of the project steering group and project collaborators, many of whom work in healthcare environments which deliver services to people with dementia. The study was advertised within these services (e.g. by displaying the project poster). Finally, the study was also advertised to the general public on websites and social media sites of reputable and well-known national dementia and healthcare organisations.

In all cases potential participants 'opted-in' to study participation by contacting the research team directly by telephone, after being given or seeing study details. Eligibility (criteria listed in Table 2.2) was ascertained during an initial phone conversation and later confirmed face-to-face before data collection. The research team sent information leaflets and consent forms to potential participants who opted in and appeared eligible to learn more about the study.

**Table 2.2.** Participant Inclusion and Exclusion Criteria

| PwYOD- Inclusion criteria                                  | PwYOD- Exclusion criteria   |
|--|---|
| Living with a diagnosis of YOD (self-reported)             | Any person under the age of 18  |
| Having received a diagnosis of YOD in the previous 5 years | Living with a co-morbid diagnosis of intellectual disability <sup>^</sup> |
|  | Persons who are deemed to be lacking in capacity to consent               |

| Family Member- Inclusion criteria   | Family Member- Exclusion criteria |
|---|-----------------------------------|
| Is a close family carer of a person with YOD (i.e. involved in co-decisions about their care) | Any person under the age of 18    |
| Their relative was diagnosed with YOD in the previous 5 years                                 |                                   |

<sup>^</sup>People with an intellectual disability were excluded as the NDO have commissioned an upcoming report specific to the needs of this population.

## 2.2.4 Sample

The project requirements specified that interviews would be conducted with a small cohort of people living with YOD and their family care-partners to provide insights into the lived experience of dementia. Individual interviews were conducted with people with YOD, and with family members of people with YOD. People with YOD were offered the choice of attending the interview with a friend or family member, or alone. In case of the former, dyad interviews were held when explicitly requested by the person with YOD. It was deemed that the final number would be decided on by the point of data saturation.

**Table 2.3** Demographic details of the people with YOD and family members who participated in the interviews

| Category                                      | N         | N              | N        | N               | N        |
|---|-----------|----------------|----------|-----------------|----------|
| <b>People with YOD</b>                        | <b>10</b> | <b>Spouses</b> | <b>8</b> | <b>Children</b> | <b>4</b> |
| Female  | 6         | Female         | 7        | Female          | 3        |
| Male  | 4         | Male           | 1        | Male            | 1        |
| <b>Dementia sub-type</b>                      | <b>10</b> |                |          |                 |          |
| YOD (specific type unknown or unspecified)    | 6         |                |          |                 |          |
| Alzheimer's disease                           | 2         |                |          |                 |          |
| Logopenic progressive aphasia                 | 1         |                |          |                 |          |
| Lewy body dementia                            | 1         |                |          |                 |          |
| <b>Employment status at time of diagnosis</b> | <b>10</b> |                |          |                 |          |
| Stopped work prematurely due to dementia      | 4         |                |          |                 |          |
| Did not specify                               | 2         |                |          |                 |          |
| Early retirement due to dementia              | 1         |                |          |                 |          |
| College/volunteer work                        | 1         |                |          |                 |          |
| Not working                                   | 1         |                |          |                 |          |
| Early retirement (reason not specified)       | 1         |                |          |                 |          |
| <b>Interview type</b>                         | <b>15</b> |                |          |                 |          |
| Individual interviews                         | 8         |                |          |                 |          |
| Dyad (joint) interviews                       | 7         |                |          |                 |          |

Participants were offered the opportunity to attend alone, or with a significant other. While most attended alone, others opted to attend with a family care-partner. Dyad interviews have strengths and limitations. A strength identified in the current study is that it followed the preferences and request of the person. Additionally, this inclusive method of dyad interviewing aligns with relationship-centred approaches to care, an alternative framework to patient-centred care which recognises the centrality of relationships, families and the community, and how these influence healthcare experiences and outcomes (Soklaridis et al., 2016). It also allows for the opportunity for triangulation of experiences, stories, and accounts of past events (Wilson, Onwuegbuzie and Manning, 2016).

A potential limitation is the risk that individual voices are not given adequate opportunity to be heard, and narratives or experiences overlooked. To minimise this risk, dyad interviews in this case were closely monitored by the researchers to ensure no experience was overlooked. However, the primary consideration was to value and respect the choice of the individual research participant.

### **2.2.5 Ethical considerations**

All interviews were conducted by two members of the core research team, both experienced researchers who have conducted interview research with people with dementia previously. Relevant guidelines for conducting psychosocial research with people with dementia were followed, including the Alzheimer Europe position paper (Gove et al., 2018) and key publications relating to ethical issues, participatory research and active involvement of people with dementia in research (Bartlett and Martin, 2002; Dewing, 2007; Dewing, 2008; Hellström et al., 2007; McKeown et al., 2010). Ethical approval was obtained from the relevant Research Ethics Committee at University College Cork.

All participants were fully informed on the study prior to obtaining consent. Participants were advised that participation was voluntary and there was scope for them to withdraw from the research at any time. Prior to the commencement of the interview we revisited the topic of consent, the objectives of the research, and afforded participants the opportunity to ask questions prior to written and verbal consent. Each participant was provided with full contact information for the research team and the relevant local contact details to receive additional support if required (i.e. Regional Dementia Advisor service, Alzheimer Society National Helpline, Carer's Association numbers). We aimed to ensure that the rights and preferences of the individual interviewees played a central part in the research activities.

### **2.2.6 Data analysis**

Interviews were tape recorded and transcribed. The software nVivo 12 was utilised to support data management and analysis. The interview data were analysed using Thematic Analysis, which is a qualitative method of data analysis used for identifying, analysing and reporting patterns (themes) within data (Braun and Clark, 2006). It is a flexible and useful research approach which allows for a rich and detailed account of data while also allowing for complexity (Braun and Clark, 2006). Thematic analysis involves searching across sets of data (e.g. interviews) to identify repeated patterns of meaning and to construct illustrative and coherent themes (Braun and Clark, 2006). The phases of thematic analysis as outlined by Braun and Clark (2006, p.87) are: 1) process of familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. However, it is suggested that the analysis follow a recursive rather than linear process, insofar as the researcher has scope to move back and forth between steps as the process warrants.



## 2.3 Methods III. Exploring Perspectives of Health and Social Care Professionals

Chapter six sets out the results of the interviews with HSCPs. The research questions guiding this phase of the study were:

1. What health and social care services for people with YOD currently exist in Ireland?
2. What are the primary activities of these services? Who are the key healthcare workers involved in these services?
3. What are the barriers to providing health and social care services for this younger population, and how might current services be improved to better meet their needs?

### 2.3.1 Design

A qualitative design was used, employing semi-structured in-depth interviews. In line with the semi-structured approach, a topic guide was used and adapted accordingly to suit each interviewee's role and setting (indicative topic guides provided in Appendix II). This approach also allowed the researcher to probe and ask follow-up questions on new and interesting topics as they emerged.

### 2.3.2 Recruitment

The goal was to explore different experiences in various settings around Ireland. It was planned that 4-5 sites would be chosen for maximal variability, and that HSCPs involved in diagnostic and/or PDS would be recruited from each site. The aim was also to speak with HSCPs from a range of disciplines across acute, tertiary and community services. It was planned that 20 to 30 interviews would be conducted, with the final number of interviews ( $n=25$ ) decided based on the point of data saturation. Individual participants were recruited via the networks of the research team, collaborators, and oversight group members. In some cases, one person in a service was contacted first, who then provided details of their colleagues where appropriate.

### 2.3.3 Data collection

All interviews were conducted by two experienced researchers. Participants were given the option of completing the interview face-to-face or over the phone, whichever was their preference. All interviewees were provided with an information sheet prior to the interview and signed a consent form which they returned to the researcher. Most interviews lasted between 30-60 minutes (range = 10-80 minutes). Interviews were audio-recorded (with permission), and later transcribed. The text was pseudonymised during transcription.

### 2.3.4 Ethics

Ethical approval was granted by the relevant Research Ethics Committee of University College Cork. As described under Methods II, the requisite ethical considerations were adhered to.

### 2.3.5 Data analysis

The interviews provided rich textual data, which was analysed using Thematic Analysis following the framework of Braun and Clarke (2006). This has been described in detail above, under the methods for the interviews with people with YOD and families.

### 2.3.6 Methodological considerations

As this is a qualitative study, the goal is to gain a rich, in-depth understanding of purposively selected cases, not generalisability of the findings. This approach complements previously completed work such as national surveys. For context, it should be noted that this sample of HSCPs were recruited as they had some level of prior experience with YOD, therefore they may be more knowledgeable than a randomly selected sample. Also, some people worked across more than one setting, or had previously worked in a different setting and brought up these past experiences, therefore one HSCP may report experiences from different settings.

### 2.3.7 Sample

The final sample consisted of 25 HSCPs (see table 2.4). Of the sample,  $n=2$  HSCPs completed the interviews face-to-face

and  $n=23$  opted to complete a telephone interview. The HSCPs were recruited from across five sites in Ireland; two cities; two urban/rural (i.e. towns which also serve a large rural population) and one rural. For the rural site, HSCPs serving a variety of different counties were recruited as these HSCPs typically served large catchment areas and could all speak to the issues common to regions outside of major cities and towns. Of

the memory clinics included, one memory clinic was a specialist diagnostic service; two others offered diagnostic and post-diagnostic services. Where possible, different members of the multidisciplinary team (MDT) at a service (i.e. memory clinic) were interviewed, as well as community HSCPs in that same region. This did not apply to the general practitioners (GP) or neurologists.

**Table 2.4** Demographic details of HSCP sample

|   | <i>N</i> = 25 |
|---|---------------|
| <b>Profession</b>                           |               |
| Geriatrician                                | 4             |
| General Practitioner                        | 3             |
| Neurologist                                 | 2             |
| Clinical Nurse Specialist - Dementia        | 3             |
| Occupational Therapist                      | 3             |
| Advanced Nurse Practitioner                 | 2             |
| Dementia Coordinator                        | 2             |
| Dementia Advisor                            | 3             |
| Nurse Manager                               | 1             |
| Staff Nurse – Memory clinic                 | 1             |
| Neuropsychologist                           | 1             |
| Social Worker                               | 1             |
| <b>Gender</b>                               |               |
| Female                                      | 20            |
| Male  | 5             |
| <b>Setting</b>                              |               |
| Primarily Diagnostic Service                | 9             |
| Primarily a Post-Diagnostic Service         | 8             |
| Remit for both Diagnostic & Post-Diagnostic | 8             |

The following chapters outline and detail the findings of the literature review and qualitative data collection.

03



# Chapter Three: Literature Review - Diagnostic Pathways

## 3.1 Introduction

The results of the literature reviewed for this project are presented in two chapters. In this chapter, the findings on best practice diagnostic models for YOD, derived from national and international literature, are presented, and in the chapter to follow, the findings on best practice post-diagnostic models for dementia are presented. The research questions which guided the literature review on diagnostic models were:

- i) What models are available nationally and globally for the diagnosis of people with YOD and what is their evidence base?
- ii) Are there differences between diagnostic processes and pathways for people with YOD versus those with late onset dementia (LOD)?

## 3.2 Care Pathways

At the outset and in terms of contextualising this literature review, it must be pointed out that the concept of *care pathways* has been used extensively since the 90s to assist service planners and clinicians overcome some of the uncertainties associated with different disease trajectories. Terms such as 'care pathway', 'clinical pathway', 'integrated care pathway' (ICP), 'clinical care pathway' or 'care map' have been used to systematically plan and revise patient care and arrange follow-up. The use of care pathways, and staging YOD based on the disease trajectory, is considered a helpful framework to develop service responses and has been reflected in the literature (Bakker et al., 2010; Bakker et al., 2014). More recently and in the context of dementia care, Samsi and Manthorpe

(2014) have identified specific time-points in the *dementia care pathway* to include (i) early symptom identification and first service encounters, (ii) the assessment process, (iii) diagnostic disclosure, (iv) PDS, and (v) appropriate interventions.

This literature review chapter on YOD presents findings on specific time points broadly classified as *diagnostic pathways* and *post-diagnostic pathways* (as defined by Samsi and Manthorpe (2014)). Both diagnostic and post-diagnostic pathways and the relevant supports available to people living with dementia at such junctures is a topic that has caught the attention of policy makers increasingly over recent years. There is probably an economic argument for this interest as the loss of socially and economically productive roles is said to result in the doubling of the economic cost of the condition for young people compared to their older counterparts (Kandiah et al., 2016). In addition, policy makers are well aware that when adequate support is available, the person with dementia is less likely to require long-term residential care or hospital care (Spijker et al., 2008). But before reporting on literature findings on pathways to diagnosis, and the differences between young onset and LOD, it is first important to define what is meant by YOD and to discuss prevalence rates, and some of the possible causes for this more rare form of dementia.

## 3.3 Definition of Dementia and the Meaning of Young Onset Dementia

The prevalence of dementia increases exponentially with age (Prince et al., 2016) and after the age of 65, prevalence rates

<sup>1</sup> Although this study's publication date falls outside the scope of inclusion criteria used for this literature search, it is one of the first and most well cited studies on YOD prevalence rates and for this reason has been included here.

double with each five-year increase in age (Harvey, Skelton-Robinson and Rossor, 2003)<sup>1</sup>. Accordingly, dementia is most often seen as a condition in older people and until recently, its occurrence in younger people tended to be overlooked. Although rare in its presentation and often difficult to recognise and diagnose (van Vliet et al., 2012), when dementia occurs in younger people its impact is particularly profound. In Ireland, dementia in people aged less than 65 has been reported to account for up to 10% of all cases (Pierce et al., 2014).

Dementia describes a range of cognitive, behavioural, and psychological symptoms that can include memory loss, problems with reasoning and communication, and changes in personality that impair a person's ability to carry out daily activities (NICE, 2018). Although some debate exists in the literature about the correct terminology to use when describing people who develop dementia before the age of 65 (Kelley, Boeve and Josephs, 2008; Rossor et al., 2010; Koopmans and Rosness, 2014), with words such as 'working life dementia', 'early onset dementia' and 'younger people with dementia' often used (Rossor et al., 2010; Koopmans and Rosness, 2014), the term 'Young Onset Dementia' was adopted for this study. This was the term agreed to by the International Psychogeriatric Association's *Shared Interest Forum* to recognise this rare but particularly challenging form of dementia (Koopmans and Rosness, 2014).

This term 'young onset' makes sense as it clearly refers to peoples' age as opposed to the staging or timing of the disease. It also avoids the confusion that can arise due to some authors using the term 'early onset' to refer to the early stages of the condition and not to the early age at which dementia can present. The age cut off of 65 is arbitrary: it has no specific biological significance and is more reflective of a tendency in Western society to conveniently assign people to age categories based on employment/retirement age. Indeed, a small minority of studies use an age cut off of less than 45 to denote young people with dementia (Kelley et al.,

2008). Likewise, although a requirement for a diagnosis of dementia has conventionally meant evidence of a decline in memory and thinking that interferes with the capacity to undertake activities of daily living (Jefferies and Agrawal, 2009), the dominant presenting symptoms for people with YOD are not always memory loss problems per se but can be behavioural/neuropsychiatric symptoms (Rossor et al., 2010).

### 3.4 Prevalence Rates

Compared with LOD, few recent prevalence studies of YOD exist (Renvoize, Hanson and Dale, 2011; Bakker, 2013a; Pierce et al., 2019) and the published research on prevalence rates (Shinagawa et al., 2007; Renvoize et al., 2011; Lambert et al., 2014; Withall et al., 2014) has generated at times variable (Sansoni et al., 2016) and discordant results (Werner et al., 2014). This is probably due to different study designs: the inclusion in research of a variable mix of dementia subtypes (Lambert et al., 2014) and different methodologies used, including variable age cut offs to sample populations with smaller sample sizes is likely to skew results.

The well-cited English study conducted by Harvey et al. (2003), and undertaken in a large catchment area in London, provided detailed prevalence rates for age categories below the age of 65. In this study, the prevalence of dementia in people aged 30–64 was estimated to be 54.0 per 100,000 (95% CI 45.1 to 64.1 per 100,000). For people aged 45–64 years, the prevalence rate was estimated to be 98.1 per 100,000 (95% CI 81.1 to 118.0 per 100,000). From the age of 35 onwards, the prevalence of dementia doubled with each 5-year increase in age. Extrapolating these figures, the authors suggested that nationally, and at the time, there were 18,319 (95% CI 15,296–21,758) people living with dementia aged under 65 in the UK (Harvey et al., 2003).

Probably the largest ever attempt to estimate prevalence rates of YOD is the Japanese study reported on by Ikejima and colleagues (2009). This study collected data

from about two and a half thousand medical and non-medical institutions. It achieved a high response rate and reported prevalence rates of 42.3 per 100,000. As might be expected, prevalence rates increased with advancing age. For example in the 60 to 64 age categories, prevalence rates were estimated to be 33 times greater than that amongst people aged 35 to 39. In their review of the global prevalence of dementia, Prince and colleagues (2013) conclude that age standardised prevalence rates for those aged under 60 varies globally between 5% to 7% in most world regions. Prevalence rates, they note, are distinctly lower in Sub-Saharan African regions (2% to 4%) compared with Latin America where they were estimated to be 8%.

Accurate prevalence rates of YOD in the Republic of Ireland remain unknown since no Irish-based epidemiological study has been undertaken to date on this topic. However, at the time of writing the most recent evidence produced by researchers applying the Eurodem age-specific standardised prevalence rates to the 2016 Census population, estimated that there are about 55,000 people living with dementia in Ireland, of whom a little over 4000 (10%) have YOD (Pierce and Pierse, 2017). A more recent paper, using both Eurodem/EuroCode prevalence rates and Delphi Consensus estimates, calculated there were somewhere between 39,272 to 55,266 people in Ireland with dementia of whom a figure of between 2906 to 4311 were people with YOD (Pierse et al., 2019).

### 3.5 Causes

A diverse range of diseases and conditions has been identified as causing YOD and detailed coverage of these is beyond the scope of this literature review. However broadly speaking, the distribution of diagnosis differs significantly between older and younger people, with younger people, more likely to have atypical presentations, often non-amnesic in nature (Hayo, Ward and Parkes, 2018; O'Malley et al., 2019); more unusual dementias (Bakker, 2013a); additional

neurological networks (Hutchinson, 2013) and a greater likelihood of genetic or metabolic disease (Rossor et al., 2010). Although with some few exceptions (see Ikejima et al., 2009), Alzheimer's disease (AD) is by far the most common dementia in both groups, accounting for only about one third of all cases in YOD compared with about two thirds in older people (Kwon and Lee, 2017; Hayo et al., 2018; O'Malley et al., 2019), the occurrence of fronto-temporal dementia (FTD) and alcohol-related dementia is much higher in younger people (Jefferies and Agrawal, 2009; Koopmans et al., 2013).

In contrast, dementia with Lewy body and vascular dementia comprise a smaller proportion of all cases in younger people (Koopmans et al., 2013). Interestingly, certain dementia sub-types presenting in younger people are reversible and include alcohol-related dementia, normal pressure hydrocephalus and HIV related dementia (Koopmans et al., 2013). There is a large number of rarer dementias as for example Huntington's Disease, Creutzfeldt Jakobs, Korsakoff's Disease, and genetic forms of dementia identified in people under the age of 65, diseases that are problematic from the point of view of accurate diagnosis (Fadil et al., 2009).

In the context of AD, autosomal dominant familial AD, an extremely rare condition accounting for as few as 1% of all cases of AD (Batemen et al., 2011) and arising from a genetic mutation, is more common in people with young onset (Rossor et al., 2010) as is the posterior cortical variant of AD (Jefferies and Agrawal, 2009), where the individual will often have well preserved episodic memory but will experience visual problems and may have major difficulties recognising and locating objects (Rossor et al., 2010; O'Malley et al., 2019). One in three people with young onset AD will have problems associated with posterior cortical atrophy and these early rarer signs of changes may not be recognised as connected to the onset of dementia (Carter et al., 2018).



In autosomal dominant familial AD, a person whose parent has this dementia runs a 50% risk of inheriting the gene leading to the condition. Generally speaking, the clinical presentation of familial AD is similar to that of sporadic AD with an insidious onset of episodic memory problems followed by progression of cortical cognitive deficits. Symptoms are said to typically first appear in young to middle aged people between the ages of 30 and 50 years, but people in their 20s may also be affected (Bateman et al., 2011). Regarding young onset sporadic AD there are also significant phenotypic variants (variations in expression of the genetic code of organisms) found. Those who have non-amnesic deficits comprise about 33% of all cases compared with about 5% of all cases in later onset presentations (Rossor et al., 2010).

Across the world efforts have also been made to estimate prevalence rates of YOD within groups of people with a similar dementia sub-type. A systematic review looking at the prevalence of FTD over a 27 year period (1985 to 2012) revealed that it accounted for an average of around 3% of all dementia cases in studies of older people (those aged 65 and over), compared to 10%, in studies restricted to those aged less than 65 (Hogan et al., 2016a). A similar systematic review investigating prevalence of dementia with Lewy bodies revealed that this type of dementia accounted for 3.2% in older persons compared with 7.1% in people aged less than 65 (Hogan et al., 2016b).

### 3.6 Differences between Late Onset and Young Onset Dementia

There is a widespread discussion in this literature about how developing, living with, and dying from dementia at a younger age is different from that of LOD (see for example McMurtray et al., 2006; Arai et al., 2007; Toyota et al., 2007; Marshall et al., 2007; Gaugler et al., 2009; Dutt and Ghosh, 2012; Bakker, 2013a; van Vliet et al., 2013; Millenaar et al., 2016a; Novek, Shoostari and Menec, 2016).

Apart from differences in sub-types, and the fact that presenting symptoms may be non-memory related, other differences include the fact that, unlike late-onset dementia where if the person has children they are likely to be grown-up and independent; people with YOD may still be rearing their children, working in the labour market (Rose et al., 2010; Chaplin and Davidson, 2016) and are likely to be supporting their families financially (Jefferies and Agrawal, 2009; Roach and Drummond, 2014). Younger people are also more likely to be physically fit and sexually active, and the unanticipated nature of dementia at this early age is more likely to be associated with higher levels of caregiver stress and to relationship breakdown (Koopmans et al., 2013).

As mentioned, the young person is also more likely to have a rarer form of dementia that affects behaviour, mood, social functioning, speech or decision-making in the early stages (Rossor et al., 2010) and to be either misdiagnosed (Werner, Stein-Shvachman and Korczyn, 2009; O'Malley et al., 2019) or have their dementia attributed to some alternate cause (Armari, Jarmolowicz and Panegyres, 2013; Draper et al., 2016). Many young people have enormous difficulty obtaining an accurate early diagnosis (van Vliet et al., 2010) and compared with their older counterparts may have heightened awareness of their cognitive deficits (van Vliet et al., 2013). It is not unusual for the individual to spend several years being referred from one specialist to another before a final diagnosis is reached (Rochford Brennan, personal communication, 2017).

Other outcome variables investigated in research studies that explicitly examine differences between young onset and LOD include (i) time to diagnosis (van Vliet et al., 2013; Novek et al., 2016), (ii) presentation of symptoms including behavioural and psychological symptoms (Bakker et al., 2013a), (iii) quality of life (Millenaar et al., 2016a), (iv) life expectancy following diagnosis (Brodaty, Seeher and Gibson, 2012),

(v) time between diagnosis and admission to long term residential care (Bakker et al., 2013a;) and (vi) the impact dementia has on the individual (Marshall et al., 2007; Bakker et al., 2014) and on the family caregiver (Spijker et al., 2008; Flynn and Mulcahy, 2013).

In general, there is broad agreement in this literature that outcome variables are poorer, both for the person and for their family caregivers. For example, there is some consensus that the average time to diagnosis can be considerably longer (Draper et al., 2016) and in some cases almost twice as long (Novek et al., 2016); that survival rates are lower (Koedam et al., 2008) with one study reporting mortality risk being twice as high when the effects of age on mortality are taken into consideration (Chang et al., 2017). Family members are more likely to report significantly higher psychological and physical morbidity (Rosness, Mjørud and Engedal, 2011) and greater perceived difficulties or burden often associated with responding to non-cognitive symptoms of dementia (Arai et al., 2007; Millenaar et al., 2016b).

### 3.7 Diagnostic Pathways

Better awareness of dementia and increasing diagnostic rates are now an international and national health priority (WHO, 2012; DOH, 2014) and remain key objectives of most countries' national dementia strategies (Pot and Petrea, 2013; WHO, 2017; Cahill, 2020) and there is a burgeoning body of published literature pointing to the benefits (medical, social, emotional, psychological and economic) likely to accrue to the individual and family from an early diagnosis (Milne, 2010; Alzheimer's Disease International (ADI), 2011). However atypical presentations of the common dementias in younger people often lead to clinical under-investigation, misdiagnosis and significant delays in diagnosis (Carter et al., 2018). A recurrent theme echoed repeatedly in this literature is the difficulties, including significant time delays, people encounter attempting to obtain a diagnosis (O'Malley et al., 2019). Reasons put forward for such delays are

multiple and include the heterogeneity of symptoms (Picard et al., 2011), the fact that symptoms are not always dementia-specific (Mendez, 2006), lack of awareness among general practitioners (GP), and lack of recognition of unusual symptoms (van Vliet et al., 2012).

#### 3.7.1 Guidelines for diagnosis of dementia in older people

In the UK, joint guidelines were published (NICE/SCIE, 2007) for the diagnosis and management of dementia. Within these guidelines, reference was also made to the need to develop specialist multidisciplinary services linked to existing dementia services for the assessment, diagnosis and care of younger people with dementia. Also in 2006, the UK's Alzheimer Society and the Royal College of Psychiatrists made recommendations for service development that included having a named professional responsible for planning services for younger people with dementia and a consultant assigned for medical input provision (Council Report, 2006). However despite these guidelines, findings from a recent UK-based survey - conducted on services for people with YOD (Rodda and Carter, 2016), that captured the views of a large and diverse range of medical practitioners and other health service providers ( $n=250$ ) across 76 National Health Service trusts - showed that in the UK, older adult mental health services are most likely to be responsible for the diagnosis and on-going care of younger people with suspected dementia.

This online survey revealed that more than half of the sample had no access to a consultant with a special interest in YOD and not all respondents had the opportunity to review their cases jointly with old age psychiatrists (69%), neurologists (25%) care of the elderly physicians (8%), psychologists (51%) and neuro-radiologists (26%) (Rodda and Carter, 2016). Findings also demonstrated that despite the Royal College of Psychiatrists' report that recommended involvement of old age psychiatrists in the diagnosis and management of YOD, this was not always the



case. Furthermore, the involvement of generic and ageless mental health services as opposed to specialist services in this area had serious ramifications in relation to the quality and consistency of care provided. Care pathways were described by some as chaotic and the dominance of mental health teams in this area meant that multidisciplinary expertise targeting the unique needs of people with this rare form of dementia was often lacking (Rodda and Carter, 2016). Of critical interest in the context of this survey was the finding that only 11% of respondents could identify access to age-appropriate respite care and only 14% identified access to age-appropriate long-term care facilities.

Outside of the UK, many other countries fail to offer any specific form of services for this very vulnerable group of people (Carter et al., 2018; ADI, 2011) and cross-nationally, considerable variation exists regarding the delivery of YOD diagnostic services (Koopmans et al., 2013). Compared to Ireland, even countries with a significantly longer history of developing dementia-specific services such as Norway and Sweden and others such as the US and Australia with a longer history of developing national dementia strategies/frameworks, lack coordinated policies to shape the development of YOD services including diagnostic services. Some countries like Australia and France apply a strict age cut-off for dementia services such as consultation with geriatricians, old-age psychiatrists and memory clinics, so younger people with suspected dementia may fall between the cracks in service systems while in other countries like Canada, no differentiation is made between persons over and below the age of 65 (Koopmans et al., 2013). Two key but poorly answered questions that emerge from a perusal of this literature are: where should assessment ideally take place and who has responsibility for the diagnosis of the individual with suspected YOD?

Difficulties answering these questions arise probably because YOD has a vast differential diagnosis and GPs may think an old age service

is not well equipped to diagnose and may refer their patients to adult mental health services where health service professionals may not always be trained in the area. In addition, mood changes and changes in cognitive function such as visual perception or word-finding difficulties that present more commonly in YOD can often be attributed to depression or anxiety (Mendez, 2006; Woolley et al., 2011). This significant overlap between psychiatric disorders and neurodegenerative disease means that high rates of misdiagnoses including incorrect psychiatric diagnosis are not uncommon (O'Malley et al., 2019). A lack of awareness that people under the age of 65 years can develop dementia may result in early signs and symptoms being attributed to depression, stress, menopause and other illnesses (Bakker et al., 2010; Alzheimer's Society, 2014). In addition, the symptomatic person and family members may be in denial and may choose to ignore the difficulties for a prolonged period.

### **3.7.2 Pathways to diagnosis and numbers of physicians seen by people with suspected Young Onset Dementia**

There are few prospective studies on YOD that report on the type and number of clinicians consulted by the individual and family member(s) prior to a final diagnosis and that identify the discrepancies that may exist between first non-dementia diagnosis and final diagnosis of dementia. One exception is an Australian study (2016) undertaken by Draper and his colleagues. This study investigated factors likely to contribute to the timing of when a final diagnosis of the dementia sub-type is made, according to the stage of the diagnostic process. The study included 88 people with YOD. Findings revealed that the mean number of clinicians or services involved in diagnostic pathways was 3 (range 1-6) and the mean time between symptom onset to first consultation was 2.3 years and to the final diagnosis of the type of dementia was 4.7 years. GPs were the most frequently seen clinician ( $n=70$ ) and were usually the first port of call for

most individuals ( $n=66$ ). The first specialist consulted was usually a neurologist ( $n=47$ ). Interestingly, memory clinics were the most frequent provider of the final diagnosis ( $n=25$ ), followed by neurologists ( $n=22$ ) and geriatricians ( $n=18$ ). From first consultation, factors found to be associated with a delay in final diagnosis included younger age, the presence of mild cognitive impairment (MCI) or depression, and having FTD. Alternate diagnoses that probably include misdiagnosis, and referred to in this study as 'non-dementia diagnosis' (a first alternate diagnosis before dementia was eventually diagnosed), occurred in about half of all participants. These included depression in about one third of the sample, MCI ( $n=15$ ), alcohol use disorder ( $n=5$ ), traumatic brain injury ( $n=3$ ) sleep apnoea ( $n=3$ ) schizophrenia ( $n=2$ ) post-operative amnesias ( $n=2$ ) and a range of medical, neurological and other psychiatric diagnoses in 15 participants.

### 3.7.3 The optimum care pathway

'Young Dementia UK' has developed an optimum care pathway along with gold standards for best practice in the area of YOD (Carter et al., 2018). This optimum care pathway provides explicit recommendations for diagnosis that are broadly reflective of the recent NICE guidelines for diagnosing dementia (NICE, 2018). The YOD pathway includes an initial consultation with a skilled GP knowledgeable in YOD. After this consultation and the ruling out of a potentially treatable dementia, the GP will promptly refer the person and family member to a locally agreed specialist service where a pre-diagnostic review is undertaken. This review includes counselling, support and advice. The final stage is the diagnosis. This should take place either in a specialist service department or at a memory clinic by a skilled clinician specially trained in YOD, and sensitive to the impact the diagnosis will have on the individual and family. The clinician needs to take cognisance of the fact that the person may still be gainfully employed, have young dependent children and other care responsibilities.

It is recommended that designated YOD leads are employed in such specialist centres and that a multidisciplinary team (MDT) conducts a comprehensive assessment. During this more specialist consultation, relevant questions must be asked to establish informed consent. Information should be sought as to what the person wants to know about their diagnosis, who else they would like to have present when the diagnosis is given and whom they would like to be informed.

Key elements recommended in the diagnostic assessment include history taking, including the taking of a collateral history from a key informant, a neurological examination, blood screening for rare causes, neuroimaging, advanced cognitive assessment with a neuropsychologist, and a consideration of the need to undertake an electroencephalogram (EEG), cerebrospinal fluid (CSF) analysis and genetic testing. Depending on the person's wishes and preferences, feedback is delivered to the person about diagnosis in a confidential setting. Where diagnosis is undertaken in a national or regional centre, there must be a clear exit plan which links the person back into their local services.

## 3.8 Diagnostic Pathways in Ireland

While reference is made in the Irish National Dementia Strategy (DOH, 2014) to the specific and unique needs of people with YOD, with the exception of specialist services recommended for those with a dementia that is secondary to intellectual disability, no other explicit commitment is found in the Strategy to the development of age-appropriate specialist services for people with YOD. The Strategy acknowledges the pivotal role GPs play in diagnosis but acknowledges that for sub-typing, specialist input is required: '*a confirmatory definitive diagnosis and identification of the dementia sub-type {this} remains a specialist task*' (p. 20). The Strategy also underscores the particular difficulties involved in diagnosing dementia and states that in 'atypical or complex presentations and cases presenting under

65 years' (p. 20) neurologists, geriatricians, old age psychiatrists and memory clinics all have a role to play in dementia diagnosis and subtyping.

A recent Irish literature review of dementia diagnostic services (Reves et al., 2018) has shown that the complexity and magnitude of dementia means that no one-size-fits-all response applies. This literature review acknowledges that best practice must emphasise flexibility and fluidity between assessment at primary, secondary, and tertiary levels, with regional specialist assessment readily available for atypical and difficult to diagnose cases. The review concludes that dementia diagnostic pathways for Ireland need to take on board a range of different assessment and diagnostic models designed to meet the varying levels of complexity within the needs of different client groups. Drawing on the international literature, the authors argue that the evidence to support different models of assessment and diagnostic services is still evolving. Reves et al. (2018) claim that the local context is probably every bit as important as the evidence to support any particular model. This review identifies potential settings of diagnostic services to include: (i) regional memory clinics, (ii) local memory clinics, (iii) primary care and (iv) community mental health. The review concludes that the cost of diagnosis does not depend so much on the setting but on the complexity of the process, with the significant cost components pertaining to imaging, genetic testing, and specialist time, especially where travel is involved.

This literature search has uncovered only three published Irish studies undertaken on the topic of YOD within the timeframe of this review. The first conducted almost fifteen years ago (Haase, 2005) was a study that initially set out to interview people living with dementia but failed to achieve this aim, possibly due to the stigma of dementia in Ireland at that time. Accordingly, the researchers resorted to collecting data from primary caregivers, of which there were 61. The most pertinent issues reported by caregivers in this Irish study

were: (i) the need for a timely diagnosis, (ii) informing the individual of their condition, (iii) supporting flexible care arrangements, (iv) improving home help, (v) improving day care, (vi) improving respite care, (vii) improving medical care, (viii) improving residential care, (ix) providing counselling and (x) improving financial supports.

Based on this study's findings, thirteen recommendations were forwarded, the most notable of which were: (i) the setting-up of an awareness programme about YOD for GPs and the promotion of multidisciplinary assessment, (ii) the establishment by the Health Service Executive (HSE) of a pilot project specifically targeting the development of person-centred plans for younger people living with dementia, (iii) the careful review of financial supports available to people affected by YOD and their caregivers and (iv) consideration by the HSE to creating the required structures to overcome service fragmentation such as that between services for the elderly, mental health and disability services. It is of note that some 15 years later, none of these recommendations have been piloted or implemented.

The second study (Flynn and Mulcahy, 2013) undertaken in conjunction with the Alzheimer Society of Ireland (ASI) used a convenience sample of only seven participants each of whom were family caregivers. Like the former study, this research some ten years later also concluded that in Ireland people with YOD are a hugely neglected group from a policy and practice perspective. This very small-scale study revealed that family members deliver most of the care required by people experiencing this progressive and irreversible illness and receive very limited support. The authors of this study appealed for more specialised community supports and services including home help, information services, nursing specialists in YOD, day care and age-appropriate support groups.

The third and most recent Irish study (Tan et al., 2019) undertook a secondary analysis on all patients with YOD admitted to three large

urban hospitals over an eight-year period. Information collected included demographics, medical and psychosocial history, functional capacity, last hospital admission, mortality and details regarding an advance care plan (ACP), using a standardised extraction form. A total of 121 patients were identified, of whom half were male. Interestingly, the most frequently presenting sub-type was dementia secondary to Down's syndrome (16%), followed by vascular (14%), front-temporal (13%) and AD (13%). Although 70% of people with YOD had an indication for an advance care plan (i.e. one or more markers of limited life expectancy), only 11% had any ACP recorded.

### 3.9 Useful Irish Resources and Information on Dementia Diagnosis

Recently an update on the first review of memory clinics in Ireland (Cahill, Moore and Pierce, 2011) was undertaken by the Dementia Services Information and Development Centre (DSiDC) and the National Dementia Office (NDO) (Gibb and Begley, 2017). In this update, a total of 25 memory clinics or memory/cognitive assessment services were identified in Ireland, of which only four were privately run. All but six of these services applied no age restriction and offered assessment/diagnostic services to people aged less than 65 years. A further three services provided limited services to those less than 65 years, services on a case by case basis, or referred on to other clinics.

A recent meeting (May 2019) convened by the DSiDC investigated memory assessment services in Ireland, including diagnostic services for people with YOD, concluded that people with this rare form of dementia are regularly discriminated against in the Irish health and social care service system (Unpublished Report, 2019). Findings from this multidisciplinary discussion revealed that in some memory assessment services and in medicine for the elderly services, age cut-off restrictions are strictly applied, and younger

people may be denied access to diagnostic services including old age psychiatry and geriatric medicine. In addition, it was reported that younger people with suspected dementia might not qualify for a medical card, which makes accessing primary care physicians costly. If listed for neurology services, they may have prolonged waiting times as there are a limited number of neurologists in Ireland with a special interest in this type of dementia. A conclusion drawn at this meeting is that pathology-based approaches to the diagnosis of dementia should be undertaken to reduce the risks younger people encounter when presenting with symptoms.

More recently (August 2019), the findings from an online survey exploring Irish clinicians approaches to dementia diagnosis, disclosure and follow-up was published by the NDO. This survey captured the views of 56 clinicians, 24 geriatricians, 19 neurologists, and 13 psychiatrists of later life identified through HSE records and other sources and achieved a 35% response rate with more than half of all clinicians residing in Dublin (NDO, 2019). Notable findings from the survey included the fact that GPs were the largest single source of referrals for assessment. The average waiting time for specialist assessment was often long (in one case the waiting time for a new or urgent referral was four years) and the waiting time for Neurology services was considerably longer than for psychiatry of later life services.

The survey found that most assessments took place in general clinics rather than in memory clinics and considerable variation existed nationally in relation to dementia diagnostic and disclosure practices. Key components of a good service identified by clinicians included (i) rapid access with good referral pathways between for example geriatric medicine, psychiatry of later life and neurology, (ii) access to a multidisciplinary team, (iii) assessment with access to diagnostic tests, (iv) disclosure, (v) post-diagnostic support, (vi) continuum of care and (vii) appropriate information, specialist memory clinic services

and on-going education. In this survey 85% of participants reported they assessed people with a cognitive impairment aged less than 65. However, barriers and restrictions to providing an assessment diagnostic service to this age group were identified by several participants.

### 3.10 Chapter Summary

To summarise this section, countries vary in relation to diagnostic practices and the literature reviewed here reveals that timely diagnosis is one of the most pressing problems confronting this vulnerable group of people and their family members. The review suggests that the essential elements of diagnostic service provision include (i) clear pathways to assessment, (ii) diagnosis and disclosure and (iii) referral to both specialist and generalist post-diagnostic services. At a systems level, service integration is critical and there is compelling evidence that there is a need to integrate diagnostic services

(primary, secondary and tertiary) and to streamline pathways to diagnosis.

The use of multidisciplinary teams is critical to timely diagnosis, as is the development of more effective links between the range of services likely to be providing support to the individual, their family members and carers along the illness trajectory. Key service design includes (i) an individualised model and access to specialist diagnostic services, (ii) on-going symptom management services, and (iii) regionally based integrated and coordinated interagency partnership and pathways (Sansoni et al., 2016). Although many clinical practice guidelines exist on the diagnosis and management of dementia, there are currently no specific practice guidelines for the diagnosis of YOD; although recommendations on best practice specific to certain areas are available (see for example Rossor et al., 2010 and Sorbi et al., 2012). There is a need for best practice guidelines on diagnosis to be developed in this area.

04





# Chapter Four: Literature Review - Post-diagnostic Support

## 4.1 Introduction

This second literature review chapter now advances to a discussion of post-diagnostic pathways and supports (PDS) and the identification of best practice models or guidelines for good practice for people with YOD based on the evidence. The literature findings are based on the methodology presented in chapter two. The opening section discusses PDS services for people with late onset dementia including the Scottish five-pillar/eight-pillar model. It then progresses to a more specific discussion of post-diagnostic services for people living with YOD. But before advancing to synthesise these literature findings, it is first important to clarify why post-diagnostic support might be important for younger people living with dementia and what are the main aims and objectives of PDS. To recap, the research questions guiding this second part of the literature review were:

- i) What models are available nationally and globally for the PDS of people with YOD and what evidence is available to support these models?
- ii) Are there differences between post-diagnostic processes and pathways for people with YOD versus those with LOD?

## 4.2 Dementia and Models for Post-diagnostic Support

It is said that the main aim of PDS is to: “help people to continue living well in the community, provide information and support, help people to manage issues as a result of getting a diagnosis, and delay admission to long term residential care” (SCIE, 2014). The World Health Organisation’s report on dementia as a public health issue (2012) provides a six stage model for the acceptance

of dementia as a disability and highlights the need for support services to assist family caregivers engage in future care planning and make the best use of their current circumstances (O’Shea, Keogh and Heneghan, 2018). PDS can be the first step in the development of an individualised response to dementia and can lead to enhanced social contact, thereby helping to reduce isolation (O’Shea et al., 2018). Effective PDS may also mediate negative feelings such as hopelessness and low self-esteem that are often associated with a diagnosis of dementia (O’Shea et al., 2018).

The importance of PDS is also clearly referenced in many countries’ national dementia strategies. For example objective 4 of the English Dementia Strategy (DOH, 2009) was to make it easier for people to access care support and advice following a diagnosis, and the English Strategy helped establish 40 demonstration sites where people with dementia could access support from advisors and peers (Clarke et al., 2013). Priority 3 in Australia’s National Framework for Action on Dementia (Australian Government Department of Health, 2015) focuses on ‘accessing care and support post-diagnosis’. Scotland’s second National Dementia Strategy (NDS) focussed specifically on improving PDS for people living with dementia (Scottish Government, 2013) and its third and most recent NDS (Scottish Government, 2017) maintains a focus on improving quality of care for people living with dementia including PDS. Likewise, the Irish NDS (DOH, 2014) highlights the need for PDS where it explicitly states: ‘[a] person with dementia and their carer(s) need a clearly signposted pathway that directs them to the right care and support, in the right place and at the right time’ (p. 25). Few national dementia strategies however make

specific reference to the particular PDS needs of people with YOD.

### 4.3 Post-diagnostic Support for People with LOD

In an attempt to provide guidance on the type of PDS that should be available to people living with dementia, the British Faculty of the Psychology of Older People published a paper titled "Post-diagnostic support for people living with dementia" (Watts et al., 2013). Aware of the need to balance individualised care with limited resources, the authors suggest a 'matched care model'. Within this model it is claimed that the person can benefit from individualised and/or family centred care interventions: these interventions should be spread across four tiers (steps) based on the individual's level of distress, from a low level of distress (step 1) to a high level of distress (step 4). Within this model, PDS focus largely on the individual living with dementia and include cognitive rehabilitation and training, social support networks, the promotion of health and wellbeing, cognitive stimulation, reminiscence therapy, enhanced social inclusion, peer support, Alzheimer Café, and individual and group therapy for people who are distressed (Watts et al., 2013). The authors argue there needs to be a balance between evidence-based clinical good practice and cost effectiveness. It is noted that good PDS should include opportunities for rehabilitation and adjustment through peer support groups and psychotherapy.

### 4.4 Scottish Key Worker and Five Pillar/Eight Pillar Model

The Scottish five pillar model for PDS (Alzheimer Scotland, 2011) refers to (i) understanding dementia, (ii) managing the symptoms, (iii) supporting community connections, (iv) peer support and (v) planning for future decision-making. A Scottish person recently diagnosed is guaranteed a minimum of 12 months personalised flexible services delivered proactively and sensitively by a well-trained service provider, skilled in developing a supportive relationship with the individual and family members. The main aim of these

Scottish post-diagnostic services is to enable the individual and their family members to live well and independently with dementia for as long as possible. The five-pillar model includes the appointment of a link worker commissioned to develop a personalised care plan drawing on all that person's own natural supports, while establishing new peer support and community support networks. Each person diagnosed requires a unique approach and no template exists for the delivery of PDS.

The Scottish 8 Pillars Model (Alzheimer Scotland, 2015) builds on the one-year PDS model and attempts to sustain the impact of investment in early interventions. The 8 pillar model includes (i) a dementia practice co-ordinator, (ii) therapeutic interventions to tackle illness symptoms, (iii) support for carers, (iv) personalised support, (v) community connections, (vi) the environment, (vii) mental health care and treatment, and (viii) general health care. This model sets out a comprehensive approach to the integrated support of people with dementia living at home during the moderate to severe stages of the illness, and builds on the resilience of people with dementia and their carers to enable them to live in the community for as long as possible.

Some core aspects of the Scottish model have recently been highlighted by O'Shea et al. (2018) where the advantages of appointing a *link worker* assigned to people recently diagnosed has been emphasised. In their review of post-diagnostic services for people living with dementia and their families, O'Shea and colleagues write: 'Having a dedicated person to link directly with people newly diagnosed with dementia is important for continuity and the development of personalised care within an integrated system of provision. People with dementia and their carers need someone to help them navigate their way through existing services and supports. Whether that person is a dementia specialist from a clinical or social background requires further consideration, but whatever their origins, they must have the leadership,



expert knowledge and credibility to influence decision making' (p. ix). The Scottish model provides a useful framework for consideration in the Irish context where there is a veritable absence of services for this very vulnerable group of people.

## 4.5 Post-diagnostic Support for People with YOD

Since dementia is more prevalent in older people, obviously service supports for people with dementia have been designed with older peoples' needs in mind and this has resulted in the development of health and social care service supports that are not always relevant to the unique and complex needs of people diagnosed with YOD (Carter et al., 2018; Cations et al., 2017). Where age-appropriate post-diagnostic services are available, the evidence base on the effectiveness of these supports is weak and this literature review has not uncovered many examples of best practice in the strict sense of rigorously evaluated interventions such as randomised controlled trials.

For example, a search of the Cochrane Library on PDS for younger people with dementia yielded only five results. Amongst these five papers, two projects remain incomplete (the Rhapsody and Angela Projects) with no conclusive results available. One paper is based on a pilot study of e-learning courses for people with YOD (Diehl-Schmid et al., 2017). Another (see Appelhof et al., 2018) reports on an evaluation of an intervention for the management of neuropsychiatric symptoms in younger people with dementia. The fifth paper evaluates executive functioning, comparing a small sample of those with fronto-temporal dementia (FTD) with those with early onset Alzheimer Disease (Barrows et al., 2015).

Accordingly, the literature to be presented here will focus on good practice service models, the evaluation of which are broadly speaking based on the anecdotal experiences of younger persons with dementia, their care partners and HSCPs and on evidence arising

out of practical experience rather than on scientific evidence (Thompson, 2011). So much of what follows in this chapter will discuss projects identified in recent literature reviews for which there is less rigorous scientific support. Reviews based on a limited number of studies using small sample sizes and lacking rigorous methodologies cannot inform best practice models. Nonetheless their findings can help to identify delivery attributes effective for people with YOD and can provide clear guidelines about what constitutes *good* as opposed to *best practice*. For example, it goes without saying that the younger person's level of satisfaction with services or interventions is probably the best reflection of the success of that service or intervention (Thompson, 2011). The examples that follow of post-diagnostic interventions involve younger people who have participated in activities, for example, volunteering, creative expression programmes, workplace support programmes, meaningful participation and so on. The section to follow will report on the most notable of these literature reviews from across the world.

## 4.6 Post-diagnostic Support and their Effectiveness for People with YOD

### 4.6.1 Systematic reviews

Richardson et al.'s (2016) systematic review investigated the impact of psychosocial interventions on people with YOD and their family caregivers. In particular it attempted to answer three research questions namely– (i) what psychosocial interventions are effective for people with YOD and who benefits most? ii) Are psychosocial interventions effective in improving cognitive ability, functioning, self-esteem, memory, communication, quality of life, well-being and the progression of dementia? And (iii) how effective are these interventions in reducing caregiver burden, stress and anxiety, supporting caregiving and promoting the carer's quality of life and well-being? The study's inclusion criteria were: (i) a focus on people with YOD and

their carer, (ii) an evaluation of the outcomes of psychosocial interventions and (iii) peer reviewed research reporting on quantitative or qualitative or mixed-methods studies. Of the 498 records identified, only three (Kinney, Kart and Reddecliff, 2011; Hewitt et al., 2013; Robertson, Evans and Horsnell, 2013) satisfied the inclusion criteria. Two were qualitative, one used mixed-methods and all three studies involved work-based interventions for people with YOD.

In one study i.e. 'get out of the house' project (Kinney et al., 2011) a small group of participants with YOD liaised with local zoo personnel where they spent six hours weekly undertaking supervised voluntary work. Zoo staff also gave participants guided tours of animal exhibits and discussed their care. This programme had a strong social element with a lunch served on site. Benefits reported included friendship, stimulating entertainment and meaningful work provided in a safe environment. In the second study (Hewitt et al., 2013) 12 participants were collected from home by communal transport and attended a structured programme spanning a 12-month period. The programme, run by an occupational therapist (OT), horticulturalist and psychologist along with others consisted of a weekly two-hour group-planning meeting, followed by a one-hour gardening session, followed then by a group-meeting to reflect over activities. Findings showed that participants experienced enjoyment, independence, a sense of achievement, reduced anxiety, and feeling valued. The third study identified in this review involved younger people with mild dementia (Robertson et al., 2013). This study showed that with appropriate support people with YOD could be upskilled to re-engage with meaningful enjoyable workplace activities. The programme consisted of a preparatory session, followed by a four-hour shift of work duties alongside an allocated buddy and finished up with group activities which included debriefing. The project provided participants with the opportunity to reconnect with the community and make

supportive friendships, and workplace/ occupational interventions gave participants a sense of identity and purpose. Participants reported enhanced self-esteem, a sense of value, purpose, self-worth and social inclusion.

The Richardson et al. (2016) review concluded that work-based interventions that provided support and meaningful work outside the home were beneficial and there was no evidence to indicate any negative effects of the reported interventions. Most important was the careful allocation of tasks to current levels of functioning: matching abilities to tasks was considered salient both in the short and long term. It also concluded that there was a need for better quality, mixed-method research involving large sample sizes. The review argued that future projects focusing on interventions to keep people with YOD in employment for longer may help people live longer. Broadly speaking, these three studies were of variable methodological quality and none investigated cost effectiveness, nor did the review assess the impact these interventions had on family caregivers.

A more recent systematic review of age-appropriate services for people diagnosed with YOD (Mayrhofer et al., 2018) identified 20 articles. Ten were descriptive and ten peer-reviewed; of which only one used standardised measures. Accordingly, the review cannot report on the effectiveness of the interventions identified in the primary studies but rather on 'perceived effectiveness'. Overall, most of these studies were small scale, UK regional-based and investigated the impact of the intervention on the younger person diagnosed and in some cases on the family caregiver. The descriptive pieces included demonstration projects such as the evaluation of a feasibility study of work-based activities for young people with dementia (Robertson et al., 2013), single-case studies of behavioural and cognitive rehabilitation (Tonga et al., 2016), pre- and post-assessment counselling (La Fontaine et al., 2014) and support with legal and financial concerns (Wheeler et al., 2015). Reflecting the

instability and ad hoc nature of such service interventions, a number of these projects have since been discontinued.

The ten peer reviewed projects, all of which were positively evaluated, included community-based day centres for people with YOD (Beattie, McInnes and Fearnley, 2004), community-based football club activities (Carone, Tischler and Denning, 2014), community-based gardening projects (Hewitt et al., 2013), community-based volunteer-led programme at a zoo (Kinney et al., 2011) and a hospital and rural based telehealth online support service. Only six of these interventions reflected user involvement in the design of services (Barker and Johnson, 2008; Chaston, Pollard and Jubb, 2004; Davies-Quarrell et al., 2010; Kinney et al., 2011; O'Connell et al., 2014; Parkes and Ward, 2015). For those recently diagnosed, post-diagnostic services were reported as useful if they were informative, educational and could signpost the individual to community-based supports. Community-based services were deemed effective if the service facilitated social interaction, created a sense of normality, inclusion and purpose, facilitated changing care needs and offered continuity over extended periods of time. In particular, PDS relating to work, legal and financial matters was recognised as critical but seriously under-researched (Mayrhofer et al., 2018).

In the studies selected for this review, other variables such as user satisfaction, quality of life and health and well-being were not reported as discrete entities but rather were described broadly through concepts such as social connectedness, participation and inclusion, adjustment, normalisation and caregiver support. The systematic review found several examples of services that created a sense of normality (Beattie et al., 2004; Carone et al., 2014), were supportive, (Barker and Johnson, 2008) and provided meaningful activities (Hewitt et al., 2013; Robertson et al., 2013). The review concluded that while the literature highlights the

extensive needs of people living with YOD, there is very limited evidence of service development for this vulnerable group. In addition, approaches to involving people living with YOD and their caregivers in the design of age-appropriate services also remains under-explored. The review claimed that service continuity was compromised by the short duration of projects and the ad hoc nature of service delivery.

#### **4.6.2 Scoping review**

A Canadian scoping study that reviewed the literature to investigate non-pharmacological interventions for people with YOD (Aplaon et al., 2017) identified 398 articles published in English in peer-reviewed journals, out of which only seven met the studies' inclusion criteria. Of these, only four studies consisted of social programmes involving the community as part of the intervention (Mayer, Bishop and Murray, 2012; Hewitt et al., 2013; Robertson et al., 2013; Carone et al., 2014), another two were case reports focussed on a cognitive-based intervention (Roca et al., 2010; Kinney et al., 2011) and one was a case report with a focus on a cognitive behavioural intervention (Tonga et al., 2016). The cognitive training interventions were successful in improving perceived functional outcomes and affective symptoms. For example, Tonga and colleagues (2016) showed how cognitive behavioural therapy could improve depressive symptoms and cognitive functioning; both the person with YOD and family caregivers were satisfied with the intervention. The Roca study (2010) showed that cognitive rehabilitation training and psychoeducation resulted in subtle differences in visuo-perceptual tasks and the structured social engagement interventions were successful from participants' and caregivers' perspectives. As in other already cited studies, sample sizes in each of these non-case studies was small ranging from seven to 20 participants.

#### **4.6.3 Rapid review**

Sansoni et al.'s (2016) rapid review of the literature on YOD captured 300 articles and focussed on both diagnostic and

post-diagnostic service supports. The review considered social, economic and environmental factors that support people with YOD. In terms of post-diagnostic pathways and supports, this rapid review identified the need for more individually tailored service supports addressing life cycle issues and further examination of service utilisation, costs of illness and cost effectiveness of programmes. Like other studies, the review concluded that despite a broad range of community-based programmes and interventions identified for people with YOD and their family members, most of the literature yielded limited evidence about programme effectiveness.

The review found that existing services for older people living with dementia may not always have sufficient flexibility and capacity to address the wide range of needs a person with YOD and their family members will have. For example, staff in dementia services may lack the required skills to address clients' financial and employment concerns and other issues likely to arise when a person is forced into taking early retirement due to dementia. The review demonstrated that there was a need for a seamless service with a central point of contact, and the adoption of case management or key worker approach and for existing services to provide programmes that are more age-appropriate for people with YOD. The authors of this review concluded that effective service provision for people with YOD required the integration of aged care, health care, and disability services and that there was a need for more robust studies using larger sample sizes, triangulating methods and considering the potential of confounding factors to enhance evidence-based practice.

#### **4.7 The Most Optimum Post-diagnostic Care Pathway for People with YOD**

As demonstrated, this literature search has yielded few examples of evidence-based interventions that might contribute to best practice models for PDS. In the UK, as cited

by Carter et al., (2018) Young Dementia UK have developed an optimum care pathway for people with YOD that includes both diagnostic and post-diagnostic pathways. In their model, post-diagnostic care pathways have three stages: (i) specialist support immediately following diagnosis, (ii) support while living with YOD, and (iii) end of life care support. During each stage, an emphasis is placed on ensuring that regular reviews take place between the key worker, the young person and their family, the clinical team and other HSCPs involved in that person's care.

At stage one immediately following diagnosis, the key worker's responsibilities include: designing a care plan with the individual family appropriate to their life-stage; providing all relevant advice and information including that on YOD, evidence-based treatments, psychological supports and admiral nurses. It also includes providing support with employment, mortgage and financial obligations and future financial planning, along with links to health and social care services, advance care planning and signposting to meaningful activities.

At stage two, on-going and regular contact and joint reviews continue to take place between the key worker and the clinical team with access to specialist nurses, OTs, psychologists and social work services. At stage three - and as the person reaches end of life - the review needs to be adapted to ensure that short term respite opportunities become available; that acute care if needed is provided in dementia friendly wards, and that long term care, if needed, is age-appropriate and provided in residential care or at home if this is what the person wants, age-appropriate palliative and end of life care and finally bereavement support for carers and families.

From the individual and family members' perspective, PDS should be delivered by HSCPs and staff who have specialist knowledge and skills, and who can assist them in understanding the illness, acquire coping skills, retain relationships (Lockeridge and Simpson, 2013), and promote social

connectedness (Johannessen and Möller, 2013). Persons with YOD and family members state they would prefer meaningful activities that are pleasurable and focus on their retained abilities and strengths and activities that can enable them develop new interests and skills (Peel and Harding, 2014). Peer support is also rated as very important for family members to enable them to share experiences and learn from each other (Hayo et al., 2018). Bakker and colleagues (2010) contend that specialist services for younger people can improve well-being for both the symptomatic person and their families.

In the context of guidelines for good practice for people with YOD, another model of interest is Alzheimer's Australia, 'Key Worker Programme' that has recently been evaluated (Westera and Fildes, 2016). This programme set out to address the difficulties young people with suspected dementia experience, undergoing multiple referrals and assessments and falling between the cracks in the service sectors. Over a three-year period, the programme employed 40 'Key Workers' who supported nearly 3,500 clients. Many people supported by the programme were facing significant relationship, emotional, financial and social difficulties due to the unexpected impact of the illness. It was noted that these highly skilled 'Key Workers' were successful in navigating complex service systems across ageing, disability, health and general community services. Their physical co-location within the broader Alzheimer's Australia network has meant that clients can tap into a broad array of dementia education and support services, including specialist counselling.

The 'Key Worker' Programme has allowed people with YOD to remain active, socialise and acquire peer support, continue to play an active role in the lives of their families, social and community networks. New resources have also been produced to enable other community groups gain awareness of YOD and learn how to be more inclusive of people with YOD, their families and carers. The broad remit of the programme, where

the focus is on individual support as well as sector development and capacity building, has required significant creative thinking especially for those working in rural and regional areas.

## 4.8 Key Differences in Post-Diagnostic Supports for People with YOD versus those with LOD

### 4.8.1 Working with a diagnosis of dementia

Earlier, reference was made to the lack of fit between PDS for older people living with dementia versus their younger counterparts. This is not surprising since major differences exist between the two groups regarding their respective health and social care support needs. For example, the younger person is likely to be still gainfully employed at the time of symptom presentation; indeed, sometimes at the height of their career, and will probably have significant financial commitments including a mortgage and/or school or college attending children. If as the evidence suggests, the person's diagnosis is delayed and dementia remains 'hidden' for some time, symptoms may place them under increasing pressure at work (Chaston, 2010) where they may be expected to manage new work-related tasks or master significant work-related challenges (Johannessen and Möller, 2013).

Multiple impairments such as language difficulties, visuo-spatial problems, memory loss difficulties, the inability to plan ahead, personality changes including apathy and so on, may interfere with work performance; lead to the individual being subjected to regular review; their job being threatened and ultimately their being dismissed or asked to leave the workforce prematurely (Sakata and Okumura, 2017). The limited research that exists on this topic highlights the lack of employer support for workers living with dementia (Egdell et al., 2019). This may be attributed to employers' lack of knowledge



surrounding dementia, its causes, risk factors, treatments and effects. Poor employment practices with the absence of employer support have been noted to be of particular salience in lower ranked occupations (Chaplin and Davidson, 2016).

#### **4.8.2 Disability and dementia in the workforce**

Dementia is a disability under most countries' equality/disability acts (Cahill, 2018) and under international human rights law. It is included under Irish legislation in the Employment Equality Acts and the Equal Status Act. Therefore, both national and international legislation provide the necessary framework for the cognitively impaired individual to request that employers make *reasonable adjustment* to support their continued employment. *Reasonable adjustment* can be defined as '[the] necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms' (United Nations, 2006). Stated simply it means that the employer must make practical and realistic adjustments to the work environment to assist the cognitively impaired person to continue to perform their job albeit in a modified form (Hayo et al., 2018).

It is likely that many people with YOD and their family members are not aware of their rights vis-a-vis continued employment and the limited research that exist reveals that employees with dementia are not usually offered 'reasonable adjustments' (Lockwood, Henderson, and Thornicroft, 2014) because of a lack of understanding of dementia as a disability (Tolson et al., 2016) and probably due to a lack of understanding of dementia as well. Accordingly, most people of working age once given a diagnosis, choose to stop work since they find the work situation unsustainable (Travis, 2014).

#### **4.8.3 Addressing the barriers: Some work assisted programmes**

Interestingly, Alzheimer's Australia's Background Paper to the 2009 summit on YOD (2009), noted that people living with dementia would ideally prefer to stay in the workforce for as long as possible but highlighted a number of concerns regarding continued employment. Included amongst these were: (i) discrimination arising due to employers' lack of understanding of dementia and (ii) difficulties in accessing sickness/disability benefits and superannuation. The report on the Newcastle study (Reed et al., 2007) recommended the development of work-assisted schemes, either in mainstream work settings or in sheltered environments, as one component of a suite of services for people with YOD. There are several other ways that a person's workload and work performance can be adjusted to ensure they cope better in the workforce despite having YOD. According to Hayo et al. (2018) these include (i) the allocation of tasks in a staged way along with matching tasks to abilities, (ii) adjusting the environment and providing more regular breaks, (iii) the provision of assistive technologies, (iv) establishing a work buddy system and work collegial support, (v) providing verbal support to continue to work, (vii) reducing role responsibilities and (viii) changing roles and responsibilities. Being supported to continue to work for as long as possible may help the individual and family cope with the diagnosis and maintain a clearly defined daily routine.

#### **4.8.4 Quitting work because of dementia**

As mentioned, YOD can often alter significantly the employment and career prospects of both the individual experiencing the symptoms and family members (Hayo et al., 2018) but few studies have been undertaken that address this specific topic. One exception is a recent Japanese prospective study that used matched cohorts (Sakata and Okumura, 2017). This study followed up 143 employees and 77 family members and monitored the post-diagnostic employment patterns of these young people recently diagnosed over

a protracted period of time. Not surprisingly findings showed that in the employee cohort, patients with YOD were more likely to leave their jobs than controls.

Apart from its psychological and social effects, the financial consequences of ceasing work because of a deterioration in skills and dementia-related inabilities can be profound given the symptomatic person may be the main bread-winner in the family; contributing their full or partial salary to family household income. A loss or reduction in household income may also arise because a spouse or partner may no longer be able to deliver on their normal working hours because of the demands of caregiving. For example, some caregivers may need to adopt more flexible working practices including reducing their hours or quitting work indefinitely to create time for caring. Conversely, others may have to commence work or increase their work hours to compensate for their spouse's loss of income due to the dementia.

In addition, there are also many direct medical and non-medical costs associated with YOD (Kandiah et al., 2016) along with hidden and indirect costs such as taxi charges, charges for the purchase of assistive technologies and expenses associated with purchasing in home private services. Sickness benefits and invalidity pensions are likely to fall short of normal monthly salaries and retirement income may not be immediately available because the individual is too young (Koopmans et al., 2013). From a caregiver's perspective the Carer's Benefit or the Carer's Allowance is also likely to reflect a reduction in household income. A recent study revealed that for caregivers under the age of 65, entitlements are lacking in Ireland and the challenge of financial support from the Irish state was discussed as a negative impact (Flynn and Mulcahy, 2013). In terms of policy, people living with YOD require special consideration since eligibility for social/medical supports or old age/retirement experience considerable difficulty accessing any financial support.

## 4.9 Other Family Issues

### 4.9.1 Impact on young children

Another key difference regarding the PDS needs of younger people versus their older counterparts is that the younger person is likely to have dependent children who may be seriously emotionally and psychologically affected by a parent's dementia (Haugen, 2014; Barca et al., 2014; Hutchinson et al., 2016). As mentioned, YOD has a different clinical manifestation compared with LOD and may, as for example in the case of FTD, be more often characterised by behavioural and psychological symptoms, language difficulties and apathy. Children may have strong reactions to a parent's changed behaviour and may feel shame or embarrassment at what for them appears like 'weird' behaviour. Shame can lead to social isolation as for example the young child no longer feeling comfortable inviting friends home (Thompson, 2011). They may also become anxious about what they also perceive as difficulties in their parents' relationships (Koopmans et al., 2013).

The young child may no longer feel loved or of any importance to a parent as the affected parent may become emotionally distant from the child, resulting in the loss of a close relationship (Haugen, 2014). The child may have difficulty accepting the changes witnessed in a parent's personality and behaviour and may feel the situation is hopeless and irritating (Thompson, 2011). Some children will be required to take on the caring role (Allen, Oyebode and Allen, 2009; Hutchinson et al., 2016) and may feel obliged to remain at home for longer rather than move out in order to help care for a parent and help keep a sense of normality in evidence in the household (Allen et al., 2009; Millenaar et al., 2014; Hutchinson et al., 2016).

One study (Allen et al., 2009) that focussed on teenagers to adolescent children whose father had YOD reported that children can experience stress, guilt and other psychological factors related to changing family relationships. Adult children may also

feel obliged to remain living at home rather than moving out in order to care for both parents and help to keep a sense of normality within family life (Allen et al., 2009). For the young child or adolescent, conversations with experts skilled in YOD can help to build trusting relationships. However, the timing of these conversations should be carefully selected and decided upon in consultation with parents (Millenaar et al., 2014). Children often need to talk to someone else with expertise in YOD (Millenaar et al., 2014) and it can be most reassuring for them to meet other children who have had similar experiences (Haugen, 2014). Sansoni et al.'s review (2016) demonstrated that few studies interview children of people with YOD and where they do, sample sizes tend to be small. Stigma, shame/embarrassment, family conflict, burden, the physical challenge of caring and problems at school are cited. Many children reported undertaking a demanding care role whilst confronting the challenges of growing up. Overall, there is little guidance in this body of literature about the service needs of young people.

#### **4.9.2 Impact on the individual**

Other key differences between YOD and LOD is that with the former, a diagnosis is generally made when the person is in the prime of their life, sometimes at the height of their career. Therefore the news of having dementia will inevitably come as a major shock and will require very considerable adjustments. Although much recent research has been undertaken on the topic of the impact of YOD on spouses, relatively little is known about stresses and strains and challenges confronting the individual experiencing the symptoms.

Few studies have interviewed people living with dementia about their own subjective experiences (see for example, Roach et al., 2008; Pison-Young et al., 2012; Johannessen and Möller, 2013; Clemerson, Walsh and Isaac, 2014; Greenwood and Smith, 2016). Most of these studies use small sample sizes (fewer than 20 people), are qualitative, utilising thematic analysis.

The common themes identified across these studies include difficulties obtaining a diagnosis and shock on its disclosure, difficulties adjusting to the diagnosis and its stigma, lack of access to age-appropriate services and financial difficulties. These studies also uncover the type of acute losses experienced including loss of independence and autonomy, loss of empowerment and a feeling of being excluded from any decision-making often because of well-meaning service providers and caregivers.

Bakker et al.'s study (2013b) showed that the individual experienced high levels of unmet needs in critical areas of daily living including daytime activities, social company, intimate relationships, sensory communication, memory, mobility and psychological distress. A more recent and larger scale study undertaken by Greenwood and Smith (2016) that employed a meta-ethnographical approach and collated information on the subjective experience from 87 younger people diagnosed with dementia showed that many individuals experienced difficulties both in obtaining a diagnosis and afterwards accessing supports. Participants reported feelings of social exclusion loss of meaningful activities and many tried to regain control of their lives through peer support.

#### **4.9.3 Impact on spouses**

There is broad agreement in the literature that spouses of people diagnosed with YOD experience unique problems specific to their life cycle stage and because of this the illness has a more profound effect on family life (Koopmans et al., 2013). Having to cope with the behavioural and psychological symptoms of dementia is one major source of stress for spouses. These symptoms are considered of greater concern due to the person's physical strength and physical ability and partly due to the comparatively higher prevalence of FTD in this age cohort (Koopmans et al., 2013) and there is evidence that spouses of people with young onset FTD experience higher levels of depression (Kaiser and Panegyres, 2007). Johannessen and colleagues recent work (2017) showed that spouses needed



individualised and specialist support through the entire progression of the illness, from relief at diagnosis to support in negotiating pathways to nursing home care.

Findings from the Dutch-based NEEDYD study; a prospective cohort study examining needs, showed that people with YOD were cared for at home by spouses and other family members for longer than their older counterparts. The prolonged duration of home care culminated in high levels of caregiver burden (Bakker et al., 2013a). Despite such difficulties, caregivers were more likely to use informal care services than statutory services and had limited opportunities for respite. This was mainly because respite services were not age-appropriate; they were costly or had inconvenient opening hours. In addition, the stage in the life cycle for people with YOD compared with late onset is such that the dementia has costly social, emotional, psychological and financial consequences for family members. The additional loss of the carer to employment market and the changes

dementia provokes in intimate and family relationships including the children who may not yet be independent.

## 4.10 Chapter Summary

Most of the literature focusing on PDS for people living with dementia is predicated on the belief that self-management is possible (O'Shea et al., 2018) and highlights the importance of keeping the individual strong, socially connected and engaged in meaningful purposeful activities immediately post diagnosis (Mayrhofer et al., 2018). Less is known about the PDS needs of younger people at later stages in the illness trajectory especially towards end of life (Koopmans, van der Steen and Bakker, 2015; Carter et al., 2018). In the conclusions chapter, key factors will be presented based on the literature search conducted for this work, as well as the primary data gathered from the interviews, that we would argue need to be carefully considered when developing policy to address the PDS needs of people living with YOD in Ireland.



# Chapter Five: Perspectives of People Living with YOD and Family Members

## 5.1 Introduction

This chapter explores the perspectives of people living with YOD, and family members in relation to their experience of accessing diagnosis, and of post-diagnostic supports and services. Qualitative interviews were conducted with a small cohort of people living with YOD across three regions in Ireland. The research questions guiding this part of the study were as follows;

1. What is the experience of receiving a diagnosis of YOD, from the person and the families' perspectives?
2. What is the experience of living with YOD in Ireland?
3. What extra (post-diagnostic) supports do people with YOD and

their families feel that they would benefit from?

## 5.2 Sample

The final sample consisted of 22 participants (10 people with YOD; 8 spouses and 4 adult children). Participants were sampled from three regions of Ireland (Connaught, Leinster and Munster). People with YOD were offered the choice of attending the interview with a friend or family member, or alone. The demographic details of the sample are discussed in further detail in Chapter two (Methodology) and also presented in Table 5.1.

**Table 5.1** Demographic details of the people with YOD and family members who participated in the interviews.

| Category                                      | N         | N              | N        |
|---|-----------|----------------|----------|
| <b>People with YOD</b>                        | <b>10</b> | <b>Spouses</b> | <b>8</b> |
| Female  | 6         | Female         | 7        |
| Male  | 4         | Male           | 1        |
| <b>Dementia sub-type</b>                      | <b>10</b> |                |          |
| YOD (specific type unknown or unspecified)    | 6         |                |          |
| Alzheimer's disease                           | 2         |                |          |
| Logopenic progressive aphasia                 | 1         |                |          |
| Lewy body dementia                            | 1         |                |          |
| <b>Employment status at time of diagnosis</b> | <b>10</b> |                |          |
| Stopped work prematurely due to dementia      | 4         |                |          |
| Did not specify                               | 2         |                |          |
| Early retirement due to dementia              | 1         |                |          |
| College/volunteer work                        | 1         |                |          |
| Not working                                   | 1         |                |          |
| Early retirement (reason not specified)       | 1         |                |          |
| <b>Interview type</b>                         | <b>15</b> |                |          |
| Individual interviews                         | 8         |                |          |
| Dyad (joint) interviews                       | 7         |                |          |

## 5.3 Findings

Interviews were held with 10 people with YOD, with eight spouses of people with dementia and with four adult children (total  $n=22$ ). Relating to the person with a diagnosis of dementia, four had dependants and were living with young children, and three were living with only a spouse or partner. One lived with a daughter who assisted with caregiving activities, and two participants lived alone.

Findings will be discussed in three sections, with further sub-headings under each of these. The first section provides an overview of participants' experiences of the time leading to diagnosis, assessment and disclosure of dementia. The second section will outline the experience of living with the diagnosis, including impact on the individual, family, employment, finances, social connections, and wider engagement. The third section details participants' experiences of post-diagnostic support (PDS) and discusses suggestions for optimal, relevant and meaningful models of care. Illustrative quotes are given to support the data interpretation (the person with dementia is listed as *PwYOD*, and the family member, e.g. spouse or child, is listed *FM*). Where joint interview excerpts were deemed to complement each other, they have been presented together.

## 5.4 Findings on Early Post-diagnostic Support after Disclosure

### 5.4.1 Time leading up to diagnosis

There was variation across participant accounts relating to time prior to diagnosis. Some reported a relatively straightforward path to diagnosis. Other participants shared examples of challenges obtaining initial assessment and referral. Specific challenges related to the difficulty of persuading relevant healthcare professionals that an issue was present and obtaining specialist referral for further investigations. Others cited delays in undergoing diagnostic procedures.

### *How changes were first noticed*

Initial signs recognised by the person themselves included becoming confused with daily tasks, such as misplacing medication. Some participants and family members reported insidious early changes, only apparent in retrospect. In some instances, it was a healthcare professional who first identified the issue of dementia. Others could report very clearly how the changes were first noticed.

.....  
*An hour and a half it took me to find my car. That was the first time I remember that just there's something wrong here. That was the very first time... And it frightened me that day. I never thought it'd lead to this. [PwYOD 9]*  
.....

Pre-morbid conditions complicated pathways to diagnosis. Examples included pre-existing multiple sclerosis, past history of brain haemorrhage, and migraine. One family member, a young woman in college but still living with parents, described how this issue complicated her mother's diagnosis.

.....  
*She'd been going to the doctor for years but they were telling her that she was too young.... She was going to the GP for years saying there was something wrong but they were telling her it was her fibromyalgia and the brain fog ...We all just thought it was the stress of everything and it was just part of all that. [FM 8]*  
.....

In several cases, problems were first identified during work. Participants reported greater difficulty managing their workloads, running businesses, and supervising work teams. In some instances, it was noticed by others, for example, a participant's manager at work persuaded her to visit her general practitioner (GP) for tests.

.....  
*I worked in the health services and I moved from an institution to the HSE and I discovered that I was making mistakes... I discovered that I hadn't actually recorded things that I thought I had. I*

*was shocked because I always would've been very diligent like that. [PwYOD 4]*

In some cases, the early signs related to changed behaviours rather than memory, for example two families described sudden unusual behaviours. In one instance, an incident of physical aggression occurred. Because there were young children present, the Child and Family agency Tusla were involved, which added to the distress experienced. In another example, a father of young children impulsively spent €23,000, at a time when his employment was already precarious.

*.....*  
*It was unbelievable, the revenue and everything came bang bang bang within a week. ... I sat and cried for two weeks, we had no money for (their son's) future. When they were looking for the money, banging on the doors, he cashed in his life pension....Everything went completely wrong. Not alone was he not in a good place at that time but he strapped us to the bone with our finances... So I went to the doctor just over two years ago, when I saw things wrong..... [FM 4]*  
*.....*

There was a sense that in some cases, crises would precipitate family to take steps to obtain an assessment. One participant, a daughter, spoke of gradual changes she had noticed, which then became evident to her mother's colleagues, and finally, there were two minor car accidents in the space of two weeks. A change in office location prompted another person to notice issues in her memory, and led to her to seek a review with a private neurologist.

#### *Delays in pursuing diagnosis*

When it was apparent that cognitive impairment was present, participants started the process of seeking assessment. Within the sample, it varied as to who first sought diagnosis. Usual first steps saw the individual with memory concerns attending their GP, and most participants spoke of the need for persistence at this time. Delays were cited,

particularly in cases where initial symptoms were atypical. In some accounts, the family GP queried stress or work-related factors. This was particularly the case when the person with YOD attended the GP alone. One participant hoped he would score poorly in the cognitive tests, believing this would progress answers, but he passed each time all the while feeling a cause for concern.

*.....*  
*I was going mad... it felt like I wasn't being listened to... one GP was saying it could have been my medication or else my mental health which could have been causing it. Even ... before I was fully diagnosed I went to the memory library ...to see would anything help and they gave me little tips about putting up little signs or writing up little notes. [PwYOD 1]*  
*.....*

Spousal caregivers were often the driving force at this time, accompanying the person with YOD to the appointment and trying to persuade the relevant clinicians to consider a memory issue and to enact a specialist referral process. A daughter shared her experience of trying to obtain clarity regarding her mother and memory issues and felt that action was taken only when she herself pushed for further consideration of the issue. Caregivers recounted seeking second opinions, or attended for repeat visits, to progress diagnosis.

*.....*  
*You also have to be quite persistent because we went to his GP twice.... And we were told that there was no (issue)..... To be fair to his GP who has known him for years, he's only in there for a few minutes so it's fair that he didn't notice any difference. [FM 2]*  
*.....*

Another participant, an 18 year old son, described this early time as 'horrible', with the family knowing that something was not right with his father (who had FTD), but feeling unable to access help.

.....  
*It took a long time to get the result. It took months, but I think that was because of how uncommon his type of dementia was... It was just kind of horrible they just couldn't pinpoint it for such a long time, you know? We had to wait for him to get a lot worse ... We were oblivious, we didn't know what was going on... It's just the unknown factor- it wasn't nice at all. [FM 3]*  
.....

Relating to this, there was a sense that concerns were overlooked, or misattributed. This was particularly challenging for family members who in some cases had taken considerable steps to persuade their family member to attend the GP.

.....  
*...His doctor, she actually has put it down to stress. He used to go down to her... himself and (GP), best of pals, he'd be chatting away to her, and she'd just be saying you're stressed... You're just worried about this, and worried about that. ...In the end I said I'm going down to the doctor because... he was just... changed totally ... I can't put my finger on how I knew, but I knew. And we went down to the doctor and I (spoke) with her and she eventually said OK.... [FM 10]*  
.....

In some instances, despite the concerns of family, the GP did not pursue an investigation. This meant that assessment was not progressed until a later timeframe. Although participants were mindful of the understandable reasons for delays, in some cases the GP was identified as an example of an additional barrier to accessing further investigation. One family member lived in a rural location with her spouse who was later diagnosed with Alzheimer's.

.....  
*I went in to the GP and I said, I want you to tell me, does he have dementia? And he sat back and with his arms folded and he said.....ah that's very interesting. Why do you say that? And then he changed the subject. That was it. [FM 12]*  
.....

In this sample, many reported negative experiences, however there were also examples shared of positive diagnostic processes. One participant reported being thankful that her GP listened, and was willing to consider dementia, rather than querying menopause or stress related factors, which she had feared. In one case, it was a visiting GP who listened to the person's concerns about dementia and agreed to conduct further investigation (7 months via the public system). In another, a family member brought her young son to add weight to her accounts, and the processes moved swiftly.

.....  
*Well that was two months which was great. But I think that was because my son was with me because I brought him so they wouldn't (disregard it). So my son (aged 17) said it how it is. And they listened. [FM 4]*  
.....

GPs that were aware and pro-active, were particularly valued. In one account, after several months of noticing worrying repetition in her husband, one couple attended their GP who processed the referral immediately.

.....  
*She (GP) was on the ball and to this day, I do appreciate the route that she sent me on and she got me sorted. [PwYOD 4]*  
.....

#### *Pathways from GP to specialist*

Almost all participants reported having been referred to a specialist via their GP. Once the process of specialist follow-up had been commenced by the GP, subsequent delays and challenges occurred. Descriptions of pathways to diagnosis were variable. In some cases, pathways appeared to be complicated and prolonged, perhaps owing to the insidious onset of the illness, to family postponement, or the individual experience. It was challenging for participants to definitively provide time to diagnosis. Examples include a lengthy timeframe (2-3 years), though a period of months (~ 10) was more common. Examples



of challenges included difficulty accessing timely specialist appointments.

.....  
*I was tearing my hair out because we got an appointment, in the post for May... and it was cancelled before (this time)... I couldn't take it.... I was terribly stressed at work as well. I just didn't know what (he) was doing when he was at home...I was very worried about him. And then he started drinking... He kind of knew himself... It was dreadful. That's what happens ...you're saying, 'Oh this is great I can't wait to go to this appointment', and then the next thing it's cancelled. [FM 10]*  
.....

The process of accessing specialist diagnostic consultation varied. Some participants spoke of receiving referrals to neurology consultation, and others were referred to a memory clinic. Several participants reported taking a private referral route, and did not cite delays as others had. For example, one participant described the process of obtaining a rare diagnosis, progressive logopenic aphasia, in a relatively straightforward way. Even at diagnostic facilities, owing to many factors, there were delays accessing confirmation of diagnosis. Cognitive tests or imaging produced negative or subclinical results. This served to add to the confusion experienced, and disagreement within the family.

.....  
*He came out skipping with 29/30 from the first test, saying "See ...there's absolutely nothing wrong with me".... At that stage it was causing problems between us because he thought I was trying to tell them that there was something wrong [FM2].*  
.....

Where diagnostic tests and procedures displayed no findings, and symptoms not readily observable, there was a sense that they had been placed into a holding pattern, and participants reported waiting months for the next chance to be reviewed.

.....  
*It first came back as ... depression but that was obviously incorrect because it was such a complicated dementia (FTD)....It was hard for them to pinpoint them so we were kind of in a big cloud for ... months hopping from diagnosis to diagnosis, different things...My mom told me (once confirmed)... And he was just in complete denial and to this day is in complete denial. [FM 3]*  
.....

There were accounts of diagnostic processes that were positive and straightforward, and which occurred at an acceptable pace for the person. One person described waiting about 10 months, and travelled for about 2 hours to attend the hospital for the appointment, which was deemed to be reasonable.

.....  
*He did MRIs and bloods and whatever and he did the memory tests. He was asking me the same questions but I couldn't remember...He told me to come back in a couple of months. [PwYOD 1]*  
.....

For another family, the wait for confirmation of diagnosis was deemed to be too long and stressful.

.....  
*PwYOD: it was like there was a piece missing in the jigsaw like I couldn't put things together. They're all little things so like, cooking the meat and veg and not the spuds. Or putting the apple pie in the oven but forgetting to turn it on.*  
*FM: Yes definitely, it took a whole year from when we went in, until she even got the (diagnostic procedures), and it was three months after that she actually got the diagnosis of Alzheimer's. It should all be in the same day like it's crazy. [PwYOD 3 and FM 5]*  
.....

For those who experienced delays, this time meant that for many participants, life continued within a context of uncertainty. Several important issues that families needed to rectify or progress, such as work-related issues or finances, were impacted by the delay.



.....  
*The GP said "I have no diagnosis (to give you) but I agree it is presenting as a dementia syndrome"....But we needed it for work and stuff.....If you don't get your diagnosis, you can't get your pension...for social welfare, to sort out the invalidity. There wasn't any emotional connection with (the diagnoses). It was just for legal purposes, you know? [FM 5]*  
 .....

#### **5.4.2 Disclosure/How diagnosis was confirmed**

There were mixed accounts of how competently a disclosure of the dementia was handled. For some, there was a gradual element to it, so confirmation of diagnosis was somewhat anticipated. For others, it was felt that the confirmation of the diagnosis, and the gravity of the situation was more immediate and confronting. For example, one family attended a private clinic attached to a university hospital. At this consultation it was suggested that the person undergo additional tests as an inpatient, where diagnosis was confirmed shortly thereafter. Neurology and memory clinics were cited most frequently as the place where diagnosis was confirmed. One participant who had been seeing a psychiatrist previously, stated that it was this doctor who helped diagnose.

.....  
*The psychiatrist knew something was wrong, she said the tests would show up more, but she wouldn't tell me over the phone what was wrong. [FM 4]*  
 .....

In this instance, owing to young age, a referral was made to Neurology and a neuropsychologist for confirmation. Several participants expressed relief in receiving their diagnosis and the clarity that was brought. Another family member, who lives in a large urban location, cited being able to ring the memory clinic directly once issues had been identified, and this was viewed as a positive.

#### *Who should be present*

It was felt that greater consideration should be afforded to the contextual factors impacting on disclosure. For example, one participant living with YOD described receiving his diagnosis alone. His wife and he (a couple in their 40s) reported that this information would have been better received if he had had the support of a significant other. In this instance, his wife was also alone when she heard that her husband had dementia. The physical setting, a busy hospital ward, was also deemed to be an important factor.

.....  
*PwYOD: he said to me then that ... it was a form of dementia, I was by myself. ....I suppose when I was told that day in the hospital maybe more of an explanation there and then because it did go over my head a bit, if I was given more information as to what he was saying.*

*Spouse: I was (abroad) at the time... I think if (he) had someone with him and if I had someone with me. You shouldn't be alone for something like that... I know that's the consultant's call... but I do think a more private setting as well is a big thing. Because it's never going to be nice getting news like that.....The overflow ward in casualty is absolutely atrocious there isn't even a screen put around you. But anyway, they told him when he was by himself. [PwYOD 7 and FM 9]*  
 .....

Offering a different perspective, a family member described her experience of a disclosure meeting with her husband (not a participant) who did not seem to have insight, and their experience of receiving a diagnosis of FTD. She argued the full weight of the diagnosis fell on her and the family, and that in this instance, it would have been preferable to hear the diagnosis alone, or afforded the opportunity to follow up with the relevant HSCP alone.

.....  
*I think if we had had a consultation before the diagnosis when (names husband) wasn't there, we would have been able to ask questions. We didn't get to do that. Also, if there was someone there to speak to afterwards, to be able to go to and ask questions...[FM 7]*  
 .....

*Clarity of diagnosis*

For some participants, the explanation that symptoms were dementia-related was important. One participant shared her experience of attending the memory clinic and starting cholinesterase inhibitor medication, without being told their diagnosis.

.....  
*(The memory clinic) asked would I be willing to take medication so I said of course because all that was on my mind was (her children). So I got home .... I looked up the medication on my phone and the medication was for Alzheimer's. So, none of that was conducive. It wasn't a right way to do it. [PwYOD 6]*  
.....

Another person felt that that the naming and confirming of Alzheimer's disease (AD) was overwhelming, having attended the memory clinic for what he had thought was a treatable issue. Although this is an individual choice, it was felt by most that clear confirmation of diagnosis was a positive step, and would offer an explanation for the many changes they had been experiencing.

*Provision of information*

After diagnosis was confirmed, several participants stated that they received little information, and were given little indication about where to turn next. Examples of information that was provided included contact details for the Alzheimer Society of Ireland (ASI). Furthermore, a gap in the information available was identified by several participants who received atypical diagnoses. For some, the only piece of information they received in this early stage was that which was available on the internet. Typical first steps in this instance was that participants researched available supports themselves, once they returned home.

.....  
*We never got a leaflet, information sheet or any information, nothing leaving that hospital. Even if it's something that you put in the drawer*

*and look at a month later .... We didn't get any numbers or anything...you spend so much time afterward ringing around here and there [PwYOD 7 and FM 9]*  
.....

The importance of provision of written information and detailed explanation was mentioned often, particularly by those who were not expecting the diagnosis.

.....  
*They told mum that she has YOD, but they were not able to give us any other information. We were just left to go home with the diagnosis. [FM 11]*  
.....

There were also some positive accounts of disclosure meetings. In one instance, where a diagnosis was made to a man with a very young family, a disclosure meeting was held, led by the neurology team within the hospital. A private setting was used, and key additional multidisciplinary colleagues were asked to attend to provide information and support.

.....  
*They asked if I could be there for eight o' clock at the team meeting. And oh lads, they were well prepared for me, to be fair to them. They had everything prepared and they wanted me to understand what was happening and they wanted it all to sink in. They had a liaison officer there as well and I was put into the family room in the overflow ward.... [FM 9]*  
.....

In one instance, it was a crisis that precipitated the diagnosis confirmation. It was obvious during the disclosure meeting that the clinicians were concerned about delivering a diagnosis of FTD. In this case, the family reported the staff took steps to ensure they understood fully what was under discussion, and they felt adequately informed. There were accounts shared of optimal information provided at disclosure. A participant recounted how, prior to disclosure, the clinicians had a conversation with them on how much the

person would like to know, and how much detail they would like provided.

.....  
*There was a consultant and (another) doctor. He said 'How do you want to play this, do you want the truth, the whole truth or nothing but the truth .... or something else?'.... We said the truth. [PwYOD 2]*  
.....

#### *Individualised approach*

A small minority of participants shared examples of being provided with too much information at the time of disclosure. These participants were advised to begin planning for the future, such as filing an Enduring Power of Attorney and organising a driving assessment. Again, the unsuitability of the physical setting for disclosure was emphasised:

.....  
*They didn't even have a proper room to go into ... somewhere to go to talk, somewhere to break the ice a bit, and a bit of comfort you know. Now they did tell us together but like this is life impacting stuff and it's very robotic you know, next, next. It's very rushed you know. And this is devastating stuff you know. It needs to be handled a bit better for all concerned. [FM 4]*  
.....

### **5.4.3 Pathways after diagnosis**

The types of support needed immediately after diagnosis varied greatly. In the majority of cases, it was the person with dementia, or a family member, who made initial contact to source information and support, and key post-diagnostic services in their area.

.....  
*I was referred back to my GP, from the memory clinic... And as it turned out I didn't see anyone again for four years. I never got a call back... there's no real security there if I had a real problem... I wanted to see the community health nurse and they said I couldn't because I wasn't 65. ... I had to fight to see her. [PwYOD 6]*  
.....

This was reported several times, a sense that the early stages of accessing information, getting onto the correct pathways, was a challenge. A woman who lived with her daughter, age 15, was keen to establish community supports as soon as possible (for the sake of her family) and requested a medical card, but found this process challenging to do without guidance.

#### *Timing of information and signposting*

The timing of information and signposting was identified as important, as it was often when the person and family had begun to absorb the gravity of the diagnosis, and questions had begun to arise after the disclosure meeting. One participant described how his father, who had been diagnosed with FTD, experienced side effects from new medication prescribed. The family felt unsure who to contact (e.g. the GP or memory clinic staff), or what action to take. In another example, a family asked their GP to arrange another, earlier specialist appointment to help address some uncertainty, but the appointment when given was in 13 months' time. This point, on the integration of pathways, is particularly important when related to diagnostic-only services, and the potential for disconnect between primary and secondary services during initial first steps.

.....  
*They did make it very clear and said we are diagnosis only so that's all we can do from here, there will be no follow up and you must go to your GP. And the GP never proactively sought us out. We had to do all that ourselves and thankfully we were able to navigate the system. We were well able (but) we had to do all of that ourselves, we had to push all of that. (When followed up with the GP) he said that he couldn't do anything about the medication without getting the notice from the clinic... Then there was some admin problems as well which delayed it on part of the clinic. [FM 2]*  
.....

Furthermore, the amount of information provided during this initial phase varied from person to person. Some participants were provided with the ASI national helpline

number, and there was variation in who provided these details, from the staff at the diagnostic/memory clinic, or the GP. Once contact was made with the helpline, some participants described a positive process in which information was received, and signposting occurred. In some instances, they were signposted to the incorrect services, outside of their catchment area. In another, the only information the person received was from the UK Alzheimer Society.

*Linkages between and within diagnostic and community services*

Participants identified a need for greater linkages between and within diagnostic and community services. This was particularly the case in the time immediately after diagnosis. The following quotation highlights how support may be needed immediately following dementia disclosure:

.....  
*When I got my diagnosis, I cried outside the clinic, it was Valentine's Day. And I got dropped home and I was by myself at home so I rang the helpline for Alzheimer's, I said I had just been diagnosed today and I said I felt pretty bad.* [PwYOD 3]  
.....

Some participants had never made or received contact with dementia services, and so in turn, had not been visited by or assigned dementia specific support (e.g. dementia advisor). Similarly, very few of the participants were referred to community HSCP such as an OT or social work at this time. Several participants shared examples of contacting ASI services before they had received a diagnosis, owing to their own concerns about memory issues. Relating to this, it was deemed important that access to such services was allowed, even in the absence of a confirmed diagnosis.

.....  
*I rang (names DA) a lot and she would tell me I'm doing great. But (she) was there for me before I ever even got my diagnosis. She was very good. She always said cognitively, if you have a problem, you need help. So that was brilliant.* [PwYOD 3]  
.....

Many of the participants in this sample had been visited by a DA, and spoke positively about this resource and the additional supports the DA typically enacted (e.g. linking to other community supports). However, there was disparity relating to when and how this commenced for those in the current sample. There was a sense that there needed to be a standardised minimum set of steps enacted at disclosure, or soon thereafter. The most pressing information at this time seemed to relate to 'next steps': what the person with dementia or a family could do, in order to be pro-active and to live as well as possible. The ASI helpline number was deemed to be important, but participants were clear that this was not sufficient in and of itself.

### 5.5 Findings on Living with YOD in Ireland

This section details the experiences of the participants and what impact the diagnosis brought. It outlines experiences relating to employment, finances and the barriers faced by study participants. This section also outlines the experiences as shared by family and children.

#### 5.5.1 Impact on the person

Participants shared honest accounts of the impact the diagnosis had on them, and their experience of living with the changes. For some, confirmation of dementia came as a relief and brought some explanation to the changes they had been noticing. Participants discussed having to change their living situation, having to leave work and having to give up aspects of their day-to-day life. Because of the time of life the condition occurred, many participants had begun to anticipate a new start in life, for example, one

person had hoped to return to college after her children were finished school.

.....  
*There is a grief that isn't recognised from the moment of diagnosis and that's something that people don't talk about and that's ongoing every time a skill is lost.... It's a rollercoaster of sadness to me like wow. Again it's something that you don't anticipate and you don't think about.* [PwYOD 6]  
.....

When discussing their experiences of living with dementia, worry for family was often cited as the most distressing aspect.

.....  
*I'm worried about my family definitely like I want to look after them. My daughter's been great but my son doesn't understand it at all. He (is young) so it's hard for him. My son could definitely do with some help because he gets so annoyed for me repeating myself all of the time as well.* [PwYOD 5]  
.....

Social activities and pastimes were reduced as a result of the dementia. One of the reasons for this was driving-related factors. Other reasons included sensory issues, and a reduced ability to tolerate noise and crowds. Participants reported feeling anxious and less confident in some activities. The topic of independence was discussed, and the reaction of others to the diagnosis. This is related to a whole-of-community understanding of dementia, but also interpersonal reactions.

.....  
*Daughter: I think the way people act is very unjust. It's just like all of a sudden, everything's like "no don't do that, you can't do that". ... People go into overdrive but.... I'm not going to take (independence) from her while she's okay... I agree with the driving (assessment), the legal aspect of that...that's fair and I understand, but with everything else you should be supported and encouraged to do the most instead of taking everything away*  
.....

.....  
*PwYOD: Yes I'm very angry... it's nobody's fault... But it's all about the lack of control and everything being taken away.* [FM 5 and PwYOD 3]  
.....

#### Reaction of others

In general, the reaction of others had an understandable impact. In two examples, the parents of the person with YOD had been unable to accept the condition. Other friends and family members did not believe the diagnosis, perhaps because of the young age at which the dementia had occurred or the unseen aspect of the condition, or both.

.....  
*People are in denial or disbelief of it... Loads of family members don't believe that anything is wrong. For the first year his sister didn't believe us, his uncle didn't believe us. They were demanding a second opinion. And we were saying we (can't afford) that, you know? So we didn't have anyone to support us* [FM 3]  
.....

.....  
*They say oh I forget things all the time, we all do that, that's nothing... I know they're trying to make it seem better but it seems as if they are just dismissing it or minimising it* [PwYOD 5].  
.....

The topic of stigma was raised, though mostly indirectly. Participants acknowledged that social connections had become reduced, for different reasons. Some friends and acquaintances became distant once they became aware of the diagnosis. One example was shared of a family member, a parent, moving away very soon after her son was diagnosed with YOD. Other participants spoke of being well supported by others. For example, a participant had adopted an open disclosure approach to her diagnosis. She recounted an instance of feeling unwell in the local village, and was supported home safely by staff from the local coffee shop and by other members of the community. By being open and attending groups and initiatives, participants found value in new connections that had been made, with others in similar situations.



.....  
*My family is my family through Alzheimer's now. [PwYOD 6]*  
.....

## 5.5.2 Impact on life

### Finances

The issue of finances was discussed by many of the participants, and the financial impact that dementia had brought. There were several aspects to this. For example, some participants with dementia spoke of having to take early retirement, or having to discontinue contract or occasional work.

.....  
*My biggest problem is finance, I had no money .... There is so much that I want to do but I just can't afford it. The finances are not there. [PwYOD 6]*  
.....

A family member, a spouse aged 51 shared the example of her husband missing time at work and in the end, failing to maintain his contractual commitments. She attributed this to issues with colleagues, and also the driving required. Because it was precarious employment, not enough PRSI credit had accumulated, and so the establishment of welfare payments was a challenging and protracted process. Similarly, family members faced changes to employment, for example, one resigned from her job as a nurse in order to oversee childcare, manage the household and to support her husband. Other family carers reported this dilemma with their own work, balancing their working life with caregiving, and facing the option of leaving work.

One participant who lives in a rental property with her daughter (age 15) has been told she had to re-locate in the coming months. Because of her family and concerns for the future, this participant has begun the process of planning for long term care. Another participant, a young son still in school, had understandable concerns about finances and worried on behalf of his family after his father's diagnosis.

.....  
*What struck me the most was my fear of the future ... my safety, my mum's safety and maybe even our financial situation. They are the things that struck me as the scariest. So I was very anxious, and very scared for the financial (situation). I was worried will we be OK? Will we be homeless? Even though my mom told me not to (worry)... I had heard of... how expensive it can be .... and he can't work now because of (the dementia). At the time it took us a year to get (financial) help ... So we had nothing, we were just every week going down and down and down and down... It took a year for my mom...to just get it confirmed (that they would be entitled to invalidity pension/carers allowance). [FM 3]*  
.....

Apart from having reduced income, many participants also reported additional expenses as a result of dementia. Two families described having to move house from a rural area to be closer to family and a community. Others recounted how HSCPs had advised them to take numerous steps to ensure safety and well-being for the family, for example, booking driving assessments, an appointment with a solicitor to sort legal affairs, removing gas cookers, and organising counselling sessions for children in the family. Though important, in the context of a reduced income, for some this caused financial concerns and hardship.

Assessing the relevant social welfare, pension and disability entitlements was felt to be challenging for participants. Navigating the various systems, offices and requirements was described as stressful, with long delays to access entitlements. For example, a participant shared how she had delayed the process of applying for Carers Allowance, to allow herself time to acclimatise to the changes the family were facing. Once she applied, she was told that she would have to wait many more months to be considered for a review of eligibility. Another shared her experience of trying to access entitlements;

.....  
*I was told to try for a discretionary medical card but I just suppose it's the hassle of having to fill out all those forms and I know I'll be told no .... And then to go and fight it? I'm just (not able for) that at the moment. [FM 10]*  
.....

Several found this so difficult they circumvented these processes by requesting help from their local government official, which progressed matters.

#### *Barriers to access*

In the absence of a diagnosis, making legal arrangements (such as organising an Enduring Power of Attorney), managing finances and accessing entitlements, was challenging. Some shared examples of employment and income stopping, and difficulties securing financial assistance. One participant described how her husband's income stopped when he was no longer was able to undertake his casual/contract work. Despite growing financial issues, and deterioration in her husband's condition, General Data Protection Regulation (GDPR) requirements meant that she was unable to access the necessary information help manage his finances, and was unable to apply for welfare assistance on her husband's behalf.

.....  
*I had to cut down my work hours down to eight hours a week, huge financial strapping. ... (I worried about) my mental health and my son. I had to be mother and father figure. I didn't know anything about the bills, he used to do them. I was pulling my hair out trying to sort them. There was money missing out of the account, I couldn't understand where the money was going. [FM 4]*  
.....

#### *Occupation*

Participants shared their accounts of how YOD had impacted upon their employment. Five of the participants with YOD in the sample had been working at the time that dementia symptoms first occurred. Of these five, four

reported having to stop work, though under what circumstances is not always clear (e.g. on health grounds, or resigning owing to work strain). One participant reported taking early retirement when he identified issues. Another participant had been planning to complete a college course but was unable to commence this.

In some instances, the decision was made by the employer owing to mistakes and difficulty managing daily workload. In one example, a workplace manager asked the person with YOD to have their health reviewed. Aside from paid employment, participants gave up voluntary work and adult education. In other examples, owing to the complexity of the condition, families shared differing viewpoints of how employment ended. For example, some reported opting for an early retirement, with the family member believing in truth that this choice was because of dementia.

.....  
*PwYOD: Well ... I was doing a lot for work... I wasn't able to do full reports or make a proper decision as such, from that... so I moved from that area then, I just sort of got moved into another area that didn't involve that type of stress. I didn't really want to make it... common knowledge either, you know?*

*FM: None of us recognised it at that stage. (I just thought he felt...) I have enough, I have 40 years done in a job, I'm 57, I'm...had enough, and then he had ... very difficult staff to deal with ..., and they all had issues ... one after the other. And in the end he left, I thought too soon. But I think now maybe he just couldn't cope anymore, really. When we look back, we see things differently now. [PwYOD 8 and FM 10]*  
.....

Current employment status remains unclear for several participants. Some examples were cited that highlighted the absence of employer and peer understanding of participants' dementia. One example was shared of incidents of harassment towards



the person with dementia at the end of their time at work which has only lately been realised by family (and remains unresolved in terms of employment status and salary). Another example of current work impact was a mandated period of extended leave. In this instance, the person has requested to return to work but is awaiting occupational health assessment.

.....  
*I always enjoyed my work like I would've done things, like I don't know was I trying to prove to myself that there was nothing wrong. I love to do something the best way. I brought a lot of hardship on myself and I didn't need to do that. I don't know was I trying to prove to myself that there was nothing wrong with me? [PwYOD 3].*  
.....

**5.5.3 Impact on family**

Family members described some of the changes they had faced following the onset of the illness. There were significant social, financial and lifestyle impacts discussed by participants. Families had to change their working conditions, and their living situation. Others described impacts on multiple parts of their life and health.

.....  
*It affected my mental health, it made me spiral, it made me ill, it made me financially strapped. I now have a breathing condition caused by stress. I have a heart condition. [FM 4]*  
.....

Families shared their insights on how they felt their marriage and family had been impacted. Family members reported managing alone, with no-one monitoring their level of coping or stress.

.....  
*(There is a) lack of recognition when it's a couple. It has to be the loneliest place for someone in a couple watching their loved one go, and to remain there for the person as well... I would argue that the younger the couple, the harder it is ...it would be a lot more difficult for a younger couple. That couple dynamic is*

*so under recognised. It scared me the impact ... that this disease is having. I've never heard any professional ask "how are things in your marriage" or "how is your relationship?" The person needs to be cared for but their loved one needs to be cared for as well... [PwYOD 6]*  
.....

Some maintained an optimistic outlook, and acknowledged the many positive aspects of their life and their relationships. However, families reported significant concerns for the future, and grief at the changes they saw ahead.

.....  
*(He) and I have a great life. We didn't have children, so we lived quite independently, we're great together....we had our own friends, we had our own holidays... that's all gone. I'm listening to my friends going here, there, and everywhere, and I don't think I'll be doing that anymore. I just have to decide this is not my life anymore. And I mean it sounds very selfish but...it's real...And thinking about the future and worrying about the future [FM 10]*  
.....

*Impact on children*

Participants shared their experiences of being the child of a parent with YOD. One participant, a young woman in college, described the time she found out about the diagnosis.

.....  
*She rang me when I was in college... she rang me and told me she had Alzheimer's and I started crying. I think I was crying out of relief ... because I thought that she would get help then....It (also) made me more worried about her...I don't like her going anywhere by herself ... I know that's silly but even if we're in the supermarket I get worried. [FM 8]*  
.....

This participant later described the changes she has made to care for her mother, such as cancelling holidays with friends and reducing her part-time work. She shared the worries she experienced on behalf of her family.

.....  
*My dad has cancer and ... has depression as well so I try to watch him a lot more. And my brother keeps everything in, so you don't really know how he's feeling so I try to watch him a lot as well....When we got the diagnosis at the start of the year, the lecturers (at college) saw me crying and I explained what was wrong so they were so helpful and gave me the option to get extensions on my assignments and stuff. They were so good. [FM 8]*  
.....

Participants discussed experiences of psychological and emotional impact on their children. A woman in her 40s with a diagnosis of YOD reported how she had not yet told her children her diagnosis. She had the impression that they had sensed issues, but were not yet of an age where they would understand a dementia diagnosis. Others described their children's struggle with the changes, and support they had received from the consultant.

.....  
*My son ...(it) threw him completely. His mental health was really bad and then my own mental health, when Tusla got involved. My son needed help ... I definitely think the children need some sort of immediate attention after receiving a diagnosis...It's wrong because children really do need a lot of support. But he was brought in eventually ... the two of us were brought together, that was by the neurologist ... [FM 4]*  
.....

After diagnosis, there followed a realisation of the seriousness of the condition and of the future. This participant later describes how this initial period, just after diagnosis, was a challenging time for her.

.....  
*It was just a big worry about what it was going to be like and stuff. If anything happened. I don't know how we'd cope. [FM 8].*  
.....

Because of the added dynamic of young children in the home, two separate families spoke of the involvement of TUSLA, which added to the distress felt.

.....  
*We had a social worker telling us that we had to put an emergency plan in place and TUSLA got involved because of the violent episode. Then we got the psych team involved who really didn't know what to do. It got very, very messy then... [FM 9]*  
.....

Assessing information was deemed to be difficult, especially information that was understandable and relatable for children. A participant shared a positive example of the neurologist setting up a dedicated appointment, for information and questions for the two children in the family. Two participants [spouses] reported that they were advised to organise counselling for their children. In one instance, this was set up for them by a voluntary agency. The other was not, and the participant described feeling extra pressure to ensure she organised counselling for both children despite financial concerns.

## 5.6 Findings on Post-diagnostic Support

This section relates to PDS. It covers three main sub-sections; pathways to accessing support, the types of support commonly accessed, and level of satisfaction with these, and finally, suggestions for optimal models of post-diagnostic pathways. The types of support commonly accessed, and suggestions for preferred models of support, varied from person to person, highlighting the individualised nature of the illness experience.

### 5.6.1 Pathways to post-diagnostic services

Many participants received information and signposting from DAs in their area, of note this may be because some of the participants were recruited via the ASI. The DA often had

the remit of assisting with access to PDS (e.g. support groups) or provided support to the person in an individual capacity. Accessing the requisite information about supports was problematic for some participants. One participant described gaining access to one service, a support group, via a friend of a friend who worked at the hospital. Having a professional understanding of the healthcare system, in this instance community care, was also deemed beneficial.

.....  
*Because I had the background in it, I'm lucky. But my god if I hadn't, I don't know how I would have accessed it. I don't know. Would they have come out and done an assessment? Would they have given me contacts? I just don't know. [FM 9]*  
.....

The ASI was cited most frequently as the main source of written information, signposting and contact details for relevant services. The ASI was accessed on the advice of those who had assisted with diagnosis, the GP, or by the individual themselves. One found the ASI contact details through social media channels. The timing of PDS was deemed to be important but varied widely from person to person. For example, one participant described accessing no support or input for a full year after diagnosis, out of preference. In contrast, another couple described receiving the diagnosis in September and being offered a place in a group that November, with the aim of optimising cognition and strategies, the timing of which was welcomed by the couple.

*Information*

Information on post-diagnostic services was often by word of mouth. The most salient information was often received from others in a similar position, rather than from healthcare professionals. For example, a conversation with a contact with dementia led to shared understanding of sensory challenges, and the sharing of relevant coping strategies for this issue.

.....  
*I have met some amazing people along the way who have given me advice and information. I really believe knowledge is power. So give me the information, give me the knowledge and I can do what I want with it, it's my right and my choice. I really get angry when people struggle for information because it's not a real resource demand. The knowledge and the information can help us set up. Like it's helping to do things safely. [PwYOD 6]*  
.....

*Barriers to services*

Access to certain healthcare services was denied owing to age or perceived level of need. For example, two participants had requested public health nurse (PHN) support, and experienced challenges receiving initial assessment for and information about home support. This was deemed particularly important considering that the PHN is often an access point to other community services. The subject of residential respite care (e.g. one to two weeks) was raised by two participants. Respite was requested by one family in particular, to bring the children on holiday, however this was declined on the basis of age. Two participants with dementia stated that they were refused personal safety alarms because of their age.

.....  
*I wanted to see the community health nurse and they said I couldn't because I wasn't 65. The panic button was what I really needed when I was at home alone and I was told that I couldn't get one because I wasn't 65. And that's why I want to push this. It impacts me and it impacts others. [PwYOD 6]*  
.....

Participants discussed variability in supports across locations and called for greater flexibility with same. For example, a participant received information for an intervention for people with dementia that receives Health Service Executive (HSE) funding, but because of their home address

and the catchment area, they are unable to utilise this service.

#### *Access to entitlements*

During interviews participants spoke about the infrastructure that surrounds many services and entitlements. This was deemed to be onerous, with examples of participants being given incorrect advice at times (e.g. being told to apply for Illness Benefit when the correct option was Invalidity Pension). This resulted in months of delays before benefits and finances were established, and a lack of support in navigating these processes.

.....  
*PwYOD: Well they were telling me to do this and do that and fill out this form and that form, and a lot of that just went over my head. I couldn't remember. Or I'd fill it out and it'd be wrong or there would be something missing.*

*Daughter: Yeah that happened a lot where they'd sent it back and there'd be something wrong and then sure by time it comes back again. It's a whole lot of red tape. Everything's a whole lot of red tape. [PwYOD 3 and FM 5]*  
.....

### **5.6.2 Types of support accessed**

The types of post-diagnostic services discussed included some services designed specifically for the person with YOD, for family caregivers, and for children in need of support. These were not universal and were offered only in certain locations. Uptake in service use varied depending on many factors. Individual preference was key, but also a factor was the current level of need, geographical location of services, availability or unavailability of services and finally age-relevance. In some cases, the participant was not utilising any post-diagnostic services at all.

#### *HSE services*

In relation to contact with formal services, often the only source of contact that was maintained was with the medical consultant and their team. Reference was made to ongoing community support received by one

family from their neurology and psychiatry teams, in the form of telephone calls and home visits.

.....  
*FM: We had the psych service and they were outstanding, and their social worker was absolutely brilliant*

*PwYOD: Yeah they were marvellous. [PwYOD 7 and FM 9]*  
.....

Several participants described accessing HSE-based dementia initiatives, and joint initiatives run in conjunction with other organisations, such as Genio. Examples of the support received there included training and information courses, in addition to a dementia choir. The latter generated mixed responses from participants who had attended, highlighting the individualised nature of intervention design.

#### *Community and home-based support*

On the subject of HSE community support (e.g. public health nursing), participants reported variable accounts. Several participants questioned the efficacy of traditional home help models of care. Although there may not be a physical need for help with activities of daily living, it was felt that people with YOD could benefit from support in the community to maintain their usual, preferred activities, but that the current focus of community health provision did not reflect this. Only one participant reported being granted HSE home support. It was deemed beneficial in this instance, and the amount of care time provided allowed other family members (a spouse and two young children) to go on activities and day trips.

.....  
*We want to keep as our family unit. So at least with the carers here we are keeping it together. You need to know that he is safe and he is happy. You need someone to be there that has experience working with people with cognitive impairment [FM 9].*  
.....

*Mainstream dementia supports*

There was general consensus that dementia services such as day care and respite care were of little relevance to participants in the current study. This was evident from an absence of uptake, however, several participants acknowledged that they agreed to try certain dementia services when advised by HSCPs. Day centres were accessed by two participants, and one recounted a positive impression of it.

.....  
*I find it great. I go one or two days (a week) to the dementia day care .... I love the art class. They're great. Now, they're all older than me and that's the only thing. [PwYOD 1]*  
.....

Another participant attended day care only for a short spell, before they opted to not return, perhaps owing to the age profile and relevance.

.....  
*FM: It (Day care) didn't seem very age-appropriate you know. At the start he'd be telling us about the staff and all of the other clients and then after a while he stopped speaking to us. He became very upset after it, and I had to say no. You know we couldn't send him somewhere where he wasn't happy. Now it was never going to be easy, like the first day that he went to that daycentre I had to pull in at the side of the road because I was (crying). I said this is so wrong ... Now the staff were brilliant, absolutely outstanding*

*PwYOD: Yeah the staff were great. [PwYOD 7 and FM 9]*  
.....

The topic of long-term care was raised by a participant. This was in a case where a family were encouraged by community services to consider long term care. At the time, this discussion happened too early for the family and caused upset and discord with the services involved.

*Alzheimer Society of Ireland services*

The ASI was discussed in terms of being both an access point for information and signposting, and as point of service/support provision. Relating to services, those which were commonly utilised by participants in this sample were the support and information from the DA. Also discussed were drama groups, choirs, and memory or Alzheimer cafés. Some participants in the current study raised the topic of the ASI Dementia Working Group(s). This is an advocacy initiative of people who have been diagnosed with dementia, and is an independent campaigning voice for the lived experience with members throughout Ireland. It was discussed as a means of engaging in a positive, supportive initiative with others in similar positions. Participants living with dementia in the current study discussed the guidance, information and peer support that such groups could offer.

.....  
*PwYOD: One of the things that I found particularly helpful was meeting other people with Alzheimer's and mingling with them. I found it brilliant. I was amazed by people's individual stories... when you're talking to people... it is that sense of positivity that you get from people and I think that helps ....[PwYOD 8]*  
.....

Of specific consideration was the type of work undertaken by this initiative, and its primary objectives, which sets it apart from other groups (e.g. information sessions, peer support groups). The working groups undertake specific, focussed work-based tasks, such as policy development, and this work was deemed to be of value to those who had participated.

.....  
*FM: They are looking at the whole idea of dementia and work because there's obviously that issue. (Husband with YOD) also has a wealth of knowledge ....on how to get employers to deal with people with dementia and how employers accommodate that. It's*



*important to look at what people can do, because he is able to do loads.....[FM 2]*

*Memory technology resources/cognitive rehabilitation*

The HSE's Memory Technology Resource Rooms (MTRR) were cited as a useful resource, and helped persons with YOD and their families to identify relevant strategies and resources. Only one participant reported having accessed a cognitive rehabilitation intervention, but had identified this as beneficial.

*I (was asked) if I wanted to get involved in this thing in the (research centre)..... Which I found very helpful because you're looking around then and thinking ... I'm not the only person with this. We worked on strategies to improve your memory. I felt up until then that I was the only one in Ireland, you know? We spoke about things to help your memory [PwYOD 2].*

This was another example of a service which was accessible without a formal diagnosis in place. This is key considering that it was deemed beneficial during the early stages of symptom identification.

*Even ... before I was fully diagnosed I went to the memory library ... to see would anything help and they gave me little tips about putting up little signs or writing up little notes. [PwYOD 1]*

*Other supports*

Outside of the ASI and the HSE, there were examples of local, voluntary, dementia initiatives. Several participants described how they established their own support initiatives, namely local support groups or groups established for the purposes of fundraising. Counselling services were accessed by two participants, in one instance funded by a voluntary body, and mindfulness courses were mentioned. There were other examples of local post-diagnosis services

accessed, for example, a non-HSE dementia-specific peer support group. Funding from the Carers Association was utilised by a second participant, which allowed the person with YOD and a support worker to go on outings, such as to the swimming pool or to a coffee shop.

**5.6.3 Family support**

Participants discussed some of the factors that supported them in their role as caregiver. For most participants, the confirmation of the diagnosis was found to be beneficial, and allowed for clarity and for processes to be started.

*For me it was a huge relief because [it] explained to me and also it said, yeah you weren't imagining things. That was it. But for everybody else it was devastating. [FM 12]*

Open disclosure was deemed to be of value to many family members. Receiving confirmation of the diagnosis prompted participants to discuss issues openly with friends and family. It also opened avenues to accessing post-diagnostic services.

*Some people who have husbands or wives diagnosed with dementia don't talk about it and they close the door and they can't talk about it to anybody they don't want anyone to know. But that's how they deal with it. [FM 12]*

Several family members were also invited to attend family carer training, and this in turn acted as a gateway to additional services.

*A lot of the information that we had got was from the Alzheimer's society, so I actually contacted them myself. They were amazingly responsive, and I got on one of the family carers courses which was really, really good. A lot of the focus was on upholding the autonomy of the individual. I proactively looked for the course... (It should be the case) that after*



*diagnosis you are encouraged to do something like that... [FM 2]*

Participants discussed the issue of age-relevant supports. For example, dementia caregiver supports, as with other dementia services, are typically attended by older people, with potentially different issues. This meant that interventions such as carer support groups were limited in relevance for some.

*I would worry that you're sitting with people in their 70s and 80s for whom the problems are... very different ... It is helpful and it's not helpful. And they try their best. [FM 10]*

#### *Support for children*

Children discussed the supports they had accessed, with variation across accounts. One adult child of college age stated she had not been offered any support. One spoke of attending Jigsaw (National Centre for Youth Mental Health), where they received 1:1 counselling by a trained counsellor. This participant also reported that he was invited to visit with his GP for support and information about dementia. Another family were invited to have an information session with their father's neurologist. When asked how best to support children of persons with YOD, one participant stated that psychological support for her mother (with YOD) was a priority, as this would indirectly reduce the stress felt by her and her siblings.

*That would take the stress off of us as well knowing that she was getting help and being taken care of... Even something once or twice a month that she could go to or someone she could talk to who was in a similar situation would be a great relief. [FM 8]*

The role of the DA (and similar community dementia workers roles) were cited as invaluable, and a particular support to children in the current sample. One participant, aged 18, spoke of the help his mother and he had received.

*She's very helpful ... she always emails she tells me to email her and everything. She got loads of information about FTD from (the internet) for young people and how to deal with it. She's very good- she is definitely our biggest and strongest support. She's brilliant, but without her we have nothing else really besides her. [FM 3]*

#### *Maintaining usual activities*

It is important to note that for many participants, continuity with their usual, preferred activities was deemed important. Rather than the establishment of and inclusion in YOD-specific supports, participants preferred to maintain their usual activities such as volunteering, attending events and courses, and maintaining their role in the family and in their community. In addition, participants described some strategies they had identified themselves as beneficial since their diagnosis. Strategies for living well included more walking and spending time outdoors, in addition to maintaining a healthy diet and lifestyle. Participants developed their own memory strategies at the home, such as notice boards, and spent time completing puzzles and keeping up to date with current affairs.

## **5.7 Suggestions for Improvement**

Much of the discussion on post-diagnostic pathways related to the lack of relevant and accessible models of support. There was a broad consensus that interventions and support should be individualised to enhance relevance and timing.

*What makes it so complex is that we don't all have the same symptoms at the same time and then we all bring our own context. [PwYOD 6]*

It was evident that PDS should be outcomes-focused, and that individual preferences ascertained, rather than HSCPs conducting needs assessment, or planning care around typical dementia interventions such as day care. This would facilitate the support people

need to meet outcomes relating to aspects such as occupation, day to day issues and family concerns.

.....  
*Not one person sat in front of me and asked me what are my difficulties? What are your challenges? What are you struggling with? What areas do you need help and support with?* [PwYOD 6].  
.....

It was apparent that information after diagnosis was vital. It was deemed important that written information be provided at diagnosis, and that people are informed of the relevant HSCPs who could assist them.

.....  
*I think it would be great if there was a service which handed you a package you know, read that, this is what we do, this is how it works, counselling, neurology, GP. If you knew these steps it would be better going forward being informed.....Definitely leaflets and brochures something more. I know they want you to digest it and break the ice to come to terms with the diagnosis but there definitely has to be something better in place going forward* [FM 4]  
.....

*Integrated diagnostic and post-diagnostic services*

Participants described a lack of integration and communication across community services and supports, with examples identified of similar services running in close geographical areas. This was particularly the case when services were accessible to some and not others. They key here was reported to be;

.....  
*...Offering what they have to other groups as well. But it's trying to find out who they are or trying to get them to make themselves available.* [PwYOD 8]  
.....

The time immediately after diagnosis was cited as an important time to enact individualised support. The importance of having a key-

worker, case manager, or dementia advisor was highlighted in the words of one of the participants when she said:

.....  
*If I had it back again if I had a wish list, when I got my diagnosis, I would like someone who I could contact if I had concerns, be given a little card. I would like to be given her contact details and then I would like her to come to my home, not a doctor's surgery, not a clinic or a hospital. I would have liked her to ask what difficulties I had, what challenges I have. I would like to be asked what I would like support with. Then I would like signposting. So, the appropriate information at that stage.* [PwYOD 6]  
.....

*Key worker/support worker*

Participants cited that greater awareness of YOD was warranted amongst healthcare professionals. In particular it was suggested that nurses in the community, and home care workers receive dementia-specific training with particular reference to YOD. Awareness was particularly important in relation to HSCPs with a remit for diagnosis, and also for HSCPs who have a remit in community support and referral, for example, PHNs. For the participants who had not been assigned a DA, a nominated point of contact was cited as important. It was felt that ongoing support visits from someone on an ongoing basis was important, not necessarily a DA, but perhaps similar to a peer support worker.

.....  
*Immediate help and (ongoing) assistance would help your mental health, for children would avoid mental health problems ..., because the children are greatly affected by the diagnosis. I think someone should check on you, because your mental health could be very affected. Someone needs to check on the people in the family, even .... once a month.* [FM 4]  
.....

On the topic of mental health support, the importance of psychological support for either the person with YOD, or family member was

highlighted as important, if deemed relevant to the person.

.....  
*Counselling is so important as well, if you're open to it. That whole anticipatory grieving ... that's constant. It's not really recognised .... it isn't talked about. [PwYOD 6]*  
.....

The provision of a companion was discussed, somebody to go to a sporting event with, or similar. The provision of regular contact could potentially safeguard against isolation or adverse changes experienced within the family.

.....  
*There was a suggestion about a buddy system, which would be fantastic really. (He) was a businessman, there isn't relations around. We don't have much people around because we're not from (this area)... any of these support services are so beneficial. [FM 6]*  
.....

*Assistance with finances, entitlements and employment*

The process around access to entitlements was deemed important. Participants stated that more information was needed around finances and entitlements, what processes they needed to undertake in order to access specific entitlements. In addition to information, participants stated that they would value professional support to navigate these processes, for example a community liaison officer or social welfare liaison.

.....  
*There should be a letter that goes straight to social welfare that get things sorted straight away. There should be an advocate with the person as well so if they need someone, they (can help) get it sorted. And everything should be instantaneous, there shouldn't be this fighting for this and that and getting TDs to get people to sort things. You shouldn't have to fight for this, it's disgraceful. It's your diagnosis. [PwYOD 3]*  
.....

Several participants stated that they needed information about employment and dementia. One shared how anxious she is to receive information or assistance relating to YOD and employee rights, but has been unable to find anything relevant to her situation. Another participant who had discontinued work since receiving her diagnosis argued that help in this specific regard would have been invaluable to her.

.....  
*If you're working, can you stay working? ...I need someone to come negotiate with me which jobs I can do and which jobs that I can't do? [PwYOD 6]*  
.....

*Support for children*

Considering the significant changes the person with dementia in facing, it was felt that a non-family member might be best placed to provide information to children about the diagnosis and the condition. This was said to be particularly true in the case of single parent families.

.....  
*Oh it's very, very different. A nightmare, an absolute nightmare... They're still in school. How do you tell a child? How do you tell them that? It has to be such a scary prospect for children....I gave (my children) very little info... Is the parent in the best place in those early few months to be able to do that and navigate that and disclose that to the children? [PwYOD 6].*  
.....

The model of peer support was discussed, as a means to provide ongoing peer support for children of people with YOD.

.....  
*I think peer support is probably the best. I don't think there's enough of that. There's that natural bond there where you don't have to explain, it works very well and it doesn't cost a lot. So, I'd love for that to be done for teens or children in time. [PwYOD 6]*  
.....

### Wider community

Participants cited that greater awareness in the community was important. Greater awareness might help address understanding amongst the general public, particularly in relation to stigma and also the 'invisible' nature of dementia.

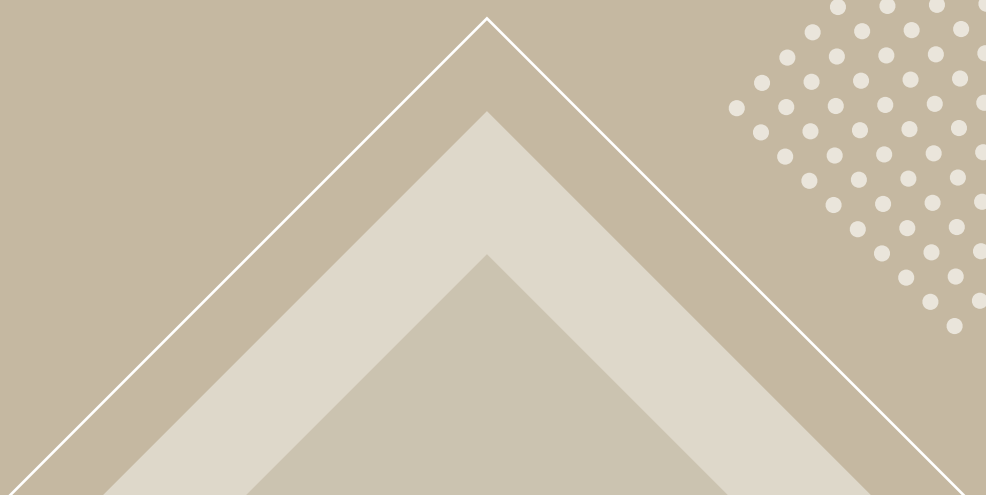
.....  
*The stigma, especially when you're young. For the likes of my age. People brushing it off 'oh you don't do that, you're too young to have that'.... when you're out in the community, just because it isn't a physical condition. [PWYOD 1]*  
.....

Participants also discussed the importance of creating links with mainstream community services. Examples included gardening groups, social groups, or adult education. Costs associated with public transport and taxis was also cited as a barrier, with participants stating this was particularly the case when driving had been limited or stopped. Participants called for a review of the categorisation of dementia, for example, a consideration of placement under the Long-Term Illness scheme to help reduce financial costs associated with health and medical care, or more broadly speaking, classification of dementia as a disability.

## 5.8 Chapter Conclusion

This chapter reports on some of the experiences of the person living with YOD and the experiences of family members including partners, spouses and children. The rich narratives highlight critical concerns including the delays people experienced prior to diagnosis, the effects such delays had on them, how diagnosis was disclosed and how this affected people emotionally and psychologically. The accounts highlighted the importance of establishing post-diagnostic pathways at time of diagnosis or shortly thereafter. Post-diagnostic pathways should start with ease of access, namely through readily accessible information, or via local DAs. Interventions should be individualised and should seek to support the person to maintain preferred occupation or activity. Specific information and support is required relating to finances, entitlements and employment. Family support should be considered when identifying YOD models of care.

06



# Chapter Six: Health and Social Care Professionals' Perspectives

## 6.1 Introduction

This chapter sets out the results of the interviews with health and social care professionals (HSCPs); the methods were presented in chapter 2. The findings are discussed under the two broad headings of 'Diagnosis' and 'Post-Diagnostic Support', although there is some crossover between these sections which will be highlighted. Illustrative quotes are used to support the findings. To maintain anonymity as much as possible, only the HSCP's discipline and whether they are involved mainly in Diagnosis, Post-Diagnostic Support (PDS), or both equally, will be reported.

The research questions guiding the interviews with HSCPs were:

1. What health and social care services for people with YOD currently exist in Ireland?

2. What are the primary activities of these services? Who are the key healthcare workers involved in these services?
3. What are the barriers to providing health and social care services for this younger population, and how might current services be improved to better meet their needs?

## 6.2 Sample

The final sample consisted of 25 HSCPs. The HSCPs were recruited using purposive sampling via the networks of the project collaborators from across five sites in Ireland; two cities; two urban/rural (i.e. towns which also serve a large rural population); one rural. The demographic details of the sample are discussed in further detail in chapter two (Methodology) and also presented in Table 6.1 below.

**Table 6.1.** Demographic details of HSCP sample

|   | <i>N</i> = 25 |
|---|---------------|
| <b>Profession</b>                           |               |
| Geriatrician                                | 4             |
| General Practitioner (GP)                   | 3             |
| Dementia Advisor                            | 3             |
| Clinical Nurse Specialist - Dementia        | 3             |
| Occupational Therapist                      | 3             |
| Advanced Nurse Practitioner                 | 2             |
| Dementia Coordinator                        | 2             |
| Neurologist                                 | 2             |
| Nurse Manager                               | 1             |
| Staff Nurse – Memory clinic                 | 1             |
| Neuropsychologist                           | 1             |
| Social Worker                               | 1             |
| <b>Gender</b>                               |               |
| Female                                      | 20            |
| Male  | 5             |
| <b>Setting</b>                              |               |
| Primarily Diagnostic Service                | 9             |
| Primarily a Post-Diagnostic Service         | 8             |
| Remit for both Diagnostic & Post-Diagnostic | 8             |



### 6.3 Findings Relating to Diagnosis

The findings regarding diagnosis of YOD will be discussed under three headings: I. Time leading up to diagnosis; II. Diagnosis disclosure; and III. Time soon after diagnosis, with further sub-headings under each of these.

#### 6.3.1. Time leading up to diagnosis

##### *Complexity of YOD & barriers to diagnosis*

The HSCPs largely discussed the complexity of YOD. One identified barrier to diagnosis was that HSCPs and people themselves might not expect dementia in a younger person, leading to a misdiagnosis or even delayed diagnosis. Dementia in the younger person may be misdiagnosed as depression or attributed to some other cause. Others presenting with YOD "look well" and their concerns may be wrongly dismissed. This is compounded by the fact that YOD is relatively uncommon, thus HSCPs such as GPs do not have a lot of experience with it.

.....  
*Barriers for diagnosing dementia in younger people, it's just not very clear precisely because you don't expect a younger person to have dementia. You are going to be constantly looking in the wrong direction, and there isn't a huge level of interest and expertise across all GPs. [Social Worker, Diagnosis]*  
.....

HSCPs acknowledged, "There are still many unknowns about the brain". In fact, one HSCP recognised that no-one fully understands dementia, and that we may discover more causes of dementia in the years to come, again highlighting the complexity of this disease:

.....  
*There was a time when nobody had ever heard of fronto-temporal dementia (FTD) or dementia with Lewy bodies, and now we all recognise them coming in the door. We have our classification system and we can say that's what you've got and that's what we're going to*

*do about it, so for all the clarity we've gotten with things like FTD I'm sure we're seeing people coming in the door these days who don't fit into these recognised classifications of conditions but in 10 or 15 years somebody might be calling it something else and a whole bunch of these people might have a recognised syndrome. [Neuropsychologist, Diagnosis]*  
.....

When discussing memory clinics, the HSCPs reported waiting lists which varied greatly. In some clinics referrals are triaged by the consultant as they come in and younger people are generally prioritised, as are people in an emergency situation, although the typical wait times can be much longer - often up to a year.

.....  
*So when referrals come in, I look at them and then they're triaged by the consultant ... if it is triaged as a routine, they are waiting about the 10-month mark at the moment, but if it looks from the referral that there are safety concerns or a person is living alone that's very impaired, then that referral would be prioritised, and we would see them ... hopefully within two to three weeks. [Advanced Nurse Practitioner (ANP), Diagnosis and PDS]*  
.....

Some clinics kept their waiting lists short by screening for inappropriate referrals, only seeing people with isolated memory impairment, and rejecting or referring on people with co-morbidities elsewhere.

Another factor that can delay a diagnosis is access to diagnostic tests. Some clinics order tests such as Lumbar Punctures frequently or as routine, others only order these tests where the diagnosis is particularly complex or unclear. At clinics where these tests are not routinely ordered, delays can occur.

.....  
*But you come to the consultant clinic and actually it looks like you have an early onset dementia, now there's a delay because we might decide, "Okay, this person needs CSF,"*

and we're not actually sure when it's going to get done, and we have to tell people, "Oh you'll be called," and then "You might be cancelled," because it depends on what the bed situation is like in the ED and all of that kind of stuff, and you have worried people at home getting a phone call or no phone call and no test done. [Geriatrician 3, Diagnosis]

Nationally, the waiting lists for an MRI is very long through the public health system, reportedly 12-18 months at worst, and while some patients have health insurance or can afford to pay privately, those who are waiting on the public system can experience significant delays in getting their diagnosis. Typically, the consultant cannot confirm a diagnosis until they have the results of an MRI, and other tests.

However, some of the wait time before a diagnosis is unavoidable. As part of the diagnostic process the doctor may need to 'wait and see' how the dementia progresses, especially in complex cases. Doctors reported wanting to be sure of a diagnosis before they disclose it.

*But the diagnosis here ... might not be made on the first or second visit because ... It's not given unless we're kind of really sure about it, but we would be saying, "We think it's mild cognitive impairment, or it could be- We're not 100% sure. There is [sic] definitely memory problems. We're going to send you for more tests. [ANP 2, Diagnosis and PDS]*

Non-dementia diagnoses may need to be considered; sometimes the only way that the team can be sure they are dealing with Alzheimer's is by ruling out other causes, including cancer or a language disorder.

*There are very few certainties. You can never say 100% like you know what's going on especially with Alzheimer's. The only diagnostic*

*certainty is post-mortem. So yes, sometimes people come in and this is a diagnostic service by exclusion as I say: we know it is not. [Social Worker, Diagnosis]*

A differential diagnosis might also involve waiting to see if the symptoms progresses over 6-12 months to see whether it is a neurodegenerative cause or not.

*We monitor them, and once we are reassured that it's not getting worse, then we know that it's not neurodegenerative because it is in the name, like something that degenerates. So if it doesn't dis-improve with the passing of the time, it must be something else, we just don't know what it is. [Social Worker, Diagnosis]*

### 6.3.2 Reasons for referral

In the experience of these HSCPs, younger people who are worried about their memory are usually more proactive in seeking help, as it could be impacting their work or relationships, or they may have more insight and be more aware of existing services. One neurologist from a general neurology clinic said that they are also seeing more 'worried well' people, i.e. people who have seen the ads on TV about dementia and become concerned about their own (benign) memory issues. However, conversely, a barrier to referral might be a lack of insight from the patient or their family about their problems, meaning they do not seek help. This may be especially relevant for FTD:

*I would say [a barrier to diagnosis is] the lack of insight, where the person themselves doesn't see that anything is wrong. So people are not diagnosed until things spiral out of control. That would be more around the FTD. [Dementia Advisor (DA) 2, PDS]*

The memory clinics often get referrals from other doctors who are looking for a second opinion, GPs or consultants from other

general clinics, who may be less comfortable diagnosing dementia in the younger person.

.....  
*We get loads of referrals, a second opinion for example, and that tends to happen a lot with a YOD. Not many GPs for example would be happy to diagnose a dementia.* [Social Worker, Diagnosis]

.....  
However, the geriatricians in memory clinics reported that they are becoming more comfortable diagnosing YOD themselves, and only sending the highly atypical or complex cases for a second opinion at the specialist diagnostic memory clinic.

**6.3.3 Source of referrals**

Findings showed much variability regarding pathways to memory clinics; some of the memory clinics would accept a referral 'from anywhere'. Some would even accept self-referrals. Others would only accept a referral from a medical professional, their reason being that they need a HSCP to refer back to, to continue care after the diagnosis has been made. In this case, where the clinic was contacted by someone looking to self-refer, they would be advised to go to their GP and ask them to complete the referral. The specialist memory clinic was unique in reporting that it also receives referrals from occupational health physicians. However, all clinics said that their primary source of referrals was GPs.

**6.3.4 Diagnostic process in YOD vs LOD**

For most HSCPs, the actual process of diagnosing dementia, including the memory assessments, in a younger or older person is similar.

.....  
*I worked closely with my consultant Dr XX in developing the clinical assessment pro forma booklet. So, yeah, we don't do anything different to someone under 65 comes in. So everyone goes through the same assessment routine.* [ANP 1, Diagnosis and PDS]

.....  
*Regardless of whether it's a 30-year-old or a 90-year-old, those appointments will be scheduled pretty much the same way.* [Nurse Manager, Diagnosis and PDS]

*We do give the same service to everybody.* [Social Worker, Diagnosis]

.....  
However, they acknowledged that the outcomes and care priorities are different, e.g. a person with YOD may want support primarily to continue work, or driving.

**6.3.5 GP diagnosis**

The GPs acknowledged that they and their colleagues may sometimes be uncomfortable diagnosing dementia in the younger person. As discussed, diagnosing dementia takes a lot of time, of which most GPs feel they are lacking. The GPs in this sample also reported that they either don't have access to all of the required diagnostic tests, or it would take longer for them to access them.

.....  
*I think that's the thing with younger onset, you want to make sure that you're not missing out on anything.* [GP 2, Diagnosis and PDS]

.....  
However, some GPs felt that they or their colleagues can be comfortable diagnosing YOD, where the presentation is not unusually complex. GPs may take a history, undertake a cognitive screening test such as the General Practitioner Assessment of Cognition (GPCOG) and refer on for investigations such as MRI. Some GPs who are comfortable making the initial diagnosis still prefer to refer on to a specialist for confirmation, sometimes as pressure is felt coming from the family or the person. Something that was particular to GPs, is that often the family member would be the one to first come to discuss their worries about their loved one, rather than the person who is themselves affected.

.....  
*I think invariably even though a GP would make the diagnosis, the GP would invariably be referring on because of the implications of the diagnosis and because of the implications for the wider family. There's often pressure to seek specialist referral. [GP 3, Diagnosis and PDS]*  
.....

A common barrier reported by GPs is that they are often unsure of where they can refer a younger person worried about their memory. GPs reported being more likely to refer to a neurologist where the person is younger, and/or where they had an atypical presentation. They also have little insight into what happens at a memory clinic, thus can't reassure their patients in this regard.

.....  
*So, yes, sometimes I would refer on to a geriatrician, but to be honest, if they're less than 65, my concern would be that very often there's a chance that the referral would be rejected, depending on the geriatrician that I would refer to. I know the memory clinics sometimes do see people, but I'm not sure if that's a service they offer ordinarily, or do they decide that on a case-by-case basis? So it's not actually clear to me as a community provider or a community person referring in to the secondary or tertiary services. It's not clear to me which services are more likely to accept the referral than others, and I think it depends. If I know the geriatrician here locally, I might... but I'll often feel like I'm asking them a favour by asking them to see a patient, that it's not kind of the norm, that it seems to be possibly... not that it would be outside of their remit but that it would be outside of their normal workload. That would be my perception anyway as a GP. [GP 3, Diagnosis and PDS]*  
.....

One GP worried that patients could be dismissed by the specialist if their scans are clear, which may make them less likely to accept future referrals from that GP and was overall conscious of the long waiting lists and overburdened memory clinic staff.

.....  
*As regards access to scans and further investigations. I think if people have a legitimate concern, they should have access to these scans. People could say that they have memory concerns but then their bloods, their memory tests could come back as normal so when these preliminary tests are ok it's difficult because there still may be something else but you can see from the other side of the fence saying well I'm getting these referrals from the GP and the waiting list is already so long. Obviously the memory clinics are probably overburdened as well. [GP 2, Diagnosis and PDS]*  
.....

GPs often refer for driving assessment and help patients with the completion of forms for social welfare and benefits, and were comfortable with their skills to help in this. As for other PDS services, the GPs were unsure of what existed in their areas. Overall, whether or not the GP makes the diagnosis or refers on, training for GPs is important as most often they are the first point of contact for a younger person concerned about their memory.

### **6.3.6 Diagnosis by neurologist at generalist clinic**

Firstly, the general neurology outpatient clinics waiting lists were reported to be typically longer than that of the memory clinics. The two neurologists who took part in this research generally diagnosed people with YOD at a general neurology clinic, or as an acute inpatient. There was a tendency perhaps for the neurologists to be referred the more atypical cases:

.....  
*I would have also diagnosed YOD in inpatients admitted with a spectrum of presenting features, so including anything with movement disorders, and seizures, or in patients admitted under medical services who I would have seen under a consult basis, so I would have diagnosed either directly under my direct care or in conjunction with other services. [Neurologist 2, Diagnosis]*  
.....



Neurologists also reported a very wide range of referral sources:

.....  
*Yes, so quite a spectrum [of referrals] including from neurology colleagues who perhaps knew that I had a background interest in, in particular white matter disorders, so I would have got neurology phenotype referrals, referrals from GP's, medical colleagues and occasionally depending on the symptom complex, the age and maybe if there were other features like a movement disorder, from geriatric care of the elderly colleagues for an opinion. [Neurologist 2, Diagnosis]*  
.....

One neurologist outlined that about three appointments are necessary to establish a diagnosis of YOD. Appointment time slots at a general neurology clinic were perceived to be too short, that there was not enough time to allow for an optimal disclosure meeting. Although one of the neurologists did say that they could schedule a 90-minute appointment if they knew they were going to be diagnosing YOD. However, commonly at a general neurology clinic the neurologist does not have a lot of support from a multidisciplinary team (MDT). They often disclose the diagnosis on their own.

.....  
*I have to say ... I've found it quite challenging because of not having the other component, you know a case worker, a social worker, an occupational therapist, psychologist, psychiatrics, so, it tends to be a bit of trying to manage it in conjunction with a family member asking a GP, or putting responsibility on a GP who may or may not be prepared or trained specifically to say 'look you know if you do have questions after you leave here' to say 'that your GP may be able to help to point you in the right direction' [Neurologist 2, Diagnosis]*  
.....

A neurologist may link in with colleagues depending on the phenotype or sub-type, for example with psychiatry where psychiatric

features, such as "psychosis, hallucinations" are present. However, neurologists said that they would appreciate the dedicated support of a nurse, ideally a dementia nurse specialist, or a social worker or occupational therapist (OT), or similar, to provide support around the diagnostic disclosure, and for immediate PDS. Overall, they would value an MDT on top of a diagnostic team including these professions and also ideally a neuropsychologist.

There was a perception from some other HSCPs that neurologists "are interested in Parkinson's and in motor neuron disease and similar... but not in early onset dementia. They won't see them." A HSCP in PDS had the following to say about feedback she had received from clients who had gotten their diagnosis through neurology:

.....  
*Most young people get diagnosed by a neurologist. People say that they get diagnosed by a neurologist but that's it. They get no information or referrals to anyone else, no direct pathways to any support groups or services or to the Alzheimer's society. It's very much a diagnosis- get their meds and are told come back in six months. It's very loose and so they are sort of left hanging. [DA, PDS]*  
.....

This is confirmed by neurologists themselves who were unsure of what PDS are available. One said that they were unaware that memory clinics could take on the PDS of a younger person, and so have not been referring to them.

## 6.4 Findings on Disclosure

### 6.4.1 Time

A common theme which emerged was the time needed for an optimal disclosure meeting. Many HSCPs felt that disclosing a diagnosis to a younger person requires more time than for an older person; those who had the facility to do so would schedule longer appointments for this age cohort where possible. Typically, a diagnosis of

mild cognitive impairment (MCI) would not require as long of an appointment. Having adequate staffing levels is also important to ensure enough time can be allocated. As one example, this was discussed as a barrier to diagnosing YOD in a general geriatric clinic:

.....  
*I mean the reason we don't see them is I can't bring a 50-year-old to my clinic with 25 other 80-year-olds, they have a different set of problems and it takes more time. So you need somebody who can dedicate an afternoon to see five or six people in their 50s as opposed to my clinics where it's 25 people in their 80s in an afternoon. [Geriatrician 1, Diagnosis]*  
.....

### 6.4.2 Communication

Effective communication was another theme around good disclosure practices. Most HSCPs felt that they were becoming better at being very clear in using the word 'dementia'.

.....  
*We are quite definite about telling people if they have dementia or not. [Geriatrician 2, Diagnosis]*  
.....

For some, the 'pre-disclosure appointments' are a time to prepare patients for the possibility of a dementia diagnosis, with the intention of alleviating the shock somewhat.

.....  
*The patient comes in initially for the pre-assessment with our ANP and she would do the memory test... X does fantastic work, I think anyway, for maybe laying the groundwork. So it's not as if somebody just walked in the door and been told, "You have a dementia." That bit of groundwork is done for everybody regardless. They're not just walking out of here thinking, "I'm fine." [Nurse Manager, Both Diagnosis and PDS]*  
.....

Most of the HSCPs tried to get a sense first of what the person felt was wrong, and how

much insight they had, so that they could disclose the diagnosis at an acceptable pace. All had a policy of disclosing directly to the person with YOD, although acknowledged that in some cases such as a very progressed dementia or in FTD, it may be necessary to talk mostly or sometimes separately to the family as well. Most of the HSCPs talked about balancing hope and also giving people a realistic perception of dementia. Many advised patients who were doing well or in the early stages to keep living as before.

.....  
*I suppose what we are trying to instil is a perspective of hope, just saying, "Look, this is a chronic disease." We do say out loud, "There is no cure for it. It will get worse. But there is a medication which may help with the symptoms [Social Worker, Diagnosis]*  
.....

Communication style has to be tailored to the individual depending on their personality and individual situation. Some people might ask straight out "how much time they have" and want a lot of information, others may initially be in shock and may not be able to take in much more than the word "dementia" and will need time to absorb this information before hearing more. HSCP felt that a good disclosure meeting will be paced to meet the needs of each individual.

Importantly, most clinicians said that they would give patients written details about the diagnosis, as well as verbal.

.....  
*So we explain in plain English what we think is going on, and we name it. We say, "We think there is an Alzheimer's process going on," or, "We think that the vessels in the brain are affected and this is a vascular dementia." So we name it, and they take it home with them in writing. Because when you go to a doctor with all the stresses and to get results, and especially for memory, wouldn't it be ironic if we expected them to remember? [Social Worker, Diagnosis]*  
.....



### 6.4.3 Who is present

Settings varied in relation to who was present for a disclosure meeting. All HSCP said that they ask the person to attend with a family member for the disclosure meeting. Some neurologists or geriatricians may be the only HSCP present for the diagnosis, especially if they are making a diagnosis during an inpatient admission. Other clinics typically reported having more HSCPs, and this was endorsed as promoting better disclosure practice. Other HSCPs present included a neuropsychologist, psychologist, social worker, nurse specialist, and a DA. In some cases these HSCPs were not actually present for the meeting, but were available in a room next door if the patient wanted more time after finishing with the doctor. It was felt that having too many HSCPs facing the family all at once might be intimidating. While this set-up is typical at memory clinics, diagnosis by a GP or a neurologist at a general clinic may differ.

.....  
*Unfortunately, we should have more personnel, for the diagnostic process but it is very old school, [just] a doctor. We don't have a clinical nurse specialist, we don't have an OT that is purely linked to the cognitive [clinic], we have an OT who I tend to only use on post-diagnostic, because for young onset we need support. So for the diagnostic process it's just a doctor.* [Neurologist 1, Diagnosis]  
.....

### 6.4.4 Information

Detailed verbal and written information is usually given out at the disclosure meeting, including information on the type of dementia, medication if being prescribed, and modifiable risk factors (i.e. diet, exercise, alcohol). Some HSCPs will bring up legal issues such as future planning and wills, although the disclosure meeting was generally not felt to be the time to go as far as to discuss advance healthcare directives. Some gave information on other legal/lifestyle issues such as employment and financial help. Most discussed driving and the need for a driving assessment now or in the future, and recognised that that was a

particular concern for their patients. Giving information on the medical tests that have been completed was reported to help people to accept the diagnosis.

.....  
*I suppose we have written information that is given to the patient ... it goes through what we based our reasoning on, so is the summary of the history and the testing so there from the families and protesting in quite basic language we might mention the scans that we've done as well in the written information and we would say how certain we are of the diagnosis. Then we'd outline all these discussions around medication around future planning and then the follow-up as well that would be discussed.* [Geriatrician 1, Diagnosis]  
.....

Policies differed in that some HSCPs had a standard information pack that is given to everyone diagnosed with YOD, others had information packs that would be tailored to the individual before being given. Others simply left the information leaflets on the desk and asked the person to take any they felt might be useful. Each clinic had their own reasons for doing it their way, and found their approach worked well. For example, the clinic where leaflets were left out on the table had a dedicated HSCP providing phone follow up after diagnosis so there was a further chance to impart this information.

While most felt that giving written information about the diagnosis was important at the disclosure meeting, where there was a good local PDS system, it was preferential to give further information at a slower pace over a few weeks by a clinic nurse who would remain linked in with the person and family.

### 6.4.5 Emotional impact of diagnosis

HSCPs were very aware of the acute grief experienced by the person receiving a diagnosis. Even for those who may be expecting the diagnosis, it can still come as a shock.

.....  
*There's fierce loss and there's all sorts of feelings come up, and people are devastated, so even though you're doing your best for them, it's a horrible thing to be telling them and people are devastated ... we do our best, but it's still what you're telling them is devastating. [Clinical Nurse Specialist 3, Diagnosis]*  
.....

HSCPs identified some positive aspects of a diagnosis disclosure. Some people reported to their HSCPs feeling relieved knowing what was wrong, and finally having a name on their condition. As wait times can be long and stressful, sometimes finally getting to the diagnosis is a relief. However, as will be discussed, many HSCPs involved in disclosure are dismayed at the limited PDS available.

#### **6.4.6 Time soon after diagnosis**

The weeks and months following a diagnosis of YOD were recognised by HSCPs as a critical time where people with YOD and family members needed support. One specialist memory clinic was 'diagnostic' only, and would discharge the person back to the referring doctor once a diagnosis was established and disclosed. Except in the case of MCI or an unclear diagnosis where people are 'kept on the books' and given a follow up appointment for 6-12 months. They may still discharge medically even someone with MCI if they have no change in cognition after two or three appointments, although telling them that they can always come back if something changes. The other memory clinics who diagnose YOD would give routine follow-up appointments for either a nurse or consultant clinic for every 6 or 12 months. At the same time, most clinics will allow someone to come back sooner than the 12-month appointment if something changes, although it was unclear how explicitly this is made known to the patients. In the best exemplars, other clinics will keep patients 'on the books' indefinitely, and will provide phone support between appointments.

.....  
*Once people are diagnosed we follow up with a phone call. The phone call is usually pencilled in for about three months after diagnosis. So when they go out of here we are ringing them in three months' time and if they haven't come to the support group that's another time to sow the seed. Because it's like any kind of bad diagnosis all you hear is the diagnosis you don't hear anything else. So we do follow them up. [Staff Nurse, Both Diagnosis and PDS]*  
.....

Following a diagnosis, a summary letter would typically be sent back to the referring doctor and/or GP.

.....  
*In terms of feedback and who hears what from who, we always write – the medical doctor will always be writing a medical summary back to the referring doctor. If the referring doctor is not the GP, the GP will always be copied in on the correspondence as well. [Neuropsychologist, Diagnosis]*  
.....

However, inconsistencies were apparent as some HSCPs involved in PDS said that they are often unaware of someone diagnosed with YOD in their area until a crisis happens, therefore there seems to be a break in the chain of communication and not all relevant parties are being corresponded with.

The PDS information given out following a diagnosis varied. At a minimum, patients are typically being given the phone number for the ASI, however this alone was not considered sufficient as 'PDS'. Many clinics gave patients a phone number where they could ring up after the diagnosis had sunk in, with any follow up questions. Some clinics went a step further by actually phoning every patient a few weeks after diagnosis to check in with them. One consultant who did not have the support of an MDT gave out their email address and would handle queries via email. Such supports were reportedly very well received by patients.

Some clinics would give out information about specific PDS services, typically if a person is diagnosed in their local memory clinic. These include Memory Technology Resource Rooms (MTRR), peer support groups, and the ASI. Others would go a step further and directly refer the person to the local post-diagnostic support services, this is typically where the same staff worked across the diagnostic and PDS services. This typically worked very well for keeping patients in a loop of care. If a patient lives outside of the local area for PDS, and the consultant doesn't know of their local PDS services, they will be given the ASI number instead. Some HSCPs said that they would like information leaflets specific to YOD, that don't have pictures of grey-haired people.

Some patients may be referred for genetic testing if they request it, although consultants and doctors located outside of Dublin were sometimes unsure of how to access this. There is only one place in Ireland that offers this, and one person in London was mentioned who will do it privately if families are interested. A few memory clinics also gave patients information about research trials and studies and noted that younger people were more likely to request this.

### 6.5 Findings on Post-diagnostic Support

The general consensus among the HSCPs interviewed was that while diagnostic processes for YOD are improving, the provision of PDS remains suboptimal. Many HSCPs involved in diagnosis felt that they were good at establishing and disclosing the diagnosis, but then had little information to advise the person around PDS, often simply because no such support was available.

.....  
*We do the diagnosis bit and the breaking of the bad news very well, but, to me, saying you have something wrong with you and there's nothing for you, and the government don't want to know, and like that's awful - awful for them and awful for us to have to even say it. [Clinical Nurse Specialist 3, Diagnosis]*  
 .....

However, it was clear that in certain geographical areas around the country there are pockets of good practice and examples of post-diagnostic processes and pathways, and there is useful learning from both the good and the bad.

#### 6.5.1 Access to PDS

Cost can be a barrier to people accessing PDS services. Positively, there are a number of new PDS services that are being implemented around the country and are provided at no cost to the client such as the MTRR, support groups, Cognitive Stimulation Therapy (CST) and Cognitive Rehabilitation Therapy (CRT) programmes, Health Service Executive (HSE) home care packages, etc. While valuable to those who access them, they are limited services and it was noted that relatively few of the overall numbers of people living with YOD or indeed late onset dementia (LOD) can access these. Other free (to the client) services are men's sheds, dementia support workers, and DAs. HSCPs reported how people can refer themselves to services such as an MTRR, support groups, CST and CRT programmes; a lot of these are listed on the Understand Together website service finder. However, many supports, particularly HSE provided supports such as home care packages were notoriously difficult to access across all regions.

For some services in some areas, age could be a barrier to accessing PDS services, again particularly those provided by the HSE. In these cases, the HSCP has to fight for the right of their client to access a service.

.....  
*When you're over 65 with a diagnosis of dementia, you fall under the manager for older persons within the HSE, but if you're under 65, some managers will say "Well that's not in my remit because I'm the manager for older persons." And it varies from area to area within the HSE. Some managers for older persons will absolutely just take on board somebody with a diagnosis under 65, but we have come across managers that would, I suppose, argue that it's not strictly under their remit. [DA, PDS]*  
 .....

Another issue identified was where people don't want to accept help, or admit that they need help, thus they don't engage with available services. One HSCP suggested that a registry of people diagnosed with YOD and LOD would be beneficial, so that they could make regular phone contact with everyone in their area to ensure that they are linked in with services.

Where PDS supports were available in an area, access to them was more straightforward when a local memory clinic was referring into local PDS services directly. One problem mentioned was that private consultants who are operating outside of the public system and/or based in national clinics outside of the person's locality, are diagnosing YOD. They may not be able to - or know the details of how to - signpost and refer to the person's local PDS services.

An important part of running a PDS service is promoting it. Many HSCP within well-resourced PDS services felt that access was not an issue, once people were aware of the service; promoting the services to clinicians was thus most important. They also felt that having a national push behind the promotion of services is beneficial.

### 6.5.2 Referral pathways

A major barrier to accessing PDS is that the referral pathways are unclear, particularly for the younger person. HSCPs are unsure which branch of the HSE should be providing services for younger people with dementia. Clinicians are often unsure what services are available in their area. The biggest problem is linking into the pathway in the first place. Also where someone is diagnosed with MCI and not dementia, they might have difficulties accessing dementia services, although HSCP did note that this practice is changing. Families who are actively seeking services might get "worn down" from the process of trying to access services and give up. Some HSCPs felt that it was not enough to just give the patient the phone number for the ASI, that there should be a direct referral onto a care pathway.

.....  
*I'm sick of listening to people say to me that when they were diagnosed they were basically told, "Get in touch with the Alzheimer Society," and they left the hospital, so... I mean imagine getting a diagnosis, you're 57, you're living with your husband who has just been diagnosed and you've basically been told, "Look, best thing to do would be to contact the Alzheimer Society." I think that in every single place of diagnosis ... even in memory clinics to start off with, I think that there should be a direct pathway [to PDS services]. [DA 1, PDS]*  
.....

#### Timing of services

Certain issues impeding access have already been discussed, which account for the reasons for delays in accessing PDS. Sometimes by the time a person or family makes contact with PDS services, they may already be in a crisis and might have been struggling for a long time. Again, it was deemed best that a PDS pathway be put in place soon after the diagnosis for effective support.

.....  
*The amount of times people say "God I wish I just contacted you earlier. I wish I had known about this earlier." But why didn't they know? [DA 1, PDS]*  
.....

### 6.5.3 Key worker

A very common theme from the interviews with the HSCPs was the importance of a 'key worker' role.

.....  
*Absolute best case scenario is some sort of a key worker that could meet you quite regularly, meet you where it suits, can be your advocate, can signpost you to services, can be your friend...-ish. [OT 3, PDS]*  
.....

The key worker would be familiar with the diagnostic and post-diagnostic pathways, would link in with people soon after diagnosis, and maintain regular contact, so as to avoid crises. Most felt that the key worker should be



a healthcare professional but could be from any discipline. They would have a dedicated role for supporting people with dementia (of all ages) rather than a PHN or GP whose time and expertise is already stretched. They would be one point of contact for the person with dementia, and would become familiar with each family. Some services have key worker roles, or people which fulfil a similar role, such as the DA or community dementia coordinator, and these were seen to work very effectively.

.....  
*We are the one point of contact, it can't happen everywhere, but the big thing I would say about replicating the services, there needs to be a point of contact. The people need... If you're talking to strangers the whole time, you'll miss information. [ANP 2, Both Diagnosis and PDS]*  
 .....

**6.6 Findings on Current Services**

**6.6.1 Information and Advocacy Services**

Some HSCPs felt that in the earlier stages of disease people with YOD need information and advocacy more than healthcare. They need information about the different medical and social supports available to them, and signposting to services in their area. The ASI was one commonly cited source of information. Citizen's Information Bureau was another source of information about employment and illness benefits, etc., although the perception of the quality of the local Citizen's Information centres varied across the country. The Understand Together website was seen as another valuable source of information. Again, HSCP felt that it was important that someone like a key worker link in with everyone diagnosed with YOD, as while these information sources exist, not everyone would have the same ability to look these up.

**6.6.2 Financial advice**

One factor that must be considered in the context of PDS, is the huge financial impact of YOD. This is worst if the person is still in employment and has to reduce their working hours or resign from work or take early retirement. In some cases, the person diagnosed may be the primary earner in the household. Often they are still paying a mortgage. A few HSCP negatively compared YOD to a cancer diagnosis, where at least you would get financial support.

.....  
*I think financial is probably the biggest [barrier] because it's an added stress. So when somebody is diagnosed with dementia and if they're in a job that they can no longer do, there's an income dead in the water. So that's huge. It adds so much more stress. [DA 1, PDS]*  
 .....

HSCPs recognised that families need support in navigating their rights and their options around finances, and that this is an important element of PDS.

**6.6.3 Support Groups**

Perhaps the most commonly discussed PDS which was being offered to those affected by YOD was a support group. Most of the areas included had a support group, although there were many differences between how these were organised. Many felt that people with YOD in particular can benefit from peer support.

.....  
*It's very, very hard for people to even fathom that 'you're telling me I've dementia and I'm only 45' like they think they are the only one in the world and it's very, very helpful for them to meet someone else in the same boat, and you can kind of learn from them, or even just...even knowing they're there is nice. [Clinical Nurse Specialist 3, Diagnosis]*

*What I know is working is the peer support ... the peer support helps a lot where the people know each other or wives or spouses of a person with YOD, and because there are so*

*many common things, they end up giving each other a hand. [Social Worker, Diagnosis]*

.....

In some areas a separate support group was established for younger people and this was generally preferred, as established Alzheimer Cafes often catered to an older population and were not seen by these HSCPs as appropriate. In other areas, owing in part to smaller numbers of people with YOD, support groups contained a mix of ages. In other areas people with YOD attended a 'Mild Cognitive Impairment' support group. The age mix was not necessarily a bad thing, as it was deemed more important that all of the people attending are at a similar earlier stage of dementia. In some groups family members were welcome, for others family members or 'memory supporters' had a separate support group.

Most of the support groups were operated on a 'drop in' basis. Some groups (some age-specific, others not) were facilitated by HSCPs, this was seen as an advantage as the HSCP can quickly link them back in with services if a problem is expressed at the support group; although it was considered better that the actual location for the support group be in a non-clinical setting, such as a community centre. In one group, the facilitators sent reminder messages to everyone the day before a group, which worked well. Some support groups organised for guest talks from dieticians, personal trainers, mindfulness coaches, etc. which were very well received. However, the peer support element was essential.

.....

*We were kind of saying 'is there certain thing ye want to do'... we were beginning to feel maybe a little bit ... do they want to do extra stuff like and they were saying 'no, this is it, just coming in meeting and talking, we don't need to be doing something every week'. From time to time we'll have talks, so there's information talks you know maybe once a month or something, but they say 'we don't need to be doing something specific all the time, to be able to come in and meet and chat, this is therapy in itself' [Clinical Nurse Specialist 2, Diagnosis and PDS]*

.....

Some barriers to support groups were discussed. In regions with low numbers people had to travel far to attend a group, at their own expense, or there may be insufficient numbers to run a YOD specific group. For family support groups, carers can find it difficult to get time to attend if their family member requires full time care. A lot of time is required from the HSCP(s) to organise and run the groups, which is sometimes delivered voluntarily, thus requiring a committed staff. It is also difficult when people become too advanced for the peer support group and the facilitator has to gently suggest that other supports may be more appropriate going forward. Also HSCPs recognised that not everyone will be suited to group support, and that other individualised support options must also be available as options.

#### **6.6.4 Cognitive Stimulation Therapy (CST) and Cognitive Rehabilitation Therapy (CRT)**

Other common supports referred to by some HSCPs were CST and CRT, likely as the National Dementia Office (NDO) made national funding available to support these. While there was some variation in how the supports are run, there were also common features.

CST was typically run as a small group over about five sessions, and typically involved a facilitator who would teach strategies to improve and help memory problems, and/or general activities aimed at stimulating people's attention and memory. Peer support from the group element was reported to be a beneficial secondary outcome. CST can be tailored to suit a younger or mixed group, meaning it works well for YOD. As with peer support groups, CST was reported to work best where the people in the group are at a similar stage (i.e. mild or moderate), more important than simply a similar age. CST might involve:

.....

*Looking at different strategies, things that are going to assist with your memory like the clock, it could be the calendar, keep a diary, family members are involved [DA, PDS]*

.....



CRT is delivered one-to-one, often by an OT. Typically, the person with YOD sets their individual goals at the start, and the facilitator helps them to achieve these over about 6-8 sessions. In some areas the person will travel to the HSCP, in others the HSCP will travel to meet the person in their home where feasible.

.....  
*The Cognitive Rehab Therapy ... essentially [is] getting them to identify what the goals are that they want to work with over a period of time. So it might be remembering grandkid's names, it might be managing money, it could be remembering appointments, whatever it is that they want to work on. [OT 3, PDS]*  
.....

This is a very flexible and individualised form of therapy, again very suited to YOD, and HSCPs reported improvements in and positive feedback from their clients.

**6.6.5 HSE's Memory Technology Resource Rooms**

MTRRs were another common support. All the MTRRs referenced in this study were open to people with dementia of any age, and all were run by an OT. People come with specific problems and the OT can show the person with YOD how to use a variety of assistive technologies as part of individual goal-focussed work.

.....  
*People come in and we help them with specific problems they're having difficulty with and we use assistive technology in order to help them [OT 2, PDS]*  
.....

In some places it worked well where a person could borrow one of the assistive technologies for a month or so before deciding whether it was worth investing their own money in it. The MTRR can be another place for signposting to further supports, as often the OTs running these are also involved in other PDS in the area.

Some barriers to effective use of assistive technologies were discussed. Family commitment is needed for the effective use of assistive technologies, and the person also needs some insight into their condition and be accepting of it for such interventions to be effective. Sometimes the OT can find it difficult discussing some of the assistive technologies with younger people as they are anticipating future decline.

**6.6.6 Social supports**

Many HSCPs felt that, especially for the younger person, and especially at an earlier stage, social interventions and supports are extremely important. People with YOD need support to keep living as normally as possible, to stay active, to keep up their hobbies, possibly to be helped to find a new sense of purpose and structure to their lives if they have been forced to give up working. Many examples of social supports or interventions were discussed. The main barriers discussed around these services were the questions: do these services fall under healthcare? Who should fund and provide these services?

*Befriending Service*

One area had set up a befriending service, where trained volunteers are matched with a person of any age with dementia, although it was particularly used for those with YOD.

.....  
*A new service that we set up ... very much specifically targeting the early onset dementia would be what we call a volunteer befriending service where we would train volunteers and match them with a person who has diagnosed dementia and work alongside them. ... It's enabling the person with dementia to continue participating and engaging in activities that without that service they wouldn't be able to do. So that's going very well [Dementia Nurse Specialist 1, PDS]*  
.....

Feedback from volunteers and people with YOD has been very positive; the volunteers get satisfaction from making a difference in

someone's life, and the people with YOD are able to continue to participate in activities that they might not otherwise have been able to. Volunteers, for example, can drive and accompany people with YOD to activities or appointments. The most important reported element to success is matching the person with YOD to the most appropriate volunteer. Support Worker. Other areas had a similar service in a dementia support worker, to support people particularly in the weeks and months following a diagnosis. Where the diagnostic team feel that a person may benefit from having a support worker assigned, they will offer this to the client, and though not all opt for this, those who do have reported positive feedback. The client is matched with the support worker most suitable to them. The support workers have helped people with dementia to continue with activities such as shopping, swimming, golfing, attending matches, or might simply spend time with the person as a supportive friend.

.....  
*So, even though ... she wouldn't have qualified for ... a home help is the thing but she needed help to actually be able to live her life. So we actually put in [a support worker] and it was only 2 hours once a week, but it actually brought her back out, got her back out moving in the community, back out walking, back out going to the shop, ... she got involved in a group that was running locally, and the support worker went with her, she wouldn't have gone on her own because she became very anxious and withdrawn, where she went back out doing things once the support worker was with her [Nurse, Diagnosis]*  
.....

#### *Other social supports*

Men's sheds (organised by the Irish Men's Sheds Association), although not specifically for people with dementia, were reported to be valued supports for some men living with YOD.

.....  
*For the men where their social circle is starting to shrink and they've had to leave work - I've*

*had a man there recently ... he came to the nurse support clinic and he left here going to the Men's Sheds and then as it turns out his friend got a diagnosis that week, they're both in their fifties, but one man is better than the other man, and now they're both going to the Men's Shed together. And the Men's Shed we have seems to be very inclusive- everybody can do something, if it's painting or whatever it is, everybody can do something. [Staff Nurse, Both Diagnosis and PDS]*  
.....

Other examples included a knitting group, an Irish language and culture group, dementia friendly tours of art galleries, dementia friendly choirs and dance clubs, and the ASI dementia working groups. These groups don't have to be dementia or YOD specific but are organised and run by trained facilitators (not necessarily HSCPs).

#### *Wider communities*

As the social care element for people with dementia is so important, it is perhaps unsurprising that community and public supports emerged as a key theme. Community awareness raising and training is important so that people with dementia, particularly YOD, can remain engaged in their community and continue to live as normally as possible. Some HSCPs identified the positive impact that the Understand Together media campaign has already had on tackling stigma around dementia and YOD. Community awareness is very important as people with YOD can have much better experiences and outcomes where they are supported by their family, friends, and neighbours:

.....  
*Community awareness is a huge thing ... The daughter had to leave the room when she was getting the collateral to us because 'Jane' asked about her friend, and 'Jane' went out to her and she said, "They just all stepped away. They just all stepped away." And I suppose a lot of the time it's not out of cruelty. It's out of lack of knowledge and what they can do to help the person [ANP, Both Diagnosis and PDS]*  
.....

HSCPs spoke about promoting dementia in public places like libraries, shopping centres, and local clubs. Some clubs associate being dementia friendly with being disability friendly (e.g. having ramps), although they are two separate issues and this needs to be addressed by increasing knowledge and understanding. At the same time, they also said that many of the ways to make a service dementia friendly are simply good elements of being universally friendly. In one example a local shopping centre advertised a regular 'inclusiveness' day where lights were dimmed, music was turned off, and this was coupled with staff education. Some HSCPs were involved in giving talks to students in secondary schools. Other work had also been done to promote community awareness by dementia champions. All of these community initiatives will result in much better experiences for people with YOD.

.....  
*But if we keep promoting Alzheimer's and dementia as something that could happen to anybody, it's not contagious, you shouldn't be worried about it, it's only a person just like you and I, then we could have... If we gave training to retail staff, if we gave training to community centres, libraries even. Like libraries are a fantastic resource where people could go, but you would need staff who are going to know how to treat and how to handle a person with dementia, especially in the early stages, and it's not that complicated. [ANP 2, Both Diagnosis and PDS]*  
 .....

Some HSPCs felt that this community inclusiveness should go beyond awareness raising to more practical tasks, and local shops and services should be helped to take on people with YOD as volunteer staff, and were able to give some examples of where this had worked well previously.

**6.6.7 Home help**

This is a critical service for people with YOD, particularly for those with functional decline and where they may require personal care

services. Home help is also an important resource for carers, who may be struggling to provide this care themselves. Often, for families of people with more advanced dementia, home help was considered the most important support. Unfortunately, access to obtaining home help was difficult in all regions. Again, much variation existed regarding eligibility for home help. In some areas, a person needed a medical card to access home help, in other areas access was possible without a medical card, but the waiting list was very long. In some areas home care support hours were distributed from the ASI via the HSE, and so any age was eligible, but in other areas a public health nurse (PHN) may have to directly apply to the HSE and could struggle to get services for someone under 65 (of note, home help now falls under home care support).

Further to assisting someone with functional decline, many other HSCPs felt that home care should provide for practical non-care tasks for people with YOD. Some examples where this had worked well were provided:

.....  
*I have got a really good situation for people in Kerry where they got a homecare package, where the person is at home and they prepare the evening meal together. It's helping him with skills, he has got a role. Where he has lost his job, he's not financially able to support himself and being able to prepare the meal for his wife when she comes home is a great thing. They've been incredibly innovative in that area. The whole thing has got to be reviewed because the only way that that is going to work is if we incorporate that in some way into the training. [DA 2, PDS]*  
 .....

**6.6.8 Respite, day centres, long term care**

Of all of the PDS services discussed, these were seen as not age appropriate and the most unsuitable for the younger person in their current format, and also as difficult to access. HSCPs spoke of people with YOD deteriorating in respite, and the emotional

toll seeing a poor respite experience has on the family- although these comments were not universal.

.....  
*Respite might be good if the family might need a little break, but there's no place for them to go because ... they're going to be in with all the over 65s even though the unit might be willing [to take them] [ANP 2, Both Diagnosis and PDS]*  
.....

Sometimes where a family needed a break, a person with YOD was admitted for respite under psychiatry services. Overall, it was agreed that effective respite should be beneficial to both the person with YOD and the carer, and the ideal service should be delivered in the person's home. Long term care was also difficult to access as it is not designed with a younger person in mind.

.....  
*If and when the need arises, residential care for those people is a huge problem because... funding for nursing home care very often doesn't apply to them, or if it does and if they're going through the Fair Deal Scheme, it often will impact quite negatively from a financial point of view on the spouse and family. So, accessing residential care if and when it's needed is more difficult for this group, I think, than it is for the elderly population. [GP 2, Both Diagnosis and PDS]*  
.....

### 6.6.9 PDS provided by memory clinics

#### *Follow up appointments at Memory Clinic / Nurse Support Clinic*

Another important element of PDS was follow up care provided by the diagnostic team, such as the memory clinic, or GP. Only one of the memory clinics represented in this study did not offer PDS support to people with dementia. The others generally offered routine follow ups with the consultant, typically after 12 months. Most memory clinics would see someone who already had a diagnosis of dementia (received elsewhere)

for follow-up support; people would be seen sooner where the clinic decided they did not have to go through a diagnosis process again.

.....  
*And I do see people back as well for... We would have GPs that would refer people back in with the diagnosis... They already have a diagnosis, so I mean they don't need to go through all of the initial stage again of the clinical assessment and the Addenbrooke's and coming in to see the consultant. So they would come in to see me for the assessment, and I might just do an MMSE (mini mental state exam) and see where are they now cognitively, where they are functionally... day-to-day what problems are they having at home, what problems are the family having, what are their worries and concerns, and then to be able to advise them on what's the best step... best thing to do and to direct them to the services that they're entitled to be linked up with and referred to. [ANP 1, Diagnosis and PDS]*  
.....

HSCPs reported that people with YOD and their families' value medical appointments, even though there may be little medically that can help for the first few years. It is important for people to feel that they are still 'in the system', and thus they appreciate their regular clinic appointments. Some memory clinics ran a complimentary nurse clinic, which had a shorter waiting list, and where people with dementia including YOD could get support for any other problems not relating to diagnosis which they may be experiencing.

#### *Other follow-up support from clinic*

One reportedly highly valued post-diagnostic service provided by some clinics was phone support. Most of the memory clinics gave out a phone number to their clients so that they could contact a known staff member if they had any questions following a diagnosis, or further down the road. Often the clinic can give advice over the phone of another service that may help. A few clinics went a step further and actually rang each patient a few months



after diagnosis, and sometimes at regular intervals when a person may be advancing in their condition or the family might be experiencing a particularly difficult time. When a person reaches advanced dementia, often it is the families who ring for advice. This phone support was seen as essential element of care, and could potentially help avoid crises by arranging more timely intervention.

A dedicated role such as a community dementia coordinator went a step further; families that need extra support would get their contact details after meeting them in person at a clinic appointment. The coordinator might offer advice and signposting over the phone, or might get involved as an advocate, getting benefits and supports on behalf of the person. One excellent example was:

.....  
*I suppose that is one thing with our programme, it's very individual in so far as we don't kind of say 'oh we'll give somebody an appointment, we'll see them, give them information, goodbye'. If we feel that person needs more engagement, we're prepared to follow up with them and even offer a second and a third appointment, go out to their house, it's really trying to be very responsive to them, and at the end of the day, everybody has our number here and they can ring us at any time, so even though they might come in and it might be sufficient for somebody to get one visit with us, get information, they don't need the support worker, they don't need anything else at the moment, but maybe six months down the road they might have a query, that they've met us, they know the face and they know who they are coming back to...I think that's helpful for people as well. [Clinical Nurse Specialist 2, Diagnosis]*  
.....

### 6.7 Findings on Supports for Families

As shown in detail in the previous chapter, people diagnosed with dementia at a younger age can have young children who may be

greatly impacted by a parent's changed behaviour. HSCPs involved in PDS were very aware of these issues, some supported families who have children in school, doing the Junior or Leaving Certificate, or in college. They saw how family members' roles can change dramatically, especially for children.

.....  
*If you're the son or daughter [of someone with YOD] and also they're getting married at that stage of their life, they're not expecting to have to mind their parents.*  
.....

The whole dynamic of the household is massively impacted when a mother or father gets dementia. Financial strain is common, and affects the whole family. Where a spouse needs to take on more caring responsibilities, two incomes might be impacted.

.....  
*Very often you'd have grown up children having to contribute to ongoing mortgage payments or nursing home care or whatever it is. They do incur hardship as a result of it, there's no doubt about it. [GP 3, Both Diagnosis and PDS]*  
.....

Where a person has a type of YOD that brings personality changes, this is extremely stressful for their families especially children.

.....  
*FTD seems to have a phenocopy, where [they are] seeming for all the world like they have had a change in personality, and behaviour that makes him difficult to live with difficult to hold down a job [Neuropsychologist, Diagnosis]*  
.....

Despite them being greatly affected, HSCPs spoke about how spouses can get "lost" in the diagnosis, and while it is correct that the person with YOD should be at the centre, it must also be recognised that the families need emotional support. Often, as with the person themselves, the families might mostly need practical supports. If they are

providing full time care they might need time to themselves where the person with YOD is being looked after, to do shopping, collect children from school, or just to have a break.

.....  
*On one occasion a lady who came to us whose youngest son was ... 8, she came to the group one time and she was incredibly stressed, and I said to her "Mary, if I could wave a magic wand and could give you whatever services that would make life more manageable for you, coping with everything you have to cope with, what would it be?" and she sighed and she sat back into her chair and she said, "Do you know something, if I could have anything," she said "it would be to have somebody that would be able to help me in the morning to take my children to school," she said, "or after-school activities or collecting them from school." She was saying at the time, "My husband is no bother because he's very quiet and he's happy to sleep on in the mornings, and when he gets up, he'll watch TV or he's quite happy and content as long as he is in his home environment." But she said, "I'm still nervous about leaving him in the house on his own," so she said, "For me, I can no longer just say to the kids, 'Come on, hurry up, jump into the car, let's go,' because now, I have the worry of my husband being in the house on his own. [DA 1, Diagnosis and PDS]*  
.....

As families provide so much of the care, it is very important that they are supported, if the goal for a person with dementia to stay living at home in the community is to be realised.

### 6.7.1 Counselling

Counselling was identified as an important service particularly for the younger group, but one most consistently identified as a service which is universally lacking. As discussed, people with YOD experience many losses, which might include giving up work and driving, and experience huge grief following a diagnosis. Counselling should also be available for family members including younger children, particularly around diagnosis. In some areas counselling was gotten for a person and their families through subsidies and fundraising, others

were informed of services but that they would have to pay privately. Nowhere was this available as part of standard care services.

## 6.8 General Barriers to Effective PDS

### 6.8.1 Geographical barriers

Certain barriers to providing PDS were in evidence in rural regions. Nationally the numbers of people living with YOD are relatively small, and sometimes in rural areas there simply aren't enough people with YOD at a similar stage to hold targeted group supports or interventions. Transport is an issue in rural areas. There may be people who would like to attend a certain PDS service, but who would be unable to travel far on a regular basis to attend. Some HSCPs servicing rural areas felt that people there are used to having to travel to attend all kinds of services, and are willing to travel if a service is of benefit, particularly for more occasional appointments, however overall rural transport remains an issue in the provision of services.

.....  
*When you're providing services in rural areas as well, trying to actually just get the attendances can be tricky because of transport and because of distances and all those things. [OT, PDS]*  
.....

Similarly, DAs, supports workers, and others who visit people in the community can obviously visit less people within a set amount of time if they are living over a large rural catchment area. A final geographical barrier discussed was the inequity depending on where people live in the country with regards to what PDS will be available.

### 6.8.2 Numbers of people with YOD

Many HSCPs reported that they are seeing more people with YOD attending their surgery, clinic, etc. They suggested reasons such as increasing numbers and/or more people recognising and seeking help for their symptoms earlier owing to awareness campaigns. However, overall the numbers of



younger people presenting with dementia are relatively small. As discussed, this is a barrier to providing group supports in some areas. It is also a barrier in that many HSCP, especially GPs, simply do not get enough experience of supporting someone with YOD.

.....  
*And I suppose younger onset dementia is less common, you know what I mean? So, I suppose people don't... GP's wouldn't be seeing it every day either, so it is hard to know what to do when the person comes into you. It would be hard. [Geriatrician 2, Diagnosis]*  
.....

**6.8.3 Training in YOD**

As discussed, the relative rarity of YOD means that doctors and other HSCPs are not very experienced with it, even some of those who are working in memory clinics. Training for HSCPs even generally in dementia was also seen to be poor. There was a perception that certain groups such as some neurologists don't have an interest in YOD. Many HSCPs working in specialist dementia services have chosen to complete postgraduate or further education in dementia to upskill, and reported the positive effect this had on their practice.

**6.8.4 Cost and staffing**

Several of the PDS services currently available have been established with a once-off grant from the HSE dormant funds and/or a charitable fund, thus their long-term existence may be uncertain.

.....  
*We ran [the support group] for about 18 months and we couldn't get the funding to keep it going, so we had to let it go which was a very big pity [Clinical Nurse Specialist 3, Diagnosis]*  
.....

Some HSCPs were involved in fundraising in their local community to continue supports, and to offer extra supports such as access to counselling for families who could not afford it.

A lot of roles for HSCPs working in PDS are part-time, and can take a while to be established. For services that offer one-to-one support the

numbers of staff needed are large, especially if the staff are supporting people with dementia at any age. 'Generalists' supporting people with YOD such as PHNs are reportedly overworked with a significant caseload.

**6.9 Other Recommendations for Planning Appropriate Services**

**6.9.1 Integrating Diagnostic and Post-Diagnostic Supports**

A universal theme arising in these interviews was that diagnostic and PDS need to be well integrated for the delivery of the optimum care pathway. A few HSCPs spoke of the problems that arose where people travel out of the region to get a diagnosis, particularly at the specialist diagnostic centre, and then are not linked in with the post-diagnostic services in their own area. Often there is no integration of care services and these people do not know where to turn for help.

.....  
*We have a woman that is way younger than me and just completely hit crisis and probably is going to go into go into Department of Psychiatry, not even Psychiatry of Later Life, because she's only 58. I'm not saying her trajectory will be any different, but the husband is not even engaging because he can't cope, whereas I suppose if we had known when she was diagnosed in XX and even if we were ringing her and she's saying, "I'm perfectly fine. I don't want you" if every three months [we did that] at least she'd have a relationship even if she didn't like it, ringing every three months, eventually the husband might talk, and when things would start to slip, he would say it. But they slipped and slipped and slipped and slipped and now they're in a, you know. So we're trying to avoid that. And it's not saying that that wouldn't be... That's just the way her journey is going, but they would have had more support in it. That's all. [ANP 2, Diagnosis and PDS]*  
.....

In some instances, the diagnostic and PDS services were all arranged through the one site, and here the services were obviously integrated well. As the same staff were involved across services, or different staff but who knew each other well, it was better for the person with YOD who would get to know the care team. It also meant that the person is getting consistent information from all members of a team.

HSCPs felt that where someone is diagnosed in a specialist clinic, it is not sufficient for a clinic letter to be sent back to their local GP (who may not be aware of local PDS) but there should also be communication with the closest memory clinic to the patient. One HSCP provided an anecdote of a person who was diagnosed in Dublin and given information about local PDS there, and kept travelling to access these supports not knowing that there were options available in his own locality.

### 6.9.2 Flexible, individualised, and specific services for YOD

As people are affected by YOD in unique ways, the services on offer must be flexible and individualised. HSCPs said that more one-to-one services would be valuable, to really allow the HSCP to see where the person might most need help, and to put very individualised strategies in place. HSCPs felt that there should be a variety of services on offer to suit people at different stages of dementia.

.....  
*I suppose it's looking at each individual because ... I suppose we would have many people with a diagnosis of a dementia, but everybody is an individual and every family and every situation is different. So looking at this, each individual case, and trying to map out the appropriate course. And I think the important word there is "appropriate", and to see where the person is at number one from the person with the*

*diagnosis' point of view to be able to support them to live an as active and fulfilled life as possible. [Clinical Nurse Specialist 1, PDS]*

.....  
In one example of good practice, the service gave the client a list of post-diagnostic services following their diagnosis and they were able to tick which ones they would be interested in, resulting in a person-centred service. Other services tried to be flexible in their approach by listening to the client's needs, and suggesting services and supports that might be most relevant.

A lot of HSCPs spoke about how, while PDS services will accept a younger person, the services are not geared specifically towards this group. Some HSCPs felt strongly that there should be specific supports available for people who are diagnosed with dementia at a younger age. While some problems experienced by people living with dementia will be similar regardless of age, undoubtedly people with YOD also face unique challenges.

## 6.10 Chapter Conclusion

The interviews with HSCPs were rich and informative as they uncovered common practices around diagnosis and the PDS of people with YOD. It should be noted that the sample of HSCPs mostly had some interest or experience in YOD, and thus they might have better practices than others. At the same time, they are a useful cohort in that they could provide insight into supporting this under-represented group. Importantly these HSCPs were able to identify aspects of their practice that worked well, aspects that could be improved and where there were gaps in services. Together with the findings from the literature review, and the interviews with people with YOD and their families, recommendations to improve the diagnostic and post-diagnostic processes and pathways for people with YOD can be made.

07



# Chapter Seven: Conclusion and Recommendations

This study employed a mixed-method approach to explore current and optimal diagnostic and post-diagnostic care pathways for people living with Young Onset Dementia (YOD) in Ireland. A consistent finding across the literature reviewed for this study, and the data collected from both people living with dementia and their caregivers and health and social care professionals, was the significant impact a diagnosis of YOD has on the individual and their families, and the particular difficulties the person and family members face when coping with the symptoms of dementia at a younger age.

Unfortunately, although there were examples from the research of some people living well with YOD, the overall findings suggest that people with YOD and their family members are significantly disadvantaged in the Irish health and social care system where there is a dearth of age-appropriate services (Hutchinson, 2013). Although a minority in numbers, this should not result in lack of access to age-appropriate services, and we can see from other countries that appropriate service provision on this scale is possible. For example, Norway, a country with a population size similar to that of Ireland, had in 2011, a total of 26 day care centres dedicated to people with YOD, five YOD nursing homes, six support groups for people with YOD and 12 support groups for spouses (Haugen, 2014).

## 7.1 Diagnosis: Path to Diagnosis, Assessment and Initial Diagnostic Processes

In the earlier stages of symptom onset, timely diagnosis is the most pressing problem confronting this vulnerable group of people

and their families. Delays in diagnosis and misdiagnoses with symptoms attributed to other causes, are very stressful for all affected. A finding echoed across the two qualitative phases of the study was that people with more unusual variants of YOD, such as FTD, might have limited insight, again delaying diagnosis perhaps until a crisis happens. It is also stressful and frustrating for people when their concerns are dismissed as anxiety or attributed to other causes. As diagnosing YOD is relatively complex, some delays may be unavoidable. However, other delays can be minimised. One of the delays identified in this research was that of accessing diagnostic services such as MRI scans or lumbar puncture tests. Rapid access to required diagnostic tests and clear communication between all clinicians involved in care is vital. Furthermore, to reduce stress around the process of diagnosis, details about the tests being carried out, why they are being done, and the reasons for any unavoidable delays with expected timelines should be clearly articulated to the individual and their family. This relatively simple step can have a hugely positive influence on people's experience.

Essential elements of timely diagnostic services include clear pathways to assessment, good diagnosis and disclosure patterns and referral to both specialist and generalist post-diagnostic services. The use of multidisciplinary teams (MDTs) is critical, as is the development of more effective links between the range of services likely to be providing support to the individual, their family members and carers. As general practitioners (GP) are often the first point of contact for people worried about their memory, it is imperative that GPs have access to MDTs, are well trained in the

presentation of YOD, and know how and when to access specialist services for their patient. GPs should be afforded with the minimum information relating to a) who the key diagnosing clinicians are in their area who will see someone under 65 years old, b) if none, which regional/national centres will accept referrals, and c) clarity around how to process the referral.

Another finding emerging from this research was the importance of access to MDTs when making a diagnosis and immediately thereafter, and this was particularly the case for certain specialities (e.g. Neurology) which did not always have access to full MDTs. Where specialities such as neurologists or psychiatrists are making the diagnosis, they should have the support of a MDT to ensure that the person is fully supported during diagnosis and immediately after. Consideration should also be given to providing access to dementia and community services for people with cognitive issues while diagnosis is being pursued. It is of note that some people might never get a diagnosis, or may spend some time awaiting diagnosis, but an appropriate level of service should still be available to them.

Many clinical practice guidelines exist on the diagnosis and management of dementia, however there are currently no specific practice guidelines for the diagnosis of YOD (although recommendations on best practice specific to certain areas are available, see for example Rossor et al., 2010 and Sorbi et al., 2012). There is a need for best practice guidelines on diagnosis to be developed in this area. That said, the National Dementia Office (NDO) has progressed some key priority actions, in addition to recent comprehensive national reports. Although these do not have a specific emphasis on YOD, it is likely that many recent changes will progress positive effects. Also important when discussing current system shortcomings, is to be mindful of the current contextual and service level limitations. HSCPs are working within circumstances of resource limitations; from

this study it was evident that they would like to enact better care, but are constrained.

### 7.1.1 Diagnostic disclosure

A poorly delivered diagnosis disclosure of dementia can have a profoundly negative psychological impact on a person receiving a diagnosis of YOD, and their family. Poor disclosure both in terms of the circumstances surrounding the disclosure (e.g. planning, environment and personnel in attendance) and lack of appropriate follow-up was a finding identified in the literature and borne out in the interview chapters.

A good disclosure meeting takes time, and should be directed at the person receiving the diagnosis, however people with YOD, their families, and HSCPs all agreed that the person should be encouraged to have a family member present for disclosure. Findings from this project highlighted examples of pressing information needs that people have at the time of disclosure. These are information about the diagnosis, treatment, some key first steps, and a nominated point of contact. Written information relating to these should be provided to supplement what is discussed during the meeting. There should be a named point of contact provided to the person; those in attendance should get clear instructions on who to contact should they have any follow up questions. Ideally, this HSCP should make contact with the family within a few weeks following disclosure to offer extra support. Currently this occurs only in some settings, but has been reported to work well. Some consideration should be given to what information is raised in the disclosure meeting, and where appropriate, what could be raised at a later time point (e.g. six-month review meeting).

Notably, while most of the HSCPs felt that they were "good" at diagnosing YOD, people with YOD and family members gave many accounts of poor experiences of receiving their diagnosis. This discrepancy may be accounted for by a few reasons. The current sample of HSCPs may have had better

practice than most. Possibly, diagnostic practices have improved in recent years; for example, although still longer than the ideal, time to diagnosis seems to now be somewhat shorter than in the past. There could also be a discord between how HSCPs perceive the disclosure meeting, and how well the person with YOD and their families felt it went. A disclosure meeting is always going to be emotive for the person, even if they report some contradictory emotions such as relief, thus HSCPs must remain very sensitive to the individual's response and conduct the disclosure meetings to a consistently high standard.

### **7.1.2 Service integration: diagnostic and post-diagnostic services**

The use of MDTs is critical in dementia assessment and diagnosis, as is the development of more effective links between the range of services likely to be providing support to the individual, their family members and carers along the illness trajectory. At a systems level, service integration is critical and there is compelling evidence that there is a need to integrate diagnostic services (primary, secondary and tertiary) and to streamline pathways following disclosure. There was some evidence emerging from this study that services were not always well integrated and teams not adequately resourced, for example a lack of MDT support in neurology services. There were also uncertainties along with gaps and tensions in communication between primary and secondary services. Memory clinics for example should make available clear information on their referral criteria, critically if they do accept people younger than 65, as currently this is not clear to community health and social care professionals. HSCPs were further unsure which branch of the HSE is responsible for providing care for younger people with dementia. While some of this information is available online (e.g. 2017 Review of Memory Clinics in Ireland) HSCPs were not aware of these resources.

Following diagnosis, it is vital that pathways

to post-diagnostic supports (PDS) are readily accessible. To facilitate this, the integration of services is paramount, from diagnostic to post-diagnostic services, and from specialist to primary/community services. Important factors at this time are to establish links with the personnel, services and organisations with a remit for PDS.

## **7.2 Holistic Assessment for Post-Diagnostic Supports: Outcome Focused Approaches**

In addition, the person should be offered different options on their pathway through care, so that person-centred services are offered that are tailor-made and individualised. This relates to approaches that are guided by personal preference, and are based on what outcomes the person would like to work towards. In the interviews with people with YOD we heard powerful statements from people asserting that they would have valued simply being asked '*What areas would you like support with?*'.

Accessing pathways to care is complicated by the timing of the diagnosis, the dementia sub-type (including whether it has a genetic component), the existence of co-morbidities and the life-cycle stage where the person is at. It was clear from the interviews, in particular those with people with YOD and their families, that everyone is affected in a unique way. Individual circumstances are complex and may need to be addressed by multiple sectors, including those outside of healthcare. For example, parents with young children in this research needed practical help to cope with the competing demands of work, childcare, school, and family activities whilst providing for the care of a family member with YOD.

Therefore, there should be a range of PDS options available to them so that support can be tailored to suit their individual needs. A 'one-size-fits-all' model will never apply. Furthermore, findings from the research



highlight that in many cases, rather than dedicated post-diagnostic models of care, consideration should be given to supports that will facilitate people with YOD to live well, and to continue their own preferred and usual roles, occupation and interests. Holistic assessments that are outcomes-focussed may help to ensure these are of central consideration.

A notable theme emerging from the in-depth interviews and highlighted in the literature is the importance of a “key worker” role. Some specific examples were offered in the interviews of how a key worker can be a valued support to a person and their family in the months following a diagnosis. In the current study, this took varied forms (e.g. dementia advisor), community psychiatric nurse, HSCP attached to memory clinic) but in essence it was the provision of one point of contact for the family to have. The literature also highlights a need for seamless services with a central point of contact and the adoption of case management or key worker approach (Sansoni et al., 2016).

Optimum models of PDS and interventions would have the key worker assigned at the time of diagnosis, prepared to assist the individual and family member understand the illness, what the diagnosis means, and what support is available including financial and legal planning. For example, in the optimal care pathway developed by Young Dementia UK, during each post-diagnostic stage, an emphasis is placed on ensuring that regular reviews take place between the key worker, the person and their family, the clinical team and other HSCPs involved.

### **7.3 Post-Diagnostic Support: Services and Interventions**

Historically, dementia care services in Ireland have been under-funded and under-prioritised and many traditional service supports are underpinned by deficit-based policies that regard people with dementia as highly dependent and at high risk. Services have also tended to focus on care needs

and the needs of family caregivers, and not on the preferences and interests of the person living with dementia. It was evident from speaking with people with YOD, their families, and HSCPs, that PDS in Ireland currently is inadequate and is not fully meeting the unique needs of this group. Regarding pathways to PDS and based on the literature, it is difficult to identify any one evidence-based post-diagnostic model that covers all the potential elements of support for people with YOD their families. It is also difficult to identify any specific interventions. This is probably due, at least in part, to the fact that no two people living with dementia or their families, will have similar needs or preferences. The development of a model is further complicated by the timing of the diagnosis, the dementia sub-type (including whether it has a genetic component), the existence of co-morbidities and the life-cycle stage where the person is positioned. While some other countries have more comprehensive PDS pathways which could be useful to model, the evidence base for these models is limited. In addition, Irish contextual factors would have to be considered.

Findings from in-depth interviews with people affected by YOD reveal that many PDS services available in Ireland are delivered in an ad hoc manner, and are contingent on once-off or NGO funding or are pilot/research-based. These can be discontinued at short notice. This has implications in that people may be severely affected by a service they rely on being withdrawn with no replacement. Furthermore, mainstream dementia services in Ireland such as these are often inappropriate for young people who may be very well and may feel stigmatised spending prolonged periods in the company of older clients whose dementia may be more severe. Of the many examples discussed, it was evident that residential respite, day care, and long-term care options were mostly at odds with the needs of, and unacceptable to, younger people. Many of the sedentary activities delivered at day care centres such as bingo, quizzes, and reminiscence will have

limited appeal to younger people. Existing services for older people living with dementia currently lack sufficient flexibility and capacity to address the diverse and specific needs that people with YOD and their family members have.

Findings highlighted the fact that mainstream dementia supports can be either empowering or disempowering for people with YOD. Some post-diagnostic services could serve to add to the distress experienced by people owing to stigma or inappropriateness. It is understandable that HSCPs will signpost to local dementia services, but it is important to consider the individual and family circumstances before referring to usual generic dementia supports. There are also broader considerations relating to the way in which dementia care is situated within the wider health and social care policy, and in turn where YOD fits within this context. For example, the experiences discussed in the current interviews point to inequities in home care services, highlighting a lack of regulation and a need for universal availability regardless of age. A recent review of YOD concluded that effective service provision for people with YOD required an integration of aged care, health care and disability services (Sansoni et al., 2016), a point which would potentially mitigate age and diagnosis related barriers that people experience.

For those recently diagnosed, the literature (Mayrhofer et al., 2018) suggests that post-diagnostic services were beneficial if they were informative, educational and could signpost the individual to community-based supports. Community-based services were deemed effective if the service facilitated social interaction, created a sense of normality, offered peer support, inclusion and purpose, facilitated changing care needs and offered continuity over extended periods of time. Despite a broad range of community-based programmes and interventions identified for people with YOD and their family members, most of the literature yielded limited evidence about programme effectiveness.

Most importantly, consideration should be given to interventions that are age-relevant, participatory and strengths-based. Exemplars within the literature and qualitative interviews include cognitive stimulation therapy, cognitive rehabilitation therapy, psychoeducational programmes and psychosocial interventions as potential options for young people with dementia and their family members; of most importance is that these need to be readily accessible to all who wish to avail of them and can benefit from them. The evidence base for many interventions is limited, for example the evidence for cognitive rehabilitation is weak and for people with a more moderate to severe dementia very weak. However anecdotal evidence is often positive and must be considered in light of the dearth of research. Other examples of beneficial initiatives are advocacy groups or working groups which encompass elements of peer support, information sharing and contribute to ongoing policy, research and awareness in dementia. However, overall there is limited evidence of service development for this vulnerable group (Mayrhofer et al., 2018). Sansoni et al. (2016) have called for more robust studies using larger sample sizes triangulating methods, and considering the potential of confounding factors to enhance evidence-based practice. In addition, involving people living with YOD and their families in the design of age-appropriate services remains under-explored.

Support for family members, including younger children, teenagers, and young adults is critical as many examples of the devastating impact a diagnosis has on the wider family were discussed. Having information about dementia that is suitable for children who need it, and want to know more about YOD, may be of benefit. Peer support is equally rated as very important for family members to enable them to share experiences and learn from each other. There is scope to formalise the processes around peer support for children of people with YOD,

who will often be much younger than other dementia support group attendees. This could take the form of regional peer support groups, in addition to the consultation of this cohort in policy and service design.

Consistently, counselling was identified as a much needed, yet unavailable support. Availability of trained counsellors for people with YOD and their families to access if desired is crucial. Of further importance to this cohort is genetic counselling. The availability of counselling services for children and teenagers who wish to talk over their concerns about a parent's illness would be helpful. However, it is vital that any provisions or service developments in regard to counselling for families and young children are mindful of out-of-pocket costs.

The literature highlights the importance of staying socially connected and engaged in meaningful purposeful activities immediately post diagnosis (Mayrhofer et al., 2018). This was reflected in both sets of interviews. It may be challenging to develop comprehensive, age-appropriate services that provide a broad range of activities likely to promote dignity and personhood and empower people with YOD to use their existing skills to enjoy a good quality of life. A further challenge is to ensure these services are widely accessible and affordable. However, there are many examples of existing non-dementia initiatives operating in communities (e.g. Men's sheds) that could be made accessible to people with dementia and their families. All HSCPs should consider social prescribing when supporting and advising people with YOD to improve the social and environmental aspects of their lives. For example, social prescribing might encourage links to local communities through by volunteering, befriending or activities provided by community organisations (Alzheimer UK, 2020). As evidenced throughout this research, this may be of immense value to people with YOD in particular.

Raising awareness within wider communities

could optimise access and participation, particularly efforts that seek to reduce stigma and focus on strengths and opportunities rather than barriers. Findings support such a call; in the current study, social supports that enable people to maintain valued contact with others, to keep up preferred routines and to stay engaged in the wider community were very well received. The Understand Together Community Activation Programme is supporting communities, services and businesses to be dementia inclusive; this should specifically include YOD. There are other awareness-raising efforts which could prove beneficial. Community-based HSCPs are ideally placed to enable people with YOD and their families to establish and maintain links with social networks and preferred activities. Again, this relates to increased awareness and reduced stigma amongst frontline community staff on YOD, and a move toward approaches that are rights-based, and outcomes-focussed rather than restrictive or risk-averse. Community services should undertake to be more flexible, responsible and individualised whilst remaining cognisant of the unseen challenges that people are experiencing.

In terms of health and social care policy, there are specific needs that people with YOD have that warrant more careful recognition. People with YOD and families should be provided with support and information about employment, finances and governmental financial and entitlement assistance. Findings from the qualitative data highlight the significance of occupation, employment rights and YOD. Although several participants described issues with employment, some prominent examples included abrupt loss of employment, or untenable working conditions forcing people to leave prematurely. Because YOD occurs during working age, employment is often affected, but research relating to the financial and social burdens of this is limited (Sakata and Okumura, 2017). In order to address the lack of clarity in this area, there needs to be specific guidance developed on employment rights and entitlements. Furthermore, employers

should receive training to ensure they are sufficiently knowledgeable on employment rights and YOD. For example, support in area of employment might enable people with YOD to continue in the workforce albeit in another position or part-time.

Along with reduced employment capacity, people with YOD experience reduced family finances, and additional expenses are incurred as a result of the diagnosis, leading to a double economic strain. This research highlights the many direct and indirect economic costs associated with YOD. These include the medical expenses associated with seeking out a diagnosis, making adaptations to home and daily life (e.g. driving assessments, safe-proofing the home, taxis where no longer licenced to drive, counselling for children) and the legal costs associated with updating wills and obtaining Enduring Powers of Attorney. Delay in diagnosis can directly delay the granting of financial supports. A delay in diagnosis can also result in the person with YOD engaging in poor decision-making that can have serious financial ramifications as one of the accounts in this research has shown. There may also be significant costs associated with financing residential care while still maintaining the family home.

Clarity is needed on welfare information, and how welfare support can be enacted for people with YOD and their families. This relates to information around governmental supports and entitlements and also employment, remuneration and pension status. There is also a need to establish good referral pathways to appropriate bodies for advice on legal and financial assistance. Staff in existing health and social care services for older people with dementia may not have the skills to deal with their client's financial and employment concerns. Based on some of our interview data with people with dementia and family members, it appears that there is also a lack of clarity and barriers faced within work organisations and government agencies (e.g. Department of Employment Affairs and Social Protection). Although it is outside of

the scope of this research, it may be of future consideration for research to be undertaken in Ireland for organisations, employers, Human Resources, etc. Suggestions for models of post-diagnostic (and diagnostic) models should be cognisant of this point.

From the literature, relatively little is known about the PDS needs of younger people at later stages in the illness trajectory and especially towards end of life. Whilst models of care along critical junctures at later stages was outside of the scope of the project, it was evident from the interviews, that information about advance care planning and end of life care for this cohort was lacking. Many people with YOD did not want this to be discussed during a disclosure meeting, so it is important to ensure that a designated healthcare professional – perhaps the key worker – will discuss these issues at a time point a little later on, but critical is that this discussion is had by someone.

A conclusion drawn from the literature review and from the qualitative findings is the need for specific post-diagnostic services to be developed for people with YOD and their families and for more research to be undertaken in this area. Research is needed to help shed light on 'what works' and 'what does not work' and more scientific evidence is needed to inform and guide the design of future services. Post-diagnostic services should be designed with input from people living with dementia and their family members. Services should be three pronged, targeting (i) the individual, (ii) the spouse and (iii) children affected by the dementia. For the individual, services need to be flexible, age-appropriate, and designed to provide information, maintain skills, develop friendships, promote hobbies, foster peer support and enable the person to remain active in their local communities. For the spouse, post-diagnostic services should include information services, counselling, and advice on income supports and financial and legal planning. Lastly, for children, a 'whole family' systems approach should be used

with services designed to alleviate some of the fears, shame, emotional distress, isolation and loneliness young people often experience when a parent has this rare form of dementia.

## 7.4 Comparisons with LOD

Some of the unique experiences and challenges faced by people with YOD have been highlighted throughout this report. However, it is also important to note that some experiences and needs expressed by people with YOD are also common to all those affected by dementia. These include the need to have a Dementia Advisor or a “key worker” or “link worker”. In several countries across Europe, for example in the Netherlands, the UK and Denmark, the appointment of this type of front-line worker has been a feature of part of the dementia care landscape for a long time. The service is only at a relative early stage in its gestation in Ireland but was highlighted in the Irish National Dementia Strategy.

Another finding was that in the earlier stages of disease, following a diagnosis, people with YOD will often be physically well. Thus, their need for information and advocacy might be as great as their need for healthcare and mainstream dementia services such as Day Care. The optimal model would therefore include all of these healthcare and non-healthcare services if it is to best meet the needs of people with YOD.

## 7.5 Service Design

Many of the topics discussed by interview participants were also borne out in the literature on service planning. Overall, key service design includes (i) an individualised model and access to specialist diagnostic services, (ii) on-going symptom management services and (iii) regionally-based integrated and coordinated interagency partnership and pathways (Sansoni et al., 2016). The literature showed variation between countries regarding diagnostic practices, however the essential elements of diagnostic service provision include (i) clear pathways to assessment from

GP to the nearest accessible diagnostic clinic, (ii) timely diagnosis and disclosure that is planned and individualised and (iii) referral to both specialist and generalist post-diagnostic services.

Finally, compared with other overseas countries, such as Australia, Canada, the US, the UK, the Netherlands, Sweden, and Norway, Irish services for people living with YOD are either non-existent or under-developed. This is despite the fact that, for the best part of the last two decades, calls have been made for more investment in the area, with Irish research repeatedly demonstrating gaps and service deficits in this area. The commissioning of this project on YOD by the NDO augurs hope. It shows that people in Ireland with this rare form of dementia and their family members are being recognised as an identifiable group who have complex needs that require both mainstream and age-appropriate services. This is clearly a step in the right direction that will hopefully, in the foreseeable future, coincide with appropriate resources allocated to enable people with YOD and their family members to live well and enjoy a good quality of life.

## 7.6 Priority Areas and Key Recommendations

There are a number of specific priority areas arising from this research project. These, along with actionable recommendations, are presented in the final section of this report.

### *Individualised approaches.*

The individual and unique needs and experiences of every person with YOD must be a central consideration across all aspects of dementia care, from assessment and diagnosis, to the timing and planning of post-diagnostic models of supports in the community, to long term residential care and to end of life care.

### *Streamlining diagnostic processes.*

The current processes of assessment should be reviewed, and streamlined, with the specific



needs of people with YOD in mind. All HSCPs including primary care staff, staff employed in secondary services, and those in the acute sector, need to be aware of YOD as a condition and assess and/or refer younger people with memory complaints appropriately. There are key resources available to GPs to aid with timely referral, for example, the new national e-referral facility for memory clinics (DSiDC, n.d.). Information about such resources should be widely disseminated. Pathways to specialist consultation, testing and imaging should be straightforward, easily and readily accessible, and timely. At the point of diagnosis, the person making the diagnosis needs to make all relevant HSCPs aware of diagnosis confirmation (e.g. GP, local memory clinic if diagnosed elsewhere). Critically, the person must be kept informed about this process throughout. Wider awareness is required amongst community-based HSCPs regarding YOD assessment and diagnosis.

1. Recommendation: HSCPs (for example GPs) should have clear pathways to accessing assessment for patients in their area and nationally. HSCPs need to be fully informed as to where they can refer, which specialists in their local area are accepting referrals and which have age restrictions.

2. Recommendation: All people, regardless of age, should have access to specialist services for assessment and diagnosis.

### ***Disclosure.***

There should be greater consideration given to the process and impact of disclosure, including provision of protected time, space and personnel to support an optimum disclosure meeting. Only key HSCPs should be part of the disclosure meeting. The preferred contact for the person (such as a family member) should be encouraged to attend and included in the meeting, unless the person chooses otherwise.

3. Recommendation: The process of disclosure should be planned and cognisant of the time and privacy needed. HSCP should ascertain the individual's wishes vis-a-vis disclosure

and only necessary personnel should be in attendance.

4. Recommendation: A nominated HSCP from the clinic should be available to provide early support post-disclosure (e.g. if required on the day, and a follow-up call in the following days).

### ***Information provision at disclosure.***

People with YOD have specific, unique information needs. However too much information given at the same time may not be absorbed and may be harmful. At disclosure, key information should be provided in a readily accessible but staged format. Consideration should be given to what is discussed at disclosure, and what can await discussion at the next review meeting. The person should also be provided with written information to supplement what is discussed during a diagnosis meeting. Information relating to key first steps should be offered at this time e.g. contact details for dementia organisations, and information on how to access local supports.

5. Recommendation: Information provided on day of disclosure should focus on diagnosis, treatment and on that person's and family member's urgent information needs at the time. The person should be invited for a return visit 4-6 weeks post-disclosure, when additional, detailed conversations can be held.

6. Recommendation: Written information should be provided at time of diagnosis relating to YOD, the specific diagnosis sub-type and treatment. Written information should be supplied in the form of leaflets and/or information cards signposting the person to key dementia and community organisations and their contact details.

7. Recommendation: The person/family should be provided with specific guidance relating to financial and legal issues, at the appropriate time.

### ***Service level integration.***

There must be clear, channels of



communication between diagnostic and post-diagnostic services. There should be clear pathways for the person and for HSCPs to easily access and navigate services, facilitating early intervention. These pathways should be available at the time of diagnosis, and must be responsive to preferences and changing needs of the person (and family).

8. Recommendation: At diagnosis, families should be provided with a named point of contact from within the specialist services (e.g. a nurse, advanced nurse practitioner (ANP), health and social care professional, or similar from within the clinic MDT).

9. Recommendation: If this is not possible, the specialist and GP should liaise to ensure clear channels of communication and information with the person with YOD.

#### ***Named point of contact- post diagnosis***

A person diagnosed with dementia should be given a named point of care within community settings, such as a key worker, for PDS. A dementia-specific HSCP would be optimal, as a point of contact to support them on an ongoing basis. It is important that community-based HSCPs (e.g. community and public health nurses) are aware of the specific issues experienced by people with YOD. They need to be aware of those living in their area with YOD, and who may potentially have young families and specific needs.

10. Recommendation: The person with dementia should be provided with a named point of contact for ongoing post-diagnostic support in the community, e.g. DA or Dementia care co-ordinator.

11. Recommendation: Community-based HSCPs should receive education and training and be aware of the specific issues relevant to YOD, models of care and key local and national services.

#### ***Post-diagnosis (outcomes-focused approaches)***

Post-diagnostic approaches and interventions

should be planned with specific consideration to individual preference, pitched at the appropriate time and level. Outcomes-focused approaches to care planning and post-diagnostic service signposting should be adopted. These approaches will support and enable the person to maintain an optimal standard of living and engage outlets that are empowering and meaningful.

12. Recommendation: There should be a range of PDS options available to address the individual and their family members' needs. In addition to dedicated dementia models of care, consideration should be given to non-dementia supports that will facilitate people with YOD to live well, and to continue their own preferred and usual roles, occupation and interests.

13. Recommendation: Community HSCPs should utilise an outcomes-focused approach to care, guided by the person. Decisions about interventions, and timing of interventions, should be led by the person.

#### ***Legal and Financial advice/information.***

Specific information and advice should be given to people with YOD and their family members on key areas such as employment rights, financial supports, welfare entitlements, driving and legal issues such as appointing assistant decision-makers and arranging Enduring Powers of Attorney. This is key not only for people experiencing the symptoms of dementia and others such as family members affected by dementia, but also for the HSCPs involved and relevant others such as state institutions, employers etc. Specific guidance documents should be prepared by key dementia organisations such as the NDO or the ASI.

14. Recommendation: Guidance should be available to employers highlighting the unique circumstances that YOD presents. Guidance and information should also be available to people with YOD on their rights and entitlements in the workplace.

15. Recommendation: Staff in key government agencies such as the Department of Employment Affairs and Social Protection and Disability Services should be made aware of the specific challenges confronting the individual and family members where a diagnosis of YOD is made.

***Family support.***

There needs to be dedicated information and support services for families of people with YOD, including young children. These need to be provided in a timely manner and in a format that is accessible to families.

16. Recommendation: Specific information leaflets suitable for children of people with YOD should be developed by key dementia organisations such as the NDO or the ASI.

17. Recommendation: There should be dedicated support interventions for young families of people with YOD. Of particular value may be informal mentorship/peer support groups.

18. Recommendation: Counselling programmes should be made available as an option for the time after diagnosis and as part of PDS.

***Advanced care planning / Palliative care.***

Information on palliative care and Advanced Care Planning should be made available at the appropriate time to the person with dementia and family carers by a HSCP who has the appropriate skills and expertise.

19. Recommendation: Conversations on advanced care planning, including end of life decision-making, must commence early and be reviewed and organised over time. HSCPs must document and facilitate care preferences as outlined by the person.

***Wider community approaches.***

A whole-of-community approach should be taken to increase awareness and to address stigma experienced by people with YOD. A community that is knowledgeable and aware of YOD could potentially empower people with this condition to remain connected and socially engaged and ultimately enjoy a good quality of life

20. Recommendation: Existing community activation initiatives could be further extended to increase awareness of YOD and the unique issues experienced by the person and their families.

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Appendix I

Appendix II



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# Appendix I:

## Interview Topic Guides for People Living with Young Onset Dementia and for Family Members

### Semi-structured interview schedule for persons living with YOD.

Introduce self

- o Explain study and its rationale
- o Explain that interview will be recorded, and obtain permission to record
- o Reinforce anonymity/confidentiality
- o Confirm informed consent with participants on the recording

|  |  |
|--|--|
| <b>Demographics*</b>                   |  |
| Gender                                 |  |
| Age                                    |  |
| Relationship status                    |  |
| Employment status                      |  |
| Other family members (esp. dependents) |  |
| Location (rural or urban)              |  |
| No. of years since diagnosis (approx.) |  |

*\*To be completed by interviewer*

#### **Before diagnosis**

- Can you tell me about the time leading to diagnosis?
  - o What were the symptoms or signs that made you first aware that something was wrong?
  - o First steps, who did you tell, where did you go, etc?
  - o How long did this process take? How did you feel about that...?

#### **Diagnosis**

- What was the experience of getting a diagnosis like, for you?
  - o How did you receive confirmation of diagnosis (which professional or service)?
  - o What was the GPs/Neurologists initial response – (what were you told? how did you feel about that...?)
- Do you feel you got sufficient information about your dementia at diagnosis?
- What was the most difficult aspect for you of obtaining a diagnosis?
  - o any services that worked well/did not work so well? Inaccessible services/age restrictions?
- What could have made this period of time around diagnosis easier for you?



### Post-diagnosis

- What help from health and social care services did you receive after your diagnosis?
  - How did you access these initially?
- Can you tell me about the services you have used?
  - What services/supports are particularly valuable?
  - How could the current supports be improved? (E.g. relevance, timing, information, advice etc.)
- Is there support that you need that is **not** available to you?
  - (E.g. specific services, social support, information etc.)
- Are there any supports or services available to you that you have chosen **not** use?
  - Why/Why not?
- What for you at the moment is the most difficult thing about having a diagnosis of younger onset dementia?
  - For example having to;
  - stop work
  - tell other family members
  - tell friends
  - stop driving
  - stop social activities
  - other

### **Final questions**

- Is there anything else that would make life easier as a person living with younger onset dementia?
- Is there anything else you would like add? Something we did not mention?
- **For the pilot:** This was the first in a number of interviews. Is there anything you think we could improve or change?

## Semi-structured interview schedule for caregiver of person living with YOD

- o Introduce self
- o Explain about the research and its rationale
- o Explain that interview will be recorded, and obtain permission to record
- o Reinforce anonymity/confidentiality
- o Confirm informed consent with participants on the recording

|  |  |
|--|--|
| <b>Demographics*</b>                   |  |
| Gender                                 |  |
| Age                                    |  |
| Relationship to PlwYOD                 |  |
| Marital status                         |  |
| Employment status                      |  |
| Other family members (esp. dependents) |  |
| Location (rural or urban)              |  |
| No. of years since diagnosis           |  |

*\*To be completed by the interviewer*

### **Before diagnosis**

- Please can you tell me about the time leading up to diagnosis?
  - o When did you first notice your relative was showing signs and symptoms of dementia?
  - o What were the signs/symptoms that made you concerned/aware initially?
  - o What did you do first (who did you tell, where did you go, etc?)

### **Diagnosis**

- Can you tell me about the experience of getting the diagnosis confirmed?
  - o How was diagnosis confirmed (responses from professionals or services)?
  - o What initial services were utilised? (i.e. GP, consultant)
  - o What was the length of time between first symptoms and diagnosis (How simple was this process? how did you feel about this?)
- Were you satisfied with the amount of information your family received at the time of diagnosis?
  - o What were you told? What was your relative told?
  - o Any information you needed at that time, which was not available? Specify?
- Any gaps in services relating to diagnosis that did not work so well? (prompts; inaccessible services/age restrictions?)
- How did the news of the diagnosis impact on you?
  - o How did the news of the diagnosis impact on other family members? Impact on immediate and wider family/life?
- Looking back to the time of your relative's diagnosis, is there anything that could have been done that would have made the experience better for you and your relative? (E.g. timing, information, advice etc)

### **Post diagnosis**

- What has your experience of services for dementia/younger onset dementia since diagnosis pathways been?
  - Who currently supports you and your family member? (i.e. dementia advisors/HSE services/ASI services/ other HSE services?)
  - How did you first find out about and access post diagnosis services (E.g. GP, Dementia Advisor, self-referral?)
  - How could the current supports be improved? (E.g. relevance, timing, information, advice etc.)
- Any gaps or services that did not work so well, or were not accessible to you?
  - If so, why?

### **Carer- specific post diagnosis support**

- What **carer-specific** services/supports were particularly valuable?
- What would make support/services more beneficial to you? (E.g. relevance, timing, information, advice etc).
- How do you find accessing support outside of your family?
  - Social support
  - Healthcare support (e.g. day care, dementia advisor?)
  - Support in daily life (from whom...?)
- What, if any, significant changes in your lifestyle have you had to make because of your relative's diagnosis, e.g.:
  - reducing working hours
  - giving up work
  - taking over driving
  - looking after family finances
  - other – please specify
- What would make your role as a caregiver for a person with YOD easier?

### **Final questions**

- Is there anything else you would like to tell us? Something we did not speak about?
- **For the pilot:** This was the first in a number of interviews. Is there anything you think we could improve or change?

# Appendix II:

## Health and Social Care Professionals

### Interview Topic Guides

**Note:** These topics guides provide indicative questions and may be modified where a question does not apply to a particular participant, or additional questions or probes are warranted.

#### **For services primarily involved in diagnosis:**

##### **Background/demographics**

1. What service are you working in? What is your role? How long (approx.) have you worked there? How many years' overall experience do you have in healthcare?

##### **Topic Guide**

1. What type of diagnostic services do you provide to people suspected of having younger onset dementia?
2. How many people with suspected young onset dementia are typically seen by you each month?
3. How many people do you diagnose with younger onset dementia on a monthly basis?
4. Who refers people with suspected younger onset dementia to your services?
5. Who are the key personnel involved in the diagnosis process?
  - a. e.g. Geriatrician, Neurologist, GP, Old Age Psychiatrist, Neuro-Psychologist and other?
6. What information do you typically give around diagnosis?
7. What for you are the real barriers in attempting to diagnose dementia in people who belong to this age cohort?
8. What service supports might help you more easily diagnose dementia in people belonging to this age cohort
  - i. Easier access to other specialists
  - ii. Easier access to diagnostic equipment
  - iii. Better training in dementia
  - iv. Other (specify)
9. Which if any post-diagnostic supports do you refer patients with younger onset dementia to?
  - a. How easy/difficult is it to access these?
  - b. How far would patients and their families typically travel for such services?
10. What additional post-diagnostic supports do you think would be useful for patients with younger onset dementia in your care?
11. Could you provide some specific examples of a time your service supported someone with younger onset dementia very well? Not very well?
12. What do you think an 'ideal' diagnostic service for people with young onset dementia might look like?
13. Do you have any additional comments relating to the above questions?

## For services primarily involved in post-diagnostic support:

### **Background/demographics**

1. What service are you working in? What is your role? How long (approx.) have you worked there? How many years' overall experience do you have in healthcare?

### **Topic Guide**

1. Please give me a brief overview of the service that you are working in which provides post-diagnostic support for people with younger onset dementia?
  - a. What are the primary activities of the service?
  - b. Who are the other key personnel involved in your service?
2. How do people with younger onset dementia and their families access this post-diagnostic service?
  - a. Any barriers to access specific to people with younger onset dementia?
  - b. How far do people have to travel typically?
  - c. At what stage are people typically referred? E.g. soon after diagnosis / further down the line?
3. Are there any other supports in your area, which complement your post-diagnostic service for people with younger onset dementia?
  - a. e.g. local community support services, ASI, information and advice, support groups, home care, respite care, memory technology resource room
4. Are there any problems encountered by your service, specific to providing post-diagnostic support of people with younger onset dementia?
5. What other types of post-diagnostic services do you think might be helpful for people with younger onset dementia and their families?
6. What do you think an 'ideal' pathway for post-diagnostic support for people with younger onset dementia should look like?
7. Do you have any additional comments relating to the above questions?

## Notes





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