Evaluation of The Alzheimer Society of Ireland Dementia Adviser Service Report

Item Type	Report
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Rights	CC0 1.0 Universal
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Link to Item	http://hdl.handle.net/10147/623818

Evaluation of The Alzheimer Society of Ireland Dementia Adviser Service

Report

31st August 2018

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Recommended Citation:

Coffey, A., Cornally, N., Hegarty, J., O'Caoimh, R., O'Reilly, P., O'Loughlin, C., Drennan, J., Clarke, C., Hartigan. I (2018). ***Evaluation of The Alzheimer Society of Ireland Dementia Adviser Service.***

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Abbreviations

AD	Alzheimers disease
VD	Vascular dementia
FTD	Fronto-temporal dementia
PD	Parkinson’s disease
VD	Vascular dementia
FTD	Fronto-temporal dementia
LBD	Lewy Bodies disease
PD	Parkinson’s disease dementia
NDS	National Dementia Strategy
HSE	Health Service Executive
ASI	Alzheimer Society of Ireland
PLWD	Person Living With Dementia
DA	Dementia Advisor
DAS	Dementia Advisor Service
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RCT	Randomised controlled trial
PHN	Public Health Nurse
UCC	University College Cork
UK	United Kingdom

Acknowledgements

This research was commissioned by the National Dementia Office with the support of the Office of the Nursing and Midwifery Services Director (ONMSD) Ms. Mary Wynne.

The authors wish to acknowledge Professor Charlotte Clarke Head of the School of Health in Social Science International Dean, College of Arts, Humanities and Social Sciences University of Edinburgh and Professor Jonathon Drennan Professor of Nursing and Health Services Research School of Nursing and Midwifery University College Cork who acted as expert advisors and collaborators for this review.

In addition, the team would like to acknowledge the guidance of the steering group: Dr John Linehan Office of the Head of Operations and Service Improvement, Ms Anna de Siún Senior Project Manager - National Dementia Office HSE and Ms Samantha Taylor*,* National Information & Advice Services Manager, The Alzheimer Society of Ireland.

The authors especially wish to thank the clients, family members, Health and Social Care professionals and the Dementia Advisers that participated in this research.

Executive Summary

Background

In Ireland, it is estimated that there are approximately 55,000 people living with dementia (Department of Health 2017) and this figure is predicted to reach 113,000 by 2036. The Irish National Dementia Strategy (NDS) launched in 2014, has identified priority action areas focused on timely diagnosis and intervention and integrated dementia care pathways. Navigating a health system can be challenging, frustrating and time consuming and a process compounded by a diagnosis of dementia. The Alzheimer Society of Ireland (ASI) piloted a Dementia Adviser Service (DAS) in Dublin and Cork in 2013 to build on and enhance existing information services, such as ASI's national Helpline. By the end of 2014, a further six Dementia Advisers were in post and by 2015, a total of eight were in post. Since 2016, the Health Service Executive (HSE) has co-funded this service.

The specific mandate of the DAS was to provide support and information to people with dementia and their carers living in the community. Subsequently, the National Dementia Strategy (NDS) stated that the HSE would "consider the provision of a Dementia Advisors on the basis of the experience of demonstrator sites, with an appropriate number of such Advisors to be dedicated to the needs of those with early-onset dementia" (p.23). To address this action and to inform the strategic direction and future policy for the management of dementia care in Ireland, an independent evaluation of the DAS was commissioned by the Irish National Dementia Office.

Aim

To evaluate the existing Dementia Adviser Service in Ireland from the perspectives of all key stakeholders.

Evaluation Design

The design of this evaluation is informed by best practice in evaluative research. A mixed-method approach was used which was underpinned by the RE-AIM framework (Green and Glasgow, 2006) as an organisaing framework to examine the Reach; Efficacy; Adoption; Implementation and Maintenance of the service.

Evaluation Methods

A mixed methods (qualitative and quantitative) approach was used to explore the DAS from a number of stakeholder perspectives. The evaluation was informed by the findings of a review of empirical and grey literature focused specifically on evaluations of dementia adviser or similar services internationally. This review informed the content of interview guides and the development of survey questionnaires.

Data collection methods were individual interviews and focus groups with current Dementia Advisers (n=7); Surveys distributed to three distinct stakeholder groups: (1) Clients of the DAS in 2017 who were Persons Living with Dementia (PLWD) (n=78); (2) Clients of the DAS in 2017 who were Family Carers (n=155) and (3) All Health and Social Care Professionals on the HSE email distribution list. Surveys were distributed to PLWD and family carers via post by the Alzheimer Society of Ireland and the survey to Health and Social Care professionals was distributed via the Health Service Executive (HSE) in email link to an online survey on Survey Monkey. In addition, case exemplars from two geographical areas were used to provide a more in -depth examination of the typical day to day role of the DA and an insight into the client cases managed by the DAS. Data for the exemplars were collected from anonymised client case documentation over a one- week retrospective period in April 2018.

Key Findings

The review of literature resulted in 16 papers identified that had conducted evaluations of a dementia adviser or similar service internationally. These evaluations were mainly conducted in the UK and all explored perspectives of PLWD and carers.

Results of the review provided evidence that the DAS was described as a single and consistent point of contact for PLWD and their carers and results suggested that the application of the DAS had a positive impact on all stakeholders in terms of support advice and signposting to other services. Only three studies had evaluated the DAS from the perspectives of Health or Social Care Professionals and although generally positive there was evidence of a lack of clarity in relation to role boundaries and calls for more integration with existing services.

Interviews and focus groups with DA's in this current study highlighted a multi-faceted role that has grown organically from an information and advice service to include advocacy, incorporating a wide variety of person-centred tasks to meet the growing needs of clients. Although the description of the role and scope of the DA is similar across regions, there are challenges with equity of access to the service as this differs according to its geographical location and in their connection with or level of embeddeness within existing Health and Social care services.

Our survey with PLWD provides evidence of overall satisfaction with the DAS particularly with the information, advice, support and signposting of services provided. The response rate to the survey was 33.3% (N=26) similar to comparable International studies. The majority of PLWD reported that the service helped them by providing support and understanding about dementia and confidence to ask questions. The response rate to the survey of carers / family of PLWD was low (24.5%) (N=38) however results show positive influences of the DAS on themselves and their family and that they valued the support and information provided. The most helpful aspects of the DAS as reported by carers were assistance with signposting to formal health and social care services, help with understanding dementia, help with legal and care planning, and help with informal social supports e.g. Carer support groups and Alzheimer café. Where the DAS service did not meet with carers expectations, this was mainly due to escalating clinical care needs or practical day to day support needs of PLDW and their inability to access such services through the DAS. Although the DAS regularly signposted clients to such clinical services, the provision of this type of support is beyond the stated role and scope of practice of the DAS.

In our survey of Health and Social Care Professionals there was 64% response rate (N=186) to the online survey with the highest response from Public Health Nurses (13%). The main reasons for contacting the DAS were: to help connect people with dementia, to learn about local supports and services, to provide information for families living with dementia especially post diagnosis, to support carers and families and the most useful stage for referral is early in the dementia diagnosis. Although Health and social care professionals mainly reported the DAS as helpful, they were not fully aware of the role and scope of practice of the Dementia Advisers. According to health and social care professionals, the DAS would improve with better integration with existing services, greater awareness of what the service provides and wider national coverage. All respondents to surveys called for an expansion of access to the DAS and stronger connection or integration with existing health and social care services.

Conclusion

The was the first evaluation of the DAS in Ireland and it has provided evidence of overall high levels of satisfaction with the service. Clients (PLWD and their carers) and Health and social care professionals reported satisfaction with the information, advice, peer support and signposting of services provided by the DA. It is evident that the current DAS has grown organically since its inception in 2014, in response to client needs. However there are some differences in the operationalisation of the service in different areas depending on the level of integration and connection with relevant local health and social care services. Neither Health and social care professionals nor clients were fully aware of the extent or scope of the DAS, therefore clarity of the role and scope of practice of the DA is needed. All stakeholders called for better integration of the DAS with existing services and greater public awareness and coverage of the service.

Recommendations

Using the Re-Aim framework recommendations from our evaluation are outlined as follows:

REACH

National expansion and development of the service:

This evaluation provides evidence of a need for an expansion of the DAS. All stakeholders (Clients, Health and Social care professionals and DAs themselves) recommended an increase in the number of dementia advisers to meet the increasing demand, as a result of the increasing prevalence of dementia. We recommend development of the service to achieve national coverage. In addition, strategies for ensuring optimization of the reach of the DAS e.g. further extending the presence of a DA at existing clinics, should be explored.

An identified Health / Social care professional to undertake the role of co-ordinator of care and clinical support:

It is evident from this evaluation that the peer support, advice, information and signposting to available services provided by the DAS are essential to PLWD and their carers. However, results show that as dementia progresses there are unmet clinical needs that are outside the scope of the DAS. To meet client’s clinical needs and promote continuity of care, we recommend the introduction of an identified Health / Social care professional to undertake the role of co-ordinator of care and clinical support. Such a role would be complementary to the DAS

EFFICACY

Equity of access to DAS for PLWD and their carers:

The impact of current DAS as evidenced from this evaluation is very positive in relation to the support and signposting of services for those PLWD and their carers who are fortunate to have access to the service. The DAS is currently not available countrywide, therefore support is dependent on the geographical location and the degree of connectivity of the DA with local community services. To ensure that the positive impact of the DAS is experienced by all PLWD in future we recommend that the service is extended and delivered within a consistent structure, with equity of access for all PLWD and their carers wherever they are located

ADOPTATION

Clarification of the role, purpose and scope of the DAS:

It was clear from our evaluation that the role of the DA as envisaged by the DA themselves and the ASI is to provide a timely and individualised information, advice, and signposting service for PLWD and their carers/ family. However the evidence shows that there was some confusion or misinterpretation of the role and scope of the DAS by both clients and carers / family. This confusion is also evident from Health and Social care professionals. We recommend that the role and purpose of the DA and scope of the DAS in post – diagnostic support for PLWD and their carers should be clarified and communicated to the public, clients and the Health and Social Care community. This would assist in meeting the persons expectations of the service and ensure no duplication of services.

IMPLEMENTATION

Early referral to DAS:

There was evidence in this evaluation that the DAS works with PLWD and their carers throughout their dementia journey. However all stakeholders agreed that the advice and information support interventions of the DAS are most appropriate and achieve better outcomes for the PLWD if accessed early in the dementia diagnosis. It is recommended that Health and Social care professionals and the public are encouraged to access the DAS as soon as possible following diagnosis in order to receive optimum benefit from the service and to have a local point of contact from the outset for further advice, signposting to other services and peer support as dementia progresses.

The development of direct pathways of communication to and from the DAS:

This evaluation provides evidence that client expectations of the scope of the DAS after initial contact went beyond the advisory and informational role of the DAS. Expectations of the service appeared to include the provision of more practical care and clinical support. Where such client needs are identified by the DAS, we recommend a pathway between the DAS and an identified Health / Social care professional who can coordinate care within existing services in each area. Where further advice and information is needed by PLWD or their carers at anytime in the dementia trajectory, direct pathways from Health / Social care professionals to the DAS would provide for a more seamless and efficient service. Ideally, such pathways should be supported by ICT.

MAINTENANCE

An efficient centralised and connected ICT support system:

As evidenced from our evaluation, Dementia Advisers play a key role in creating awareness and providing education to clients and health and social care professionals in conjunction with their substantive role in supporting individuals and their families. Although the system of administration of the service was reported by the DAs to have improved it was deemed not to be sufficient to meet the expanding needs of the service. To ensure that their time is used more efficiently and effectively we recommend that a centralised system of administrative and ICT support is made available to assist the DAs in the day to day management of workload and to ensure consistency in documentation communication and data management processes. It would be ideal and supportive of seamless support if this ICT system was connected to systems administration within Health and Social care.

Further research:

To measure the impact of support interventions provided by the DAS over time, we recommend a longitudinal study. To establish and measure the impact of the service on a number of outcomes for PLWD and carers e.g. quality of life or caregiver burden. This could include qualitative and quantitative methods to provide a more realistic and holistic view of the impact of the service on client's carers and the health and social services with which they are connected.

Chapter 1: Introduction

Background and Context

Dementia is an umbrella term used to describe a condition which may be caused by a number of illnesses that lead to a progressive decline in multiple areas of function including; impairment in memory, reasoning, communication skills and in the ability to carry out daily activities. At present, dementia is a progressive, incurable disease. Dementia is always caused by an underlying disease that damages brain tissue leading to disturbed brain functioning (Furnish, 2002). Dementia by definition interferes with cognitive function and performing activities of daily living (ADL). It is broadly categorized into two different types; cortical and sub-cortical dementia. The most common type, Alzheimers disease (AD), is a cortical dementia and this accounts for between 55 and 65% of all cases (Alzheimer Association, 2010). Other types of dementia include; Vascular dementia (VD), Frontal-temporal dementia (FTD), Lewy Bodies disease (LBD), Parkinson's disease dementia (PD), Mixed (AD and VD) (Goodman et al., 2017). Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their carers /family.

In Ireland, it is estimated that there are approximately 55,000 people with dementia (Department of Health 2017). Figures from the Department of Health predict that the number of people with dementia will reach 113,000 by 2036. The development of a National Dementia Strategy (NDS) was highlighted as a key policy goal under the 2011 National Programme for Government and followed the successful launch of similar strategies across the European Union. The strategy was launched in 2014 with matched funding from The Atlantic Philanthropies and has been widely welcomed by groups across Ireland and by organisations such as Alzheimer Europe. With six priority areas and 14 priority actions, it has set the scene for managing dementia care in Ireland.

The Irish NDS (2014) emphasizes the importance of timely diagnosis and intervention, integrated dementia care pathways including referral to memory clinics, and health services research into dementia including a strong commitment to dementia care research in both primary and secondary care. There are many challenges associated with managing the care of persons with dementia, in acute care or in the community, including healthcare professional-specific and patient-specific challenges. These were highlighted by Ireland's NDS (2014) as priority action areas, many of which are closely connected including:

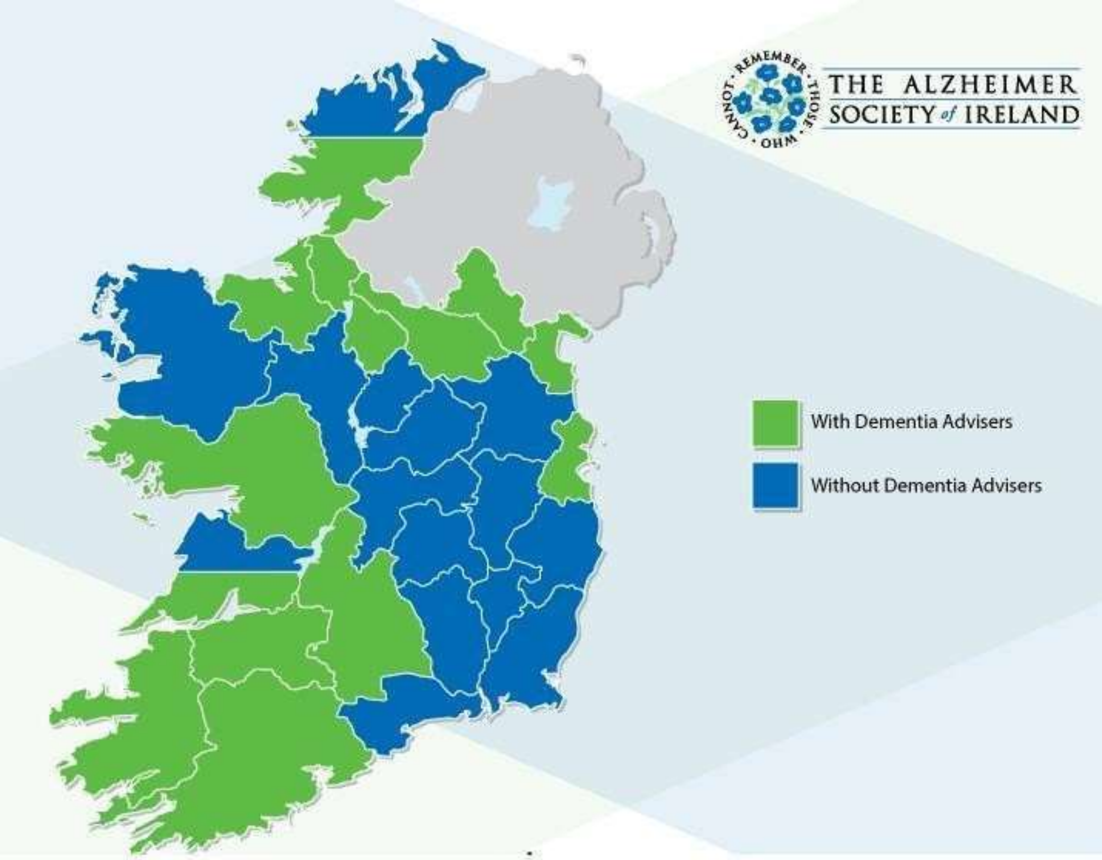
(1) Challenges to improving awareness (*Better Awareness and Understanding*),
(2) Issues relating to screening, diagnosis, and selecting appropriate treatments (balancing the risks, benefits and utility) of pharmacological and non-pharmacological interventions (*Timely diagnosis and intervention*),
(3) Providing connected integrated care for people with dementia and their families (*Integrated services, supports and care for people with dementia and their carers*),
(4) Training and Education,
(5) Research and Information Systems and
(6) Leadership

Navigating a health system in any country can be challenging, frustrating and time consuming. This process is further compounded by a diagnosis of dementia. Given the historic fragmentation of services and multiple sources of information, the need for a designated healthcare professional to co-ordinate and support the care of people with dementia evolved. Against this demographic landscape, The Alzheimer Society of Ireland (ASI) piloted a Dementia Adviser Service (DAS) in Dublin and Cork in 2013 to build on and enhance existing information services, such as ASI's national Helpline. By the end of 2014, a further six Dementia Advisers were in post and by 2015, a total of eight were in post.

Their specific mandate was to provide support and information to people with dementia and their carers living in the community. Subsequently, the National Dementia Strategy (NDS) stated that the HSE would “consider the provision of a Dementia Advisors on the basis of the experience of demonstrator sites, with an appropriate number of such Advisors to be dedicated to the needs of those with early-onset dementia” (p.23).

1.1. Dementia Adviser service (DAS) in Ireland

The Alzheimer Society of Ireland’s (ASI) Dementia Adviser Service delivers an information, advice and support service to people with dementia and their families. This service was piloted in Dublin and Cork in 2013 and by 2017, the DAS had grown to eight advisors working across twelve counties in Ireland; Cork, Kerry, Tipperary, Limerick, parts of Clare, Galway, Sligo, Leitrim, Cavan, Monaghan and Dublin. The service is co-funded by the Irish Health Service Executive (HSE) since 2015 (see appendix 1). The map below shows areas in Ireland covered by the DAS in 2017 at the time of evaluation.



The role of the DA as described by the ASI (appendix 1) *is to provide a locally based, individualised, information, signposting, and emotional support service to people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life.* This includes the provision of confidential information, advice and support to persons with dementia and their families to understand their condition, participate in their communities, to signpost to other appropriate services and supports and to provide early supportive interventions that inform their decision making and care choices. The DA's also conduct information and awareness sessions within their regions at local libraries, active retirement groups and community centres and via a mobile information service.

The activities of DA service are described as responsive to client needs and these include home visits or support by phone and email. DA's also facilitate Alzheimer Café and Carer support groups. While a key focus of the DAS is on early stage dementia and the newly diagnosed, the DA is a contact point for person's through-out the entire disease trajectory.

The operationalisation of the DA services has grown organically in each region and may differ in regions depending on the resources available and the connection of the DAS within existing health and social care services locally. In Dublin, Cork Limerick, Galway and Louth, the DA service is provided in weekly or monthly clinics within or alongside existing Health and Social Care services in addition to home visits. The service is flexible and responsive to clients needs, who can choose a home visit, or a meeting in a local ASI office or in agreed locations. Support by phone and email is also provided and at diagnostic clinics in several locations. Further detailed description of the recent developments within the DA service is provided in appendix 1.

A comparison of the DA role across France, England, Scotland, Northern Ireland and Australia by de Siún (2013), demonstrated that while many foundational features of the role are similar, some variations existed. For example, in France the DA undertakes a case management type role and is involved with disease treatment and longer-term management wherein Australia there appears to be a greater emphasis on training and education of other health and social care professionals (de Siún, 2013). According to La Fontaine et al. (2012), the role of the DA in the UK, is based on providing information on a wide range of topics to persons with dementia and their families. The most frequently sought information was related to diagnosis and disease prognosis but other topics included finance, advance care planning, social care and legal issues (La Fontaine et al. 2012). The DAS in Ireland is only in existence since 2013 but as elsewhere it has grown to meet the need of clients. Therefore to inform strategic policy and service development, an independent evaluation of the existing service was commissioned by the National Dementia Office.

1.2. Aims and Objectives of the evaluation

- To evaluate the existing DAS in Ireland from the perspectives of key stakeholders.
- To report on findings and make recommendations to inform strategic policy and service development in relation to the DAS.

The specific objectives:

- To conduct a review of International literature on evaluations of DAS and outcomes.
- To ascertain the role and structure of the DAS from the perspectives all stakeholders
- To assess the impact of the existing DAS on people with dementia and their family / carers
- To determine relevant health and social care professional's perception of the service
- To identify gaps in service provision and perceived service needs
- To make recommendations for future policy and DAS development.

1.3. Design of the Evaluation

The design of this evaluation is informed by best practice in evaluative research. A mixed-method approach was used and underpinned by the RE-AIM framework (Green and Glasgow,2006) as an organising framework. This framework was used as it places emphasis on the potential implications for delivering interventions in applied settings (Green and Glasgow, 2006). The framework according to Glasgow et al, (1999), is compatible with systems based and social ecological thinking as well as community based interventions.

The five dimensions, of the RE-AIM framework are:

- **Reach:** the proportion of the target population that participated in the service (penetration of the service)
- **Efficacy**: the success rate of the service if implemented as in guidelines; defined as positive outcomes minus negative outcomes (impact on target groups).
- **Adoption:** proportion of settings, practices and plans that adopt the service (participation rates and representativeness of the service settings)
- **Implementation:** The extent to which the service is implemented as intended in the real world (level and consistency of delivery components of the service)
- **Maintenance:** Extent to which the service is sustained over time (sustaining the service into the future at individual and organisational level)

As the aim was to include the perspectives of all stakeholders, the involvement of people with dementia was a significant part of this evaluation. The evaluation included a number of stakeholder groups: Clients of the DAS (persons living with dementia (PLWD) and their carers / family); Health and Social care professionals who refer clients to the service and the DAS providers (dementia advisers themselves). A mixed method approach was used. This combination of quantitative (survey questionnaires) and qualitative approaches (interviews, documentary analysis, open-ended qualitative comments from the survey questionnaires and case exemplars) was used to add scope, breadth and comprehensiveness to the evaluation (Patton, 2002; Twycross and Shorten, 2014). It is argued that a mixed-method approach complements and enriches different data sets (Johnson et al., 2007; Creswell et al., 2011). A particular strength of a mixed-methods approach is the use of narratives that can add meaning to measured phenomena; whilst the converse is also true, numbers can add precision to narrative descriptions, and mixed-methods can answer a broader range of research questions providing insights that may have been missed using a single method approach. All framework dimensions were examined through each phase of the study. The phases of the evaluation and relationship to the RE-AIM framework are presented in Table 1

Table 1. Phases of evaluation and relationship to framework

Framework dimensions	Phase of the evaluation
Reach: the proportion of the target population that participated in the service (penetration of the service) **Efficacy:** The success rate of the service if implemented as in guidelines; defined as positive outcomes minus negative outcomes (impact on target groups). **Adoption:** proportion of settings, practices and plans that adopt the service (participation rates and representativeness of the service settings) **Implementation:** The extent to which the service is implemented as intended in the real world (level and	**Phase 1** **Review of literature** A critical review of empirical literature and analysis of grey literature focused on reach and structure of dementia adviser service internationally. This review informed the content development of the survey questionnaires.
	Secondary data analysis to describe the service reach Analysis was conducted on available metrics from The Alzheimer society and HSE on: • Number of clients each DA has worked with and a geographic breakdown by county. • Who makes referrals into the service • What health and social care professionals engage with the service – e.g. work directly with diagnostic services with PHN's in the community • Penetration of the service
	Phase 2: Key informant interviews and focus groups Interviews and focus groups with Dementia Advisers: to identify their experiences of their role, service implementation and to identify gaps in service provision and service needs from their perspectives.
	Phase 3: Surveys of stakeholders **Three survey questionnaires:** **1.** Health and social care professionals that referred to the service. **2.** Survey of persons with dementia **3.** Survey of carers / family of persons with dementia. All surveys included both open and closed questions to capture both quantitative and qualitative data. To explore the efficacy and outcomes of the service

consistency of delivery components of the service) **Maintenance:** Extent to which the service is sustained over time (sustaining the service into the future at individual and organisational level)	**Phase 4: Case exemplars** Case exemplars of two separate geographical areas of service This included a documentary analysis of case notes and referral letters over a retrospective one – week period with examples of client cases. This was to provide a more in-depth view of the service provided in each area and the level and consistency of delivery.

1.4. Structure of the Report

This report is presented in 6 main chapters. Within Chapter 1 Introduction and background information, followed by the study's aims and objectives. In Chapter 2: a review of literature is presented outlining the methods and findings of a review of empirical and grey literature focused specirically on evaluations of the dementia adviser services internationally. Within Chapter 3 results of the key informant Interviews and focus groups with Dementia Advisers are presented. Results of survey questionnaires are outlined in Chapter 4 and Case Exemplars are presented in Chapter 5. Chapter 6 provides data integration conclusion and recommendations from the evaluation.

Chapter 2: Literature Review

Introduction

The aim of this systematic review was to:

a. Identify and discuss the empirical literature which reports on the evaluation of DAS;

b. Identify and discuss the grey literature which reports on the evaluation of DAS.

The methods employed in the Literature Review will be outlined followed by the results.

2.1 Methods

This desk-based research evidence review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher *et al.* 2009) and guided by systematic review methodology (Higgins & Green 2011a; Centre for Systematic Reviews and Dissemination, 2008). The inclusion / exclusion criteria for evidence in the review is presented in Table 2.

Table 2. Criteria for including evidence in the review

Inclusion Criteria:	Exclusion Criteria:
- English language publications, published from 2007 to date; - Publications that report on the empirical evaluation of dementia adviser service(s) or similar type services.	- Case studies, discussion or opinion papers that did not present research findings; - Research relating to general/ generic advisory services

The PICOS framework was adopted to develop inclusion criteria and a search strategy: POPULATION, INTERVENTION (dementia adviser) COMPARISON (no specific criteria applied); OUTCOMES (any measure used to evaluate the dementia adviser service); STUDY DESIGNS (systematic reviews, meta-analyses, meta-syntheses, primary studies of any design addressing the review aim).

2.2. Search strategy and search terms for empirical literature review

The process included sourcing published and grey literature, and screening journals. Search terms applied included keywords and subject headings relevant to each database Search terms included: Dementia OR Alzheimer* OR “Lewy Body” AND family N2 support OR "dementia advisor" OR Advis* OR Advic* OR “Admiral Nurs*”. A complete search strategy was developed with the support of a librarian.

2.2.1 Search processes

The following electronic databases were searched: CINAHL (the Cumulative Index to Nursing and Allied Health Literature), Medline, PyschInfo and the Cochrane Library. All references were managed and categorized using *Covidence [[https://www.covidence.org/]*. The PRISMA statement on reporting of systematic reviews (Liberati et al. 2009) guided this process. The search was run on the 24th October 2017.

2.2.2 Study Selection and Review Process

All records (n=947) retrieved during the database search process were exported to Covidence (an online software programme to enable screening of records following which duplicates (n=87) were identified and removed. Records (n=860) were screened by title and abstract, according to the inclusion criteria. The potentially eligible full text papers (n=50) were then read independently by two reviewers (AC, JH). Disagreements were resolved by consensus and if necessary involved a third reviewer. All decisions were recorded in Covidence. A summary of the search outputs from the review process is provided in Figure 1. A total of eight studies met the inclusion criteria.

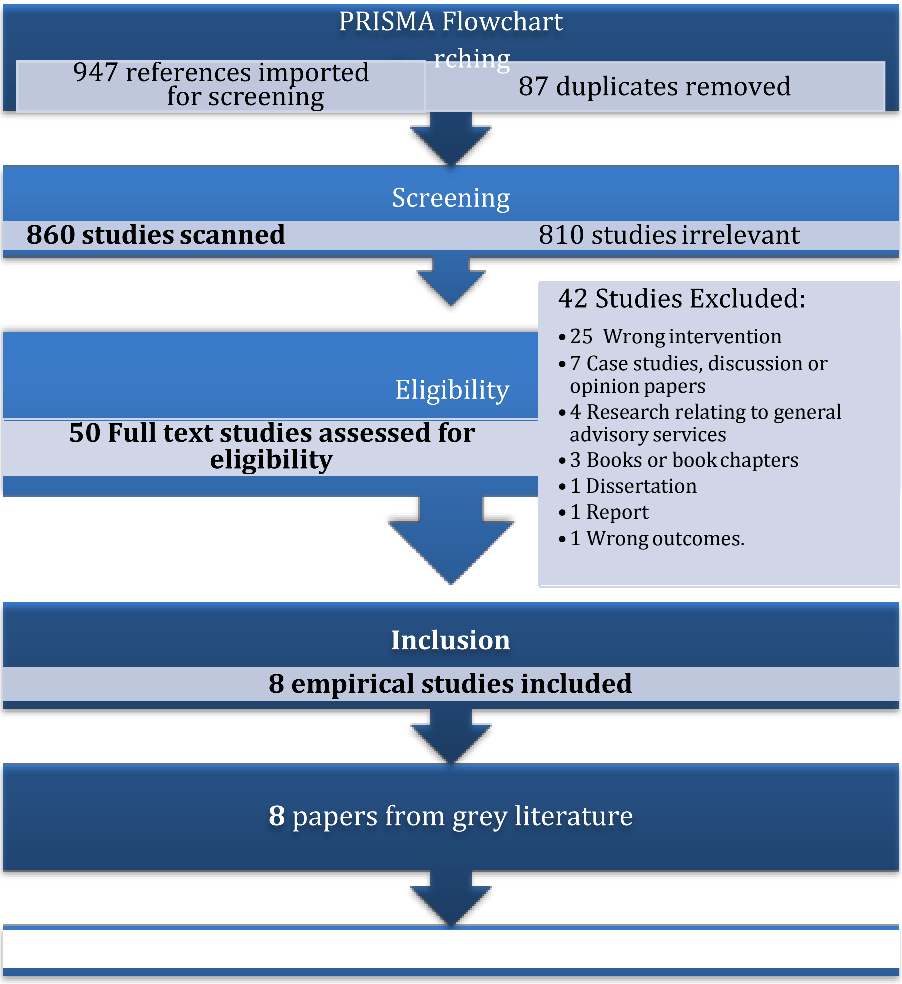


Figure 1. PRISMA Flowchart of the search, retrieval and screening process used for the systematic review of the empirical literature showing final number of studies included including grey literature.

2.3. Grey Literature Review

A grey literature search, was conducted using the same search terms as outlined for the empirical literature review. Included were unpublished evaluations, policy documents, annual reports and service plans about the dementia adviser services.

These searches were conducted in Lenus, Open Grey and Google Scholar. National and International websites that host key dementia care and services information were also searched. A further eight papers were identified for inclusion.

2.4. Data Extraction

Using a standardised form, data were extracted in tabular format by two members of the research project team (JH, AC). Included were authors, country, study design, sample, description of DAS or similar intervention, outcome measures and key findings (results) relevant to review objectives.

2.5. Data Synthesis

Results are presented under the following themes:

- Characteristics of included studies
- Description of Dementia advisor services or equivalent
- Key findings in relation evaluations of the service:
    - Perspectives of Person Living with Dementia (PLWD)
    - Perspectives of Carer of PLWD
    - Perspectives of stakeholders
- Benefits and feasibility of dementia advisor services or equivalent

Included Studies

A total of **16** studies were identified for inclusion

2.6. Review results

2.6.1. Characteristics of included studies

A total of 16 studies were included in this literature review, 8 from published empirical literature (Bunn et al., 2016; Clarke et al., 2014; Dias et al 2008; Goeman et al., 2016; Harrison-Denning et al., 2017; Kelly & Innes, 2016; Maio et al., 2016; Weatherhead et al., 2017) and eight from the grey literature (The Alzheimer Society, 2016; Daniel et al., 2011; Dayson & Bennett, 2016; de Siún, 2013; Hancock et al., 2014; Hibberd & Vougioukalou, 2012; Ipsos Mori, 2016; La Fontaine et al., 2011). The vast majority of the studies were conducted in the UK (n=11), with only one study from each of the following countries, India, Australia, Scotland and Ireland.

The methodologies employed in the reviewed studies are presented in Figure 2. These included one randomised control trial (RCT) (Dias et al., 2008); two quantitative cross-sectional studies (Ipsos Mori, 2016; Maio et al., 2016); six mixed methods studies (Clarke et al., 2014; Daniel et al., 2011; Dayson & Bennett, 2016; Hancock et al., 2014; Kelly & Innes, 2016; Weatherhead et al., 2017); one Social Cost Benefits Analysis (SCBA) study (The Alzheimer Society, 2016); three qualitative studies (Goemann et al., 2016; Harrison-Denning et al., 2017; La Fontaine et al., 2011) one of which was a case study (Harrison-Denning et al., 2017); one systematic evidence synthesis (Bunn et al., 2016), one descriptive summary (Hibberd & Vougioukalou, 2012) and one review and report (de Siún, 2013).

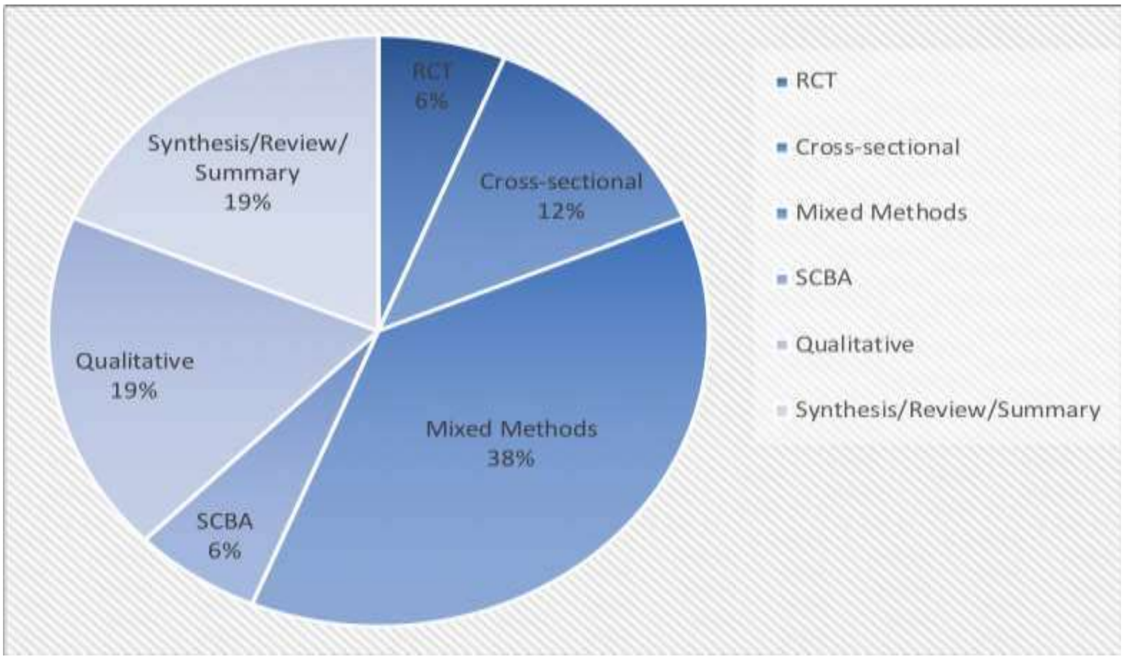


Figure 2. Methodologies used in the included studies

2.6.2 Characteristics of the dementia advisory service or equivalent

The majority of the studies reviewed were conducted in the UK. Two different terms were used referring to the provider of dementia advice: the Admiral Nursing Service which is a service provided by specialist registered nurses and the DAS. The dementia adviser is not required to have a nursing qualification and will refer medical aspects of cases onto the Admiral Nursing service or GP. Other terms for a dementia advisory / support service included the community and home based stepped care model in India (Dias et al., 2008), the Person-Centred Personalised Support model in Scotland (Kelly & Innes., 2016), a carers resilience service (Dayson et al., 2016) and a Specialist Dementia Nurse (SDN) service for culturally and linguistically diverse (CALD) clients in Australia (Goeman et al., 2016).

A similar theme throughout these studies was that the main aim or priority of the service was to enable swift and easy access for the PLWD and their carer / family, to support and advice following diagnosis. The DA and the DAS become a single and consistent point of contact for the PLWD, their carer and family throughout their dementia journey. A key feature of the DAS is that the service is embedded into and complimentary to existing services (Clarke et al., 2014; Goeman et al., 2014; La Fontaine et al., 2011). Partnerships with existing stakeholders are pivotal to the success of any DAS (Clarke et al., 2014, Dayson & Bennett, 2016; de Sun, 2013). In addition, these stakeholders were the primary source of referrals to the DAS.

Interventions provided by the DA or DAS included:

- Emotional, psychosocial and practical support to the carer and the PLWD (Bunn et al, 2016; Dayson & Bennett, 2016; Clarke et al., 2014; de Siún , 2013; La Fontaine et al., 2011)
- Needs assessment of PLWD and their carer (Harrison-Denning, Aldridge, et al., 2017 ; Dayson & Bennett, 2016; Goeman et al 2016; Clarke et al., 2014)
- Early intervention (Harrison-Denning, Aldridge, et al., 2017 ; La Fontaine et al., 2011 and crisis prevention (Clarke et al., 2014)

- Information/ advice (Harrison-Denning, Aldridge, et al., 2017; The Alzheimer Society 2016; Bunn et al, 2016; Dayson & Bennett, 2016; Goeman et al 2016; Clarke et al., 2014; de Siún , 2013; Daniel et al., 2011)
- Signposting to suitable formal and informal services (Goeman et al 2016; Clarke et al., 2014; Hancock et al 2014; de Siún , 2013; Hibberd & Vougioukalou 2012; La Fontaine et al., 2011)
- Future planning including advance care plans (de Siún , 2013; ; La Fontaine et al., 2011)
- Increasing awareness about dementia within the community (Dayson & Bennett, 2016; Clarke et al., 2014; de Siún , 2013; La Fontaine et al., 2011)

Descriptions of the dementia adviser or admiral nurse role were provided in the majority of literature reviewed. The role was described as a one-to-one single point of contact supporting someone with dementia and their carer, to access support; to self-manage; live independently, and access appropriate support and services (La Fontaine et al., 2011; The

The Alzheimer Society, 2016; Harrison-Denning, Aldridge, et al., 2017). The dementia advisers were described as persons that provided support and information predominantly for those people who are diagnosed with dementia and their family carers (Ipsos Mori,2016; Clarke **e**t al, 2014) and ease of access to appropriate care and advice (La Fontaine et al., 2011). There were differences in models of dementia support services and hence in the training and background of persons that provided the service. For example in a study by Kelly and Innes (2016) in Scotland the persons providing post diagnostic support for persons with dementia and their families were described as project managers with training in mental health and expertise in dementia, providing a type and intensity of support that varied according to assessed need. Several studies in the UK referred to admiral nurses, described as ‘mental health nurses who specialise in supporting family carers of people with dementia in the United Kingdom’ (Bunn et al, 2016; Weatherhead et al, 2017; Harrison-Denning, Aldridge, Pepper et al., 2017). In an Australian study by Goeman et al, (2016) support services were provided by a specialist dementia nurse (SDN) who was incorporated into the existing community services. The SDN undertook assessments, recorded case-notes and used a combination of face-to-face & telephone contact. The SDN undertook assessments, recorded case-notes and used a combination of face-to-face & telephone contact. In the UK Clarke et al, (2014) in their evaluation of the Dementia Adviser service described the DA as being embedded within mental health teams. Although in the studies reviewed the DAS providers were from various backgrounds, no study has compared the service provided by DAs with a clinical versus a non-clinical background.

In the UK, the role was set up as a result of the UK National Dementia Strategy to enable easy access to care support and advice following diagnosis (Daniel, et al, 2011). In Ireland the role was initiated to provide a local point of contact on an outreach basis for people who are concerned about their cognitive health or have a diagnosis of dementia and their families and friends, at all stages of the journey from diagnosis through to end-of-life (de Siún, 2013). According to Hancock et al, (2014) in the UK, the role of DA was established to provide a highly responsive individualised information and signposting service to people with a diagnosis of dementia and their carers and Admiral nurses are described as 'mental health nurses who specialise in supporting family carers of people with dementia' (Bunn et al, 2016).

Clarke et al (2016) described the DAs as enablers of access to a wide range of supports and others stressed that the DA should be responsive to the needs of their clients in order to be able to provide such an individualised and tailored service (Daniel et al., 2011; Dayson & Bennette 2016; Kelly & Innes, 2016). According to the studies reviewed the DA should have knowledge not only about dementia but also about the services in the area and about the legal and financial formal and informal supports available (Ipsos Mori, 2016; Maio et al., 2016; Clarke et al, 2014; La Fontaine et al.,

Characteristics of DA service

- Single point of contact
- Information & advice
- Signposting to services
- Personalised
- Responsive

2011;). Being proactive with follow-up was also seen as important in avoiding crisis (La Fontaine et al., 2011) and the provision of a personal service i.e. providing time and space to be listened to were also seen as important elements of the service (Hancock et al., 2014; Hibberd & Vougioukalou, 2012).

2.7. Key findings of evaluations of the DA service or equivalent

All studies included in this review evaluated the DA or equivalent services from the perspectives of persons living with dementia and family / carers.

2.7.1. Perceptions of the Person Living with Dementia (PLWD)

Studies that reported the perspectives of PLWD reported positive results in terms of information and support. Signposting by the DA to peer support networks was found to facilitate empowerment for PLWD (Kelly and Innes, 2016). In their conduct of a social cost benefit analysis of the DA services in West Lancashire in the UK, The Alzheimer Society (2016) reported a 40% improvement in building peer networks for persons with dementia. Hancock et al., in an evaluation of the Gloucestershire DA service indicated that 90% of PLWD were informed about other services and support from the DA. Similarly, in the evaluation of the Worcestershire DAS, most benefactors indicated that they knew where to go and how to get the services that they required (La Fontaine et al., 2011). Reporting on the Alzheimer Society pathfinder's dementia adviser service in the UK, Daniel, et al, (2011) found that 85% of PLWD felt listened to, respected and involved. According to this study, the introduction of a DAS was shown to enhance the PLWD' feelings of involvement in planning their care pathway, with the DA listening to, hearing and respecting their concerns (Daniel et al., 2011). An important finding for the PLWD was that they *felt supported* and that they had *someone who is on their side* (Daniel et al., 2011; Hancock et al., 2014). For PLWD living alone, Hancock et al, (2014) reported that the DA helped facilitate contact with other professionals and services and this helped build their self-esteem. A number of studies reported PLWD satisfaction with the service. For example, Hibberd & Vougioukalou (2012) in their summary of reports evaluating the Medway Dementia

Advisers Service in the UK reported that the DA service was successful in recruiting PLWD earlier in their pathway and that PLWD were satisfied with the information and support provided. However these researchers recommended more face to face assessments to improve the service. Using interviews with PLWD (n=14) during an evaluation of post diagnostic support services in Scotland, participants reported that the DA service facilitated independence and motivation by helping increase mobility and providing an individualised service (Kelly and Innes 2016). These results were similar to those reported by La Fontaine et al, (2011) in their evaluation of the effectiveness of the DA service in the UK. The key findings from semi structured interviews with PLWD (N=8) were a reported increase in self-confidence and emotional support. In Australia the CALD model of dementia support which involved the intervention of a specialist Dementia Nurse to provide clients with an advocacy service,found that the PLWD could step in and out of the service as needs changed with no time restrictions and this was seen as an important enabler of the Service success (Goeman et al., 2016).

One study included a comparison behavioural changes in the person receiving the DA service and reported that there were no changes in disturbances or behaviour of the person as a result of a DA intervention (Dias et al., 2008). In this randomised controlled study conducted in India, the intervention was a community based home care dementia adviser that provided education about dementia; management of behaviour; carer support- peer support groups; referrals to services and advice on existing schemes & entitlements (Dias et al., 2008). In general, results were that the PLWD valued the DAS, the information and the support that they received (Daniel et al., 2011; Hancock et al., 2014) and were satisfied with the information and support provided by the DA (Hibberd & Vougioukalou, 2012). A reduced mortality rate was observed in the intervention arm, though the mortality rate was still high in comparison to expected mortality rates in a western context.

Dementia Advisor
Key attributes

- Someone to trust and who is on their side
- Time & space to listen
- Flexible & knowledgeable

However it was speculated that there was insufficient time between the application of the intervention and the final assessment to observe any real changes.

2.7.2. Perceptions of Carers and family.

All evaluations of the DA and equivalent services included the experiences of the service from the perspectives of carers or families of persons living with dementia. Most were conducted through qualitative methods although there were two (Dayson & Bennett, 2016 and Dias et al, 2008) that used quantitative methods

Measures of Health related quality of life and well-being of carers [the Adult Social Care Outcomes Toolkit (ASCOT); were employed in a study by Dayson & Bennett, (2016). Results were that there was a general improvement in scores observed after the implementation of a *Carers Resilience Pilot Service* in Rotherham, UK , although the study was not powered to test for statistical significance due to low sample size and/or high attrition rate (Dayson & Bennett, 2016). Dias et al. in a study situated in India, demonstrated that the introduction of a community homebased flexible stepped-care model that included the intervention of a home care dementia adviser, led to an improvement in care giver burden and general mental health quality of life of the carer (Dias et al., 2008).

Carers perspectives on the value of the DA services

- Access to relevant timely information
- Single point of contact
- Accessible and practical advice
- Emotional Support
- Greater number of contacts equated to higher satisfaction levels

In general, carers indicated that the support from the DA was helpful (Maio et al., 2016) and they valued the DAS, the information and support that they received (Daniel et al., 2011; Dayson & Bennett., 2016; Hancock et al., 2014) and were satisfied with the information and support provided by the DA (Hibberd & Vougioukalou, 2012).

Carers that had increased contact with the service had higher satisfaction levels with the DAS (Maio et al., 2016). For example, a carer who had 5 or more contacts with the DA service was 2.2 times more likely (1.05-4.71: p=0.04) to find the service helpful and beneficial than those with less than five contacts (Maio et al., 2016).

Some of the primary concerns of the carers of PLWD related to maintaining the mental and physical health and wellbeing of the PLWD and understanding how they (as carers) could cope better, manage dementia related symptoms and behaviours (Weatherhead et al., 2017). Thus, timely and relevant information is particularly important for the carer as well as the DA being a facilitator in accessing services that would benefit the PLWD. A key theme emerging from the literature is the importance of a single source of support for the carer that is not just practical and hands on but that also provides emotional and psychosocial support (Hancock et al., 2014). The DA was seen as helpful to the carer and PLWD in accessing appropriate services (Daniel et al., 2011) nevertheless just over half (56%) of those surveyed said they would use the DA service as the first point of contact (Daniel et al., 2011). The DAS was also associated with an improvement in building peer networks for carers (The Alzheimer Society, 2016).

2.7.3 Perceptions of Health and Social Care Professionals

Only three studies in this review (Dayson and Bennett 2016; Goeman et al 2016; La Fontaine 2011) evaluated the perceptions of the healthcare professionals and stakeholders other than clients (carers and PLWD) about the DAS. La Fontaine (2011) conducted a number of interviews with key stakeholders (n=4) and health services employers (n=9) to evaluate the effectiveness of the DA service. Results indicated that the DAS was important in raising awareness of the needs of the carers, who often up to this point had not accessed services or support. Participants agreed that the DAS was a successful model of care for PLWD and their carers and had added value to existing services but they felt it important that DAS worked alongside and was based within existing services. Stakeholders identified: a poor understanding of the DA role; lack of openness to availing of the DAS; slow response to DAS referrals requests; poor capacity of services to meet the needs of

Health & Social Care perspectives

- Need more awareness about the DAS
- DA role clarity needed
- DAS needs to work alongside existing services

PLWD when signposted from the DAS as suitable services did not always exist (La Fontaine 2011).

Goeman et al (2016) interviewed Occupational Therapists and Clinical Dementia Nurses n=13 in Australia to refine a culturally sensitive model of dementia support. Although not specific to the DA advisory role respondents suggested that the role (Specialist Dementia Nurse) should have a set of core competencies and sufficient autonomy & flexibility to tailor support and information; conduct needs assessment; and manage changes in behaviour/circumstances.

Semi-structured interviews (n=7) conducted with Health Care staff in the UK by Dayson & Bennett, (2016) indicated that the service available to the PLWD and their carers had improved because of the influence of the DA: for example practice staff in GP surgeries reported to have improved communication and signage and building-adaptations for dementia service users as a result of the awareness initiatives communicated by the DA. Participants suggested that the DAS was a successful model of care but that the identification of the key role of the DAS was important and to encourage positive relationships between service providers /agencies (Dayson & Bennett, 2016). These stakeholders also suggested that challenges to the service would include maintaining the DAS intervention and the current model of care. They predicted an increase in demand for the service which may interfere with the current proactive model of DAS turning it into a reactive crisis intervention service instead (Dayson & Bennett, 2016).

2.8. Enablers and Barriers to the DA Service

Nine of the reviewed studies included a discussion of both enablers and barriers to the existing service (Bunn et al, 2016; Kelly and Innes, 2016; Dayson & Bennett, 2016; Goeman et al 2016; Clarke et al., 2014; de Siún , 2013; Daniel et al., 2011; La Fontaine et al., 2011; Dias et al, 2008). Two papers (Hancock et al, 2014; Weatherhead et al, 2017) included barriers only.

2.8.1 Enablers

The enablers mainly revolved around collaboration with other services and the type of service provided to clients. According to La Fontaine et al., (2011) the clarity of the role of the DA and the extent of the collaboration with the existing dementia services was important to its success. There was agreement that enablers of the DAS were successful partnerships with memory clinics and other community services (Dayson & Bennett, 2016; (de Siún, 2013) and a reliable and efficient, web based system of information and data collection through electronic databases (Daniel et al., 2011). However recommendations were to encourage more GP, community psychiatric nurse, social services and home care referrals to the service (Clarke et al, 2014). Once the DA role and purpose as a specialist service were clarified with other organisations there was typically a positive knock on effect for all organisations involved in the care of the person with dementia & the carer leading to facilitation and liaison with other services and professionals (Bunn et al 2016).

Enablers

- Collaboration with other community services
- Reliable data systems

A key theme from the studies revolved around the processes that were important when establishing a DAS. The most important aspect of setting up a DAS was the degree of the relationship with stakeholders and current providers of a dementia service. Both the Clarke and La Fontaine studies emphasised the importance of embedding the DAS within existing services-including having a physical space within those services. When lack of integration occurred it was usually as the result of a lack of communication and understanding about the role of the DA and the boundaries of care/intervention that a DA could or should use with the PLWD and their carer. Thus, partnership with the existing stakeholders is pivotal to the success of any DAS (Clarke et al., 2014; Dayson & Bennett, 2016; de Siún 2013).

In relation to client services, the type of service recommended in the literature is: personalised and flexible (Kelly and Innes, 2016; Goeman et al 2016; Dayson &

Bennett, 2016), with a carer centred, relational approach (Bunn et al 2016). As part of the DAS, home based and supportive group services were advocated (Dias et al, 2008) along with increased contact with the DA, hence knowledge about dementia in an emotionally supportive manner (Dias et al, 2008). Dayson & Bennett, (2016) found that the employment of additional DA staff was necessary to cope with the initial demand of the service that included PLWD with complex needs.

Two studies focused on cost savings following the introduction of a DAS. One such study conducted by The Alzheimer Society (2016) on two of their DA services using a social cost benefits analysis (SCBA), showed a 21% reduction in the cost to mental health services by helping carers to avoid breakdown-suggesting a considerable return in investment of the DAS. In India, the future success and sustainability of their dementia support intervention was enabled by keeping costs low and using the resources already available without introducing unsustainable added costs to existing services (Dias et al., 2008).

2.8.2 Barriers

Among the barriers to establishing a DAS highlighted was that the service area was a lack of awareness about the nature of the service among other healthcare professionals providing dementia services and lack of role clarification, leading to slow referrals to the service (Hancock et al, 2014; La Fontaine et al., 2011). Thus a core aspect of the DA role inevitably involved raising awareness about the role to healthcare professionals who were a potential referral source to the DAS and to other stakeholders in the community to whom the DAS signposted. Clarke et al. (2014) commented that local organisations in their area misunderstood the role and purpose of the DA service within the current dementia pathway and in some cases this fostered mistrust and competition between services. Confusion in relation to roles and boundaries and concern about the potential duplication of

BARRIERS

- Lack of awareness about the service
- Service area not prepared
- Fostered mistrust and competition between services
- Role boundaries confused
- Challenges with access to the DA service

services was also apparent in the literature. For example, Bunn et al (2016) noted that clients felt that GPs, specialists and care managers did not work with or communicate with Admiral Nurses and there was confusion among Admiral Nurses and community psychiatric nurses over the boundaries of their roles. According to Clarke et al, (2014) organisational space i.e. infrastructure within immediate services, as well as the position of DAS within the external health and social care landscape influenced the ability for effective partnership development, maintenance and sustainability of the service (Clarke et al. 2014).

Studies also found a lack of clarity among the public about the term DA and inability to distinguish the DA role from other professionals providing a dementia service (Hancock et al., 2014). Thus raising awareness of what the DAS is and the DA role is also important in the community at large. de Siún (2013) identified the challenge of time in establishing a DA service. A further issue may be an initial high demand with a significant level of crises intervention involving complex case-management (Dayson & Bennett 2016). Challenge with access to the service was highlighted as a barrier in a number of studies. For example, in Kelly and Innes (2016), PLWD indicated increasing difficulties in travelling to access services and lack of confidence in using public transport. Geographical spread was identified by Weatherhead et al, (2017) as a cause of problems with access for clients and Dias et al, 2008) reported access/mobility problems causing 46% of carers non-attendance at group meetings. The timing of access to the service was also highlighted as an issue by de Siún et al, (2013) who reported that PLWD who were least satisfied with the service were those who accessed the service later in their pathway post diagnosis; those who have little contact with the DA service and who were not linked to peer support services like dementia cafés.

Conclusion to the literature review

A limited number of studies have evaluated the DAS as a holistic service. In this review of empirical and grey literature (2007 – 2017), a total of sixteen studies were identified. The vast majority of the studies were conducted in the UK (n=11). Research designs varied with the level of evidence, in terms of study design, being low on the evidential hierarchy, sample sizes were generally small and cost benefit analysis were rare. Descriptions of the DAS or equivalent identified a priority of the service as enabling swift and easy access for the PLWD and their carer or family, to support and advise following diagnosis. The DAS is described as a single and consistent point of contact for the PLWD, their carer and family throughout their dementia journey. Four of the studies examined an equivalent service where the service providers were known as admiral nurses. The background of the DA's other than Admiral nurses was not described or discussed in studies. The supports provided included emotional, psychosocial and practical and onward signposting to community supports and services as required. DA's facilitated information/ advice and future planning. The DAS was described as an enabling service, facilitating access to a wide range of supports (Clarke et al, 2016) and responsive to the needs of clients through the provision of individualised and tailored service (Daniel et al., 2011; Dayson & Bennett 2016; Kelly & Innes, 2016). From the review the DAS service across countries is provided by individuals with different professional backgrounds. However no studies have focused on this aspect or have sought to compare the impact on services or service outcomes resulting from the clinical or non-clinical background of service providers.

All studies included in this review evaluated the DA or equivalent services from the perspectives of persons living with dementia and family / carers. The evidence presented in these studies overwhelmingly suggest that the application of a DAS has a positive impact on the PLWD, the carers, on Health and Social care professionals and on the overall quality of care available to a PLWD and their carer.

An important findings for the PLWD was that they *felt supported* and that they had *someone on their side* (Daniel et al., 2011; Hancock et al., 2014). However, PWLD called for more face to face contact to improve the service (Hibberd & Vougioukalou, 2012). An important enabler to the success of the DAS was no time restrictions in visits or access to the service (Goeman et al., 2016). Key attributes of DAS identified by

PLWD and carers were; having access to a flexible and knowledgeable practitioner; having someone to trust (Daniel et al. 2011); time and space to listen (Goeman et al., 2016).

Carers and family in general, indicated that the support from the DA was helpful (Maio et al., 2016). They valued the information and support that they received (Daniel et al., 2011; Dayson & Bennett., 2016; Hancock et al., 2014) and were satisfied with the service (Hibberd & Vougioukalou, 2012) and their support in building peer networks (The Alzheimer Society, 2016).

Only three studies in this review (Dayson and Bennett 2016; Goeman et al 2016; La Fontaine 2011) evaluated the perceptions of the DAS from healthcare professionals perspectives. Results indicated that they were generally positive about the service once it became established and roles and boundaries of the service were clarified. Recommendations from these stakeholders included; increasing awareness about the DAS; DA role clarity and reinforcement of the need for to work alongside existing services. The enablers of the DA service mainly revolved around collaboration with other services and reliable data systems. A number of barriers were highlighted in the literature. These mainly stemmed from a lack of clarity about the role and confusion in terms of role boundaries and lack of awareness of the extent of the DA service.

The complexity and ever-changing nature of the dementia journey calls for a service that is individualised and flexible in order to provide adequate and appropriate support. Evidence suggests that although there are positive client experiences of the service, more awareness and clarity is necessary about the role and services provided by the DA to encourage more acceptance and embeddedness within the existing services. There is evidence that what may have emerged as a simple model of information, advice and support for PLWD initially has evolved into a service that requires practitioners to have more depth of knowledge, flexibility and creativity and a DAS which id fully integrated with existing services to fully execute the model of care and support required.

Chapter 3: Focus groups and interviews with Dementia Advisers

Introduction

This chapter describes the methodology for the semi-structured qualitative interviews and focus groups with the Dementia Advisors and presents the results and main themes from their analysis.

3.1 Aims

The aim of the interviews and focus groups were to explore the DA's perceptions and experiences of their role and service and their perspective of gaps in service provision and service needs. This qualitative phase also sought to explore the impact of the dementia adviser service on the PLWD and their families.

3.2 Methodology

A qualitative descriptive approach was applied to this phase of the evaluation.

Following ethical approval for the study from the Clinical Research Ethics Committee of the Cork Teaching Hospitals, key informant telephone interviews were conducted with all seven DA's currently in place in Ireland. The DA's are located in seven distinct geographical areas around the country. Prior to conducting the individual interviews, participants were invited to take part in a focus group discussion. The purpose of the focus group was to draw upon collective experiences in a way in which would not be feasible using other methods. Dementia advisers were invited via email to participate. These were then divided into two focus groups conducted concurrently in a pre- arranged venue and facilitated by four of the researchers (two with each group). One of the researchers facilitated the discussion and the second acted as field note taker for each group. This facilitated open communication and allowed each DA to express their views. Prior to the focus group interviews the DA's were provided with a participant information sheet with an explanation of the study (appendix 5) and asked to provide their consent via written consent form (appendix 3) The focus group interviews were audio-recorded and semi-structured.

Interviews were semi structured, following an interview guide adapted to the context and aimed at gaining an insight into the experience of the DA role and service. The semi-structured interview schedule was developed drawing upon the available literature. Participants were asked to provide a short demographic questionnaire describing age, area of practice, how long they were in their role, years of experience, whether they had a clinical background and whether they had a qualification in gerontology. The DAs were then invited to describe their role and the structure of the DAS. In addition, the interview guide included questions that explored the impact of the dementia adviser service. Questions were purposely broad to allow participants to begin the conversation at any point of importance to them. Empathetic responses and probing were used to help elicit rich descriptions. Questions relating to the specific study objectives were also asked when not addressed during the natural dialogue of the interviews. At the end of the interview an opportunity was provided for participants to discuss the interview experience and any issues raised by the process. The key informant interviews lasted between 40 and 60 minutes and data from these interviews assisted in further clarification and extension of data collected from the focus groups.

3.3. Data analysis

Data from the focus groups and interviews were transcribed by a professional transcription service into a word document. These documents were imported into NVivo Version 11 for coding and were analysed together to ensure the anonymity of the DA’s. The data were then analysed using manifest content analysis (Graneheim & Lundman, 2004). A qualitative framework was developed based on the interview and focus group categories and this was used to organise the interview data in NVivo. The obvious components’ of the text were highlighted into nodes/themes and grouped according to the predetermined categories of the interview guide. These sections of text or statements were subsequently labelled ‘meaning units’. These were then reread and key words extracted to form ‘condensed meaning units'. These data were presented in table format for ease of interpretation and further commonalities were assembled. Codes were then developed to reflect the meaning of frequently occurring statements within each category. Common emerging codes were grouped to form subcategories. All interviews and focus groups were coded together using the interview questions and topic guide for individual interviews and focus groups as a format to establish themes. Data and trends were visualised using a tree map of nodes, word clouds across all nodes and hierarchical graphs and a node summary report.

3.4. Results

Six DA's were available for interview. Most of the DA's reported that they were in their post for more than 3 years. Two of the DA's had a qualification in Nursing and the reminder held Social work, Management or Community Development degrees. The majority had worked with older adults for more than a decade, with two working in the area for over 30 years (Range 5-30yrs, M=23).

Figure 3. Wordcloud of coded themes from interviews and focus groups

Six broad categories were used to present the data findings. Categories were reflective of the topic areas on the interview guide and served to address the key objectives of the evaluation. These included the role of the DA service structure, impact of the service, facilitators to the DA service, challenges and areas for improvement.

Category 1: Role of the Dementia Advisor:

When asked to describe their role, the DA's were in agreement that they provide information advice and support to PLWD and their families. All the DA's also mentioned their role in assisting clients to access appropriate services and in creating a link between services. Information giving was described as a central feature of the role, and also referral of clients to other Health and Social care services according to their needs. One DA felt that the role included advocating on behalf of clients as evidenced in the following quote:

> *"I suppose, where that comes in to play, where a person finds it hard to access services, and I would play a bit of a role here as well. I would contact the service providers or whoever needs to be contacted, and nearly put the case forward for why they need a certain service, in order to access it and get it up for the person. So you're kind of doing, on some cases, advocacy."*

Signposting to services and providing emotional support for PLWD and their families were described as a core attributes of the role. A unique aspect of the role of the DA was described as the ability to spend time '*to sit with*' the client and help them *navigate the complex social and health system* and *explore different solutions* to managing day to day challenges. As the following DA statements explain:

> *From solicitors to hospital consultants the DA makes links for people with information and care needs*.

> *"The DA connects people with supports and services that need not be dementia specific – depending on the stage of the dementia. They focus on quality of life and keeping people connected in their communities. This can be difficult for Healthcare professionals with time pressure"*

Although many facets of the role were described, all DAs clearly articulated that their role did not entail addressing complex clinical care needs. While the role encompassed working in partnership with other services they described themselves as *not a crisis intervention* but a *crisis avoidance or prevention* by providing advice and information to inform client decision making and care choices.

Furthermore DAs stated that counselling and/or mediation were not seen as defining attributes of the role but they did have a role to play in providing emotional support

> *"Got them linked in with who they needed to be linked in with and services they needed to be linked in with."*

Essence of the Role

"The DA is not time bound….."

"A common reaction when a diagnosis is received is to close the door and not to talk about it. Sometimes it is self- isolation or maybe social isolation. The DA can open up a world where people with dementia can continue to engage and reach out."

"The DA connects

Category 2: Service Structure:

Overview

The DA's described the embedding of their role within existing service structures as initially challenging. They spoke about the role as part of the wider multidisciplinary service structure for PLWD and their families but also being the link that brings the social and clinical services together for many families struggling to navigate the complex care systems. The importance of working together and securing their place with existing services was described by the DAs as essential to their role as in the following statement:

> *"It's working with the group, you know, the multidisciplinary team rather than, you know, on the periphery"*

> "...most HCPs are now referring to the DA, most now see the value of the DA..."

While the DA offers direct information and support services provided by the ASI , the DAs also discuss with clients their current needs to identify community services outside of the ASI provision that might best meet their needs.

"But we look outside of the ASI, The Alzheimer Society, for services. The likes of men's sheds, active retirement groups. It depends on the person, where they're at and how appropriate the service is. So we wouldn't just look internally, we would also look at community services, what's in the local community, what they're able for, what their ability is. And also what their background is."

Referrals

DA's identified the sources of referral into their service as coming from two key areas; Healthcare professionals and from the ASI. Client self-referral was also noted to be on the increase. Referrals from healthcare professionals came from a number of sources: Public Health Nurses, GPs, Occupational Therapists, Homecare Co-ordinators, Community Groups, Social Workers, Dieticians, Consultant Geriatricians and Psychiatry of Old Age, and Speech and Language Therapists. The DAs were open to taking referrals from anywhere once there was an identified need for a PLWD or their family. All modes of referral are used and accepted but these were mainly written (via letter or email), from professionals and phone calls from family members.

> *"It can be email. We have a written referral from professionals. Families can just phone us up themselves and ask us. You know, a lot of people will just phone directly. They might get the phone number off the website or they might ring the helpline and get the phone number from there may be and they would just phone us. We've had a few emails as well, particularly from adult family members who are living abroad now. People in England, America, Australia, they would say, 'Look, I've someone at home and they're in your area'."*

Interventions:

Once referred to the service the DA's described a number of support interventions that can be offered but reiterated that these supports depended on the stage and circumstances of their diagnosis. One of the DA's stated that support can even extend beyond the life-time of the person with dementia to include support and advice for the bereaved relative.

> *"Because on this journey, it may very well start off with the person living with dementia and their partner, but then you know, the relationship changes because as the person progresses through their dementia, it's the carer who's advocating their needs, you know, the assistance that they need, etc. So, your role does change and then if unfortunately that person goes into long-term care or passes away, the carer still needs you for a period of time, you know, because they've got that whole transition and it is difficult to just walk away from that."*

Specific DA interventions were described as those that range from something simple such as photocopying information leaflets on Enduring Power of Attorney to more complex support and advice requiring a series of visits and the development of an action plan. All of the DAs stressed the importance of ensuring that information and associated actions were tailored to the clients' needs.

> *"…there's a lot more people post diagnosis that are accessing the service. And with that then, there's a lot more emphasis on the legal side of things, the financial side, driving all these issues that are very relevant, particularly in the early stages of diagnosis. And again, giving the person that information at that time, that they can feel empowered, but allowing them to try to do as much of what they can for themselves."*

DAs described how they endeavoured to ensure that all members of a family are provided with the same information. This is to reduce the possibility of any conflict within families. DAs also support families to help them gain confidence in caring for their loved one with dementia. As evidenced in the following DA statement

> "I also encourage, you know, family members to support the person with dementia, to take them out, to bring them wherever they like to go, to do nice things with them, you know, and not to make them feel any different because what we're trying to do as well is to reduce the stigma"

Category 3: Impact of the Service:

The DA's described the impact of the DAS in three main areas; (1) impact on family, (2) on the PLWD, and (3) on health and social services. They perceived that the DAS had an impact but the level of impact varied and was determined by the needs of the clients and stage in their diagnosis at which they accessed the service.

As one of the DA's stated:

> *"To be honest, I think it has a big impact at every stage, because a lot of people that we meet even though, it's not early stages, might not have any interventions or any services involved. So you could be meeting someone that's been diagnosed two or three years, and nobody has been involved following on from a diagnosis. So it depends on the person, who's involved, and I suppose, the level of information you have to give them."*

(1) Impact on Family:

The impact on family was referenced in all seven of the DA interviews. In the opinions of the DA's, client and family empowerment was described as one of the keys impacts of their service. DAs expressed the opinion that with such a challenging diagnosis, providing targeted information to clients, which was case specific led to their empowerment and assisted them to navigate a complex health and social care system. Through community engagement and information sessions the DAs felt they had raised significant awareness regarding the disease among the general population; this they believe has had a positive impact on reducing the stigma associated with dementia.

> *"Like years ago families would ring me and say, oh they told me dad has dementia but they never told dad. So do you know, I think the way we're looking at and the way we're addressing it but also the way we're highlighting it in the community through the likes of your mobile bus, the dementia awareness campaign, the dementia friendly communities, you know it's given people the information, highlighting it in the community and taking that stigma piece away. So people aren't afraid to actually approach somebody with dementia or know what to do if somebody with dementia came into their shop."*

Another impact of the service related to their assistance for carers in '*making the everyday a bit easier'* This was described by DA's as giving them confidence to continue in their role or validating what they are doing on a daily basis. The DA's were of the opinion that educating family regarding the disease and what to expect had an impact on preparedness for the next stage of the disease.

> *"the vast majority is of family carers who are doing their level best and sometimes they're doing their level best and they're not hitting it right because they don't understand the condition and they're frustrated maybe on the correcting. Should I correct Mammy? No. You know and then you explain it to them and that makes life a lot easier for everyone and that's something that I feel we achieve you know?"*

Family conflict regarding the best approach to care is a frequent occurrence when a loved one is diagnosed with Dementia. The DA's felt that the DAS had an impact on this and could assist, though the provision of information, in bringing a family together to create a plan of care that would be in the best interests of the PLWD..

> *"So I feel often the biggest impact I have is getting families on to the same page with regard to a certain aspect of care planning and support planning for their loved one."*

DAs described making the journey emotionally easier for family so that they could still enjoy the person they love. One DA spoke about being '*only a phone call away*' and this created a '*sense of security for the family and reduced the feeling of isolation and helplessness*'. Reducing worry and loneliness was also supported by the feedback they received from family members.

> *"…said to me, you know, 'I wish I met you a few years ago when this all started because you would have reassured me and we wouldn't have felt so alone or not knowing what to do or not knowing where to turn, do you know'."*

The DAs felt that they had an impact on family member's knowledge and understanding of the disease and what it might be like for the PLWD. Providing this insight, albeit perceived as a simple thing, impacted greatly on relationships. The following exemplar demonstrates the direct impact of the DA on the relationship between a family member and a PLWD.

> *"I had one particular lady who had called me and that whole thing of correcting her mother and going in to the house and checking were the clothes washed, was there food in the fridge. And you know, it was just a simple little conversation I had with her, but I said you have to stop and you need to go in and visit your mother again as her daughter. Go in, sit down, go hi mam, how was your day? Simple little question. If your mother's still capable of making a cup of tea, say mam I'd love a cup of tea. Allow her to make the tea. Sit and have that, but you can subtly check the areas that you feel need to be monitored, but without doing it that way. And she actually wrote me an email back and said, I can't thank you enough because I had a conversation with my mother today and it was wonderful, and we haven't talked like that in two or three years."*

(2) Impact on PLWD:

According to DAs , for PLWD the impact of the service was far reaching, especially for people in the early stages of the diagnosis. They felt that their meetings with the PLWD supported them to '*feel empowered and reassured*'. This they felt was as a result of information sharing and practical tips provided for living well. The following exemplar provided by one DA highlights the impact of the DA service on a client's sense of empowerment and control.

> *"one man particularly was quite frightened over the diagnosis and his fear was, if he did enduring power of attorney, that was it. His family could step in, start making decisions and he would have no voice whatsoever. But once it was explained what the enduring power of attorney was, the reasoning for doing it and his role within that process, he was absolutely fine with it. But it was kind of giving back, giving back the information and giving him back the power to make that decision and he felt then more in control. And really, that meeting is*

> *… That was the effect of that meeting. He felt, going out that door, even though he had a diagnosis, he felt he was going out with control and options."*

The DAs reported that as a result of the awareness campaigns and information sessions they provided locally and nationally, they received feedback from clients that these activities helped them feel less isolated from society and more accepted in their community. Furthermore, the DA felt that their role helped to divert crisis by as they were the one constant for the PLWD. The reassurance that they can pick up the phone and have a direct conversation with someone about their diagnosis and have the same point of contact over a period of months/years can reduce worry and anxiety.

> *"I think of late what we're finding is …..for the person with dementia I think it's just unsure and they need that reassurance, do you know and it's just to pick up the phone and say listen this is what's happening for me, what do I do. It's more that reassurance, keeping that emotional piece."*

(3) *Impact on Health and Social Care:*

A somewhat negative impact described by the DAs is the increasing volume of referrals that they are making to services and the subsequent challenge that this might be having to the services, particularly if the service is already stretched and the level of demand was not planned for.

Conversely, the DA's expressed the view that if involved early on in the clients' disease trajectory the presence of their service somewhat reduces the burden on other health and social care services

As in the statement below:

> *"They would see I suppose less of the crisis coming to them, less of the inappropriate I suppose re-referrals back into maybe services. But also it's taking pressure off them"*

The DAs reported that they are often seen as a point of contact for a variety of health and social care professionals for guidance or advice. For professionals that come into contact with a PLWD, the DAS, was described by DA's as a resource that others can refer to and can complement the broader health and social care services.

An example of connection with health care professionals provided by the DA's was the option of referral from the DAS to a rapid access clinic in the Charter Medical Smithfield Clinic in Dublin. The DAS as part of a new partnership agreement can now refer people with dementia who require an urgent, but non-critical review with a geriatrician to a rapid access health screening clinic. This referral pathway was set up according to the DA's '*due to the demand for the service from healthcare professionals'.* In addition, since 2017 there are also four monthly DA clinics embedded within diagnostic services provided by Tallaght Hospital, Connolly Hospital and and St Finbarr's Hospital in Cork and a further clinic, by appointment based on demand, in St Ita's Community Hospital Newcastle West, Limerick. The DA clinics are where diagnostic teams / phn teams have agreed to provide a space and actively refer their patients into the DA service as part of their post diagnostic supports. The ASI developed these clinics with the teams over time and as relationships developed and awareness of the DAS grew.

> *"I suppose, with the healthcare professionals, it is as I said, we are a resource that they can now use. It allows them to continue doing what it is they do on a daily basis. It takes a little bit of pressure off of them because we are now in a position where we can go in and we can give that time to a family. But we're also there to advise them in relation to if they have a particular case and if they're unsure of where should I go with this? What should I do next?"*

According to the DA's collaboration with health care professionals such as in these clinics, has an impact on the workload of the professionals and also assists in the review and medical and social needs assessment of PLWD by professionals at an earlier stage in the disease, which supports better care planning.

Category 4: Facilitators of the DA Service:

Discharging the role of the DA is not without its challenges; nonetheless facilitators of the role and the service were described throughout the focus groups and individual interviews. The role facilitators named by DA's related to collaboration and relationships with healthcare professionals; support from HSE management; more recognition of a social model of dementia care; visibility of the DAS through the ASI website (staff & helpline); rapid access clinics, and the additional services that the DA can refer to e.g. Sage Advocacy and Family Carers Ireland.

Having a good knowledge of local services and good working relationships with healthcare professionals in the local and regional area was described by DA's as an important facilitator of their role. When their role is supported by the broader health and social care service this helps the DA to provide timely information and assist in the ensuring continuity of care. A good working relationship with public health nursing services is described by one DA in comment below:

> *" you know public health nurses particularly, probably more than GP's to be honest. I do get referrals from GP's but it's more…I would get more from the public health nurses. The public health nurses will ring up and they'll talk to me and they will say, what do you think….you know they might ask even for advice on a particular case. So I've a very good working relationship with them and I suppose your relationship develops and your role develops accordingly"*

In the comment below one of the DA's describes the introduction of a standardised referral form between the public health nurses and the DAS in her area and described this development as greatly helping to improve the information provided and reduce time between notification of a client in need of the service and setting up an initial meeting.

> *"I think with regards to the public health nurses, we introduced a referral to form part of that. We didn't have one. And that made life a lot easier because you're not spending time on the phone speaking to a public health nurse in relation to a client they want to refer to you. They're simply putting it down on paper and sending it in to you, so that saves time as well. The clinics that we set up, again they're enabling us to see more people in one day than sometimes we might get to see in a week."*

DAs who had an an established space in a hospital setting or community office, described this as a major facilitator. This space was described *as a means of enhancing the visibility and availability of the DA for clients in the immediate post-diagnostic period.*

Category 5: Challenges to DA Service:

Resource limitations

A number of challenges were described by the DAs and these mostly relate to the lack of forward referring services available to PLWD. For example, the DA might know what type of service a person or their family needed. However that service may not be available to this person or may not be available at the required level, as is often the case with home care hours. This was seen as a source of great frustration by those interviewed and appeared to be region specific, demonstrating the inequity of services for PLWD across Ireland. According to DAs these restrictions often hindered the effectiveness of the DAS and limited their ability to provide a comprehensive signposting service. The set-up of the HSE services and the differences in services available in different areas also impacted greatly on how the DAS could operate.

Logistical barriers

Geographical challenges were mentioned as a challenge. Particularly for DA's that worked within the rural areas when a client meeting might entail a four hour round trip. Organising their working diary, planning ahead and grouping rural visits together was described as the best solution; however this often meant that clients in rural areas might wait longer than those in an urban setting to see a DA, potentially disadvantaging them.

Boundaries (personal and professional):

DAs agreed that in their role they needed to have a health / social care background and a very good knowledge of the health and social care system and how it works. However, a challenge identified by DA's with a clinical background (e.g. nursing or social work) was in maintaining parameters as they were aware that they were not providing a service in a clinical capacity. Role boundaries also emerged as a challenge when the service first began, particularly when trying to develop relationships with the broader health and social care services. However, it was felt that the information sessions, public talks, media campaigns and face to face meetings with stakeholders provided by the DA's were crucial in the beginning to ensure that the scope of the DA role was known and that the DA service was not seen to be in conflict with other services or HCPs.

Another challenge mentioned by the DAs was in bracketing off the emotions felt during and following a meeting with a client or their family. Some meetings were described as taking place over 3-4 hours in the persons' home, with up to 5 family members and these meetings at times were emotionally charged. Looking after one's own mental health in this emotive work environment was described as essential to being able to fulfil the role on a day-to-day basis.

Accessing community services

The DAs described their frustration at not being able to link clients to adequate homecare services to meet with their needs. They bemoaned the '*patchiness of existing services'* and the lack of *'an integrated pathway'* which were described as '*sources of great frustration'* for the DA and *a significant impediment*.

Overcoming Stigma:

While reducing stigma was described as one of the areas in which the DA has had significant impact in terms of the broader community, stigma was also noted to be one of the challenges faced by the DAs as described in the following statement:

> *“the stigma that's out there would be a bit of a challenge sometimes because, you know, people maybe don't want me to go to their homes sometimes”*

Breaking down barriers as described in the statement above, was expressed as more of an issue when the service was first developed, recently with more awareness, people are being encouraged to contact the DA by friends, neighbours and the broader community. However the DAs cautioned that there remains a challenge in accessing people in ‘*certain pockets of our society’* due to perceived stigma both of the disease and in asking for *‘outside’* help.

Category 6: Improvements to the DAS:

During the focus groups and individual interviews, a number of suggestions to improve the DAS were made by the DA’s themselves. These ranged from providing professional development for DA’s to having the DAS available in all counties in Ireland

The desire of DA’s to be involved with clients from the point of diagnosis was very evident and this was based on benefits observed where PLWD were referred early to the service.

> *“Information isn't being given to them at the point of diagnosis and they're not necessarily being referred to us at the point of diagnosis. And I think it's for the clinicians out there and the different day hospitals and the different diagnostic centres to understand that the dementia advice or service should be part of the, you know, post-diagnostic service that they provide.”*

All DAs stated that the demand for their services had grown exponentially over the years and their capacity to manage workload is stretched. Importantly, the unique ability to be *‘time* *rich'* with clients and family was mentioned as potentially under threat. All agreed that there is a need, at a minimum, to increase the number of DA in the various geographical locations throughout Ireland not covered by existing services, in fact one DA per county was suggested.

> *"So even though we'll say, and absolutely we'll offer the service to anybody who needs it at that point in time, but I suppose, we always have to look at capacity as well. Our capacity to manage the returning clients as well as the new ones coming in to the services as well. So maybe that's something, making sure we have enough support to enable us to continue to do that."*

Furthermore, the DAs suggested that improvements relating to homecare services were necessary. The DAs described their frustration at not being able to link to adequate homecare services for a client with needs. The patchiness of existing services and the lack of an integrated pathway was the source of great frustration for the DA and impeded their role significantly however they agreed that this was outside of the control of the DA.

DAs anticipated an expansion of the number of DA posts nationally, and they considered that professional development for current and future DA's was essential.

> *"a lot of it we're currently doing ourselves but I think that needs to be a more streamlined structure for professional development for dementia advisors. Because it is a service that I can see growing. It is a service that I see an absolute need for"*

DA's also emphasised the need to improve the availability of interventions for PLWD such as memory gyms and cognitive simulation therapy. These were seen as critical to providing a leading service for PLWD in Ireland.

Overall, there was a strong desire expressed by the DA's in all interviews to see the service develop nationally in collaboration and integrated with the HSE and NGO's. There was a particular desire to ensure provision of equitable access to the DAS for PLWD and theirfamilies.. Investment in the infrastructural development of the service was seen as an essential element of service development.

Table 3. Summary Table: Core Categories and Sub-Categories:

Core Categories	*Sub-categories*
Role of the Dementia Advisor	Referral Signposting Emotional support Link between services Assist in accessing services Advocacy service Providing information Providing reassurance and validation Not counselling, mediation, crisis intervention
Service structure	Integrated into the health and social services Self-Referrals Referrals from Health and social care professionals Action plans
Impact of the service	**Family** Empowerment Validation Reducing stigma Making the everyday easier Reduce family conflict regarding care Better understanding and knowledge Making it emotionally easier Reducing feeling of loneliness **Persons Living with Dementia** Feeling of acceptance Reassurance and validation Control/Empowerment_______ **Health and Social Services** Increasing pressure on some services Reduction in crisis cases Reducing pressure on GPs and PHNs Increasing awareness A point of contract for guidance/advice
Facilitators	Collaborations with HCPs Support from HSE Management Recognition of the Social Model of Dementia Visibility through the ASI website DAS Rapid access, DA Clinics and memory clinics Development of broader services Internal structures of the ASI
Challenges	Role boundaries Service gaps Emotive work environment Stigma

	Rural travel times
Improvement	Services and Resources Required Involved at point of diagnosis More DAs Better homecare services Integrated Dementia Care Pathway Professional Development for DAs Memory interventions Administration support

Summary

The results of the focus groups and individual telephone interviews with all seven of the current DA's operating in Ireland revealed common themes that can be structured around six broad categories: role, service structures, impact, facilitators, challenges and potential improvements. The DA's all reported having varied but significant experience managing the care of older people. Those that had clinical background in nursing or social work felt that this assisted them in connecting with health and social care services. They highlighted the expanding and multi-faceted role of the DA, in that the role now appears to include advocacy incorporating a wide variety of person-centred tasks. The DA's highlighted that they provide information about the dementia condition and identify supports to assist PLWD and their families in managing day-to-day life. However, the DA's have an increasing role in referral, signposting, connecting and assisting clients to navigate and access other services. This expanding role was seen as particularly relevant to the needs of PLWD and their families and complemented the DA role in emotional support and guidance. Referrals to the DAS, included self-referrals from PLWD and clients were often referred from multiple sources using different media. This was a development that was viewed by the DA's as a positive improvement in awareness and accessibility to the service.

The DAS was thought by DA's to benefit PLWD and their families and the broader health and social care service. However, they also expressed concern about potential unmet client needs due to lack of services in certain areas of the country and their expanding role in terms of meeting client needs including returning client needs. Integration with existing health and social care services was seen as an important aspect to the future development of the service but DA’s were cognisant that integration would have both positive and negative effects. On one hand integration would increase awareness of the service, improve communication, and potentially help avert crises but on the other hand, there was a potential for increasing referrals and hence the workload of already over-stretched services. Although the DA service has grown organically in an attempt to meet the needs of an ageing and often geographically isolated cohort, DA’s felt that the service could not meet all the needs of clients. They expressed concerns that if the service were not expanded, it would become more challenging over time to provide a person centred service. The DA’s considered expansion of the DAS geographical coverage to be essential to ensuring equitable and timely access to information and support for PLWD and their families. The importance of DA involvement early in the dementia diagnosis was also stressed. In addition to expanding coverage of the DAS, key improvements highlighted by the DA’s were: increased access to health and social care services, integrated care pathways, administrative support and professional development for the DA’s.. Overall, there was evidence throughout the focus groups and interviews with DA’s of positivity about their role and the potential impact of the service on the lives of PLWD and their families. All DA’s expressed their desire to see the service fully integrated with the HSE and NGO’s.

Chapter 4: Surveys with PLWD, Carers and Health and Social Care professionals

Introduction

This chapter presents the research methodology and the results of the postal surveys to carers and persons living with dementia and current clients of the dementia adviser services. The results of an online survey administered to the Health and Social Care Professionals who were thought to be aware of the dementia adviser service. The results of the surveys are presented in both tabular and graphic form will be outlined for each cohort separately.

4.1 Method / Design

This phase of the study used quantitative methodology.

4.1.1. Objectives

The aim of this phase of the evaluation is to address the following objectives of the evaluation:

- To assess the impact of the existing DAS on people with dementia and their family / carers
- To determine relevant health and social care professional's perception of the service
- To identify gaps in service provision and perceived service needs

The perspectives of all stakeholders were deemed to be important, therefore the involvement of people living with dementia was a significant part of this research. Firstly a review of available measurement tools was conducted to identify any valid instruments that would address the objectives of the evaluation and to include service users (people with dementia and their carers / family) and Health and Social Care professionals working with people who had dementia and who had referred clients to the service (dementia advisers). Instruments reviewed for relevance by the team and the steering group included: The Verona Service Satisfaction Scale (VSSS), Client Satisfaction Questionnaire (CSQ) The Service Satisfaction Scale (SSS-30); Evaluation of the Irish Cancer Society (ICS) night nursing service (UCC) questionnaire; Evaluation of the ICS information service (UCD) questionnaire; Well-being measures (ASCOT); Quality of life measures (DEMQoL); Rosenberg Self Esteem Scale; Duke Social Support Scale; COPE Scale and the Wellbeing Evaluation Scale.

However no reliable or valid relevant research developed tool/questionnaire was sourced from the literature and no instrument was found that fully addressed all the objectives relevant to this evaluation. Given none were suitable to the aims and objectives of this evaluation, and following consultation with the study steering group, the research team embarked on the development of a bespoke questionnaire for each population group: PLWD, Family/ Carers and Health and Social Care Professionals. The questionnaires incorporated requests of ASI where appropriate and used their client feedback survey as a template with their permission.

4.1.2. Questionnaire development

Criteria to be covered in the newly developed questionnaires were discussed and agreed with the steering group and are outlined in table 4. Using these criteria, questionnaires specific to the service user (PLWD) (see appendix 8a), their carer / family (see appendix 8b) and Health and Social Care Professionals (see appendix 8c) were developed. Each survey questionnaire contains a mix of fixed-choice and open ended questions relating to systems and structures underpinning the provision of the dementia adviser service for their service users.

A paper based survey was developed for Clients (PLWD and family carers) and a cloud-based software known as Survey Monkey was used to distribute the survey for the Health and Social Care professionals. All surveys were anonymous. Table 4 below shows the areas covered in the development of the questionnaires for PLWD, Carers/ Family and Health and Social care professionals.

Table 4. Areas covered in the development of the questionnaires for PLWD, Carers/ Family and Health and Social care professionals.

CLIENTS (PLWD & CARERS)	Health and social care professionals
✓ Reason for accessing the service ✓ Attitudes towards the information received ✓ Identify how informed clients were by the information received ✓ Explore levels of confidence post accessing service ✓ Perceptions of the service ✓ How services contributed to their needs and understanding ✓ Explore factors that are essential to the service ✓ Explore problematic/challenging areas	✓ Definitions of patient engagement including type and/or level ✓ Perceptions of supports and challenges related to patient engagement including resources and preparation ✓ Participant roles and responsibilities. ✓ Perceptions of evaluation of engagement of patients' member's in the group ✓ How site activity fits with the wider health and social care system ✓ Impact of services on people living with dementia and carers ✓ Conditions essential to the success of services. ✓ Perceived strengths of models of Intervention. ✓ How services could be improved/future ideas.

4.1.3. Sample

4.1.3.1. Client surveys (PLWD and Carer / family)

Following statistical advice, the total population of DAS clients recorded on the ASI database for 2017 were included for survey distribution. The DAS clients on the ASI database were recorded as they presented to the DAS i.e. as either a client who was a PLWD or a client who was a carer or family member of a PLWD. Cognisant of the progressive nature of dementia, and to aid response from PLWD themselves, a decision was made to distribute the survey directly to clients (PLWD and to Carers) recorded on the database within the most recent time period. Consequently, client surveys were posted from the ASI to clients recorded on the database for 2017 as PLWD n=78, and clients recorded as family / carers n= 155. The sample of family carers received two surveys, one for themselves to complete and one for the PLWD, should they wish to complete it. The clients recorded on the ASI database as PLWD were not administered a survey for their carer/family member.

The postal surveys were accompanied by an information letter (see appendix 6) and stamped addressed envelope for return of the survey directly to the researchers at University College Cork. After two weeks a reminder letter to return the surveys was posted out from the ASI. Clients were provided with a telephone number and email address to contact the researchers for clarification if necessary.

4.1.3.2. Health and Social Care Professionals:

Health and social care professionals that had referred clients to the dementia adviser service over the lifetime of the DA service were identified by the ASI from their database and this information was made available to the HSE. A link to the Health and Social care professionals survey was then distributed to the Health and Social Care professionals by the HSE along with an information leaflet (see appendix 6). As emails for all the referring health and social care professionals identified by the ASI, were not available, the survey link was distributed via the wider HSE email distribution list. A poster and social media message were also distributed via the HSE mail distribution list to create awareness about the survey and assist with response. After two weeks two further reminder emails were sent from the HSErequesting completion of the survey.

4.1.4. Quantitative Data Analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS version 22.0). Descriptive statistics (frequencies, percent, measures of central tendency, and measures of variability) were used to summarise demographic data and questionnaire data. Charts and tables were used throughout the report to display data. Results from each of the surveys are presented here in separate sections.

4.2. Results of Survey with Persons Living with Dementia (PLWD)

The postal survey was distributed to n=78 persons recorded as PLWD on the ASI database who accessed the DAS in 2017. The total number of respondents was 26. (Response rate = 33.3 %).

4.2.1 Profile of respondents

The majority of respondents were female 48% (12/25) (one missing value). Sixteen percent (n=4) were less than 60 years of age, 32%% (n=8) aged between 60-69 years and 32% (n=8) 70-79 years respectively, with 20% (n=5) aged 80 or more years of age. An age by gender cross tabulation in Figure 4 showed that there were more females than males aged 60-69 years and 80 years or older, and a higher percentage of males than females aged 70-79 years.

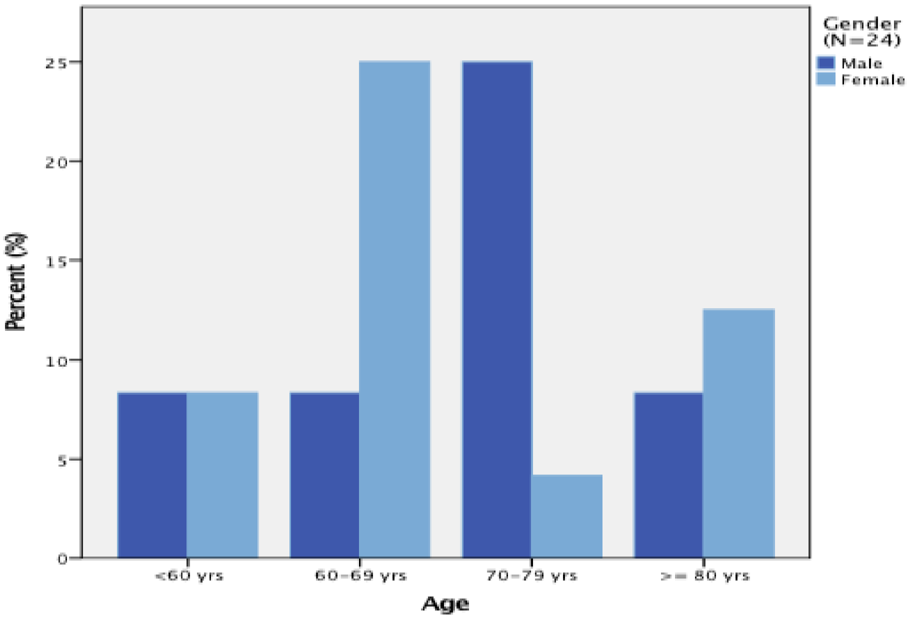


Figure 4. Clustered bar-chart of age and gender of persons with dementia

Table 5 presents the regions and the number of respondents that contacted the DAS in each region. Respondents were representative of clients from all DA services with the exception of the South Dublin DAS. Nearly 40% of respondents to the survey were in contact with the North

Dublin DAS, with 20% from Galway and 18% from Cavan, Monaghan, Louth. This question in relation to region was responded to by n=25 respondents.

Table 5. Respondent's DAS region

Dementia Adviser Service Region	N * (%)
North Cork, East Kerry, Co. Limerick, Co. Tipperary, South Clare.	2 (8)
North Dublin	10 (40)
South Dublin	0
Galway	5 (20)
Cork City, South & East Cork, South Kerry	2 (8)
Cavan, Monaghan, Louth	4 (16)
Sligo, Leitrim, South Donegal	2 (8)

*Note total number of respondents that completed this question (n=25)

Respondents were asked when their diagnosis of dementia was made. Twenty six respondents answered this question. Of these, 35% (n=9) of respondents were diagnosed in the last 2 years, 38% % (n=10) diagnosed 3 or more years, and 16% (n=4) had an unconfirmed or were unsure about their time of diagnosis (figure5).

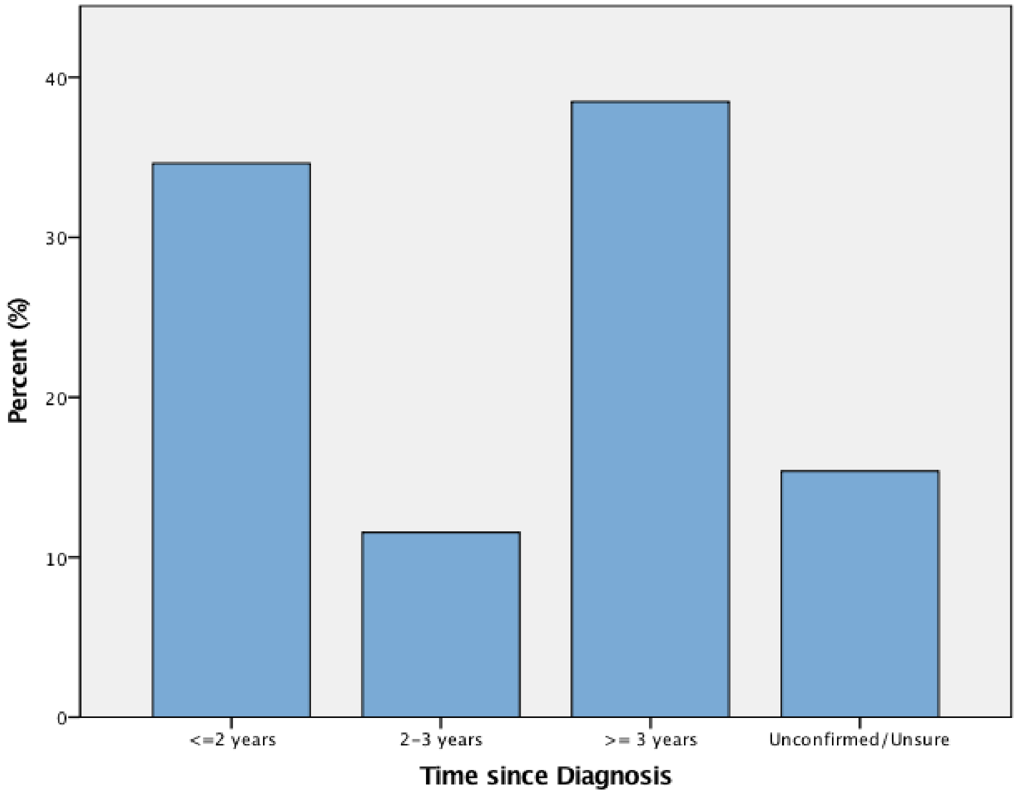


Figure 5. Time since diagnosis of dementia

4.2.2 Source of information on the dementia advisor service

Respondents were asked the sources they used to access information about dementia. Respondents were provided with a list and could tick the number of sources contacted. Figure 7 presents the sources of information accessed by PLWD (n=26). The GP (73%, n=19) was the most frequently cited source of information, followed by the dementia adviser service 50% (n=13) and medical consultant at 46% (n=12). Respondents used multiple sources of information with an average of 3 sources, the overall number of sources ranged from 1 to 7.

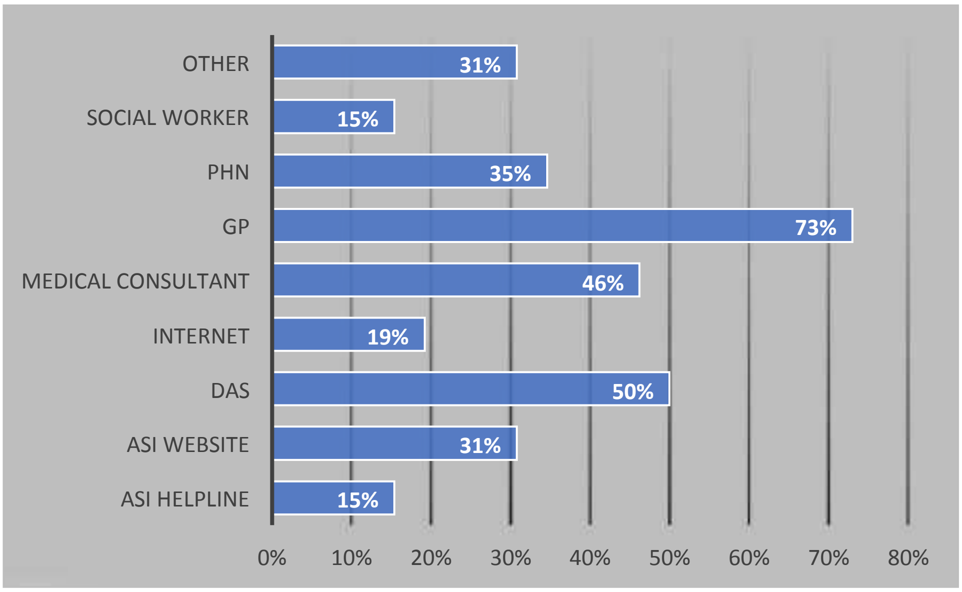


Figure 6. Sources of information about dementia (n=26).

Respondents were asked how they learned about the DAS (see figure 7). All respondents answered this question. The PLWD was most likely to learn about the DAS from their medical consultant or GP (35%, n=9; respectively) with 23% (n=6) citing other sources e.g. "notice posted in hospital".

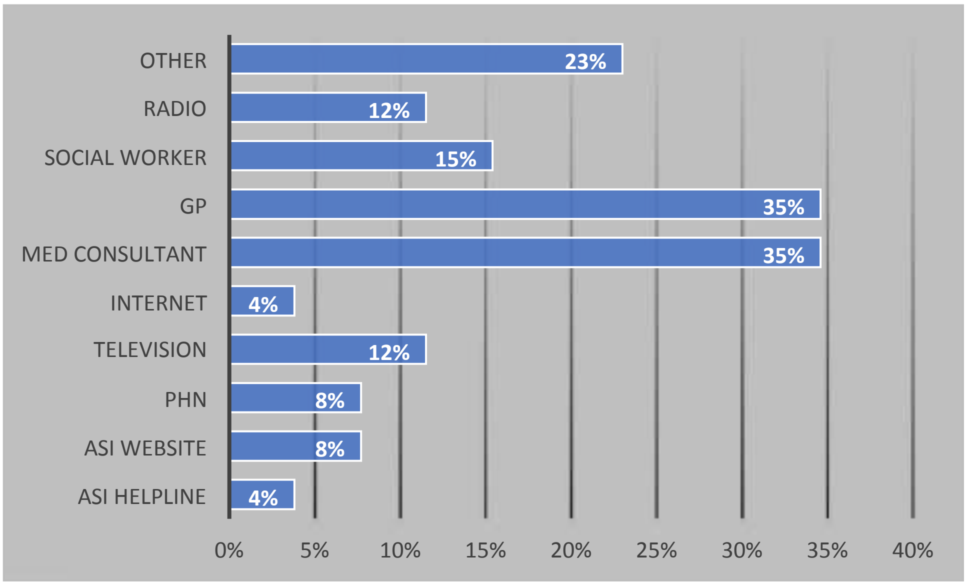


Figure 7. How the person living with dementia learned about the DAS

4.2.3. Understanding of the role of the DA Service

Respondents were asked to describe, their understanding of the role of the dementia adviser service, 19 (73%) completed this question. For this open-ended question, overall respondents reported that dementia adviser service offered support, advice and signposting to other services. The dementia adviser service was described by PLWD as a service that reduced their fears and isolation. In the following quotes, exemplify how respondents outlined their understanding of the service in their own words. The quotes demonstrate that it is likely that respondents viewed meetings such as Alzheimer Café as part of the DAS.

> *"To tell the carers/family how to care for me"*

> *"Someone who can help to alleviate your fear of the future and present"*

> *"It's helping me understand I am not alone and most important for me is to get involved and help"*

> *"The monthly meeting in X were very friendly. Nice and informative. There is a guest speaker and general questions and chat afterwards"*

> *"I get great support. I go to all the meetings its brilliant because they are so supportive. It's like my family dementia for me is not a problem because I have 100% support from them. I've had great days out at meeting the Christmas party was brilliant"*

4.2.4. Contact with the DA service

Respondents were asked how many times they had been in contact with the dementia adviser service. The majority responded to this question (n=23). Fifty two percent (n=12) of respondents indicated that they had only seen the dementia adviser *once or twice*. Less than half (48%, n=11) indicated that they had contact with the dementia adviser on three or more occasions (see Figure 8).

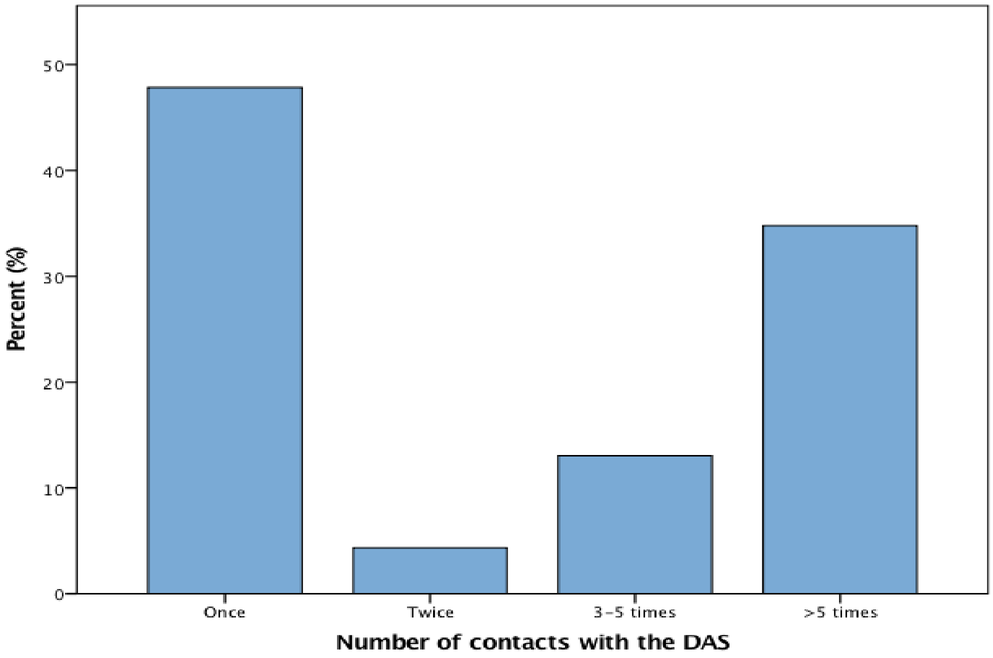


Figure 8. Frequency of contacts with the DAS

Respondents were then asked whether they would contact the service again.

Options provided were yes, no and maybe. Twenty two responded and over half of these (64%, n=14) indicated Yes (they would contact the service again), 32% (n=7) said maybe and 4% (n=1) said they would not avail of the service again.

Respondents were also invited to elaborate on why they may or may not contact the dementia adviser service. Just 32% (n=7) respondents replied to this question.

Five of these respondents indicated that they *would contact the service again if they needed further help and advice*. The remainder are summarised in the following two quotes:

"I am managing well at home with care"

"I feel they barely touched the surface of what people with dementia need"

4.2.5. What PLWD hoped to get from the DAservice

Respondents were asked to state what they hoped to get from the dementia adviser service. 81% (n=21) respondents completed this question. The recurring reply was *help, support and advice*. The following quotes summarize responses.

"To let me know what help is available and to know that I am not alone"

"An explanation of dementia, how it affects people, support you get; advise people how to help me, how should I react"

One respondent with early onset dementia described what he had got from the DA in the following quote:

> *'At the time I met adviser I had no idea what to expect. I had been discharged from memory clinic to primary healthcare – doctor & public health nurse had never met anyone with younger onset Alzheimers! I actually had to push to see health nurse – being under 65 and means I am not entitled to services – YET!! Having access to Dementia Adviser gave me confidence in know I could contact her and even if she didn't know answer-she would come back to me'.*

4.2.6. Did the service meet their expectations?

Respondents were asked if the DAS had met their expectations (n=21 responded). The majority of PLWD respondents (71%, n=15) indicated (yes) that the service met with their expectations, with 19% (n=4) indicating that it *maybe* met their expectations and 10% (n=2) said (no) that it *did not meet their expectations*. Respondents were asked to elaborate on why the dementia adviser service did not meet their expectations, 33% (n=7) of respondents completed this question. Respondents indicated that they either had '*no expectations*, or that they were '*only at the beginning of the process'* or *'new to the service'.*

4.2.7. What the DA service has done for you?

This was a qualitative question and altogether 81% (n=17) of respondents commented. The majority of respondents reported that the service helped and supported them. For example by: *bringing normality to their lives*, providing *understanding about dementia* and giving them *confidence to ask questions*. The following quotations from respondents exemplify the comments about what the service provided for people living with dementia:

> *"Given me information, support, empowered me to do as much as I'm doing. Supported my son with meeting and information. Confidence that there is someone who will listen and hear concerns. I dread to think where I would be without Advisor"*

> *"It has been very supportive and has made it easier to accept that I have dementia it's not a problem because I have support from all the great staff and other people at the meetings"*

"It prevented me from worrying about the future. It helps to talk things over with someone trained in this area"

"Support practically, in very early stages"

Respondents were then asked if their family or carer had made contact with the dementia adviser service and 92% (n=24) replied to this question. Of which, 58% (n=14) indicated yes that their carer or a family member had made contact with the service, 8% (n=2) thought that they maybe had contacted the service and 33% (n=8) reported that (no) they had not.

4.2.8. Would respondents recommend the DA Service to others?

Respondents were asked whether they would recommend the service to other people living with dementia and 85% (n=22) replied to this question. Of which 91% (n=20) stated (yes) that they would recommend the service again and 9% (n=2) replied (maybe) they would recommend the service again.

The majority (n=20) would recommend the service to other people living with dementia and three respondents elaborated when invited to provide reasons for why they may or may not recommend the DAS. One reason was given for replying that they would not recommend because *information was available online*. Reasons for recommending the service are reflected in the following quotes.

"All cases are different it's worth a try"

"It's better than nothing. But no magic formula"

4.2.9. How helpful PLWD perceived the DA Service

Respondents were asked to indicate how helpful they perceived the dementia adviser service to be. Responses to this question ranged from seventeen to twenty two (see table 6 below). Due to the small sample size, the ‘very unhelpful’ and ‘unhelpful’ categories were coded together into an overall ‘unhelpful’ category, similarly the ‘helpful’ and ‘very helpful’ were coded together into an overall ‘helpful’ category and the midpoint of the scale remained the same (see Table 6). The most helpful aspects of the service were: the information about available informal supports (83%, n=15) and availability of formal health and social care services (80%, n=16). The least helpful aspects of the service were knowledge about available financial supports (20%), how to cope with the changes (21%) and lack of communication with regard to their progress (20%). Table 6 displays the degree of helpfulness of the Dementia Adviser from the perspective of PLWD.

(Note: *Three responses to this question were coded as ‘missing’ when the responses were compared with the comments attached to the question. There was a large discrepancy. The qualitative comments were all highly positive and the quantitative responses were all very negative i.e. respondents ticked all unhelpful)*

Table 6. The degree of helpfulness of the Dementia Adviser

The degree of helpfulness of the Dementia Adviser				
		N (%)		
	Response n	**Unhelpful**	**Somewhat helpful**	**Helpful**
The DA helped me to understand dementia	22	4 (18)	3 (14)	15 (68)
The DA helped me to be able to cope with the changes	22	7 (32)	3 (14)	12 (53)
The DA helped me to know what formal health & social care services are available	23	4 (17)	3 (14)	16 (73)
The DA helped me to access services	22	4 (18)	6 (32)	12 (63)
The DA helped me to know what informal supports are available	21	4 (19)	2 (11)	15 (83)
The DA helped me to know what legal & care planning options are available	19	4 (21)	2 (13)	13 (81)
The DA helped me to know what financial supports are available	18	6 (33)	3 (20)	9 (60)
The DA helped me feel listened to	20	4 (20)	3 (18)	13 (76)
The DA responded quickly in times of need	17	5 (29)	3 (22)	9 (64)
The DA addressed my concerns & worries	18	5(28)	3 (20)	10 (67)
The DA kept me informed of progress	18	6 (33)	3 (20)	9 (60)

4.2.10 PLWD perspectives on the Dementia Adviser Service

Respondents were asked to demonstrate their level of agreement or disagreement with a number of statements about the dementia adviser service. Due to the small sample size, the 'strongly disagree' and 'disagree' categories were coded together into one overall 'disagree' category, similarly the' agree' and 'strongly agree' categories into an overall 'agree 'category. The 'no opinion' or midpoint remained unchanged.

For all statements the levels of agreement was high. Responses with highest levels of agreement were statements such as: *the dementia adviser demonstrated empathy* (95%, n=20) and *the dementia adviser seemed knowledgeable about services* and *the dementia adviser communicated well* (91%, n=20). Although there was high agreement with statements i.e. *the dementia adviser helped the person with dementia feel more confident* (80%, n=16) and *was easily contactable* (85%, n=17) these statements also had highest level of disagreement observed (although percentages are still low) (see table 7).

Table 7. The degree of agreement or disagreement with statements about the Dementia Adviser

Degree of agreement or disagreement with statements about the Dementia Adviser n(%)				
	Response n	Disagree N(%)	No opinion N(%)	Agree N(%)
The dementia adviser communicated well	22	0	2 (9**)**	20 (91)
The dementia adviser demonstrated empathy	21	1 (5)	0	20 (95)
The dementia adviser demonstrated respect	22	0	2 (9)	20 (91)
The dementia adviser spent enough time with me	21	2 (9.5)	1 (5)	18 (86)
The dementia adviser was easily contactable	20	2 (10)	1 (5)	17 (85)
The dementia adviser helped them feel more confident	20	3 (15)	1 (5)	16 (80)
The dementia adviser seemed knowledgeable about dementia services	22	1 (4.5)	0	21 (95)

4.2.11 Overall satisfaction with the Dementia Adviser Service

Respondents were asked to indicate using a five point likert satisfaction scale how satisfied they were with the service and the majority of respondents (n=23) replied to this question Responses on to categories ‘very dissatisfied’ and ‘dissatisfied’ were coded together as overall ‘dissatisfied’ and those of ‘very satisfied’ and ‘satisfied’ were coded to overall ‘satisfied’ while the category ‘mixed’ (midpoint) remained as before. Of these, 69% (n=16) indicated that they were satisfied with the service 13% (n=3) were mixed and 17% (n=4) indicated dissatisfaction with the service (see figure 10 below).

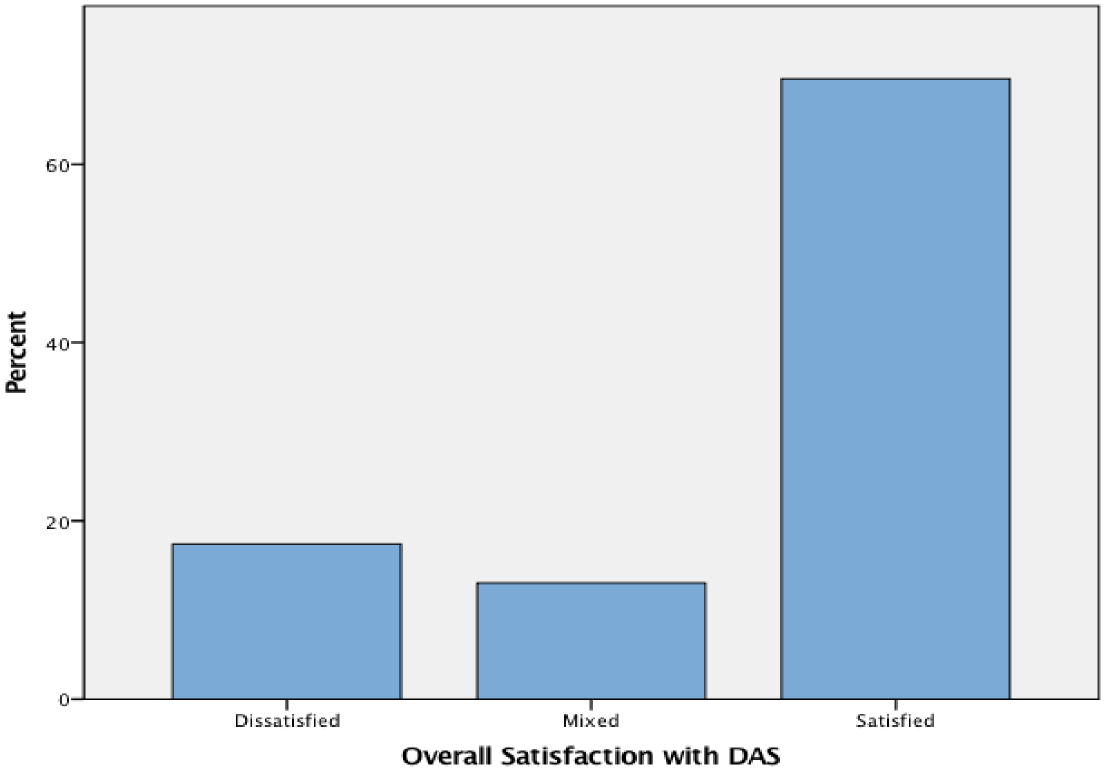


Figure 10. Overall satisfaction with the DAS

4.2.12. Perceptions on how the service could be improved

Respondents were asked if they had any suggestions of how the service could be improved. Approximately a third (n=8) of respondents presented suggestions. A key recommendation was *more dementia provisions.*

One respondent provided the following list of suggestions:

- *Everyone diagnosed should have access*
- *The link should happen at diagnosis even if not accessed immediately*
- *Linkage to all services in local area*
- *Dementia Adviser meets family so family knows what is helpful/harmful in supporting person with dementia*
- *Dementia adviser has link into OT, Health Nurse etc. – People with dementia need services now not waiting for 1 year and for Appt”*

The following quote from one respondent appears to doubt the benefit of the DA service to him/her:

> *“Leaflets booklets and sympathy is what I got. Perhaps there are people more needing than me who might benefit.*
> *Even the doctors don’t understand this disease. If (Ari) our Mem doesn’t work go straight to the scrapheap. The talk about early intervention is a fairy tale”*

Finally, respondents were asked if they had any additional comments, 42% (n=11) responded. Responses demonstrated a high level of satisfaction with the DAS. This final quote captures the overall perceptions of people living with dementia on the Dementia Adviser Service.

> *'There are many things that need to change for the person with dementia, but for me one of the very important changes is Dementia Adviser available to each person diagnosed.*
> *I am constantly shocked at the amount of people – carers and people with dementia who have been diagnosed and just abandoned.*
> *Thank you for this hard work in this area'.*

Summary

Overall, respondents reported that DAS offered support, advice and signposting to other services. The DAS was described by PLWD as a service that helped to reduce their fears and isolation. Respondents were also asked to state what they hoped to get from the dementia adviser service; the recurring themes in the comments provided were help, support and advice. Respondents were asked what the dementia adviser service had done for them. Respondents reported that the service helped bring normality to their lives, provided understanding about dementia and gave respondents confidence to ask questions. Overall, respondents concluded that they would recommend the service to other people living with dementia and highlighted that the information available online is also useful. The key recommendation was the provision of more dementia services.

4.3. Results of Survey with Carers / Family of Persons Living with Dementia

The survey was distributed via post to 155 clients who were recorded on the ASI database as carers or family members that accessed the DA service in 2017. The total number of respondents was 38 resulting in a response rate of 24.5%.

4.3.1 Profile of respondents

The majority (78%, n=29) of the carers were female, 61% (n=22/36) were a spouse or partner to the person living with dementia and 39% (n=14) were daughters. The spread of ages across the carers had equal proportions in all categories, except for the 60-69 year age group. Figure 11 shows the clustered bar chart of age group with relationship of carer to person with dementia. Spouse/partners were in the higher age groups with most aged 60 years and older. The majority of daughters providing care were aged less than 60 years of age.

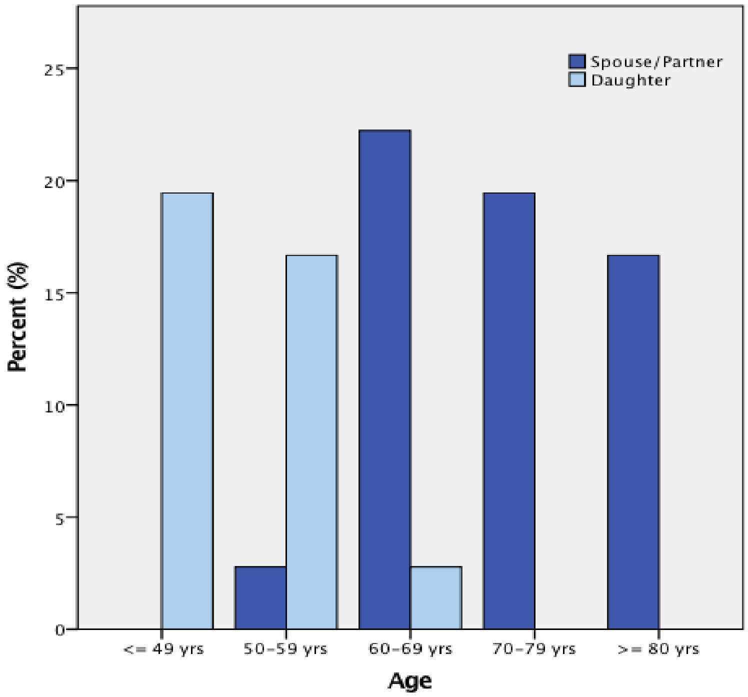
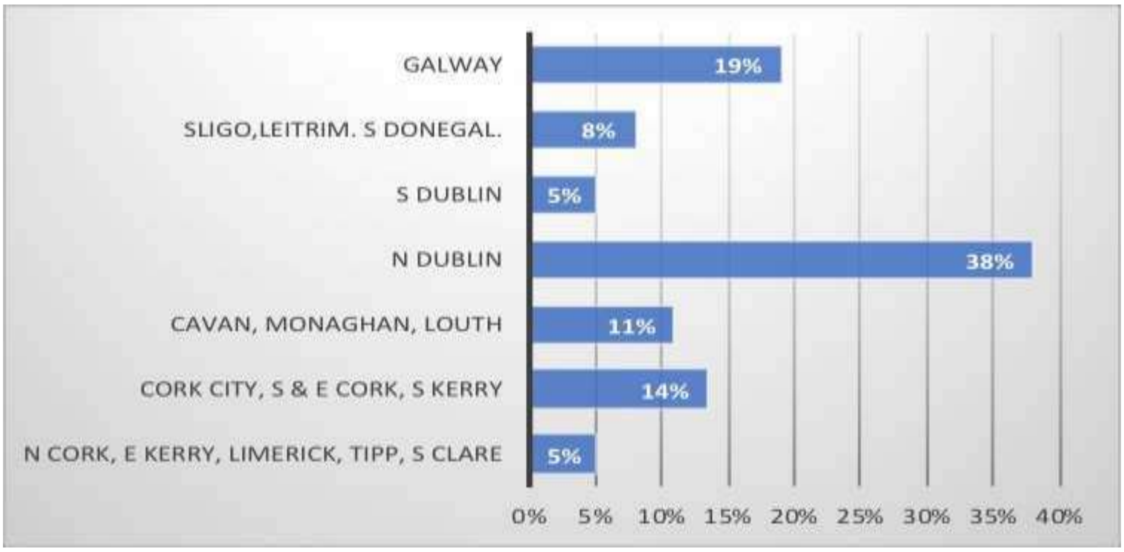


Figure 11. Age of carer by their relationship with the person with dementia

Respondents were asked the location of their DA Service (n=37 responded). The highest percentage of respondents were clients of the North Dublin DAS (38%, n=14), followed by

Galway (19%, n=7) and Cork City, South & East Cork and South Kerry (14%, n=5). All DAS services were represented (see figure 12 below).



*Note total number of respondents that completed this question (n=37)

Figure 12. Location of the carers DAS

4.3.2. Time since the dementia diagnosis of their family member

Carers / family members were asked to indicate the time since diagnosis of dementia for their family member (n=36 responded). 50% (n=18) of the PLWD were diagnosed 3 or more years and 28% (n=10) were diagnosed less than 2 years (see figure 13 below).

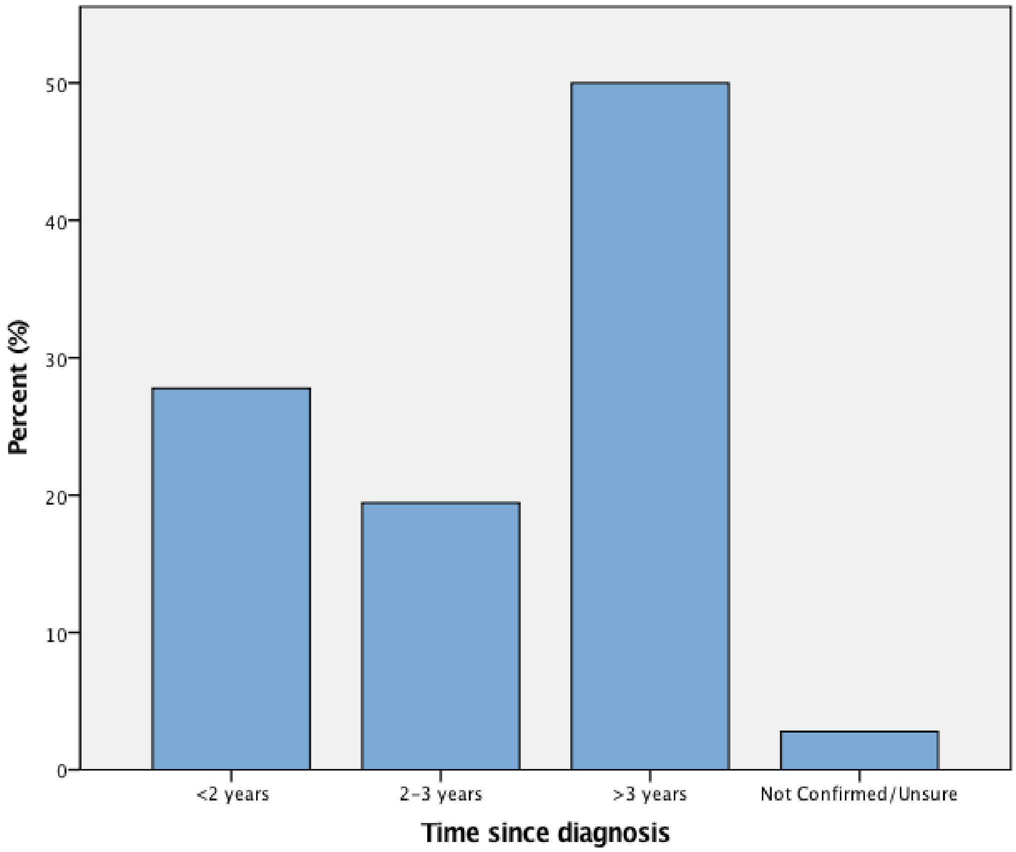


Figure 13. Time since dementia diagnosis

4.3.3. Sources of information about dementia.

Carers /family were invited to outline their main sources of information about dementia. As seen in figure 14 below the most frequently used resource for information about dementia was their GP (70%, n=26)). With similar percentages of carers accessing information from a medical consultant (46%, n=17) the public health nurse (43%, n=16) and from the ASI helpline (41%, n=15) and ASI website (41%, n=15). Twenty-nine per cent indicated that they accessed other sources of information including other website resources about dementia. On average, carers accessed four sources of information about dementia (range 1-9).

Most other sources were web based and where specified they included websites such as the Mayo clinic and Alzheimer association, books, The Alzheimer Society carers workshop and online course and various affiliated services.

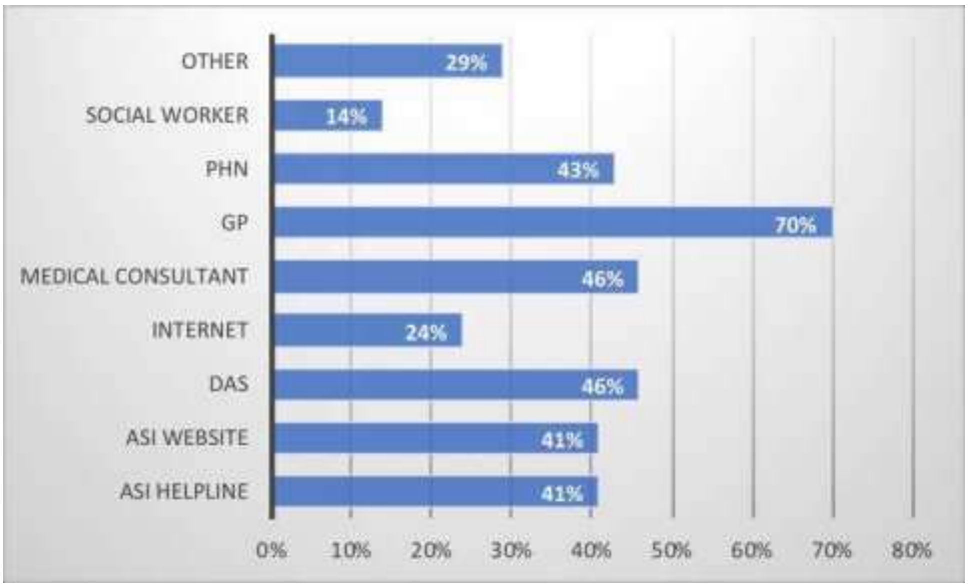


Figure 14. Carers sources of information about dementia

4.3.4. How carer learnt about the DAS

The most frequent source of information about the DAS came from a GP (42%), followed by a medical consultant (28%) and a public health nurse (22%) (see figure 15 below).

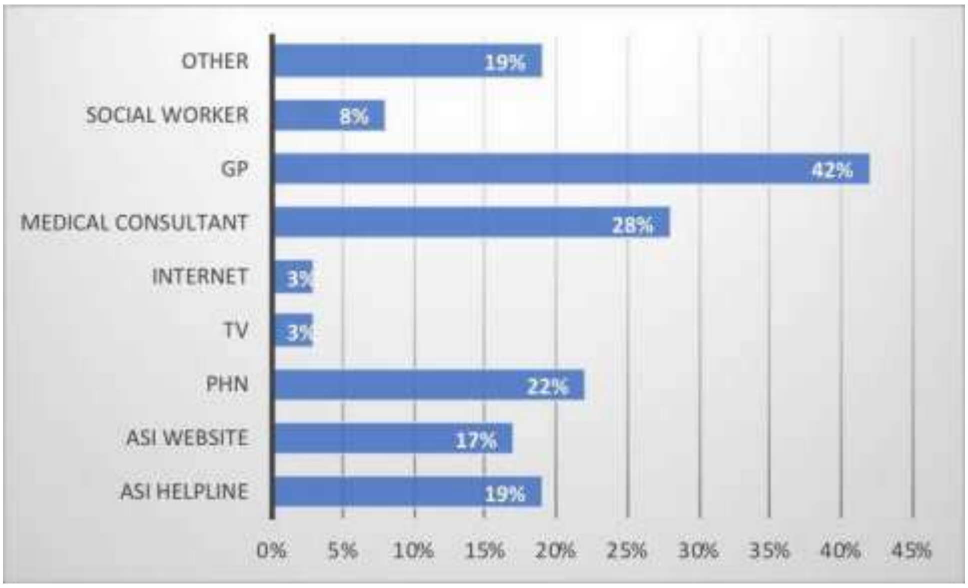


Figure 15. How carer learnt about the DAS.

4.3.5. Respondents understanding of the role of the DAS

Respondents were asked to describe, their understanding of the role of the dementia adviser service, 84% (n=32) completed this question. For this open-ended question, overall respondents reported that dementia adviser service offered support, advice and signposting to other services. The dementia adviser service was described by carers as *a service that reduced isolation and listened to clients.* The following quotes portray respondents understanding of the service

"To give advice to families/carers on what happens when a diagnosis of dementia has been given. To advise where to go for help on the following: finance support, respite, what one is entitled to and any other pertinent matter"

"A person (dementia adviser) who can counsel the carer as to what is necessary and available to live as normally as possible"

"I felt adviser would help me to understand the disease or condition more and steer me in the right direction. In order to help my spouse live and continue to engage in as normal a life as possible. Help me

"Advice, support, a listening ear, a friendly voice"

"I am only new to the whole dementia as my dad is only diagnosed about a year ago. The service has been really helpful in helping us to understand what dementia is and things to look out for and advice on the sorting out of legal affairs. It would be really helpful to have monthly gatherings for carers who are caring for people with dementia"

4.3.6. Number of contacts with the DA service

Thirty three carers responded to this question. Almost 50% (n=16) indicated that they only had one contact with the DAS, 30% had two contacts (n=10) and 21% (n=7) had 3 or more contacts with the service. The bar chart below (figure 16) displays the number of contacts with the DAS cross-tabulated with time since diagnosis. This shows that a highest percentage of those clients who were in contact with the DAS only once were those diagnosed >3 years or longer.

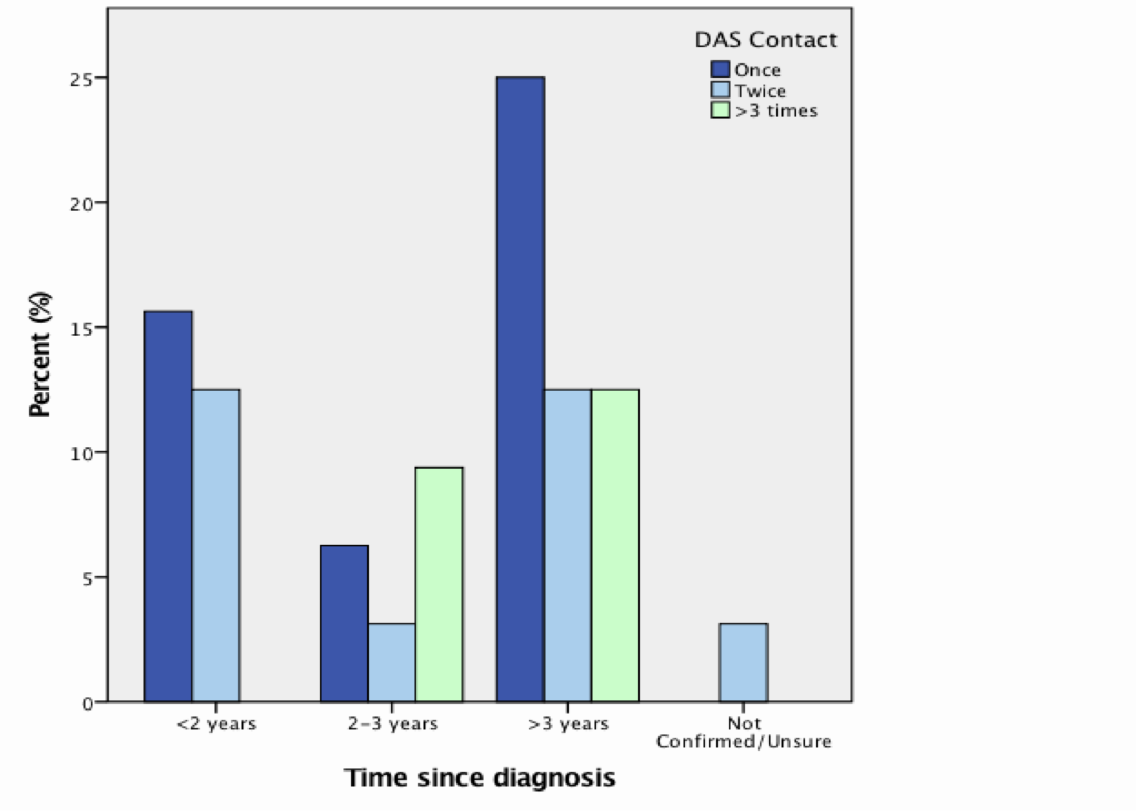


Figure 16. Clustered bar chart of number of contacts with the DAS and time since diagnosis.

4.3.7. Did the DA also meet with the PLWD?

In addition, carers were asked to their knowledge whether the DA had met with the PLWD. Answers to this question were ‘Yes’, ‘No’ or ‘Don’t Know’ (n=36). Fifty-eight percent of respondents (n=21) said yes, only 39% (n=14) said no and 3% (n=1) did not know if the PLWD had met with the DA.

Respondents were asked to elaborate on why the person living with dementia has not met with the dementia adviser, 36% (n=13) respondents gave reasons why not.

The majority of respondents stated it was because *their relative was unaware of their diagnosis or because their relative was admitted to hospital/long term care.* The following quotations summarise respondent’s views:

“I myself met with the Adviser and as my dad doesn’t know he has dementia it was decided that meeting with the Adviser would not be helpful for my dad”

“I met her for advice after my mother was diagnosed. My mother is unaware of her diagnosis and has deteriorated considerably so she would not accept help. She doesn’t think anything is wrong with her”

“I didn’t feel it was necessary. They gave me information and enrolled me in courses. They offered to meet with PWD but I didn’t feel it was necessary to date. I would be happy for them to do so if needed”

4.3.8 What carers hoped to get from contact with the DAS

Respondents were asked to state what they hoped to get from the dementia adviser service the first time they contacted the service and 92% (n=34) respondents completed this question. The recurring reply was related to seeking advice about the future, information on dementia and services. The following two quotations from respondents summarise respondent's views:

> *"As much help and advice as possible. I knew nothing about dementia. How to keep my mother safe"*

> *"I did not know what to expect but I really got some great support and advice. At first it was a little overwhelming trying to get ones head around what dementia is and the different forms of it and what to expect in the future. The adviser were great because they went step by step through different things. I know my mother really found it very helpful to understand what is happening to my dad as they have been married for sixty years"*

4.3.9 What carers hoped to get from subsequent contact with the DAS

Respondents were asked to state what they hoped to get from the dementia adviser service on subsequent contact or on follow-up, 61% (n=23) respondents completed this question.

Overall respondents stated they would like more support and follow up and others commented on their experience of the service e.g.

> *"The day I contacted the services was the day everything changed. Her listening support and advice was the most wonderful thing at a very difficult time. Her advice was invaluable and everything she recommended I put in place and it all happened as she predicted and thanks to her I was ready and prepared'.*

There were some dissatisfaction reported in a number of comments from carers and family members. For example, one respondent reported that they did not contact the DAS again and providing the following explanation

> *"I never contacted them again as felt so overwhelmed with the situation. Didn't feel first contact was much use, all about legal power of attorney. No actual support"*

Another respondent reported that their expectations of hands on support were not met as in the following quote.

> *"I had hoped for more hands on support-we are currently paying privately for dads in-home care with 4 carers on the payroll. I had hoped to obtain some hours from the Alzheimer Society, but this did not happen to date. We are registered but there are no hours available"*

Other comments were suggestive of future service and supports as in the quote below:

.

‘I think a drop-in centre would be fantastic to have even once a month would be great. Also maybe a seminar for carers about the different dimensions and forms of Dementia. Sharing with other people is always valuable in learning how to deal with different situations’.

4.3.8. Perspectives on further contact with the DAS

Thirty six responded to the question of whether they would contact the service again. Sixty nine percent (n=25) indicated that they were willing to contact the DAS again. 22% (n=8) indicated that they might and 8% (n=3) indicated that they would not (see Figure 17).

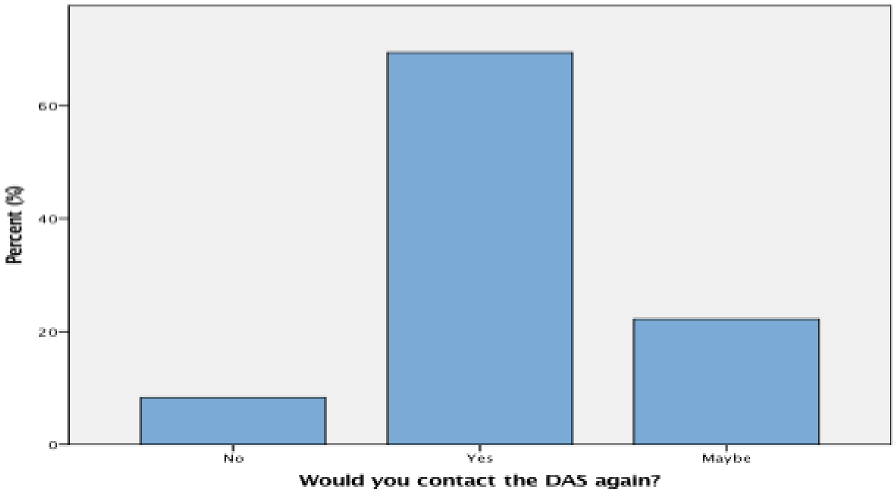


Figure 17. Willingness to contact the DAS again

When asked if they had responded ‘no’ to comment on why they would not contact the DAS again a number of reasons were advanced by respondents. The following quote provides an explanation for carers being unsure whether to contact the DA again:

> *‘Not sure. She told me to get power of attorney, which doctors told me was too late. She got me on a carer’s course but there was nobody to look after my mum while I was away, so I only could attend 2 sessions’.*

4.3.10. Would carers recommend the DA service to others

N=34 responded to this question. A little over 80% (n=28) of carers stated that they would recommend the DAS to other people living with dementia (see figure 18 below).

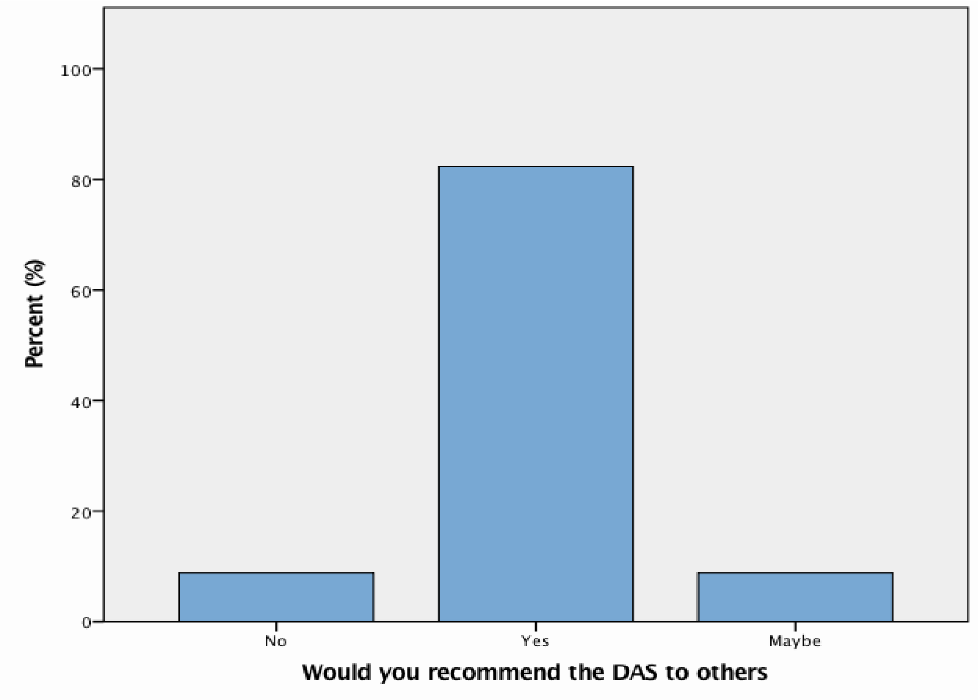


Figure 18. Willingness to recommend the DAS to other people with dementia

Respondents (n=8) that answered ‘no’ to this question were invited to provide a comment on why they would not recommend the DAS. The following quotes are examples of those provided

> *“Because they have to find out what’s good for them”*

> *“Not really. I was still on my own. No carer package, no carers benefit/allowance. It was not until my mum fell over and wet to hospital that she then got a carer’s package, four visits a day”*

> *I did not feel I could contact them unless I felt it was an emergency.*

4.3.11. Carers knowledge on whether other family members contacted the DAS?

Most carers answered ‘no’ to this question, n=37 responded and 30% (n=11), indicated that another member of their family had contacted the DAS, 5% (n=2) % indicated that they did not know (see figure 19 below).

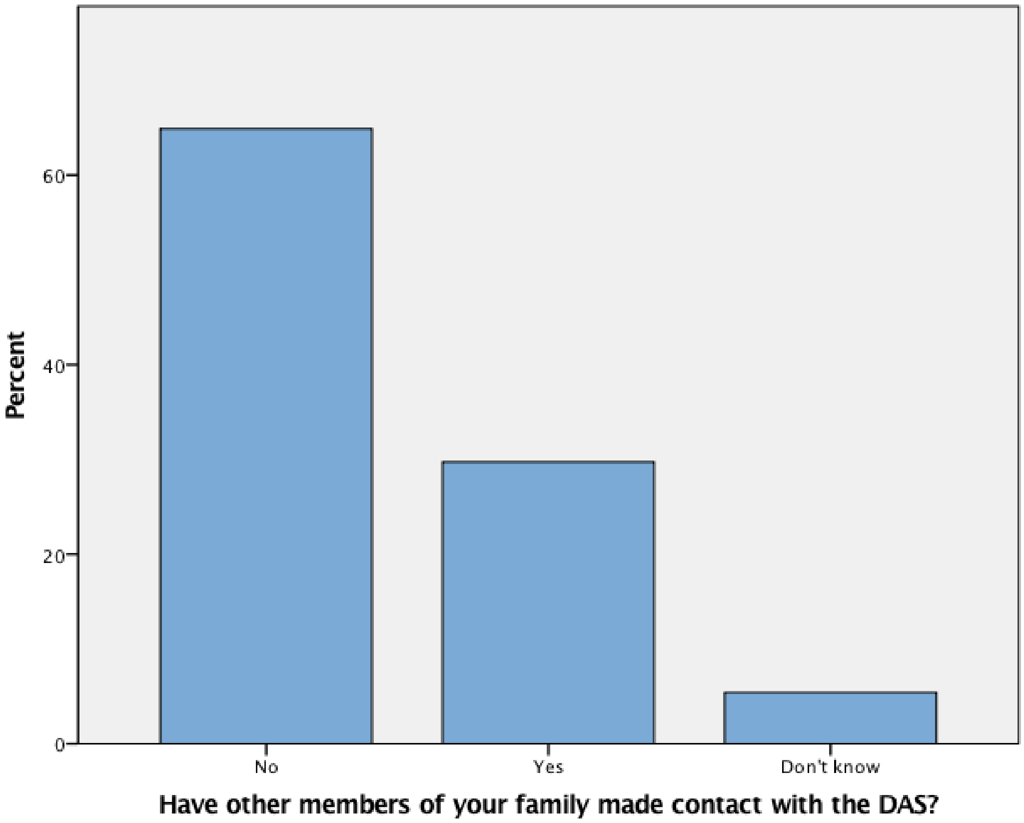


Figure 19. Have other members of the carers' family contacted the DAS?

4.3.12. Perspectives on whether the DAS had contributed to their role as carers

Respondents were asked to comment on what (if anything), has the Dementia Adviser Service done for them, in their role as caregiver. Respondents provided a number of examples of how the dementia adviser service contributed to their caregiver role: recurring themes were *advice, support* and a '*feeling of not being alone'* as in quotes below

"Pointed me in the direction of support groups (COGS). It has informed me what aid is available financially eg. Carers allowance, carers grant Advised about enduring POA"

"Someone to listen to me"

''Gave me valuable advice and information ….made me feel like I wasn't alone. They also gave me information on respite which I was able to organise afterwards"

"I got very useful advice and support which is very important for care giver as I felt very alone"

"Helped me understand what was happening and made me realise that I was not alone dealing with this situation. Helped me to try and stay patient when things get a bit frustrating as that can often happen when dealing with the situation on a daily and often nightly basis"

"Given me confidence, kindness, help with carers who come 2 hours twice a week to play chess with my husband. This is the only time I see my husband smile and enjoy himself and for me I get a lady to do a bit of cleaning 2 hours and keep an eye on my husband so I can go out and do shopping or meet a friend for a cup of coffee with an easy mind"

4.3.13. Comments on influence of the DAS on family

Carers were asked to comment on whether the DAS had made any difference to themselves or their family life; n=29 carers responded to this question. The majority of responses were positive with main focus on the value of support and information provided.

The following quotes illustrate these positive influences

> *"Gave us a life line"*

> *''It has made me feel like I am not on my own. Through their advice I think that the PWD is getting better care than would have otherwise. I am also getting respite and involved in a support group as a result"*.

> *"Given us clarity and information, so we can make informed decisions. She has met us as a family and navigated those dynamics and focussed on the best solution for mum and us as a family"*

> *"Helped us accept what is actually happening that this is a real problem and needs sensitive handling (sometimes against all odds) especially when it is a 24/7 task. Help is definitely needed to allow carer to just take a breather"*

> *"A great difference. My husband and myself live on our own. I have three children all living away, so I only have a daughter (who lives in…) who comes here every weekend. So I have got to know the staff in X so well and they are so helpful as is X [DA]. My family feel at least we have help at hand if we need it"*

However, four respondents did not feel that the DAS made a difference to them or their family as evidenced in the following quotes

> *"None. To be honest it was a waste of my time as had to arrange someone to stay with mum for an hour and a half"*

> *"To be honest I didn't want to keep annoying the woman with phone calls. I contacted her she met me on a Saturday to suit me, advised me on power of attorney and home help advice"*

> *"I never heard from the Dementia Adviser again after our meeting. So it never occurred to me to contact her. She was a lovely person, very kind. But at the end of the day I still had no support"*

> *"As unable to follow up on information given – no difference"*

4.3.14 Perspectives on the helpfulness of the DAS

Respondents were invited to indicate whether / how helpful the Dementia Adviser was to them in relation to a number of statements. Responses were provided on a five point scale (very unhelpful, unhelpful, no difference, helpful and very helpful). The number of respondents to this question varied see table 8 below carers responded to this question. Due to small sample size very unhelpful and unhelpful were recoded into one unhelpful category, helpful and very helpful were recoded into one helpful category and the midpoint of no difference remained the same.

The most helpful aspects of the DAS were the help with formal health and social care services (79%, n=26), help with understanding dementia (72%, n=23), help with legal and care planning (72%, n=23) and help with informal supports (71%, n=22). The least helpful or unhelpful aspects of the DAS was being kept informed about progress (31%, n=8), the DA responding quickly in times of need (26%, n=6) and the DA helped to know what financial supports are available (23%, n=7).

Table 8. Helpfulness of the DAS

	Unhelpful	No difference	Helpful	**Response N**
		N (%)		
The DA helped to understand dementia	3 (9)	6 (19)	23 (72)	32
The DA helped to be able to cope with the changes	3 (9)	7 (21)	23 (70)	33
The DA helped to support my family member	3 (9)	8 (24)	22 (67)	33
The DA helped to know what formal health & social care services are available	4 (12)	3 (9)	26 (79)	33
The DA helped to access services	4 (13)	9 (29)	18 (58)	31
The DA helped to know what informal supports are available	5 (16)	4 (13)	22 (71)	31
The DA helped to know what legal & care planning options are available	4 (12)	5 (16)	23 (72)	32
The DA helped to know what financial supports are available	7 (23)	5 (17)	18 (60)	31
The DA helped feel they are listened to	5 (16)	5 (16)	22 (68)	32
The DA responded quickly in times of need	6 (26)	1 (4)	16 (70)	23
The DA addressed their concerns & worries	5 (17)	5 (17)	19 (66)	29
The DA kept them informed of progress	8 (31)	5 (19)	13 (50)	26

4.3.15 Perspectives on the Dementia Adviser

Respondents were asked to comment on their experience of the dementia adviser with regard to their key attributes of the dementia adviser. Respondents were provided with seven statements of key attributes of the Dementia Adviser and indicated where they agreed or disagreed with each statement. The carers indicated high levels of agreement with most of the statements the highest level of agreement was that the DA demonstrated respect (94%, n=32). Two exceptions were that the DA helped them feel more confident (67%, n=20) and the DA was easily contactable (77%, n=24). See table 9 below.

Table 9. Response of carers to questions on key attributes of the Dementia Adviser

	Disagree	No Opinion	Agree	Response N
	N (%)			
The DA communicated well	1 (3)	3 (9)	30 (88)	N=34
The DA demonstrated empathy	1 (3)	3 (9)	29 (88)	N=33
The DA demonstrated respect	1 (3)	1 (3)	32 (94)	N=34
The DA spent enough time with me	4 (12)	1 (3)	28 (85)	N=33
The DA was easily contactable	3 (10)	4 (13)	24 (77)	N=31
The DA has helped me feel more confident	4 (13)	6 (20)	20 (67)	N=30
The DA seemed knowledgeable about dementia services	1 (3)	3 (10)	29 (88)	N=33

4.3.16. Overall satisfaction with the DA service

71% (n=25) of carers indicated that they were satisfied with the service 23% (n=8) had mixed satisfaction levels and 6% (n=2) said they were dissatisfied with the service (see figure 20 below). N= 35 responded to this question.

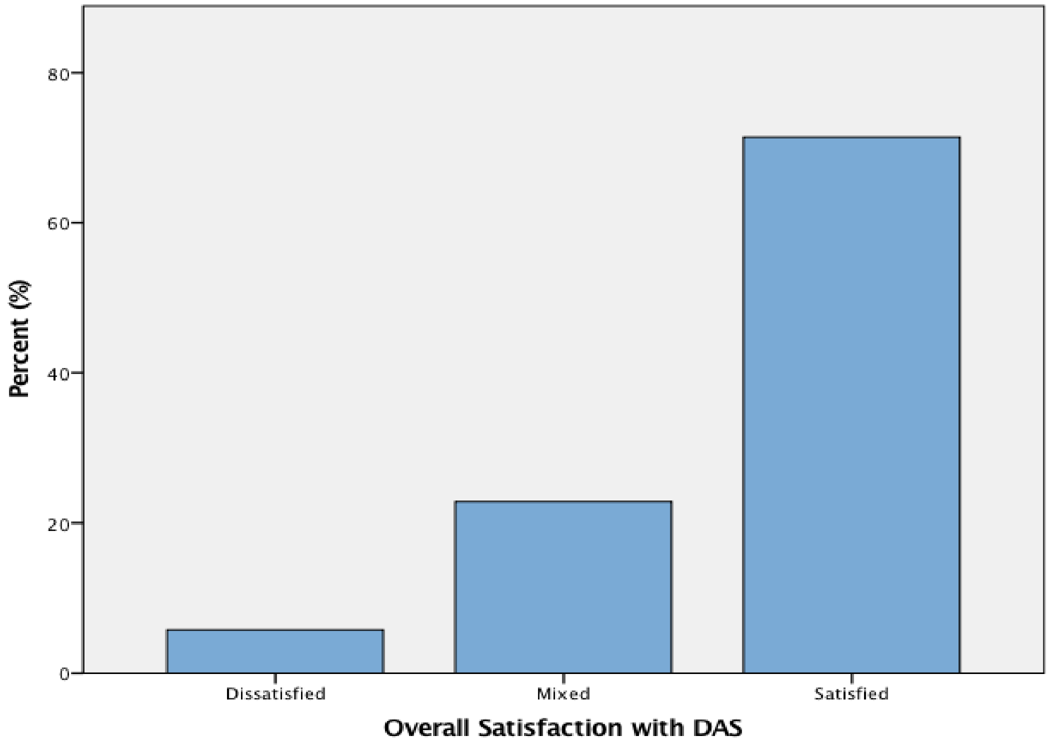


Figure 20. Overall satisfaction with the DAS

Overall satisfaction levels were then cross tabulated with time since diagnosis (see figure 23 below). All of those who were dissatisfied were diagnosed three or more years at the time of access to the service.

4.3.17 Carers perspectives on how the DAS could be improved

Carers were invited to provide suggestions on improvements that could be made to the DAS. This was an open-ended question; 63% (n=24) of carers responded with comments. Carers called for more Dementia Advisers, increased access to services and more practical assistance. The following comments reflect the carers' opinions:

"A monthly meeting was held by the advisor which was very informative. This has been discontinued"

"I would like to think that everyone had access to a DAS. I initiated the contact myself but I know somebody who lives near me whose parents both have dementia and they haven't contacted the DAS. Maybe if the PHN was to give details it might make people more comfortable about contacting them"

“Better links to practical help’. ‘Lots of nice words and sympathy not much practical help”

“More advisers required. From the ads on the TV the impression is given that Kathy has her own full-time adviser. This is obviously not the case. Also I was unaware that the adviser would come to my mother’s house. I don’t know what she would have done or what her role was. I really felt it was just to give advice”

“They could contact you again to see how you are getting on. My dad just died and my mum came to live with me. I have 3 small children, and to be honest nobody really helped me until my mum was in hospital. I had lots of forms to fill in on top of everything”

“I think the dementia adviser service is a great service. A monthly drop in would be brilliant for carers where they could tap in and get more information. Even an update on the different stages of dementia”

“The adviser I met was a lovely person, who was very sympathetic to our situation and shared a lot of knowledge with me regarding services available etc. However, due to budgets/manpower issues, there was no actual practical assistance on offer for dad and myself”‘Lots of nice words and sympathy not much practical help’.

Further comments The following quotes were added by carers invited to provide any further comments on the services provided:

> *"The advisor contacted the local dementia day care facility and helped me to get my husband to join it. It has been a great help to me and gave me 2 days a week to do shopping and whatever was necessary"*

> *"I feel there is not enough people on the frontline to call and advise carers from a practical financial and emotional perspective. So many people get this really devastating news every day. No one understands until they go through it"*

> *"You are a life supporting service. Without you're services and support I wouldn't be here to fill in this survey. The feeling that you are not alone at a very dark time. You have wonderful empathy, respect and all with a wonderful sense of humour and bucket loads of advice. Thank you very much for your help too!"*

> *'Thank you for all the work you do it is a very important service which I hope it will continue to grow and develop'.*

Summary

The section of the chapter presented the perspective of carers or family of people living with dementia. Of 155 surveys distributed only (n=38) responded. The majority of the carers were female and a spouse or partner to the person living with dementia. The North Dublin DAS was the region most frequently accessed followed by the service covering Galway and then the Cork City region. Respondents had accessed information with regard to dementia predominately from their medical consultant, the public health nurse and from the ASI helpline. The most frequent source of information about the DAS was from the GP followed by the medical consultant and then the public health nurse.

Respondents described their understanding of the role of the DAS as one that offered support, advice and signpost to other services. The DAS was described by carers as a service that reduced isolation and listened to clients. Just half of respondents indicated that they only had one contact with the dementia adviser service. Carers were asked if their relative living with dementia had met with the dementia adviser and if not why not. The main reason their relative had not made contact with the service was because they were unaware of their diagnosis or because their relative was admitted to hospital/long term care. Generally, respondents hoped the DAS would offer advice about the future and information on dementia and services. The majority of carers reported that they would recommend the service to other people living with dementia. Respondents provided many examples of how the DAS had contributed to their role as caregiver. Again the main characteristics of the service were signposting and support. The Dementia Adviser was able to listen to the carers concerns and offer information to help them understand the condition.

The most helpful aspects of the service were help with signposting to formal health and social care services, help with understanding dementia, help with legal and care planning and help with informal supports. The least helpful or unhelpful aspects of the service was being kept informed about progress. Overall, carers were satisfied with the DAS. Carers suggested that to improve the service more follow up with carers was necessary and more practical support.

4.4. Results of Survey with Health and Social Care Professionals

This section presents the perspective of health and social care professionals. Specifically, the service was evaluated in terms of respondents' understanding of the role of the dementia adviser service, contact made with the service, satisfaction with the service and recommendations for the future. The evaluation of the service was ascertained using a questionnaire specifically designed by the research team for this study.

4.4.1. Profile of respondents

A link to the surveys was distributed to through the HSE email distribution list and response received was N=186. The majority of respondents were public health nurses (PHN) 13% (n=25) followed by community therapists 9% (n=16), community nurses 9% (n=17), social workers 8% (n=15), clinical nurse specialists 6% (n=12), geriatricians 4% (n=7) and psychiatrists for old age 3% (n=5). General practitioners (GPs), practice nurse specialists and counsellors were each 1% of the total respondents. Other professions, in addition to the above, consisted of 44% (n=81) of the total respondents; these ranged from community coordinators, clinical nurse managers, therapists, care assistants, pharmacists, managers and administrators/clerical officers.

Respondents were asked to indicate the number of years they were in post, 98% (n=182) of respondents completed this question. The majority of respondents (30%) were in post for less than 5 years followed by 29% (n=52) who were in post for more than 15 years. Of the remainder 22% (n=40) were in post between 5-10 years and 19% (n=35) between 11-15 years.

Respondents were then provided with the list of DAS regions and asked to indicate the dementia adiser service they contacted. N = 162 respondents answered this question. Results show that the dementia adviser most frequently contacted (see figure 21) was in the North Cork, East Kerry, Limerick, Tipperary, South Clare region (24%, n=38). It is important to note that this region is covered by one dementia adviser.

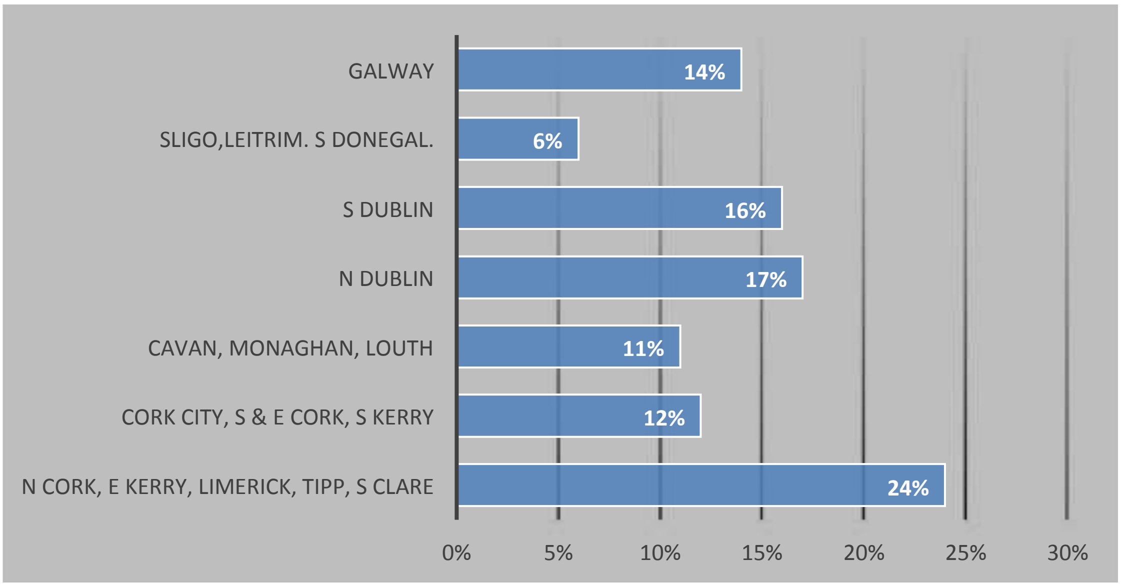


Figure 21. The Dementia Adviser Service Region contacted by respondants (n=162)

4.4.2. Respondents understanding of the Dementia Adviser Service

Respondents were asked to describe, their understanding of the role of the DAS, 72% (n=134) completed this question. For this open ended question a number of respondents (n=22) reported that they had not heard of the service or stated it was not available in their geographical area. The dementia adviser service was described by other respondents as a service to advise and support clients, families and carers on help available. Support varied from practical, emotional and moral support and was available to clients, families and carers. Signposting of services in the community was a recurring characteristic of the service as well as advocacy. The dementia advisor service was described as a service that provides education for health and social care professionals as well as clients, families and carers. Education for clients, families and carers was focused on to how to cope. Education for health and social care professionals was related to communication techniques and support services available locally. Another key characteristic of the service was linking in with relevant agencies and groups/facilities available in the community e.g. respite needed across the trajectory of dementia.

"Signposting of services
in the community"

> “a service to advise and support clients, families and carers on help available”

> “Provides education for clients, families on how to cope. For health and social care professionals on communication and local support services”

4.4.3. The DA service and referral

Respondents were asked if they use the dementia adviser service as a point of referral. 76% (n=142) of respondents replied to this question with 15% (n=21) and 34% (n=48) respectively frequently and regularly using the service as a point of referral. As seen in Table 10 which reports Health and Social Care Professionals use of the DA Service, there are similar numbers who regularly used the DAS as a point of referral and as a contact point to those who rarely used the DAS.

Table 10. Health and Social Care Professionals use of the DAS

Dementia adviser service	Frequently N(%)	Regularly N(%)	Rarely N(%)	Never	Response N
I use the dementia adviser service as a point of referral.	21 (15)	48 (34)	44 (31)	29 (20)	142
I use the dementia adviser service as a contact point for support, signposting, and information (outside of client/family referral).	15 (11)	49 (37)	40 (30)	30 (22)	134

When respondents were asked to provide a narrative comment on why they 'never' or 'rarely' used the service as a point of referral. 36% (n=67) of respondents provided reasons. Following analysis of all responses, among the main reasons provided were that they either *had not heard of the service* or were *unaware of the referral process*. *This response should be considered in the context that the survey was distributed to a wide list of Health and Social Care Professionals and the DAS does not cover all counties in Ireland. Therefore it is possible that the service was not available in the county where the respondent Health and Social care professional was based.

Other examples of reasons given for rarely / never using the service were *clients would already be in contact with the service or linked with other older adult's services*.

Yet another stated that '*alternative support avenues were available such as the multi-disciplinary team, public health nurse, or programmes such as '5 Steps to living well with Dementia''*.

One respondent stated that '*due to volume of work and limited resources, follow up by the dementia adviser was often delayed or difficult, therefore any issues that required intervention were accessed elsewhere'.*

Why professionals never/rarely referred

- Had not heard of the service or unaware of the referral process*
- Clients were already in contact with the service or linked with other older adult's services
- Due to volume of work and limited resources
- Lack of awareness of what the service provides
- Able to provide the support/information from their own role/position.

Respondents were also asked why they never or rarely used the service as a contact point for support, signposting, and information (outside of client/family referral). 33% (n=62) of respondents volunteered reasons for this. Again a number of these respondents stated that they were *not aware of what the service provided*. Again this response should be considered in the context that the DAS does not cover all counties in Ireland, and it is possible that the service was not available in the county where the respondent Health and Social care professional was based.

Others provided responses such as: '*did not think to contact the service*' or '*I was able to seek the support/information myself or from my own role or position*'.

Respondents that reported contacting the DAS were also asked to provide the main reasons for making contact with the service, 58% (n=108) responded to this open-ended question (n=78 skipped this question). The main reasons for contacting the service were as outlined below:

Main reasons for contacting the DA service

- to help connect people with dementia
- to help them learn about local supports and services
- to provide information for families living with dementia especially post diagnosis
- to support carers and families especially if they are at a crisis point or burn out
- to organise talks or training programmes for carers groups or public service providers e.g. library.

Additionally, health and social care professionals were asked to indicate at which stage / time in their dementia diagnosis the clients/carers were initially referred to the service; 55% (n=103) responded to this question. The stage when clients/carers were mostly referred to the service was early in diagnosis 63% (n=65). This was followed by 'some months after diagnosis' 61% (n=63), 'some years after diagnosis' 47% (n=48) and 'at crisis point' 41% (n=42).

Respondents were then asked to give their opinion as to what might be the most useful stage to refer clients or carers to the dementia adviser service and 61% (n=114) responded to this question. Eighty-seven per cent (n=99) of respondentsidentified early in diagnosis as the most useful stage. This was followed by some months after diagnosis at 11% (n=13).

How Satisfied with the DA service?

Respondents were asked how satisfied were they with the dementia adviser service, 56% (n=104) responded to this question. The majority were either very satisfied 48% (n=50) or satisfied 34% (n=35) with the service; 12% (n=13) of respondents were neither satisfied nor dissatisfied with the service and 6% (n=6) expressed dissatisfaction with the service.

A majority of respondents (89%) would recommend the dementia adviser service to other health & social care professionals

Respondents were asked if they would recommend the DAS to other health and social care professionals, 61% (n=113) responded to this question. The majority of respondents (89%, n=101) would recommend the dementia adviser service to other health and social care professionals, 3% (n=3) would not recommend the service and 8% (n=9) indicated that they would maybe recommend the service. Respondents were then asked to comment on why they would not recommend the DAS to other health and social care professionals; 6% (n=12) responded to this question and the reasons for not recommending this service were due *to limited capacity* and the perception that it was *an ad hoc service*. Others stated *they lacked experience of the service to recommend it*.

Respondents were asked to comment on their experience of the dementia adviser with regard to their key attributes such as communication, responsiveness, knowledge and professionalism. 57% (n=105) responded to this question and were offered a choice of five pre-coded responses with the neutral point being 'somewhat agree'. Respondents could also respond with 'don't know' if they had no experience of the service. Table 12 outlines the responses for each attribute. The majority of responses reported strong agreement with regard to communication (51%), responsiveness (47%), knowledge (59%), and professionalism (62%). Only, 6% of responses reported strong disagreement for each key attribute and 13% responded did not know for each of the key attributes listed.

Table 11. Response to questions on key attributes of the Dementia Adviser

Key Attributes of DA	STRONGLY DISAGREE	DISAGREE	SOMEWHAT AGREE	AGREE	STRONGLY AGREE	DON'T KNOW	RESPONSE N
	N (%)						
The Dementia Adviser communicates well.	6 (6)	1 (1)	9 (9)	22 (21)	53 (51)	13 (13)	104
The Dementia Adviser is responsive.	6 (6)	5 (5)	5 (5)	26 (25)	49 (47)	13 (13)	104
The Dementia Adviser is knowledgeable.	6 (6)	2 (2)	2 (2)	20 (19)	61 (58)	14 (13)	105
The Dementia Adviser demonstrates professionalism.	6 (6)	1 (1)	1 (1)	19 (18)	65 (63)	12 (12)	104

4.4.4. Was the DA service helpful?

Respondents were asked how helpful is it to their role to be able to contact the dementia adviser service, 55% (n=102) respondents replied to this question. The majority (63%, n=64)) stated it was very helpful, 28% stated it was helpful and 6% stated it made no difference and 3% (n=3) stating that it was very unhelpful.

Majority (68%) stated that the DA service was helpful

The value of the service to their role was exemplified by with the following qualitative comments related to this question:

"an adjunct'
'complements health professionals role as a 'back up support and a valuable source of knowledge"

'The dementia advisor has changed our service. We now refer direct from the memory clinic which is hugely beneficial…..

"the dementia adviser service was helpful as it provided specialist advice, signposting and guidance readily available to health professions as well as people with dementia and their families"

Other comments were related to assistance provided by the DA service to other health and social care services. For example

> *(It is) 'a service that provides support and information beyond the hospital and clinic, particularly where time is limited or the timing inappropriate in these settings'. 'Given resource restraints and limited local availability of staff to provide post diagnostic support the dementia adviser is invaluable….'*

Another H&SC professional commented that the DA……

> *'Allows me to know that after discharge, patient & family will be offered the right service & support as assessed by dementia adviser….'*

One respondent suggested that the service assisted in…

> *'ensuring the patient/family get the most appropriate and up to date information and advice suitable to their needs. I feel I would not have the appropriate knowledge to provide this information. It ensures a more holistic approach to the clients care'.*

It has greatly enhanced the role of the clinic in that we can augment a thorough diagnosis with an equally diligent post diagnostic support'.

The dementia advisor service was *recognised as another colleague to be able to dialogue with who has specialist knowledge* especially as a resource for up to date information.

"A great resource'.
It is difficult to always know
everything and keep up to date"

4.4.5. Perspectives on referral **from** the DA service

Respondents were also asked whether they would be open to receiving referrals from the DAS ; 55% (n=103) responded to this question. The majority (73%, n=75) replied 'yes' and 13% (n=130 'no' with 14% (n=15) responding 'maybe'. Of the 'no' or 'maybe' respondents, 27% elaborated further on why this might be. The main reasons were that referrals traditionally are only accepted from medical practitioners and that it depended on the dementia adviser qualifications and scope of practice.

Majority would accept referral from the DA

The next question explored if the DAS should be able to refer directly into the primary healthcare services - including GPs, PHNs, and Allied Healthcare Professionals. Only 17% (n=31) of respondents replied with 77% (n=24) stating 'yes' and 16% (n=5) stating 'maybe'. For the 'no' and 'maybe' respondents, 26% (n=8) commented on why they would not agree to DAS direct referral. The

Why unsure about accepting referrals
- Referral traditionally only from Medical Practitioners
- Would depend on DA qualifications and scope of practice

main reasons provided were that the *service is already overwhelmed* and *a medical assessments should be undertaken to inform the referral process.*

4.4.6. Relationship of DA services with other Health and Social Care Services

The following seven questions in the survey dealt with respondents perspectives on the awareness of the service and relationship of the DA service with other services. However these questions revealed a very low response rate of only 3% (n=7), therefore the results need to be treated with caution.

4.4.6.1. General awareness of the DA service

Respoondents were asked their opinion on the general awareness of the DAS. Again, the response was low at 3% (n=7) and table 14 demonstrates that overall there is a perception of awareness of the service for health and social care professionals and somewhat for people with dementia and carers/families. To improve the visibility of the service, respondents suggested *linking the service to primary care teams and medicine for older adults/neurology as well as educating the public on their role*.

Table 12. Awareness of the DAS

Awareness of the dementia adviser service	Yes	No	Maybe	Don't Know
Response (n=7)	N (%)			
Health & Social Care Professionals are aware of the Dementia adviser service	3 (43)	0 (0)	2 (29)	2 (29)
People with dementia are aware of the Dementia adviser service	1 (14)	1 (14)	2 (29)	3 (43)
Carers/Family of those with dementia are aware of the Dementia adviser service	1 (14)	1 (14)	2 (29)	3 (43)

4.4.6.2. Should the DA service have a presence within services?

The proportion of respondents who reported ‘yes’ that dementia advisers should be present at the following meetings was as follows: Community Multidisciplinary Team Meetings (57 %, n=4), Memory Clinics (71%, n=5) and Residential Care/Local Placement Fora (33%, n=2).

Respondents were asked whether they knew if the dementia adviser service liaised with other voluntary or community organisations. Of which 85% (n=6) did not know and 14% (n=1) replied yes.

Respondents were asked if the dementia adviser service duplicates other services available for people with dementia. Only 3% (n=7) replied to this question and 57% (n=4) replied no and 43% (n=3) don’t know. The impact of the dementia adviser service was described by respondents (n=7) as a personal support service.

4.4.6.3. Knowledge of the engagement of the DA service with other services

The following question examined if health and social care professionals knew if the dementia adviser engaged with other services namely, Medical Centres/ GP Surgeries, Community Based Allied Healthcare Professionals, Acute Hospital Team, and Voluntary Organisations. Table 13 presents the results demonstrating that the majority did not know. Again the response to this question was low at 3% (n=7).

Table 13. Knowledge of DA engagement with services listed

Does the Dementia adviser engage with services listed.				
	Yes	**No**	**Don't Know**	**Response N**
	N (%)			
Medical Centres/ GP Surgery	0 (0)	0 (0)	7 (100)	7
Community Based Allied Healthcare Professionals	3 (43)	0 (0)	4 (57)	7
Acute Hospital Team	3 (43)	0 (0)	4 (57)	7
Voluntary Organisations	1 (14)	0 (0)	6 (86)	7

Table 14 presents the responses to the question that examined if health and social care professionals knew if the dementia adviser refers clients to other services. The majority stating they did not know.

Table 14. HSCP knowledge of whether dementia adviser refers to services listed

HSCP knowledge of whether dementia adviser refers to services listed.				
	Yes	**No**	**Don't Know**	**Response**
Services	**N (%)**	**N (%)**	**N (%)**	**N**
Medical Centres/GP Surgery	0 (0)	0 (0)	7 (100)	7
Community Based Allied Healthcare Professionals	1 (14)	0 (0)	5 (71)	7
Acute Hospital Team	0 (0)	0 (0)	5 (71)	7
Voluntary Organisations	1 (14)	0 (0)	6 (86)	7

4.4.7. Interaction with the Dementia Adviser Service

Respondents were provided with seven statements and asked to indicate their level of agreement in terms of their interaction with the Dementia adviser service (n=98 responded). Table 15 outlines the responses.

Overall the majority of respondents (38%) strongly agreed that clients and/or family/caregivers met with the dementia adviser service in a timely manner after the referral was made. Health and social care professionals strongly agreed (54%) that the DAS supports existing healthcare services. In addition, respondents agreed (31%) and strongly agreed (26%) that the well-being of the client improved after contact was made with the DAS.

Sixty nine percent of respondents somewhat agreed to strongly agreed that they are usually not aware when a client/family has made contact with the dementia adviser service. Fifty eight percent strongly disagreed that dementia adviser service does not add value to existing healthcare services. Health and social care workers were also asked if any of their clients provided them with feedback with regard to the dementia adviser service. Just over half of respondents (n=96) replied to this question with 58% stating yes and 36% stating no. A smaller number of respondents (n=57) commented on how satisfied they thought their clients were with the dementia adviser service, of this 37% replied satisfied and 49% very satisfied.

Table 15. Health and Social Care professional interaction with the DA service

Statements Total response n=98	STRONGLY DISAGREE	DISAGREE	SOMEWHAT AGREE	AGREE	STRONGLY AGREE	DON'T KNOW	
	N (%)						**Response N**
Overall, the Dementia adviser service met with the client and/or family/caregiver in a timely manner after the referral was made	1 (1)	5 (5)	5 (5)	26 (27)	37 (38)	24 (24)	98
The Dementia adviser service supports existing healthcare services. (n=98)	1 (1)	1 (1)	5 (5)	23 (24)	53 (54)	15 (15)	98
The Dementia adviser service provides regular updates to you on any issues identified. (n=98)	8 (8)	13 (13)	19 (19)	22 (23)	16 (16)	20 (21)	98
The well-being of the client improved after contact was made Dementia adviser service. (n=98)	1 (1)	1 (1)	9 (9)	30 (31)	26 (26)	31 (32)	98
I am usually not aware when a client/family has made contact with the Dementia adviser service. (n=98)	4 (4)	11 (11)	23 (24)	28 (29)	17 (18)	13 (14)	96
The Dementia adviser service works collaboratively with other healthcare services. (n=97)	2 (2)	3 (3)	26 (27)	21 (21)	26 (27)	20 (20)	98
The Dementia adviser service does not add value to existing healthcare services. (n=98)	57 (58)	21 (22)	4 (4)	0 (0)	3 (3)	13 (13)	98

The remaining three questions in the survey were free text allowing respondents to further demonstrate their opinion of the service. Respondents were asked what the advantages and disadvantages of the dementia adviser service were and to suggest how the dementia adviser service could be improved.

4.4.8. Advantages of the DA service

Some 46% (n=86) of respondents answered this question. Characteristics associated with the advantage of the service were *support, reassurance, local knowledge and the link to national organisation*. Advantages of the service included *a resource for individuals, relatives and healthcare professionals;* a *one stop shop for dementia signposting across voluntary and statutory agencies*. The dementia adviser service has many facets as described in the following quotations:

> *"It is vital to have a named person, available at the end of a phone, home visit etc. for both the person with dementia and their family/carers"*

> *"It is a grassroots based service providing much need support and professional advice to dementia patients and their families and also to other professionals and careers in the field"*

> *"The dementia adviser is a link person along the dementia journey, who is easy to access, either in person or on the phone'. On the whole, the advisor was very approachable and adaptable to meeting at a suitable place or time"*

> *"This service allows families time to learn at their own speed with a holistic approach"*

Given the busy nature of clinical practice and the time required to address dementia specific issues, this free service was acknowledged by respondents for the time it was able to provide to individuals, relatives and carers.

‘ ‘‘It’s difficult for primary care healthcare staff to build up the level of expertise in dementia that the adviser would have so great to have access to this service”

“They have the time to offer to those with dementia and their families/carers. Time and a listening ear and two things in short supply in busy clinical practice. They are informal so clients may feel less threatened and free to ask questions”

“The biggest advantage is having one person from the time of diagnosis who knows everything that’s on offer around the area. This is also a very specialist role which can shape the service”

“It offers support in a personal centred, friendly and reassuring way and in a timely way”

Generally, the service was portrayed as a link between service users and healthcare professionals. The diagnosis of dementia can be challenging for individuals and their families, the dementia advisor helps integrate services and navigates concerns by signposting and providing support for service users.

‘Another layer of support for patients and families. Less formal than the medical setting in which families can be overwhelmed and therefore are not able to absorb in all the information and advice they are told’.

4.4.9. Disadvantages of the DA service

Forty one percent (n=76) of respondents described disadvantages of the service. For most of the respondents n= (%), the main disadvantage of the dementia adviser service was that the service did not operate in every region. Characteristics associated with the disadvantages were: lack of communication lack of integration with other services and lack of clarity about the scope of DA practice. Health and social care professionals commented that communication could be enhanced if dementia advisor communicated back to professionals involved in clients care.

> *‘”he dementia adviser does not tend to communicate with us (health and social care professional) once the referral has been made so we are not aware if they have met with the family and what information/advice was given”*

> *“Does not operate in every region”*

It was acknowledged that it was difficult to understand what the service involved and this needed to be communicated or advertised to create better awareness.

> *“The scope of the dementia adviser could be expanded if resources where made available and then they could be better integrated into primary and secondary care”*

> *“I am confused about what the service provides in relation to the Alzheimer society service and many clients are unaware that the service exists”*

Lack of integration into primary and secondary care was a reoccurring comment and this seemed to restrict the dementia adviser service. This was also associated with their scope of practice.

‘Integration with clinical services can be restricted as the service is somewhat outside of the HSE sphere”

. *‘‘Their scope could be expanded if resources where made available and a nursing qualification would be helpful”*

4.4.10. How the service could be improved

Finally, respondents were asked if they had any suggestions of how the service could be improved. Just 45% (n=84) of respondents volunteered suggestions.

Key recommendations were: better integration of the dementia adviser service with existing services and greater awareness of the service with better national coverage. The following comments depict the main recommendations:

“This service may work better if integrated with joint specialist clinics with Consultant Geriatricians/Neurology at OPD or memory clinics and ‘ development of post diagnostic supports’

“Greater integration with existing services such as day hospital older persons. Attendance at hospital multi-disciplinary meetings & live online chat times to allow healthcare professionals”

“Provide feedback from advisors on their interventions especially to PCCC and MDT”

“Presence at clinics (dedicated primary care/PHN clinics), additional dementia advisers and better integration with secondary care - posters, referral forms readily visible in clinical spaces”

“GP's to be targeted so that people will use the service more, as early intervention to managing is key to a living well with dementia The GP is the first point of contact and their intervention is crucial to the long term outcome for an individual”.

“I suppose there is room for increasing the profile of the service - I am aware that most people are unaware of its availability - maybe a need for a national media campaign but then again they may not be able to respond to demand”

Summary

The total number of respondents was 186. The majority were PHN at 13% followed by community therapist (9%), community nurses (9%), social workers (8%), clinical nurse specialist (6%), geriatrician (4%), and old age psychiatrist (3%). From these responses the dementia adviser most frequently contacted was in the North Cork, East Kerry, Limerick, Tipperary, South Clare region followed by the North Dublin and South Dublin regions.

Respondents were asked to describe, their understanding of the role of the DAS. A number of respondents (n=22) had not heard of the service or stated it was not available in their geographical area. This was likely to be due to the distribution of the online survey link to a wider population of Health and Social Care professionals, and may not have referred patients to the DAS as it was not available in their county. The DAS was described as a service that provides advice to clients, families and carers regarding the supports available to them. Support varied from practical to emotional support and this was available to clients, families and carers. Signposting of services in the community was a recurring characteristic of the service along with advocacy.

Health and social care professionals reported that they regularly used the service as a point of referral. The main reasons for contacting the service were as follows: to help connect people with dementia; to learn about local supports and services; to provide information for families living with dementia especially post diagnosis; to support carers and families especially if they are at a crisis point or burn out, and to organise talks or training programmes for carers groups or public service providers e.g. library. Questions on the survey that were related to general public awareness and awareness of engagement of the DAS with other services received a poor response (n=7) indicating a need to focus on greater general awareness and information regarding the scope and reach of the DAS.

Respondents were asked to comment on what they perceived as the most useful stage to refer clients or carers to the dementia adviser service. The majority identified ‘early in dementia diagnosis’ as the most useful stage. The DAS was reported to be ‘helpful’ as it provided specialist advice, signposting and guidance to health and social care professionals as well as people living with dementia and their families.

Overall, the majority of respondents strongly agreed that clients and/or family/carer met with the DAS in a timely manner after the referral was made. Health and Social care professionals strongly agreed that the DAS supports existing healthcare services. Overall, the main advantage of the service was seen as being a resource for individuals, family carers and healthcare professionals. The DAS was also described as a resource for dementia signposting across voluntary and statutory agencies. The main advantageous characteristics reported of the service were: support, reassurance, local knowledge and the link to national organisations. The main disadvantage of the DAS reported was that they did not operate in every region. Characteristics associated with disadvantages of the DAS were: lack of communication and integration with other services and the DA scope of practice. Key recommendations were better integration of the DAS with existing services and greater awareness of the service with better national coverage

Chapter 5: Case Exemplars

Introduction

To facilitate a more in depth view of the context in which the dementia adviser service is provided, two different regions where a DA service was provided were chosen as case exemplars. The regions chosen are representative of a mix of urban and rural areas and have similarity in the number of clients. However the two regions differ in the geographical terrain, population density, health, and social care resources available to support the provision of DA services.

5.1. Method

Data were collected in each of the case exemplar areas with the assistance of and in discussion with the DAs in each area, from a sample of anonymised client cases over a retrospective one-week period from the date of data collection (April 2018). The quantitative data extracted related to the number of clients supported by the DA over that period in each area and then case notes were subjected to qualitative content analysis. The researchers compared data from the two the exemplar areas in terms of client numbers, type of service provided in a typical week and integration with other services in the areas. The cases are presented in an integrated fashion to preserve client and DA anonymity.

5.2. Results

There were a number of similarities between exemplar areas in the numbers of clients supported over the period – see table 16 below:

Table 16. Similarities between exemplar areas

Exemplar	No of clients in exemplar week	No of clients records in 2017	Geographical areas	Average time on home visits
Area 1	n=16	N=200 new and return clients	Urban and Rural	2 hours
Area 2	n-14	N=177 new and return clients	Urban and Rural	2 hours

In both areas the Dementia Advisers were asked to outline a typical week in the life of the DA. Again there were a number of similarities in the number of home visits, the complexity of cases, the type of advice, information and referral provided and the time spent in organising carer support groups and peer support for the PLWD. The main difference was the connection with health and social care services in that in one of the exemplar areas the DA was directly linked with a memory clinic in the area and has a regular presence at the clinic. In the second area the link with memory clinics or outpatient geriatric services was not developed to the same extent.

5.3. A typical week in the life of a Dementia adviser:

In each of the exemplar areas, the Dementia Adviser travels to at least one client meeting per day. These meetings are most often held in the client’s home, but may also occur in a hotel in the area. The geographical areas covered in both exemplar areas mean that travel may involve a 1- 2 hour round trip. The average meeting time is 2 hours.

Data from client records show that client meetings via phone typically take 1 – 2hours depending on the purpose and complexity of the meeting. In both exemplar areas the Dementia Adviser reported on the administrative duties conducted in the operationalisation of their role. Examples of these include: making arrangements for facilitation of carer support clubs; sending invitation via text to carers; the production of fliers to advertise support groups and Alzheimer café e.g. in parish newsletters

A typical week in the life of a Dementia Adviser was compiled from discussion with the DAs and outlined below:

Monday	Tuesday	Wednesday	Thursday	Friday
Home Client meeting x2 2 phone calls from clients Texts to all potential guests re: reminder of Alzheimer cafe on Friday Emails and phone calls following up on client issues and organizing client visits Completion of documentation and action plans on electronic record system	Travel to client meetings x 3 DA meetings 2 phone calls from clients – information provided. Phone call to arrange the referral of a client to another service. Emails and phone calls follow up client issues and organising client visits Completion of documentation and action plans on electronic record system	Administration 2 phone calls to arrange referrals in relation to clients The preparation and organization of Alzheimer café Facilitating the café Discussions with various clients seeking information following Alzheimer café Emails and phone calls following up on client issues from Alzheimer café Completion of documentation and action plans on electronic record system	Travel to client meeting x 1 1 phone meeting 4 phone calls to and from clients 2 phone call referral in relation to client Organized counselling for 2 clients and respite for 1 client in a crisis situation Emails and phone calls following up on client issues and organising visit for next week Completion of documentation and action plans on electronic record system	1 Home Visit follow up 1 meeting on phone 1 phone call referral 3 calls from clients Emails and phone calls following up on client issues and organising visit for next week Meeting re the Butterfly initiative in local acute care center Completion of documentation and action plans on electronic record system

5.4. Integrated case examples from both areas

In both exemplar areas there were client cases identified by the DA that required a number of immediate support and follow up support interventions. The following cases provide a flavour of the type of complex cases encountered and recorded by the DAs within the data collection period.

5.4.1. Complex cases

Mrs W
PROFILE
Mrs W, lives with her spouse who is diagnosed with lewy body dementia. She was referred to the Dementia Adviser by her public health nurse. The dementia adviser met with Mrs W in her home over a period of one and a half hours.

ASSESSMENT OF NEEDS
The client (a carer) was recorded by the DA as being under considerable stress and exhaustion and unable to cope with responsive behaviours of her spouse particularly at night. The main areas of concern documented were carer stress and the safety of spouse. The needs identified were increased home care, day care and regular respite care.

ACTIONS INITIATED *BY THE DA*
Reassurance was given to the carer and referral provided to a Day centre. Information and signposting were provided on further social and health services support available. The client was supported with an application for respite care. Information was provided on a carer support group and Alzheimer cafe in the area and a follow up visit was arranged with the client in one weeks time.

Ms Y
PROFILE:
The DA was contacted by phone. The client (Ms Y) was a daughter who was very concerned about her dad who had a recent diagnosis of early / moderate dementia and also concerned about her mum who was recently discharged from acute care following surgery. Ms Y lived a distance away from her parents and ahe reported that her mum was currently the main carer for her dad. There was no additional family support available due to geographical distance.

ASSESSMENT OF NEEDS
Concerns highlighted by Ms Y during the initial discussion with the DA were mainly in relation to future planning for her dads care; getting legal affairs in order and also the lack of home support available and concernes about safety in the home.

ACTIONS INITIATED BY THE DA
The DA advised the client to contact her family solicitor and sought her permission to send details about the next Alzheimer Café and carer support group meetings where a talk would be given by a solicitor. She also arranged a home visit with the family. During the subsequent visit the DA recorded in her notes that the family were provided with forms to apply for home care, home adaptation and respite care. Information on emergency response alarms was also provided given concerns about safety. Information was also provided in relation to

legal issues including enduring power of attorney. Dates were provided for when support group meetings were on and contact information to avail of day care services. A follow up meeting was also arranged.

5.4.2. Less complex cases

Within the data collection period there were also a number of cases described by the DAs as less complex. These cases were mainly informational interventions and required less time on the part of the DA.

Mrs D

PROFILE

Mrs D in her seventies lives alone in an urban area. She has had a recent diagnosis of cognitive impairment / early dementia and contacted the DA herself for advice. Mrs D reported that she was becoming forgetful but still working part-time. Mrs D was still driving but reported becoming nervous. She had no family support nearby but had very helpful neighbours and friends. She lived in a large two storey house with a garden. Mrs D mentioned that she was finding it increasingly difficult to maintain both.

ASSESSMENT OF NEEDS

The immediate needs assessed by the DA were that of a need for peer support, information on health and social care available if needed, the need to commence future planning in relation to home support and legal issues. Information and advice were given to the client on driving assessment. Social support needs assessment was identified as necessary.

ACTIONS INITIATED BY THE DA

The DA provided Mrs D with guidelines regarding driving. Areas of support discussed with Mrs D were– driving assessment, Alzheimer café support group, life story book, pendant alarms, referral to occupational therapist; information and forms were provided in relation to the housing adaptation grant. The client was advised to consider meeting with her solicitor re planning for future. Follow up meeting was arranged.

Mr G

PROFILE

Mr G was a new client. He arranged to meet with the dementia adviser at a memory clinic. He reported that he had been a primary carer for his spouse with dementia but she was now in long term care. Mr G lived alone and was still driving but was concerned about his memory lapses. He mentioned that he had good family support nearby. He expressed an interest in reading and he stated that he enjoyed social activities.

ASSESSMENT OF NEEDS
This was recorded as a self-referral so it was noted that the client was very self-aware. His present needs were assessed as informational and support.

ACTIONS INITIATED BY THE DA
Advice was given on steps to assist with memory. Mr D was encouraged to continue with physical activities and social activities. Information was provided on local social groups and he was referred to the memory clinic again for further assessment as he expressed concern about memory lapses.

5.5. Dementia awareness and support activities

Both Dementia Advisers were involved in promoting awareness of dementia and support activities through the Alzheimer Society such as hosting the mobile Information Service (Bus) at various events in their areas. Guest speaking at Social Café events and awareness talks for various community groups and organisations in their local areas. Involvement in training courses provided by the ASI (INSIGHT) and dementia working groups.

One of the DA's was also involved in a dementia support initiative in the local acute care centre. This initiative provides opportunity for people with memory impairment and dementia to communicate this to hospital staff, enhancing awareness and this initiative also provides staff with practical training to offer targeted responses to meet the needs of PLWD.

Summary

The case exemplars provided an opportunity for the researchers to explore the typical day to day operationalisation of the role of the DA, along with an examination of the typical client cases referred to the service. Two distinct geographical regions were chosen to enable an exploration of any similarities or differences in the services provided to clients, the client cases recorded and the DA mode of operating. Notably, both DA services served a mix of urban and rural areas and each in proximity to a city and a large acute hospital. A retrospective examination of client records over a one week period in both areas found that there were many similarities between the DA services provided e.g. The numbers of clients recorded in the year 2017 was similar as was the number of clients recorded in the exemplar week. The majority of clients were family members who self –referred, with a small number referred from public health nurses or from a diagnostic clinic (memory clinic). The cases reviewed varied in both exemplar area from complex to less complex in both areas. The complexity of the cases most often related to behavioural challenges associated with the disease, a lack of practical support available or experienced by carers and carer stress. The type of support offered by the DA was similar in each area. This was mainly advice, information, referral and emotional support and follow up. A major difference observed between the DAS areas, was the difference in connectivity of the DA service with other professional health and social services locally. In one area the DAS was directly connected to the local memory clinic and the DA held a monthly clinic within this service.. As a result, of the DA presence in the clinic, clients had easy access to and awareness of the DAS and were referred directly from the medical and nursing personnel to the DAS. The second exemplar DAS at the time of this report was not directly linked within with the local diagnostic services therefore fewer referrals emanated from Health and Social care professionals. Both DA’s acknowledged the benefit of encouraging more integration with the relevant health and social services to build awareness and encourage more use of the DA supports earlier in the dementia diagnosis.

Chapter 6: Data integration Conclusion and Recommendations

Introduction

The aims and objectives of this evaluation were to independently evaluate the existing Dementia Adviser Service in Ireland from the perspectives of all key stakeholders.

To ascertain the role and structure of the Dementia Adviser service and assess the impact of the existing Dementia Adviser service on people with dementia and their family / carers and from relevant health and social care professional's perception of the service. To identify gaps in service provision and perceived service needs and make recommendations for future policy and DA service development.

The evaluation was underpinned by the re-aim framework and was conducted in four phases (Phase 1: Literature Review, Phase 2: Interviews and Focus Group with dementia adviser, Phase 3: Surveys of Persons Living with Dementia and Family / carers of PLWD and an online survey of Health and Social Care Professionals that had referred to the DA service, Phase 4: case exemplars).

Combining quantitative and qualitative data for the same subject of inquiry has been described by Carroll and Rothe (2010) as both "looking at and looking in" pg.3482.

In this chapter the summary results of data analysis from each phase is integrated and a conclusion and recommendations from the evaluation is presented.

Triangulation of evaluation findings is presented using the Re-aim framework in table 17 below

Table 17 Triangulation of evaluation findings using the Re-aim framework

Re-aim framework	Literature Review	Interviews Focus Groups	Survey with PLWD	Survey Family Carers	Survey Health & Social Care Professionals	Case exemplars
Reach: Penetration of the service	The DA role is described as Main priority of the service to enable swift and easy access for the PLWD and their carer to support and advice following diagnosis. A single point of contact	The DAs are situated within the health and social care services. Embedding the role within existing service structures was described as challenging initially. A unique aspect of the DA is their ability to spend time to sit with people with dementia and help them navigate the complex social and health system and explore different solutions to managing symptoms. A single point of contact for guidance or advice for family, PLWD and a variety of healthcare professionals	DA offered **support, advice and signposting to other services.** The dementia adviser service was described by PLWD as a service that reduced their fears and isolation *Someone who can help to alleviate your fear of the future and present'* *'I get great support. I go to all the meetings*	Described by carers as a service that **reduced isolation** and listened to clients. Recurring themes of *advice*, ***support*** **and 'a *feeling of not being alone*'.**	Majority were PHN at 13% followed by community therapist (9%), community nurses (9%), social workers (8%), clinical nurse specialist (6%), geriatrician (4%), and old age psychiatrist (3%) DAS described as a **resource** for dementia **signposting** across voluntary and statutory agencies Advantages: **support, reassurance, local knowledge and link to national organisations** to advise and support clients, families and carers on help available. Support varied: practical and emotional support	The two regions differ in the geographical terrain, population density, health, and social care resources available to support the provision of DA services. In both exemplar areas there were cases managed by the DA that required a number of immediate support and follow up interventions. Cases involved a mix of complex and less complex issues. DA's conducted at least one client visit per day. Much time spent daily on administrative processes i.e. arranging Alzheimer Café, support groups etc Differences were found in the links between the DA and local Health and Social care services.

Efficacy Impact on target groups	Evidence of improved quality of life and general wellbeing, self-empowerment and independence in PLWD Evidence of significant satisfaction levels in research with Carers Stakeholder report added value to existing services	Client and family empowerment was described as one of the key impacts. Raised significant awareness regarding the disease Making the journey emotionally easier for family A negative impact was the increased volume of PLWD that they are referring to over stretched services and subsequent burden that this might be having	The majority of respondents reported the service helped bring normality to their lives, provided understanding about dementia and gave them confidence to ask questions.	Positive influences of the DAS on themselves and their family and valued the support and information provided. Reported help with formal health and social care services, help with understanding dementia, help with legal and care planning, and help with informal supports.	Regularly used the service as a **point of referral.** The majority of respondents identified **early in diagnosis as the most useful stage** for referral. The DAS was reported as **helpful** as it provided **specialist advice, signposting and guidance** readily available to health professions as well as people with dementia and their families. DA met with the clent in a **timely** manner after the referral was made	DA's were involved in promoting awareness of dementia and support activities through the Alzheimer Society such as hosting the mobile Information Service at various events in their areas. Guest speaking at Social Café events and awareness talks for various community groups and organisations in their local areas. Involvement in training courses provided by the ASI (INSIGHT) and dementia working groups.
Adoption of the service	Generally positive adoption of the service into existing services once roles and boundaries of the service were clarified.	DA's described themselves as not a crisis intervention but crisis prevention**.** They spoke about being part of the 'Multidisciplinary team' but also being the link that brings the social and clinical services together for families struggling to	Some respondents were disappointed *I feel they barely touched the surface of what people with dementia need'* *Should be Linkage to all services in local area*	50% indicated that they only had one contact with the DAS, highest percentage of those clients who were in contact with the DAS only once were those diagnosed > 3 years.	A number of respondents had not heard of the service or stated it was not available in there geographical area The scope of the DAS was not altogether understood particularly in relation to referral from the service to	There were similarities between exemplar areas in the numbers of clients supported over the period and similarities in type of service provided

		navigate the complex care systems			Health and social care professionals	
Implementation: Level of **consistency** in delivery 'real world'	More awareness and clarity is necessary about the role and services provided by the DA to encourage more acceptance and embeddedness within the existing services	The role appeared to be extended to what was described as an advocacy service, with several references made to assisting PLWD and their families' access to appropriate services and creating the link between services. Interventions that are tailored to the needs of the family are also an essential part of the services. A challenge for some DAs with a clinical background i.e. nursing is maintaining parameters as they are not there in a clinical capacity	Majority of respondents would recommend the service	.Mixed opinions from carers regarding their subsequent contact – questioned the benefit as they needed '*hands on support'*	Advantages support, reassurance, local knowledge and the link to national organisation. The main characteristics associated with the disadvantages were lack of communication, integration and lack of understanding re the scope of practice of the DA.	The main difference was the connection with services in that in one of the exemplar areas the DA was directly linked with a memory clinic in the area and has a regular presence at the clinic. In the second area the link with memory clinics or outpatient geriatric services was not developed to the same extent
Maintenance: Sustain into the future	There is evidence that what may have emerged as a simple model of information, advice and support for PLWD initially now requires a depth of	Facilitators of DAS were collaborations with Healthcare professionals, support from management/HSE stakeholders, recognition of the social model of dementia, visibility	A key recommendation were more dementia provisions *Everyone diagnosed should have access*	Carers mainly called for more Dementia advisers, increased access and more practical ' hands on' support and assistance	Suggestions for improvement included better integration of the dementia adviser service with existing services with better national coverage.	Both DAS provided education sessions on dementia and were involved in local and nationals awareness campaigns. Both DA's dealt with complex cases that required more than informational support and

	knowledge, flexibility and creativity and an integration with existing services to adequately execute the model of care and support required.	through the ASI, Referral to Medical rapid access clinics, and development of services to refer out to including Sage Advocacy and Family Carers Ireland. Challenges were lack of forward referring services available to PLWD. Seen as a source **of great frustration. ‘ patchiness of services.** Geographical location – logistical challenges DA’s anticipated that there should be an expansion of the number of posts nationally however they felt central to this was professional developed for those that are in the role and for future DAs. Concern expressed that the DA would be **unable to meet the needs** of clients over time.	*The link should happen at diagnosis even if not accessed immediately*		Greater awareness of the service particularly in relation to the role and scope of practice of the DA.	demanded more integration with existing community services and referral pathways.

6.1. Integration and discussion of findings using the re-aim framework

As presented in the table 17 the Re-aim framework was used to integrate and synthesise the data produced in this evaluation. In the following section the results are discussed under each concept of the framework (Reach, Efficacy, Adoption, Implementation, and Maintenance).

Reach: penetration of the service

Evidence from the data collected through qualitative and quantitative methods demonstrated that the DAS was viewed by clients, dementia advisers and health and social care professionals as useful/ important situated within the health and social care services. However there was evidence of some challenges in embedding the role within existing services and a lack of awareness and understanding of the scope of the service on the part of professionals. The evaluation provides consistent evidence that the service is '*a single point of contact'* for PLWD, their carers and Health and social care professionals. The service provided is mainly that of individual support, advice and signposting to other supports and services. These results are similar to findings from our review of international literature where the service was described as enabling access to a wide range of supports (Clarke et al. 2016), responsive to the needs of their clients and an individualised and tailored service (Daniel et al., 2011; Dayson & Bennette 2016; Kelly & Innes, 2016). Persons living with dementia and their carers reported that the DA service was valued in that it assisted in alleviating isolation by providing advice and information and assisting them to navigate a complex health and social care system. This finding is similar to those of international research where clients felt supported and that they have someone who is on their side (Daniel et al. 2011; Hancock et al. 2014) and were satisfied with the service (Hibberd & Vougioukalou, 2012). However there is evidence in this study that the expectation of the scope of the DA service after the initial contact on the part of clients / carers was of more practical assistance than advice and information. .

Efficacy: the success rate of the service: impact on target groups.

This evaluation provides evidence that the DAS has had a positive impact on clients, carers and health and social care professionals. DA's themselves reported that the impact of their support interventions resulted in empowerment of individuals and family. PLWD reported positive influences including bringing normality to their lives, confidence and more understanding about dementia and their diagnosis. Similar to results from previous research (Majo et al. 2016; Daniel et al. 2011; Hancock et al. 2014), PLWD and carers valued the support and information provided and reported receiving assistance with navigating the system. There are similarities here to descriptions of the service in the UK as enabling access to a wide range of supports (Clarke et al, 2016). Although mainly positive there was some evidence that direct contact with the DAS influenced the satisfaction with the service and that after the initial contact carers and family expectations of the services were different to that which is provided within the scope of the DAS and more related to their need for practical help and support for caring in the home. Similar to previous research there was evidence of changing carer expectations from the service as the dementia diagnosis progressed and support needs changed (Goeman et al. 2016). Health and Social care professionals reported that the DAS was helpful in providing specialist advice and guidance to clients and professionals alike. However they suggested that this service was most useful and successful early in the dementia diagnosis.

Adoption: proportion of settings, practices and plans that adopt the service

Dementia advisers in this study spoke about being part of the 'team' but also being the link that brings the social and clinical services together for families struggling to navigate the complex care systems. However DA's also described themselves *as not a crisis intervention.* One of PLWD commented that the service '*only touched the surface'* of their needs. They suggested that the service should be linked more to other health and social supports and services. This suggests a misunderstanding of the role and scope of the DA service and a need of clarification. This finding concurs with those from our review of international literature where similar recommendations emerged from sHealth and Social care professionals in relation to awareness and clarity about the DAS role, and the need to work alongside existing services (La Fontaine 2011). These stakeholders were generally positive about the service once it became established and the roles and boundaries of the service were clarified (Bunn et al 2016; Dayson & Bennett, 2016). An important enabler to the success of the DAS in Australia was that there were no time or geographical restrictions (Goeman et al. 2016). The DA service in Ireland is not available in all counties and this lack of equitable service was mentioned as problematic in our interviews with DA's and also in results of the survey with Health and Social care professionals. In our interviews with the DAs, they were worried that the current level of service could not meet all the needs of clients and had real concerns that if the service coverage were not expanded nationally, the role would become even more challenging over time. Positivity about their role and their desire to see the service develop in collaboration with the HSE and NGO's was evident in analysis of interviews and focus groups with the DA's. Health and Social care profesionals in our survey called for more integration of the DAS with existing community services and there was evidence from qualitative comments that more embeddness and presence within existing services is recommended. This would result in greater adoption and understanding of the role of the DAS and improved communication / feedback between service providers.

Implementation: The extent to which the service is implemented

Data from the DA interviews suggests that the DAS has grown organically according to client need beyond advice and information to advocacy and referral to health and social care and support services. This increase in the extent of the service has posed a challenge for the DAs in this study, in that they are aware that they are referring clients to health and social care services that are already stretched. Although the majority of clients would recommend the service to others, there were mixed opinions especially from carers on the benefits of subsequent contact. The reason appears due to the changing support needs as a result of the normal progression of dementia. As dementia progresses, carers and family needs often extend beyond the advice and information the DAS can provide. Health and social care professionals acknowledged the advantages of the DAS in relation to the reassurance and support provided to clients, however there were some concerns about the lack of integration of the service and their lack of knowledge and understanding about the scope of practice of the DA's. The two case exemplars provided evidence of the differences between service areas in relation to the operationalisation of the service. One was more closely connected with diagnostic services their area and had a presence in a memory clinic. This enhanced the extent to which the service was used by Health and Social Care professionals as a source of referral and in turn assisted in referral from the DAS to clinical services andsupports.

Maintenance: Extent to which the service is sustained over time

This evaluation provides evidence of a service that can be sustained over time. Facilitators of the service identified by respondents are similar to findings of our literature review i.e. enablers of the DA service mainly revolved around collaboration with other services (Clarke et al. 2014), successful partnerships (de Siún et al. 2013) and reliable data systems (Daniel et al. 2011). The DA service providers in this study also recommended support from health and social care management and a recognition of the service that is provided within a social model of dementia care. There is an anticipation that referrals to the DAS will increase, therefore an expansion of DAS was recommended by all respondents. Both PLWD and their carers recommend that everyone with a diagnosis of dementia should have access to the DAS and carers particularly requested access to practical support. However, the DA's in this study expressed their frustration at not being able to link to adequate homecare services for their clients with those particular support needs. Health and social care professionals recommend national coverage of the DAS, better awareness of the role and scope of the service and integration with other services. These recommendations echo those of international research that called for more awareness and clarity to encourage more acceptance and embeddedness within the existing services (Clarke et al. 2014)

6.2. Conclusion

This is the first major evaluation the Alzheimer Society of Ireland National Dementia Adviser Services. The evaluation was conducted using a mixed method approach and included the perspectives of all stakeholders (PLWD, Carers, Health and Social Care professionals and Dementia Advisers).

The evaluation provided evidence of overall high levels of satisfaction with the DAS. Clients (PLWD and their carers) and Health and social care professionals reported satisfaction with the information, advice, support and signposting of services provided. The qualitative comments provided a rich narrative to support the positive aspects of the service along with an indication of some of the challenges for PLWD and their carers. There was gratitude among PLWD and carers for the advice and information provided but some comments questioned the value of subsequent contact with the service to their day to day practical needs. It is evident that the current DAS has grown organically since its inception in 2013, in response to client needs. There are some differences in the operationalisation of the service in different areas depending on the level of integration and connection with relevant local health and social care services. While DAS in a number of regions are embedded within or alongside a local diagnostic service others are not. This creates inconsistency in the awareness of the service amongst professionals and the public.

The expected growth in client numbers, and increasing rate of referrals are causes for concern amongst the DA's given the size of geographical area covered by one DA . Our case exemplars of two regional services provide evidence of at least one individual client visit by the DA per day with approximately two hours of contact time. DA's expressed concern that the ability of individual DA's to increase this level of one to one contact is limited and consequently all support needs of clients may be unmet unless the service is expanded nationally.

The majority of PLWD surveyed reported that the service helped and supported them providing understanding about dementia and giving them confidence to ask questions. Most would recommend the service to other people living with dementia and highlighted that the information available online was also useful. The most helpful aspects of the DAS reported by carers were signposting to formal health and social care services, help with understanding dementia, help with legal and care planning, and help with informal supports e.g. Carer support groups and Alzheimer café. While most carers also expressed very positive influences of the DAS on themselves and their family and valued the support and information provided, there were a small number of carers that did not feel that the service made a difference to them after the initial contact. This was mainly due to their need for day to day support beyond advice and information. Expectations of clients following initial contact with the DAS appeared to be focused on more practical ‘hands on support’. This is understandable given the progressive nature of the condition. This approach or level of service is not within the stated scope of the DA role. However, at least one of the DA’s indicated that the needs of clients, particularly returning clients have resulted in an expansion of the DA role towards advocacy on behalf of clients for care and support services. There is a need therefore to consider the introduction of an additional level of support and care intervention such as an identified Health or Social Care professional as clients’ needs progress beyond advice, information and emotional support and a clear pathway of communication from the DAS for those clients with that level of need identified.

Health and social care professionals in this study reported regularly using the DAS as a point of referral. The main reasons for contacting the service were: to help connect people with dementia, to learn about local supports and services, to provide information for families living with dementia especially post diagnosis, to support carers and families.

Overall, they strongly agreed that clients and/or family/caregiver met with the DAS after the referral was made and that the DAS contributed to existing health and social care services. The most useful stage to refer clients or carers to the dementia adviser service was indicated as early in the dementia diagnosis. They viewed the DAS as helpful to themselves and to their patients as it provided specialist advice, signposting, a resource for guidance to health professionals as well as people with dementia and their families. However, there were comments from Health and Social Care professionals that expressed confusion in relation to the role and scope of practice of the DAS and referred to a lack of consistency in the level of connection between the DAS and Health and Social care services. There was some evidence that Health and social care professionals were not fully aware of what the DAS provided however this may be as a result of the lack of DAS in their geographical area. Key recommendations for service improvements from health and social care professionals were: better integration of the DAS with existing services and greater awareness of the service and wider national coverage.

Limitations of this research

Although this evaluation was conducted using a mixed methods design and included all main stakeholders of the DAS, there are two main limitations. (1) The survey instruments used were newly developed especially for this research as available survey instruments used in previous evaluations, did not fully address the objectives of this study. However the survey instruments although not psychometrically tested were informed by evidence from literature, expert advisors and reference to former service evaluations. (2) A low response to postal survey sent to PLWD . As an independent evaluation, researchers had no direct contact with clients and were dependent on client interest and ability to respond to a request from the ASI to complete the survey. The importance to this evaluation of the involvement of service users was stressed from the outset and the response rate is comparable to that in previous studies involving PLWD. Actions taken by the researchers to assist response included the availability of a dedicated telephone number provided on the participant the information leaflet to use for help with queries related to the survey and a reminder letter sent to clients by the ASI within two weeks of the initial survey distribution. A number of telephone calls were received by the contact researcher from PLWD and family members for clarification. Although the survey response was low, the addition of qualitative comments within the surveys added a rich narrative and insight into the experiences and perspectives of respondents. It was clear that the DAS was appreciated by both PLWD and carers. The survey of Health and Social care professionals was distributed via the HSE to Health and Social care professionals that referred to the DAS but this survey link was also distributed to a wider email distribution list, therefore a number of the respondents may as a result have not had experience of referral to the DAS or had a DAS in their geographical locations. This could explain responses that indicated a lack of awareness of the services provided by the DAS.

6.3. Recommendations

Recommendations from this evaluation are presented using the Re-Aim framework as follows:

REACH (Penetration of the service)

- **National expansion and development of the service**: This evaluation provides evidence of a need for an expansion of the DAS. All stakeholders (Clients, Health and Social care professionals and DAs themselves) recommended an increase in the number of dementia advisers to meet the increasing demand as a result of the increasing prevalence of dementia. We recommend development of the service to achieve national coverage. In addition, strategies for ensuring optimization of the reach of the DAS e.g. further extending the presence of a DA at existing clinics, should be explored.

- **An identified Health / Social care professional to undertake the role of co-ordinator of care and clinical support:** It is evident from this evaluation that the peer support, advice, information and signposting to available services provided by the DAS are essential to PLWD and their carers. However, results show that as dementia progresses there are unmet clinical needs that are outside the scope of the DAS. To meet client's clinical needs and promote continuity of care, we recommend the introduction of an identified Health / Social care professional to undertake the role of co-ordinator of care and clinical support. Such a role would be complementary to the DAS

EFFICACY (impact on target groups).

- **Equity of access to DAS for PLWD and their carers:** The impact of current DAS as evidenced from this evaluation is very positive in relation to the support and signposting of services for those PLWD and their carers who are fortunate to have access to the service. The DAS is currently not available countrywide, therefore support is dependent on the geographical location and the degree of connectivity of the DA with local community services. To ensure that the positive impact of the DAS is experienced by all PLWD in future we recommend that the service is extended and delivered within a consistent structure, with equity of access for all PLWD and their carers wherever they are located.

ADOPTION: (practices and plans that adopt the service).

- **Clarification of the role, purpose and scope of the DAS:** It was clear from our evaluation that the role of the DA as envisaged by the DA themselves and the ASI is to provide a timely and individualised information, advice, and signposting service for PLWD and their carers/ family. However the evidence shows that there was some confusion or misinterpretation of the role and scope of the DAS by both clients and carers / family. This confusion is also evidenced from Health and Social care professionals. We recommend that the role and purpose of the DA and scope of the DAS in post – diagnostic support for PLWD and their carers should be clarified and communicated to the public, clients and the Health and Social Care community. This would assist in meeting the persons expectations of the service and ensure no duplication of services.

IMPLEMENTATION (as intended in the real world)

- **Early referral to DAS:** There was evidence in this evaluation that the DAS works with PLWD and their carers throughout their dementia journey. However all stakeholders agreed that the advice and information support interventions of the DAS are most appropriate and achieve better outcomes for the PLWD if accessed early in the dementia diagnosis. It is recommended that Health and Social care professionals and the public are encouraged to access the DAS as soon as possible following diagnosis in order to receive optimum benefit from the service and to have a local point of contact from the outset for further advice, signposting to other services and peer support as dementia progresses.

- **The development of direct pathways of communication to and from the DAS:** This evaluation provides evidence that client expectations of the scope of the DAS after initial contact went beyond the advisory and informational role of the DAS. Expectations of the service appeared to include the provision of more practical care and clinical support. Where such client needs are identified by the DAS, we recommend a pathway between the DAS and an identified Health / Social care professional who can coordinate care within existing services in each area. Where further advice and information is needed by PLWD or their carers at any time in the dementia trajectory, direct pathways from Health / Social care professionals to the DAS would provide for a more seamless and efficient service. Ideally, such pathways should be supported by ICT.

MAINTENANCE: (sustaining the service into the future)

- **An efficient centralised and connected ICT support system:** As evidenced from our evaluation, Dementia Advisers play a key role in creating awareness and providing education to clients and health and social care professionals in conjunction with their substantive role in supporting individuals and their families. Although the system of administration of the service was reported by the DAs to have improved, it was deemed not to be sufficient to meet with the expanding needs of the service. To ensure that their time is used more efficiently and effectively we recommend that a centralised system of administrative and ICT support is made available to assist the DAs in the day-to-day management of workload and to ensure consistency in documentation communication and data management processes. It would be ideal and supportive of seamless support if this ICT system was connected to systems administration within Health and Social care.

- **Further research:** To measure the impact of support interventions provided by the DAS over time, we recommend a longitudinal study. To establish and measure the impact of the service on a number of outcomes for PLWD and carers e.g. quality of life or caregiver burden. This could include qualitative and quantitative methods to provide a more realistic and holistic view of the impact of the service on client's carers and the health and social services with which they are connected.

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Appendices

Appendix 1

To: Professor Alice Coffey
From: Samantha Taylor

Date: 29 June 2018

Context of Service

The Alzheimer Society of Ireland's Dementia Adviser Service delivers an information, advice and support service to people with dementia and their families. In 2017, 8 Dementia Advisers worked across the following 12 counties in Ireland; Cork, Kerry, Tipperary, Limerick, parts of Clare, Galway, Sligo, Leitrim, Cavan, Monaghan and Dublin.

Backgound to the Service:

People with dementia and their families and carers have repeatedly expressed the need for a single point of contact who can assist them to navigate their journey with dementia by providing accurate, accessible and timely information and signposting. This need was verbalised across ASI's network including, our Helpline service, social clubs, support groups, family education programmes as well as to staff in our day and respite centres and home care programmes and through our Branch network.

In response, and having considered international practice in UK and Scotland in this area, ASI piloted a Dementia Adviser Service in Dublin & Cork in 2013 to build on and enhance existing information services, such as ASI's national Helpline. This pilot focused on developing the goals and purpose of the service, building understanding of the information, advice and signposting needs of clients and understanding of how the role would operate in practice. By the end of 2014, a further 6 Dementia Advisers were in post and this rose to a total of 8 Dementia Advisers in 2015. Since 2016, the HSE has co-funded this service.

Purpose and Activities of ASI's Dementia Adviser service

Purpose of the ASI Dementia Adviser Service

The role of Dementia Adviser (DA) is to provide a locally based, individualised, information, signposting, and emotional support service to people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life. Their purpose is to:

- provide information, advice and support to understand the condition, manage symptoms, support activity and maintain / encourage participation in their community,
- signpost/connect people to appropriate services and supports to assist in supporting independence and well-being and to maximise quality of life, and
- provide early intervention and prevent crisis.

The service is confidential and delivered free of charge to service users. ASI developed an information leaflet to explain this new service which is distributed to health and social care professionals, relevant places within the county (ie library, community centres) and to all service users. In addition there is a dedicated page on ASI's website to explain the service and provide contact details. On commencing work, each DA developed a plan to grow awareness of the service within the county. (Leaflet is attached)

Activities of ASI Dementia Advisers

- The service is flexible and responsive to clients needs, who can choose a home visit, or a meeting in a local ASI office or agreed locations. Support by phone and email is also provided.
- Dementia Advisers provide services at diagnostic clinics in several locations, ensuring the service is available at the earliest opportunity.
- Dementia Advisers work to
    - co-develop an information plan with the person with dementia and their family to identify their information, support and service needs and actively review this plan at agreed intervals.

  - Support clients to identify strategies to manage day-to-day life with a focus on activity and participation.
  - identify and support access to appropriate services and supports.
  - assist and support the person with dementia and their immediate family or carer to navigate the health and social care systems as required.
  - proactively assist and support the person and their family to consider planning for the future, with a focus legal, financial and care planning.
- Dementia Advisers deliver information and awareness talks to local community groups and health & social care professionals, these talks include Active Retirement groups, Age Friendly County initiatives, Health Fairs and also health and social care professional meetings, training sessions. All with a view to increasing awareness of dementia, the impact of the condition and where people can go to for support. (56 talks delivered in 2017). In addition, Dementia Advisers also were available on ASI's Mobile Information Service and provided on board consultations at events such as the National Ploughing championship, a farmers mart in Cork, Connemara in Galway and shopping centres in Monaghan, Cork and Dublin as well as bringing the service to 4 hospital campuses in the year. The mobile information service facilitated DA's in reaching rural communities in particular by bringing them right into local community settings.
- In 2017, the team facilitated 2 Alzheimer Cafes, 2 family carer support groups. 2 Dementia Advisers also supported ASI's Southern Dementia Working Group which is an advocacy group for people with dementia. One DA is also heavily involved in the Crystal Project in North Cork working directly with HSE Occupational Therapist under this Genio funded project. ASI Family carer educations programmes and CST / Cogs Club sessions are also directly supported by Dementia Advisers around the country

In order to help meet demand and to meet a stated aim of working with people as early as possible following their diagnosis, the Dementia Adviser service made a concerted effort to work directly with diagnostic teams, with relevant community based health and social care professionals and with existing community resources to ensure that the option of availing of the service was highlighted to as many people as possible.

At the end of 2017, ASI's Dementia Adviser team has developed the following:

- 4 Monthly clinics in-bedded within the diagnostic services provided by Tallaght Hospital, Connolly Hospital and Charter Medical Smithfield Clinic in Dublin and St Finbarr's in Cork and a further clinic, by appointment based on demand, in St Ita's, Newcastle West, Limerick.
- A monthly clinic within the HSE Local Health Office and linked to the public health nursing team in Thurles, Tipperary.
- Drop- in monthly clinics were trialed in community resource centres in Cavan and Monaghan during the year. A series of talks were held and promoted in the centres to help build awareness of the service in the counties.

By end of June in 2018 the following clinics have been developed

- Monthly clinics developed with the diagnostic services provided by Merlin Hospital in Galway and in Bantry, Co Cork.
- A weekly service is being established in North Louth working with the Memory Room in Dundalk (HSE led Assistive Technology Project)

After three full years in operation across 12 counties, it was critically important to review the service to enable ASI to hear from clients about their experiences and their perception of the impact of the service on their lives, to receive constructive feedback on the various information, advice and supports being provided in order to enhance future service experience and to stablish if this service investment offers value added support to those affected by dementia. To that end, ASI conducted a client impact survey over the summer months of 2017 and the report of this survey is available at http://www.alzheimer.ie/Services-Support/About-our-Services/Dementia-Advisor.aspx

ends

Appendix 2. Data extraction tables

1. Source (Year) **2. Country** **3. Type**	**1 Aim**	**1. Study Design** **2. Sample**	**1. Description of DA service** **2. Description of Intervention**	**Outcome measures:**	**Key Findings**	**Enablers/Barriers** **Strengths/Limitations**
1. **The Alzheimer Society (2016).** **2.** UK **3.** Unpublished report	To conduct a social cost benefits analysis (SCBA) of two DA services in Bexley and West Lancashire	1 SCBA case studies of 2 DA services. 2. N/A	1. one-to-one role, single point of contact supporting someone with dementia and their carer. Referral to this service is provided through the memory assessment service. Self referral, GP and Community referrals are also encouraged. 2. The role of DA is to support PWD to self manage, live independently, and access appropriate	Change in social cost benefit (SCB) attributable to the use of the service by stakeholder: Mental Health (MH) services (the state); knowledge and information (carers); building peer networks (PWD); Building peer networks (Carers)	1. 21% reduced cost to the state MH services-by helping carers to avoid breakdown; 2. 40% improved knowledge and information (carers)-enables greater independence; 3. 46% improvement in building peer networks (PWD); 4. 44% improvement in building peer networks (carers). 5. The main findings support a significant return on investment	Enablers: N/A Barriers: N/A Strengths: N/A Limitations: N/A

			support and services at the right juncture of their dementia journey			
1. Bunn et al (2016) **2.** N/A **3.** Public	Phase 1: To synthesize the literature on the scope & effectiveness of Admiral Nurses	1. Systematic evidence synthesis: A scoping of literature relating to the role of the Admiral Nurse 2. N/A	1. Admiral Nurses are described as 'mental health nurses who specialise in supporting family carers of people with dementia in the United Kingdom' (Bunn et al, 2016). 2. A Key part of the Admiral Nurse role involves the provision of emotional and psychosocial support to the carers of people with dementia, ongoing throughout the dementia journey.	Scope and effectiveness of Admiral Nurses	Phase 1 33 studies largely descriptive publications. Phase 2: 11 studies identified (5 studies were meta-analysis; remainder were narrative descriptive studies). 77=RCT's. Most studies descriptive not evaluative. Only one study conducted a controlled evaluation of the Admiral Nurse service (Woods et al., 2003) showed no improved carer outcomes when compared with conventional services. Consistent findings of carer value for the service but this was contextual and within a complex system of care.	**Enablers:** Carer centred approach; relational approach; facilitation and liaison with other services and professionals **Barriers** Carers sometimes felt that GPs, specialists and care managers did not work with or communicate with Admiral Nurses. Confusion among Admiral Nurses and community psychiatric nurses over the boundaries of their roles Potential duplication of services Some reported being unable to refuse new cases or that caseloads were

					Little evidence of impact on carer burden or depression. There was a lack of information about how Admiral Nurses used their therapeutic skills No common agreement about what this role could achieve at different points of the carer experience of supporting someone living and dying with dementia. Little evidence on how the Admiral Nurse interacted with other service providers & healthcare professionals. The manner & consistency of Education and information provision to other health care professionals was unclear and depended on the caseload of the Admiral Nurse.	sometimes too large for them to provide meaningful support to carers. Carers lack of clarity about the Admiral Nurse role **Strengths:** N/A **Limitations**:N/A

1 Clarke et al., (2014) 2. UK 3. Publication	To report on the evaluation of the implementation of the National Dementia Strategy recommendations for Dementia Adviser (DA) and Peer Support Networks (PSN) services, across 40 demonstration sites	1. Mixed Methods 3 strands Strand 1 – Activity and outcome monitoring Strand 2 Organisational surveys Strand 3 – in-depth case studies 2. N=40 Dementia Advisor and Peer support Network sites; N=8/40 case studies. Data from PWD and Carers (Strand 1) not presented here	1. Service A Provides support and information predominantly for those people who are newly diagnosed with dementia and their carers. A service for those not receiving support from a care manager **Service B** Provides access to 3 fulltime Dementia Advisers based with community mental health teams. Provides information, support, advice and signposting to relevant services if required, to people with dementia after initial diagnosis. Referrals are accepted	Strand 1: 1. Numbers & demographics of individuals accessing the sites. 2. Wellbeing & Quality of Life of PWD & their carers using Adults Social Care Outcomes Toolkit (data not presented here). Strand 2: Organisational surveys concerning, structure and development, discussions with demonstrator site leads & commissioners - 3 waves repeated measures. **Strand 3:** In-depth case studies from a subsample of 8 sites	1. Organisational structure & services varied considerably across sites. Main goals, roles and purposes across sites stated by staff in the postal survey were: information advice and signposting, enabling access to support & services, crisis prevention and early intervention, maintaining independence, well-being and quality of life; enabling participation & engagement; access to specific communities. 2. The role of the DA was described as: enabling access to a wide range of supports, in addition to signposting, the DA was to work in partnership and collaborate with other local organisations ensuring that these services followed up after DA signposting;	**Enablers**: Once the DA role and purpose as a specialist service was clarified with other organisations there was typically a positive knock on effect for all organisations involved in the care of the Person with dementia & the carer. **Barriers:** 1. The need for an organisational space for the DA service compromised the ability for effective partnership relationship development, maintenance and sustainability of the service. 2. Organisations misunderstanding of the role and purpose of the DA service

			from a range of services, including memory clinics, GPs, Community Mental Health Team (CMHT), social care, self, voluntary agencies, etc.		The DA supported immediate networks & communities surrounding PLWD & carers- using existing community resources and social networks. 86% of those accessing the services had a confirmed diagnosis of dementia, 23% were living alone and 51% were male. Specific to the DA service, 63% of the contacts were with carers of PLWD. 3. **Case studies** A need for clarity of the DA role and its purpose and how they relate within pre-existing services. Important to increase the visibility of the DAS to get more referrals and embed within existing dementia services. Partnership and collaboration pivotal to DAS success.	within the current dementia pathway in some cases fostered mistrust and competition between services. **Strengths:** N/A **Limitations:** N/A

					Important to include PLWD carers in the planning of DAS.	
1. Daniel et al., Alzheimer Society Report (2011). **2.** UK **3.** Unpublished report	1. To investigate service user outcomes of the Alzheimer Society Pathfinder Dementia Adviser sites, set up as a result of the recommendations of the UK National Dementia Strategy (2009) . 2. To examine the experiences of people with dementia and their carers in their experiences with the service in relation to information quality, support received, referral routes and contact interactions.	1. Mixed Methods 2. N=116: 70 (60%) were PLWD, 46 (40%) were carers	1. set up as a result of the UK National Dementia Strategy (2009) to enable easy access to care support and advice following diagnosis. 2. The intervention is the DA service Not descri	1. Demographic data : age gender, living arrangements, ethnicity 2. Type of client interactions: face-to-face, telephone, email, number of people involved, the type of person, description of the needs of clients and length of time at each interaction: From Electronic Client Records System. 3. Carer specific questionnaire and PLWD specific questionnaire about their	1. 32% of PWD lived on their own with no carer, average age of 77 (62-89) yrs. 58% of PLWD completed the questionnaire with some assistance. 2. Majority of referrals from local memory service clinic (37%) and Mental health trust (23%). 3. Both carers and PLWD valued the DA service and the information and support they received. 4. PLWD: 85% felt listened to and respected and involved (82%) in planning their pathway. 74% agreed information provided was relevant & easy to understand (69%)	Enablers: The electronic database facilitated reliable and efficient, web based data collection of information Barriers: Work needs to be done to encourage more GP, community psychiatric nurse, social services and home care referrals to the service. Strengths: N/A Limitations’: N/A

	3. To inform the future development of the Alzheimer Society services.			experience with the DA service. 4. Two in-depth Case study narratives describing service provision and client experience.	& the DA helped them access services (74%) and organisations (66%). 5. most was *knowledge that someone was on their side (47%)* and *information about dementia and services* (57%). 66% would consult the DA service in the future. 6. Most carers (86%) agreed that the person they care for felt listened to and respected by the DA. 63% indicated that the PLWD was encouraged to make decisions; that the information received was relevant (81%) and that the DA helped them to access other services (86%). 35% needed more help to follow-up on information provided. 56% would use	

					the DA service as the first point of contact 7. The Case studies illustrated complexity and variation of service provision & range of knowledge required by the DA and the importance of flexibility in providing this service.	
1. Dayson & Bennett 2016. **2.** UK. **3.** Unpublished report	1. Evaluation of the Rotherham ***Carers Resilience Pilot Service*** aiming to: a. understand the impact of the service on carer health and well-being; b. understand the effect on patient and carer use of NHS care and resources: c. capture stakeholder perspectives on the effectiveness of the service and identify	1. Mixed methods 2. N=7 Stakeholder semi-structured interviews. N=9 semi-structured interviews with beneficiaries of the service. N=3: in-depth client case studies. N=26 questionnaires for carers at baseline and exit from service	1. N/A 2. The carer's resilience service commenced in 2015 to support carers of PWD by providing information, advice and practical support to build carers' resilience. The service involves a number of partner stakeholders. ***GP link workers*** who engage with practices .The link worker then refers onto the ***DA.***	1. Stakeholder views Key successes and challenges, progression & evolution of service, With 3 follow-up interviews to assess change over its development. 2. Beneficiaries Experiences including: a. The kind of support b. impact	Key successes identified : a. Raised awareness of carer needs b. A successful model of care, key roles important. c. Positive relationships between agencies d. more dementia-friendly primary care/GP 2. Key Challenges identified a. High demand & significant level of crises intervention. b. Lack of engagement of a small number of GPs	Enablers: 1. Employment of additional staff to cope with the initial demand of the service that included PWD with complex needs. 2. Establishing good relationships with stakeholders. 3. Flexibility in engaging stakeholders was seen as a crucial Barriers:

	key learning to inform future delivery and commissioning. 2. Establish if this service reduces the demand for emergency secondary care for people with dementia		**The Alzheimer Society delivers the DA service** The DA conducts a needs assessment and provides support and information about the diagnosis and its implications; helps access appropriate services and signposts/refers onto other services available from public and voluntary sectors.	Practically and emotionally. 3. Carer well-being Adult Social Care Outcomes Toolkit (ASCOT); and experience of their caring role. 4. Trends in ED Admissions (April-March 2016).	3. Beneficiary and carer experience: positive general well-being, happiness and reduced anxiety. Qualitative data: a *valued and much needed service, practical and emotional support and reassurance*, and reported benefitting from *information and guidance* and the *practical advice and assistance* received. **Acute admissions** 2014-16 -reduced admissions referrals but A&E continued to rise in same period.	1. Due to high demand for the service at initial stages of the services, there was a significant level of crises intervention involving complex case-management. 2. Some smaller GP services were proving more difficult to engage with the service. Strengths: N/A Limitations'N/A
1. **de Siún (2013).** 2. Ireland 3. Unpublished report	1. To provide an overview of key areas relating to **the development of DA services and the DA role**. Looking specifically at existing evidence reported internationally and in Ireland.	1. Review and report of key evidence and publications relating to DA services up to 2013. 2. N/A	1. A review of literature and published reports. DA in Ireland: following on the UK model The main purpose of the role is: To provide a local point of contact on an outreach basis for people who are	Evidence of Service effectiveness	1. Evidence that DA role provides information and support to PLWD and their carers. 2. is more effective when delivered in conjunction with multicomponent approach 3. components necessary to discharge the service are unclear and vary with	**Enablers** 1. Increased confidence of PWD & carer in availability & access to support and services as well as having a set point of contact. 2. The information increases knowledge about dementia in an

	2. To inform the development of the Irish National Dementia Strategy		concerned about their cognitive health or have a diagnosis of dementia and their families and friends, at all stages of the journey from diagnosis through to end-of-life. Works with statutory and independent organisations and build relationships with service providers: GPs PHNs. The DA enables a range of activities such as training programmes & peer support groups. The role varies geographically		individual needs and geographical location. 4. Key elements of the role: Timing and individually tailored dissemination of information to PWD to enable future planning and appropriate decision-making; Emotional support and flexibility to the needs of their clients; Ongoing continued support of PWD and family/carer; Strong links with statutory, voluntary and private health and social care providers. **Findings of informal conversations Irish DA** 1. dealing more with families and carer than the PWD. 2. level of services available in each area differs significantly. 3. using a mixed methods information, signposting, and on-going case	emotionally supportive manner. 3. Once relationships with other dementia services are established, and its identified how the DA role fits into established care pathways, successful partnerships with the DA service have been forged, for example, with memory clinics, admiral nurses, Community MH teams. **Barriers:** 1. PWD who are least satisfied with the service are: a. those who access the service later in their pathway post diagnosis; b. those who have little contact with the DA service; c. PWD who are not linked to peer

					management approaches. A need for flexibility in the role	support services like dementia cafés. 2. It is difficult for the DA to identify and engage with harder to reach populations- ethnic minorities and PLWD who live alone. 3. lack of awareness of the service 4. Unmet service needs 5. It takes time to establish a DA service **Strengths:** N/A **Limitations**:N/A
1. Dias et al (2008); **2.** India **3.** Publication	To develop & Evaluate the effectiveness of a home based intervention with a home care advisor in reducing the burden of the carer of the person with dementia, promoting carer mental health and reducing	1. RCT 2. N=81 Persons with dementia and their principal carers: persons with dementia (n=41) were randomised to the Home Care Adviser Intervention arm or usual care (n=40).	1 Community & homebased flexible, stepped-care model with a Home Care Adviser 2. The Home Care Adviser implemented a flexible home care programme with min 1 home visit once a fortnight for 6	**Outcome Measures** EASI (Everyday Abilities Scale for India; NPI (Neuro-Psychiatric Inventory -Testing problem behaviours and distress by caregivers:	1.A significant improvement in caregiver Mental Health (1 point significant change in GHQ scores) and perceived burden of the carer (a significant 2 point reduction in NPI scores) was observed. 2. No significant reductions observed for behaviour disturbances and functional ability.	**Enablers:** 1. low cost community model enabled long-term sustainability of the project. 2. Home visits for medical and pharmaceutical management of PWD. **3.** large number of support group visits. **Barriers:**

	behavioural problems in persons with dementia.		months (average 12 per person). Provided: Education about dementia; management of behaviour; carer support- peer support groups; referrals to services and advice on existing schemes & entitlements.	Zarit Caregiver Burden Scale (ZBS): GHQ-General Health Questionnaire.	3. No significant improvement in the behaviour of the PWD. 4. Overall high mortality rate was noted in all patients but 64% lower (not statistically significant) in the Intervention study group	access/mobility problems - 46% of carers non attendance at group meetings **Strengths:** N/A **Limitations:** N/A
1. Goeman et al (2016); **2.** Australia **3.** Publication	To establish & refine a culturally sensitive model of dementia support & pathway for culturally and linguistically diverse (CALD) people using a Specialist Dementia Nurse (SDN)	1. Qualitative study using co-creation & Participatory action research (PAR) approach. 2. Stakeholders (e.g.. Occupational Therapists Clinical Dementia Nurse etc..) n=13; PWD n=62.	1. Person Centred Inclusion Model: SDN (specialist dementia nurse) service embedded within a not-for-profit home nursing service 2. SDN was incorporated into the existing services. The SDN undertook assessments, recorded case-notes and used a combination of face-	1. the SDN recorded case notes, describing interactions with each participant as well as using Reflective Practice methods to document experiences and observations following each client visit. 2. Expert Reference Group Meetings	. Increased uptake in community support services was noted 2. Reflections on the type and frequency of support-showed that CALD clients historically found it difficult to access Healthcare services, thus the SDN specifically advocated & tailored the service (e.g.. signposting) to the PWD & the carers specific needs.	**Enablers:** The person with dementia could step in and out of the service as needs changed. With no time or length of service restrictions. **Barriers:** Access to interpreters relevant to CALD clients. .

			to-face & telephone contact. Support on a needs basis with no time restrictions.	used to evaluate the SDN reflections to help develope and refine the dementia care model.	3. In association with the expert stakeholders they created a framework for a SDN community model with CALD clients: It consisted of 3 components a. Organisational support & specialised services for a CALD population; b. Set of core competencies of the SDN-with sufficient autonomy & flexibility to tailor support and information; conduct needs assessment manage changes in behaviour/circumstances, & act as an advocate.	
1. Hancock et al (2014) **2.** UK (Gloucestershire area) **3.** Unpublished report	To conduct an **independent evaluation of the Dementia Adviser service** in the Gloucestershire area, to inform practice and improve the service.	1. Mixed methods 2. Interviews: N=4 PWD, N=8 carers plus comments from N=5 carers who did not complete the interviews;	1. As a result of the UK, National Dementia Strategy, the DA service was launched and run by the Alzheimer Society in 2010. The main purpose of the DA role is to provide a highly responsive	1. Separate questionnaires for carers and PWD were developed. For the PWD, elements of the EQ-5D (REF EuroQuol, 2003) were incoproated to	1. The DA service is a highly valued service by the PWD and their carers (Bar chart data only). 2. Qualitative comments: a. The DA used a variety of methods to communicate with the	**Enablers:** N/A **Barriers:** A significant proportion of the respondents did not recognise the term dementia adviser or could clearly define

		Questionnaires, N=21: N=10 PWD, N=11 Carers.	individualised information and signposting service to people with a diagnosis of dementia and their carers. This service is envisaged as a one point of contact service. 2. Application of DA service in the National Demonstrator Site Gloucestershire area for current service users at the time of data collection.	explore the health status of the PWD. 2. Evaluation of the Carer and PWD experiences with the DA services, support and acitivities.	people they support including face-to-face, one-to-one at home or at other locations such as a memory café, and email. b. The **term** dementia adviser was unknown to a significant number of their role was also unclear. c. For persons living with their spouse the impact of the DA was greater for the spouse than the PWD in terms of advice & support. For the PWD living alone the DA helped to facilitate contact with other professionals and services and to build their self-esteem. Carers indicated that impact was in terms of advice, information, support and as a facilitator for accessing services that would benefit the PWD, and they indicated that	their role or who they were associated with. Strengths: N/A Limitations:N/A

					they felt supported by the DA and were confident that the DA would follow-up. d. DA is seen in a positive manner providing an invaluable service. Although some indicated they would like more time to talk face-to-face but were also aware that this is a stretched service. 4. 90% of both PWD and their Carers found out about other services and support from the DA and that the information provided was easy to understand.	
1. Harrison-Denning, Aldridge, Pepper et al., (2017) **2.** UK **3.** Publication	To discuss the Admiral Nursing case management approach to supporting patients and families affected by dementia, and provide recommendations	1. Case studies of Admiral nurse applications 2. N/A	1. The AN is a single and consistent point of contact for the PWD and their carer at all stages along the pathway – an example of a case management model	Benefits of adopting a case management approach within the Admiral Nurse service delivery in the UK	1. Early evaluations in different Admiral Nurse service sites are showing benefits for the families affected by dementia and have demonstrated significant cost savings, (e.g overall cost savings estimated at £450,000 in a ten-month period);	**Enablers:** N/A **Barriers:** N/A **Strengths:** N/A **Limitations:** N/

	for establishing a gold standard model of case management.		2. The AN uses a range of specialist interventions to support the PWD and their carer to live well and develop skills to improve communication and maintain relationships. There is an emphasis on early diagnosis early intervention & support, inter-sectorial support, integrated working and support for carers. The AN supports families to manage feelings of loss & bereavement		3. challenges in integrating different sectors and organisations that have a responsibility for dementia care provision. 4. the service is best situated in the community, in a primary health or social care setting enabling the Admiral Nurse to function across service boundaries and coordinate timely, efficient and effective care.	

			as the condition progresses			
1. **Hibberd & Vougioukalou** . **(2012**) 2. UK 3. Published paper	Summary of main reports evaluating the Medway Dementia Advisers Service.	1. Descriptive Summary: (This paper is a summary of Main report: Questionnaires & Focus groups to assess PWD & Carers views & satisfaction with: a. DA service b. Relationship with DA c. information they received d. Level of knowledge of DA. Survey of Local Services via Telephone Interview). 2. N=392	1 N/A	Descriptions of: 1. a. relationship with national evaluation of implementation sites; b. contextual issues for understanding need, location & delivery of service; c. how dementia advisers work; d. service outcomes such as equitability & acceptability. 2. Provide a baseline for the service.	1. The DA service was successful in recruiting PWD earlier on their pathway, providing instant support to PWD & Carer. 2. Increased signposting of PWD & carers to other services was observed. 3. PWD & carers were satisfied with Information & support provided by DA. 4. Assessments of PWD & carers would be improved by using Face to Face assessments rather than conducting telephone assessments.	Enablers: N/A Barriers: N/A Strengths: N/A Limitations: N/A

1. Ipsos Mori, 2016. **2.** England (UK) **3.** Unpublished report	To explore the provision of Dementia Advisor services available to older people in England. How the services are commissioned, the role and functions of a DA and how this differs across regions; what services are provided and how many people these services help.	1. Quantitative online survey 2. N=359 online survey of DAS within clinical commissioning groups and local authorities	1. The provision of a service for those diagnosed with dementia and their families . A service they can approach for help and advice at any stage of their illness. The DA role includes supporting the entire family; provide a single identifiable point of contact that has knowledge of and direct access to local services. The DA will give advice, signpost and enable contact with other services; Communicate with stakeholders and service users. 2. N/A	Online Survey of services available to older people with particular references to dementia adviser services. It also looks at wider availability of services relevant to older people. Issued to all Local Authorities and Clinical Commissioning Groups across England.	1. Response rate of 39% (n=89) 2. 91% say there is a DA service available; 85% indicate DA service established > 2 years. 3. 75% report DA service is provided in partnership with Alzheimer's Society; 14% with Age UK, 6% by NHS Foundation Trust, 4% by local charity. 4. Mainly they are called Dementia Advisors (72%) but also called dementia support worker, dementia care adviser, dementia navigator or nurse. Roles are similar irrespective of title.	**Enablers:** N/A **Barriers:** N/A **Strengths:** N/A **Limitations:** Responses are not from a representative sample
1. Kelly & Innes (2016) **2.** Scotland (UK)	1. To evaluate if post-diagnostic support service makes a difference to service access,	1. Repeated Measures Post-diagnostic Mixed Methods Pilot study; 2. N=27;	1. Person-Centred Personalised Support: Project Workers with training in Mental	1. Semi-Structured interviews examined two specific questions:	1. Participants reported that the service facilitated independence in the service users who availed of it.	**Enablers:** 1. Use of taxi and/or personalised transport services for access to services

3. Publication	service use for a person with dementia & their carers. 2. To evaluate if post diagnostic support services improves independence and increased choice for Person with dementia and their carers.	N=14 Persons with Dementia; N= 13 Carers	health & Expertise in Dementia [not necessarily nurses]: The roles were complimentary to existing services 2. Intensity and type of support varied according to assessed need. The duties of the role ranged from: a. One off enquiries b. participation in workshops, c. ongoing support in drop-in-cafes d. face-to-face and telephone support e. Intensive casework e.g.. future planning & self directed support, f. development of personalised support packages.	A. What difference, does post-diagnostic support service make to service access and service use for PWD & their carers? B. What difference support service make to promoting independence & choice for people with dementia & their carers. Only data relating to the semi-structured interviews are presented & discussed in this paper.	2. This also had the added benefit of increased self-confidence and motivation in the person with dementia. 3. The service filled service gaps in the existing dementia service provisions. Using a person centred approach to information dissemination, was much more effective and appreciated by the PWD & their carer . 4. Social contact was facilitated by increasing Mobility using taxi's and SDN arranged modes of transport. 5. Self-directed & individualised support networks & services was important for empowerment and fostering independence and motivation	facilitated social contact 2. Peer Socialization via Cafe's had the added benefit of reducing the PWD sense of stigma and fatalism about their diagnosis **Barriers:** PLWD indicated the increasing difficulties they had in travelling to access services and lack of confidence in using public transport.
1. **La Fontaine et al., (2011)**	1. To provide a robust evaluation of	1. Qualitative: repeated measures	1. According to the UK National	`1. For PWD & their families:	**1. Key Themes from Qualitative interviews**	**Enablers:**

2. UK 3. Unpublished report	the effectiveness & impact of the Dementia Advisors (DAs) service in one UK National Demonstrator site-Worcestershire. 2. To determine the skills, enablers and barriers to the success of the DA role. 3. To determine the DA services contribution to the national DA programme.	semi-structured interviews. The use of DA client records. Recruitment of an Intervention & Control group of PWD and their families/carerassessed at 2 points in time; A semi-structured interview with stakeholders within the areas supported by the DA; Monthly semi-structured interviews with the DA throughout the project; 2. N=12 families, N=8 PWD, N=11 family members. N=3 DAs. N=4 Stakeholders, and 9 employees within the practice. **14 interviews with 12 families at first time point.** 3 of these families had not had a	Dementia (2009) strategy, the aim of the DA service is to facilitate easy access for PWD and their carers to appropriate care, support and advice. The DA will act as a single point of contact for the PWD providing information and signposting to local services. The DA service was to be triggered at the point of diagnosis by an existing Early Intervention Dementia Service (EIDS). The role involves identifying any problems the PWD or their carers may be experiencing and facilitate engagement with the most appropriate specialist services simply and quickly.	a. understanding of a dementia diagnosis and services (Wellbeing Evaluation Scale [Popadopoulos et al., 2011] Neuropsychiatric Inventory [Kaufer et al., 1998 b. access to community and specialist services, c. coping skills d. future planning and empowerment e. quality of life (DEMQOL Quality of Life in Dementia Scale [Smith et al., 2005]), self-esteem (Rosenberg Self Esteem Scale, [Rosenberg, 1965]) and confidence for PWD and their carer; f. the service supports the PWD	**with PLWD & their families:** PLWD recruited to DAS soon after diagnosis showed increased **confidence in the DAS than those recruited** later in their dementia pathway. A strong connection with the DA initially helpful in increasing confidence in continued and ongoing support. **Aspects of the DA role valued** included information giving, advanced planning, accessing services and physical & emotional support and information about the diagnosis early in the dementia pathway. practical & extensive problem solving. **Summary of key findings from quantitative measures:** 1. **At baseline** PLWD and their carers showed moderate-good	1. A strong positive collaborative relationship with the existing stakeholders facilitated referrals and trust building between the service user and the DA. 2. Adequate regular supervision and ongoing support for the DA is necessary for this role as well as regular peer support is key to the DA service provision. 3. The clarity around DA improved as the service matured. 4. The non-statutory DAS helped in recruiting service users who did not wish to be involved with statutory services. **Barriers:**

		DA service, 1 did not complete the interview (?). **6 interviews were completed at follow-up (4 months post initial interview).** Semi-structured interviews were conducted with Stakeholders at 2 points in time with 10 months between interviews.	2. Application of DA service in the National Demonstrator Site Worcestershire	to live at home longer (Duke Social Support Scale [Koenig et al., 1993]) and support needs of the carer (COPE Scale [Balducci et al., 2008]); For stakeholders & Organisations: a. collaboration between service providers; b. use of existing community, health and social care services and resources. 2. The experience of being a DA. 3. Identify the service users, who is referring to the service, the actual interventions that occur and the impact these have on service use.	quality of life; the majority had normal self esteem. Most were satisfied with their support; lower levels of satisfaction shown by **the** PLWD living alone. 2. Most family members had experienced a degree of negative impact initially but indicated a degree of satisfaction with their care giving. Some did indicate low satisfaction with the quality of support they received initially. **Key Findings Relating to the experiences of the DA delivering the service. (16 Semi-structured interviews over 16 months).** 1. **Key aspects of the Role as seen by the DA** was to be **with the PLWD and their family through the entire dementia Journey.** Other elements of the role that are	1. Lack of awareness about the nature of the service 2. Extension of role into one that is primarily focused on the carer not the PLWD requires further DA role clarification. 3. DAS slow to set up because of lack of preparedness of the area: slow referrals, lack of awareness of stakeholders and lack of local services. 4. Establishing partnerships with key services was difficult and time consuming. 5. **Unmet need** remains an issue at all stages of dementia. 6. Difficulties in accessing *Different Populations* (eg. Ethnic minorities) **Strengths:** N/A **Limitations:**

					important include: **Assessment, Education, Information & Advice, Signposting, Networking and working with different populations.** a. Developing **trust** initially contact is enhanced when working closely with existing stakeholders. b. Importance the DA is **proactive with regular follow up**; c. DA needs ongoing **support & training**. d. **Networking & Promoting the DA role** important. e. important to be sensitive to quantity & timing of **dissemination of information** e. **Signposting**; f. Unmet needs/gaps in services is a serious concern; g. gain access to and engage services users in **Different Populations.** h The DA role supports the	1. Low numbers of PLWD recruited thus results are not generalizable and it was not possible to evaluate users self esteem and quality of life statistically. 2. Short evaluation timescale.

					whole family not just the PLWD. **The attributes required by a DA** include: Past experience and prior Knowledge, Learning and Reflecting while Doing, Counselling Skills, Knowledge of Dementia, Knowing the Area, and Resilience. **Key findings relating to the stakeholders perspective:** 1. The DA role supports the whole family 2. The role should include signposting, dissemination of information, future planning, reduce/remove crisis points and raise awareness within the community 3. Important that DAS works alongside existing services. 4. Barriers to the DAS include: poor understanding of the role	

					and lack of openness to it; slow referral uptake; poor capacity of services to meet the needs of PLWD signposted on from the DA service; stigma & labelling. 5. The DA should be based in the existing dementia services. 6. The DAS is appreciated and adds value to existing services. **Details of referrals to the service:** **1.** A higher proportion of carers (67%) are referred to the DA service **2.** The majority of PLWD are over 75 yrs (65%) most live in their own home. The family member/carer twice as likely to be female, 70% are the spouse/partner & 28% being an adult child 3. Ethnicity status not recorded adequately with 48% unknown.	

					5. The majority of referrals from the **Early Intervention Dementia Service or the Mental Health Trust**. The *highest proportion* of family members/carers self-refer 6. number of contacts have increased as the service has become established. The Dementia cafes were the main type of service that the DA signposts to.	
1. Maio et al., (2016); **2.** UK **3.** Publication	1. To assess the effectiveness of the Admiral Nurse family- centred approach from the perspective of family carers who had accessed the service	1. Quantitative - Cross-sectional Postal Survey 2. N=207 carers of PWD (30.2% effective response rate).	1. N/A 2. Not described	Postal Survey developed using the Admiral Nurse Standards and based on a previous evaluation (Clare et al, 2005). The questionnaire included demographic information, contact with the AN service, and effectiveness of the AN service in:	1. 69% of carers were living with the person with dementia and Predominantly female (75%). 2. 82% carers - support received as helpful and/or effective. 3. Aspects of the service identified for improvement: help with social activities and stimulation (69% helpful)	**Enablers:** N/A **Barriers:** N/A **Strengths:** This is one of very few published evaluations assessing Carers assessment of this service. **Limitations:** N/A

				Recognising the needs of the cater and the person they care for; building and developing relationships; knowledge and skills of the AN; the AN interventions;	and information and help with medications (66%) 4. Frequency of contact with the service had a statistically significant impact on carers satisfaction E.g. a carer with 5+ contacts was 2.2 times more likely (range: 1.05-4.71, p=0.04) to find the AN helpful in working with other professionals than those with less than 5 contacts.	
1. Weatherhead et al., (2017) **2.** UK **3.** Publication	To assess the feasibility and acceptability of a work-based Admiral Nurse clinic to support family carers during their employment hours.	1. Mixed methods 2. N=64 carers	1. N/A 2. A work-based Admiral Nurse Clinic for employees caring for a family member with dementia. Offering carer advice and support in the workplace. 4 days of Admiral Nurse Clinics at 2 work based sites were assessed (64 one hour	1. Details of each appointment were recorded by the AN into a web based clinical database. Any follow-up information required specific to the individual carer needs were also recorded on this system. 2. The Carer completed a measure of	1. Majority (80%) of attendees were female and seeking information and support about a parent. 2. Main concerns were a. maintaining mental & Physical health and wellbeing of the PWD b. How to cope better with behaviours and symptoms of dementia c. Request for more information. 3. Majority of attendees (87%) indicated that they	**Enablers:** N/A **Barriers:** The offices at the second site for the clinics was more spread out geographically thus some problems with access to the AN service. **Strengths:** N/A **Limitations:** N/A

			appointments available).	satisfaction with the clinic. Issues raised by the attendees were collated to identify what they were most concerned with.	would use this service again and (70%) indicated that the service was excellent. 4. The authors suggest that the intervention needs to be evaluated more fully and broadened to consider any longer term benefits in carer confidence and coping as well as developing a wider understanding of employment and economic benefits.	

Appendix 3. Ethical Approval Letters

Tel. + 353-21-490 1901
Fax: + 353-21-490 1919

Coläiste na hOIlscoile Corcaigh, fire
University' College Corh. Ireland

COISTE EITICE UMTHAIGHDE CL!NICIUiL
Clinical Research Ethics Committee

Lar oaate• Hall.
6 Little Hanu‹vet Sttoa1.
Cntk.

EC M 4 m › 07.*1 171? 6 ECM 3 {cccc) 1 C/01/ 1 0

1U"' January 2L'1b

Dr Ali de coffey
Senior Lecturer

University College Cork
Brookfield Heahh Scienqes Complex

Ro: Evaluation of the Alzhci mers Society of frc land dom ontia adv iso r sc rvice.

Den r Dr Coffey

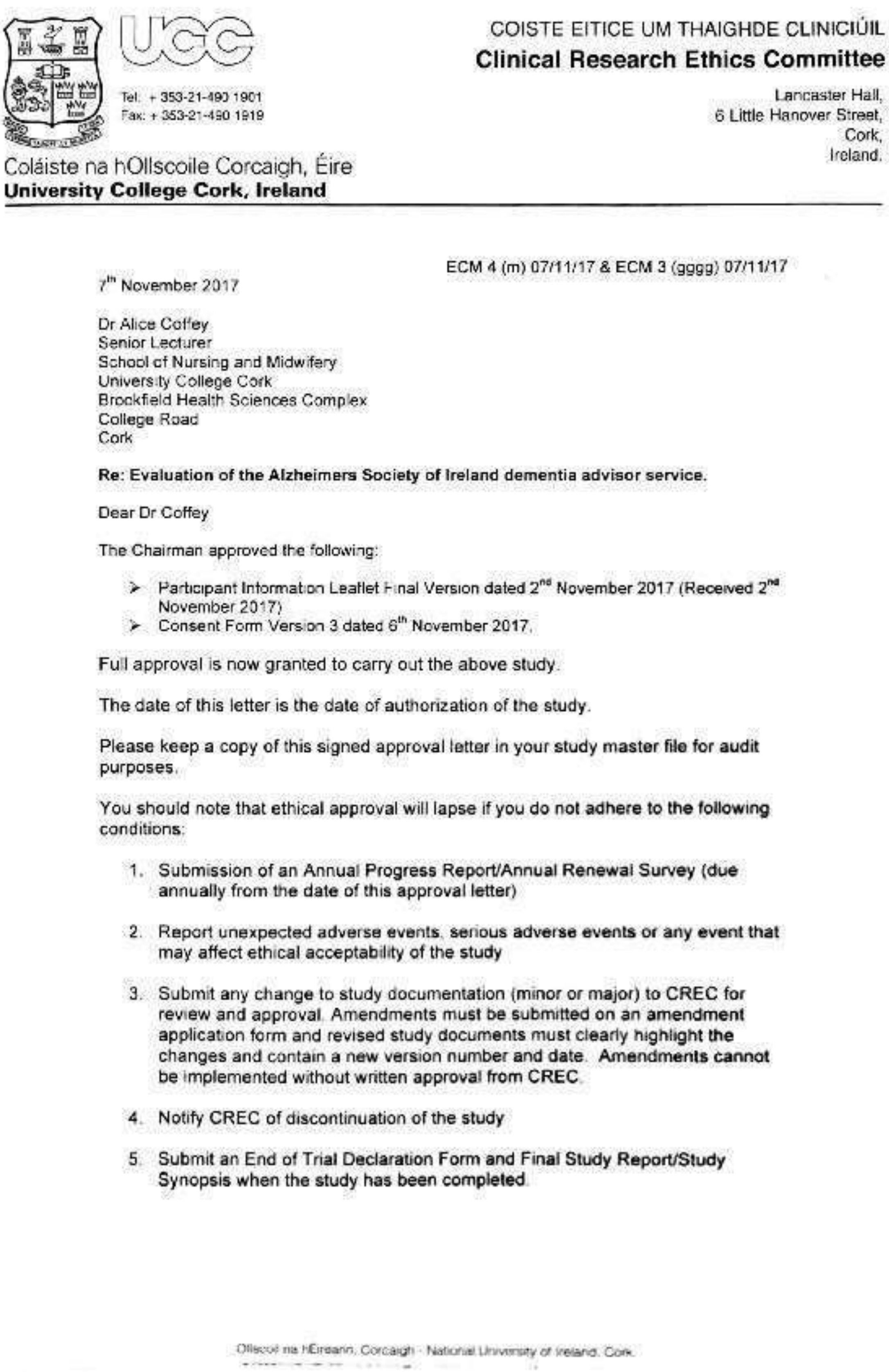
The ?hairman approved the lot owins

- Cover Lette r dated 14" December 201? (iaociv ed 8" January 2018)
- Amendment Applice:ipnFerm signed 21" December 2017
- Revised Study Protoal
- £' artioipont Infgrm etio n Leaflet Vcrsi o n 1 dated 14 NovcmLcr 2017
- sea ltn and Soclal C are rofessionals Question qaire Ve fsion 1 dated 14" Novembe • 2017
- Q uestiont w«e fu Peo ste with De rrentia Version) dated 14" November 207 7

Full *approval* is grantad •o imp lemenï this memme nt

Yours sincerely

Professor Michael G Molloy
Cnairman
Clinical Research Ertiica Committaa
of *the E c'rl* Tea chipg Hoap ical



Tel: + 353-21-490 1901
Fax: + 353-21-490 1919

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

ECM 4 (m) 07/11/17 & ECM 3 (gggg) 07/11/17

7th November 2017

Dr Alice Coffey
Senior Lecturer
School of Nursing and Midwifery
University College Cork
Brookfield Health Sciences Complex
College Road
Cork

Re: Evaluation of the Alzheimers Society of Ireland dementia advisor service.

Dear Dr Coffey

The Chairman approved the following:

- Participant Information Leaflet Final Version dated 2nd November 2017 (Received 2nd November 2017)
- Consent Form Version 3 dated 6th November 2017.

Full approval is now granted to carry out the above study.

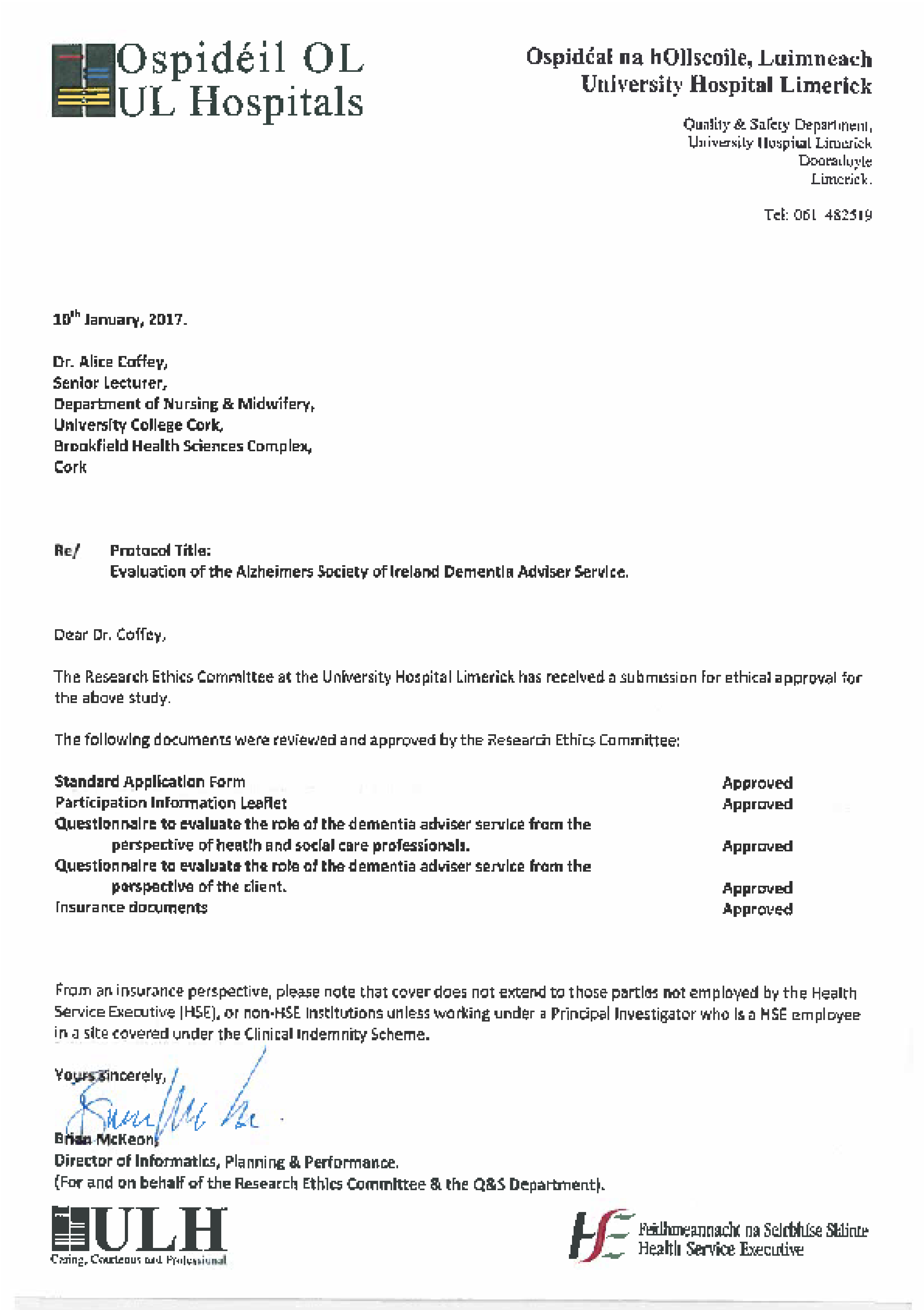
The date of this letter is the date of authorization of the study.

Please keep a copy of this signed approval letter in your study master file for audit purposes.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

1. Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter)
2. Report unexpected adverse events, serious adverse events or any event that may affect ethical acceptability of the study
3. Submit any change to study documentation (minor or major) to CREC for review and approval. Amendments must be submitted on an amendment application form and revised study documents must clearly highlight the changes and contain a new version number and date. Amendments cannot be implemented without written approval from CREC.
4. Notify CREC of discontinuation of the study
5. Submit an End of Trial Declaration Form and Final Study Report/Study Synopsis when the study has been completed.

Ollscoil na hÉireann, Corcaigh - National University of Ireland, Cork.



Ospidéil OL
UL Hospitals

Ospidéal na hOllscoile, Luimneach
University Hospital Limerick

Quality & Safety Department,
University Hospital Limerick
Dooradoyle
Limerick.

Tel: 061 482519

10th January, 2017.

Dr. Alice Coffey,
Senior Lecturer,
Department of Nursing & Midwifery,
University College Cork,
Brookfield Health Sciences Complex,
Cork

Re/ Protocol Title:
Evaluation of the Alzheimers Society of Ireland Dementia Adviser Service.

Dear Dr. Coffey,

The Research Ethics Committee at the University Hospital Limerick has received a submission for ethical approval for the above study.

The following documents were reviewed and approved by the Research Ethics Committee:

Standard Application Form	**Approved**
Participation Information Leaflet	**Approved**
Questionnaire to evaluate the role of the dementia adviser service from the perspective of health and social care professionals.	**Approved**
Questionnaire to evaluate the role of the dementia adviser service from the perspective of the client.	**Approved**
Insurance documents	**Approved**

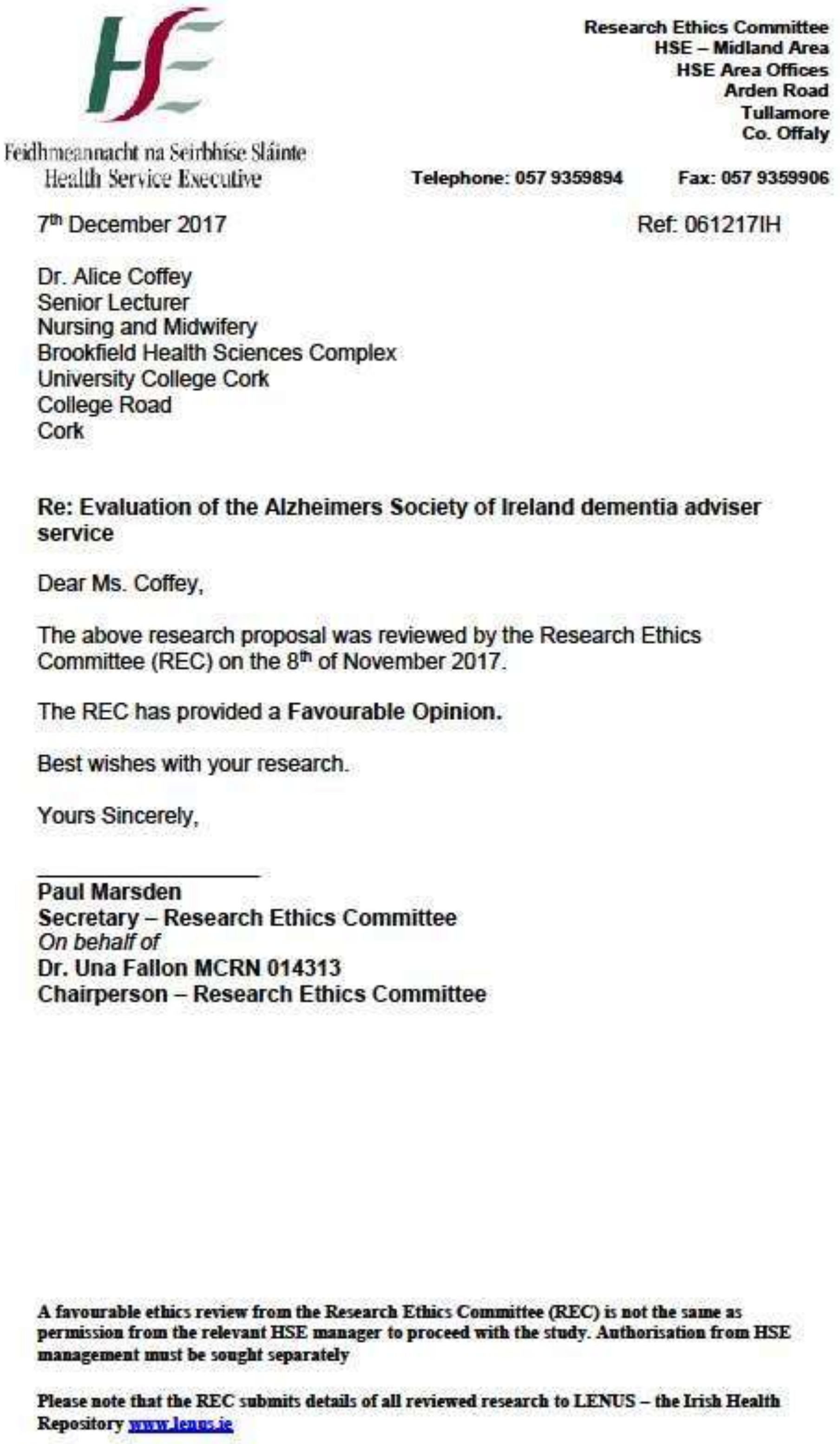
From an insurance perspective, please note that cover does not extend to those parties not employed by the Health Service Executive (HSE), or non-HSE institutions unless working under a Principal Investigator who is a HSE employee in a site covered under the Clinical Indemnity Scheme.

Yours sincerely,

Brian McKeon,
Director of Informatics, Planning & Performance.
(For and on behalf of the Research Ethics Committee & the Q&S Department).

ULH
Caring, Courteous and Professional

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Research Ethics Committee
HSE – Midland Area
HSE Area Offices
Arden Road
Tullamore
Co. Offaly

Telephone: 057 9359894 **Fax: 057 9359906**

7th December 2017

Ref: 061217IH

Dr. Alice Coffey
Senior Lecturer
Nursing and Midwifery
Brookfield Health Sciences Complex
University College Cork
College Road
Cork

Re: Evaluation of the Alzheimers Society of Ireland dementia adviser service

Dear Ms. Coffey,

The above research proposal was reviewed by the Research Ethics Committee (REC) on the 8th of November 2017.

The REC has provided a **Favourable Opinion.**

Best wishes with your research.

Yours Sincerely,

Paul Marsden
Secretary – Research Ethics Committee
On behalf of
Dr. Una Fallon MCRN 014313
Chairperson – Research Ethics Committee

A favourable ethics review from the Research Ethics Committee (REC) is not the same as permission from the relevant HSE manager to proceed with the study. Authorisation from HSE management must be sought separately

Please note that the REC submits details of all reviewed research to LENUS – the Irish Health Repository www.lenus.ie

Appendix 4. Consent form for interviews and focus group

PARTICIPANT CONSENT FORM

Participant Name:______________________

Study Title: EVALUATION OF THE ALZHEIMER SOCIETY OF IRELAND DEMENTIA ADVISER SERVICE

Name of Chief Investigator: Dr Alice Coffey

Contact Number for Chief Investigator: 0878393007

AGREEMENT TO CONSENT The research project and the treatment procedures associated with it have been fully explained to me. All procedures have been identified and no guarantee has been given about the possible results. I have had the opportunity to ask questions concerning all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to healthcare services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research. I, the undersigned, hereby consent to participate as a subject in the above described project. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the Chief Investigator listed above. I understand that the study has been approved by the Cork Research Ethics Committee of the Cork Teaching Hospitals (CREC) and if I have further queries concerning my rights in connection with the research, I can contact CREC at Lancaster Hall, 6 Little Hanover Street, Cork

Answer yes or no or insert tick boxes

- I have read and understand the study: ☐
- I agree to participate in this research ☐
- I agree to allow my interview/focus group to be audio-recorded: ☐
- I grant permission for the data collected to be used in this research only and for future research publications and project report: ☐
- I understand that my anonymized data will be stored at University College Cork for seven years: ☐

Chief Investigator Signature:________________________Date: ______________

Signature of Study Participant: ______________________________

Consent Form Version Number: 3 *Date: 06/11/2017*

Appendix 5. Participant information leaflet

PARTICIPANT INFORMATION LEAFLET

You are invited to take part in the following study:

Title: EVALUATION OF THE ALZHEIMER SOCIETY OF IRELAND DEMENTIA ADVISER SERVICE

What is the purpose of this study?

The purpose of this research is to explore the dementia adviser service from your perspective. To ascertain your views of this service and provide an opportunity for you to highlight any gaps in the service and any needs for development of this service going forward

Who is conducting the study?

A team of researchers at the School of Nursing and Midwifery University College Cork and led by Dr. Alice Coffey.

What does participation involve?

You are asked to complete the questionnaire attached to this letter.

This may be completed **either** on paper **or** online *(via the link provided on the questionnaire)*. If you complete the paper version, a stamped addressed envelope is provided for return. The questionnaire will take approx. 10 minutes of your time.

Are there any risks in taking part?

There are no anticipated risks. Taking part is voluntary, so you give consent by responding to the questionnaire.

You may refuse to respond or withdraw your response at any time, there are no consequences. The questionnaire is anonymous so you do not need to provide your name or contact details.

Who might benefit from the results of this research? The results of this study will inform decisions about the type of services that will be available to people with dementia and their families following a diagnosis.

If you have any questions please contact:

Dr Alice Coffey a.coffey@ucc.ie

Mobile number: (087) 8393007

Version 2____________Date:07/12/2017

Appendix 6. Participant information leaflet for surveys

UCC
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

HSE
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

You are invited to take part in the following study, if you have used the Dementia Adviser Service:

Title: Evaluation of the Alzheimer Society of Ireland Dementia Adviser Service

What is the purpose of this study?

The purpose of this research is to explore the Dementia Adviser Service from your perspective, to ascertain your views of this service and to provide an opportunity for you to highlight any gaps in the service and any needs for development of this service going forward.

Who is conducting the study?

A team of researchers from the Schools of Nursing and Midwifery at University College Cork and the University of Limerick.

What does participation involve?

You are asked to complete the questionnaire attached to this letter.
A stamped addressed envelope is provided for return. The questionnaire will take approximately 10 minutes of your time.
Please return your questionnaire within two weeks.

Are there any risks in taking part?

There are no anticipated risks. Taking part is voluntary, so you give consent by responding to the questionnaire.
You may refuse to respond or withdraw your response at any time, there are no consequences. The questionnaire is anonymous so please DO NOT provide your name or contact details.

Who might benefit from the results of this research?

The results of this study will inform decisions about the type of services that will be available to people with dementia and their families following a diagnosis.

Our researchers are available on the following phone number if you need support completing the survey: (086) 049 8148

THE ALZHEIMER SOCIETY of IRELAND

UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

Appendix 7. Interview questions and topic guide for focus groups and individual interviews

INTERVIEW QUESTIONS: Topic Guide for Focus Group Interview

Study title: EVALUATION OF THE ALZHEIMER SOCIETY OF IRELAND DEMENTIA ADVISER SERVICE

General Introductions:

Purpose: Thank you for agreeing to participate in this study the purpose of which is to evaluate the Dementia Adviser service from your perspective.

Structure and format explained: Lead Interviewer introduces everyone and the aim of the interview, consent form and demographic details are completed, interview is recorded, time will vary depending on the depth of answers, opportunity for interviewee Q&A at the end.

Introductory Question:

Where does the DA service sit with the model of primary care and how has the service been integrated within the local community including voluntary groups in the area. (How does the service sit within existing service provisions?)

Transition Questions:

What are the perceived service needs of the DA service?

What would you describe as the key attributes and skills required to discharge your role?

What are the Key Performance Indicators of the DA service and do these vary across regions?

What challenges are region specific and what are common across all areas?

How has the role evolved over the past number of years and where do you see the future of the role going? (What service provision or resources are required to improve the DA service?)

Ending Questions:

Is there anything else you would like to add?

Is there any questions you wish to ask me?

Prompts:

- Please explain
- Please elaborate
- Can you talk a bit more about……?

INTERVIEW QUESTIONS: Topic Guide for Individual Telephone Interview

Study title: EVALUATION OF THE ALZHEIMER SOCIETY OF IRELAND DEMENTIA ADVISER SERVICE

General Introductions:

Purpose: Thank you for agreeing to participate in this study the purpose of which is to evaluate the Dementia Adviser service from your perspective.

Structure and format explained: Lead Interviewer introduces themselves and the aim of the interview, consent form and demographic details are completed, interview is recorded, time will vary depending on the depth of answers, opportunity for interviewee Q&A at the end.

Introductory Question:

Please describe your role as a dementia adviser.

Transition Questions:

Can you describe how the service is structured in your area? (Who uses the service, who refers, what interventions occur?)

How would you describe the impact of the service you provide on?

1. patients,
2. family
3. health and social services locally

What consultations has taken place with other relevant stakeholder's e.g. local community groups to obtain views of the service and identify perceived service needs?

Can you describe the facilitators of your role?

What challenges have presented in relation to your role and the development of the service?

Ending Questions:

Is there anything else you would like to add?

Is there any questions you wish to ask me?

Prompts:

- Please explain
- Please elaborate
- Can you talk a bit more about……?

Appendix 8. Survey Questionnaires

8A. Client (Person Living with Dementia) questionnaire

UCC
colaste na hollecoile Gorcaigh, Eie
University College Cork, Ireland

EVALUATION OF THE DEMENTIA ADVISER SERVICE

Questionnaire for People with Dementia

UNIVERSITY o/ LIMERICK

EVALUATION OF THE DEMENTIA ADVISER SERVICE: QUESTIONNAIRE FOR PEOPLE WITH DEMENTIA

Please tick the relevant box, or write your answers in the space provided, as appropriate.

1. What is your gender?

Male	☐	Female	☐

2. What is your age group?

29 Years Or Less	○	60 —69 Years	○
30 —39 Years	○	70 —79 Years	○
40 —49 Years	○	80 —89 Years	○
50 — 59 Years	○	90 Years Or More	○

3. From the regions listed below, please indicate the Dementia Adviser Service you contacted:

North Cork, East I€eriy, Co. Lirrie rick, Co. Tippe rary, South Clare	○
Cork City, South & East Cork, South I€erry	○
Cavan, Monaghan, Louth	○
North Dublin	○
South Dublin	○
Sligo, Leitrirri, South Donegal	○
Galway	○

4. When was the diagnosis of dementia made?

Less than 6 Months Ago	○	3 — 5 Years Ago	○
6 — 12 Months Ago	○	More than 5 Years Ago	○
12 Months — 2 Years Ago	○	Diagnosis Not Confirrried	○
2 —3 Years Ago	○	Unsure	○

5. What sources have you used to get information about dementia? (Please tick thata

Alzheimer Society of Ireland Helpline	○	Medical Consultant	○
Alzheimer Society of Ireland Website	○	General Practitioner (GP)	○
Dementia Adviser Service	○	Public Health Nurse	○
Internet fT*1ease state any websites below)	○	Social Worker	○

____

____

Other Sources Used fT*1ease state):

____

____

____

6. How did you learn about your Dementia Adviser Service?

All heirrier Society of Ireland Helpline	○	Medical Consultant	○
All heirrier Society of Ireland Website	○	General Practitione r (GP)	○
Public Health Nurse	○	Social Worker	○
Television	○	Radio	○
Internet fT*1ease state the website below)	○		

Other Source fT*1ease state):

7. Please describe, in your own words, your nudeistaming of the role of the Dementia Adviser Service.

8. Overall, how many times have you been in contact with the Dementia Adviser Service in the lastyear?

Once ○ Twice ○ 3 — 5 Tirries ○ More than 5 Tirries ○

9. Would you contact the Dementia Adviser Service again?

Yes ○ No ○ Maybe ☐

If you answered No or <u>Maybe</u>, please state why you did so?

10. What did you hope to get from the Dementia Adviser Service?

11. Did the Dementia Adviser Service meet your expectations?

Yes O No O Maybe ☐

If you answered No or <u>Maybe</u>, please state why you did so?

12. What, if anything, has the Dementia Adviser Service done for you?

13. Did your family or carer make contact with the Demetria Adviser Service ?

Yes O No O Maybe O

14. Would you recommend the Dementia Adviser Service to other people living with dementia?

Yes O No O Maybe O

If you answered No or <u>Maybe</u>, please state why you did so?

15. Please tick the box that indicates how helpful the Dementia Adviser was to you in relation to each of the following statements. Additional comments can be written in the space provided on the next page.

The Dementia Adviser	Very Unhelpful	Unhelpful	Somewhat Helpful	Helpful	Very Helpful	Don’t Know
The De rrientia Advise r helped rrie to nude rstand derrientia						
The Derrientia Adviser helped rrie to be able to cope with the changes that have happened						
The Dementia Adviser helped rrie to know what format health and social care services are available, for example: GP, Public Health Nurse, Horrie Care, Day Centres						
The De rrientia Advise r helped rrie to access se rvices						
TheDementiaAdviserhepedme tOknOwwhdtin*Ormd1SuppOrtS aeavaabesuchassupport groupsorc1ubs;Lorexamp1e, w kinggroups,musicgroups, lock acGvites						
The Dementia Advise r helped me to know what legal and care planning Options are available						
The Dementia Advise r helped me IO kfIOW What fifIHfICifi1 SUppO£tS are available						
The Dementia Adviser helped rrie to feel that I arri listened to						
The De rrientia Advise r re sponded quickly in tirrie s of need						
The De rrientia Advise r addressed rriy concerns and worries						
The De rrientia Advise r kept rrie inforrrie d Of p rogre ss On areas we discussed						

Additional Comments:

16. Please <u>tick the box</u> that demonstrates your level of agreement or disagreement with each of the following statements about the Dementia Adviser Service.

	Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree	Don’t Know
The Dementia Adviser communicated well						
The Dementia Adviser demonstrated empathy (ability to understand your feelings)						
The Dementia Adviser demonstrated respect						
The Dementia Adviser spent enough time with me						
The Dementia Adviser was easily contactable						
The Dementia Adviser has helped me feel more confident						
The Dementia Adviser seemed knowledgeable about dementia services						

17. Overall, how satisfied were you with the Dementia Adviser Service?

Very Dissatisfied ○ Dissatisfied ○ Mixed ○ Satisfied ○ Very Satisfied ○

18. Have you any suggestions on how the Dementia Adviser Service can be improved?

19. Do you have any additional comments you would like to make about the Dementia Adviser Service)

Please return the completed form in the envelope provided. The postage has been paid for on this envelope.

This survey is anonymous; we do not need your name or your contact details.

Thazifr you reg zziuc?i for roizr *help.*

8B. Carer / Family member questionnaire

UCC

University College Cork, Ireland

EVALUATION OF THE DEMENTIA ADVISER SERVICE

Carer & Family Member Questionnaire

UNIVERSITY of LIMERICK

EVALUATION OF THE DEMENTIA ADVISER SERVICE: CARER & FAMILY MEMBER QUESTIONNAIRE

Please tick the relevant box, or write your answers in the space provided, as appropriate.

1. What is your gender?

Male ☐
Female ☐

2. What is your age group?

29 Years Or Less ○
30 —39 Years ○
40 —49 Years ○
50 — 59 Years ○
60 —69 Years ○
70 —79 Years ○
80 —89 Years ○
90 Years Or More ○

3. What is your relationship to the person living with dementia?

Spouse 'Partner ○
Sibling ○
Other he use state):
____
Daughter ☐
Son ☐

4. From the regions listed below, please indicate the Dementia Adviser Service you contacted:

North Cork, East I€eriy, Co. Lirrie rick, Co. Tipperary, South Clare ○
Cork City, South & East Cork, South I€erry ○
Cavan, Monaghan, Louth ○
North Dublin ○
South Dublin ○
Sligo, Leitrirri, South Donegal ○
Galway ○

5. When was the diagnosis of dementiamade?

Less than 6 Months Ago ○
6 — 12 Months Ago ○
12 Months — 2 Years Ago ○
2 —3 Years Ago ○
3 — 5 Years Ago ○
More than 5 Years Ago ○
Diagnosis Not Confirrried ○
Unsure ○

6. What sources have you used to get information about dementia? (Please tick all that a I)

All heirrier Society of Ireland Helpline ○
All heirrier Society of Ireland Website ○
Dementia Adviser Service ○
Internet fT*1ease state any websites below) ○
Medical Consultant ○
General Practitioner (GP) ○
Public Health Nurse ○
Social Worker ○

____
____

Other Sources Used fT*1ease state):

____
____
____

7. How did you learn about your Dementia Adviser Service?

All heirrier Society of Ireland Helpline ○
All heirrier Society of Ireland Website ○
Public Health Nurse ○
Television ○
Internet fT*1ease state the website below) ○
Medical Consultant ○
General Practitione r (GP) ○
Social Worker ○
Radio ○

Other Source he use state):

8. Please describe, in your own words, your nudeistaming of the role of the Dementia Adviser Service.

9. Overall, how many times have you been in contact with the Dementia Adviser Service in the lastyear?

Once ○ Twice ○ 3 — 5 Tirries ○ More than 5 Tirries ○

10. To your knowledge, did the Dementia Adviser meet with the person living with Dementia?

Yes ○ No ○ Don't How ○

If you answered No, why not?

11. What did you hope to get from the Dementia Adviser Service the first time you contacted the Service?

12. What did you hope to get from the Dementia Adviser Service on subsequent contact, or on follow up?

13. Would you contact the Dementia Adviser Service again?

Yes O No O Maybe ☐

If you answered No or <u>Maybe</u>, please state why you did so?

14. Would you recommend the Dementia Adviser Service to other people living with dementia and/or theircarers?

Yes ☐ No ☐ Maybe ☐

If you answered No or <u>Maybe</u>, please state why you did so?

15. What, if anything, has the Dementia Adviser Service done for______, in your role as caregiver?

16. To your knowledge, has more than one member of your family made contact with the Dementia Adviser Service?

Yes ☐ No ☐ Don't How ○

17. What difference, if any, has the Dementia Adviser Service made to <u>you and your family</u>?

____

____

____

____

____

____

18. Please <u>tick the box</u> that indicates how helpful the Dementia Adviser was to you in relation to each of the following statements. Additional comments can be written in the space provided on the next page.

The Dementia Adviser	Very Unhelpful	Unhelpful	No Difference	Helpful	Very Helpful	Don't Know
The Dementia Adviser helped me to understand dementia						
The Dementia Adviser helped me to be able to cope with the changes that have happened						
The Dementia Adviser helped me to support my family member						
The Dementia Adviser helped me to know what format health and social care services are available, for example: GP, Public Health Nurse, HomeCare, Day Centres						
The Dementia Adviser helped me to access services						
The Dementia Adviser helped me to know what informal supports are available such as SUQQ O ID QfOUQ S OI CJUL Si TOI example, walking groups, music gfO Up S, 10 C at aC tiVitie S						
The Dementia Adviser helped me to know what legal and care planning options are available						

The Dementia Adviser	Very Unhelpful	Unhelpful	Somewhat Helpful	Helpful	Very Helpful	Don't Know
The Dementia Adviser helped rrie to know what financial supports are available						
The Dementia Adviser helped rrie to feel that I are listened to						
The Dementia Adviser responded quickly in times of need						
The Dementia Adviser addressed rriy concerns and worries						
The Dementia Adviser kept rrie inforrried of progress on areas we discussed						

Additional Comments:

____

____

____

____

19. Please <u>tick the box</u> that demonstrates your level of agreement or disagreement with each of the following statements about the Dementia Adviser Service.

	Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree	Don't Know
The Derrientia Adviser cOrrirriunic ited well						
The Derrientia Adviser derrion strafed erripathy (ability to understand your feelings)						
The Derrientia Adviser derrion strafed re spect						
The Derrientia Adviser spent enough tirrie with rrie						
The Derrientia Adviser was easily c Ontactable						
The Derrientia Adviser has helped rrie feel rriore confident						
The Derrientia Adviser seerrie d knowle dgeable about derrientia services						

20. Overall, how satisfied were you with the Dementia Adviser Service?

Very Dissatisfied ○ Dissatisfied ○ Mixed ○ Satisfied ○ Very Satisfied ○

21. Please suggest how the Dementia Adviser Service can be improved.

____
____
____
____
____
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22. Do you have any additional comments you would like to make about the Dementia Adviser Service)

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____
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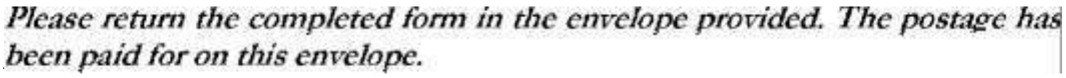
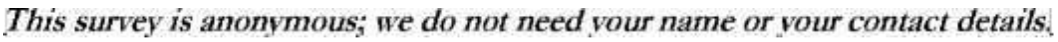


Please return the completed form in the envelope provided. The postage has been paid for on this envelope.



This survey is anonymous; we do not need your name or your contact details.

Thazifr you reg zziuc?i for roizr *help.*

8C. Health & Social Care Professional questionnaire

UCC
colaste na hollecoile Gorcaigh, Eie
University College Cork, Ireland

FmdIun‹nnacIunaS seS4inm
He:d1h cemecuuw

EVALUATION OF THE DEMENTIA ADVISER SERVICE

Health & Social Care Professionals Questionnaire

3OCIITY%1ItIfXND

UNIVERSITY o/ LIMERICK
0 7 G 50 4 7 7 W 7 M7 4GB

Please tick the relevant box, or write your answers in the space provided, as appropriate.

1. Please indicate your post:

Public Health Nurse ○
Clinical Nurse Specialist ○
Community Nurse ○
Prac Use Nurse Specialist ○
Social Worker ○

Geriatrician ☐
Old Age Psychiatrist ☐
Psychologist ☐
Counsello r ☐
Area Medical Officer ☐

Community Therapist fT*1ease state your job Title below) ☐

____

Other Please state your job Title below): ☐

____

2. Please indicate the number of years you are in the post:

Less than 5 Years ○ 5—10 Ye mrs ○ 11 — 15 Years ○ More than 15 Years ○

3. From the regions listed below, please indicate the Dementia Adviser Service contacted:

North Cork, East I€eriy, Co. Lirrie rick, Co. Tipperary, South Clare ○
Cork City, South & East Cork, South I€erry ○
Cavan, Monaghan, Louth ○
North Dublin ○
South Dublin ○
Sligo, Leitrirri, South Donegal ○
Galway ○

4. Please describe, in your own words, your undeis tanding of the role of the Dementia Adviser Service.

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____
____
____
____
____

5. Please tick the corresponding answers that best reflects your usage of the Dementia Adviser Service:

a) I use the Dementia Adviser Service as a point of referral. . .
Never ○ Rarely ○ Regularly ○ Frequently ○

b) I use the Dementia Adviser Service as a contact point for support, signposting, and information (outside of client/family referral)...
Never ○ Rarely ○ Regularly ○ Frequently ○

6. If you have ticked <u>Never</u> or Reel for Part a) or b) of the previous question, can you please comment on why this might be?

7. If you have contacted the service, please provide the main reasons for making contact with the Dementia Adviser Service?

8. If you have referred clients or carers to the Dementia Adviser Service, please tick at which stages the clients /carers were initially referred (Please tick <u>all that apply</u>)

Early in Diagnosis ○ Some Years After Diagnosis ○
Some Months After Diagnosis ○ Crisis Point ○

9. Which stage do you think is the most useful stage to refer clients or carers to the Dementia Adviser Service? (Please tick <u>one option only</u>)

Early in Diagnosis ○ Some Years After Diagnosis ○
Some Months After Diagnosis ○ Crisis Point ○

10. Overall, how satisfied were you with the Dementia Adviser Service?

Very Dissatisfied ○ Dissatisfied ○ Mixed ○ Satisfied ○ Very Satisfied ○

11. Would you recommend the Dementia Adviser Service to other Health & Social Care Professionals?

Yes ☐ No ☐ Maybe ○

If you answered <u>No</u> or <u>Maybe</u>, please state why you did so?

12. Tick the box that best represents your experience of the Dementia Adviser Service for each of the following statements.

	Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree	Don't Know
The Dementia Adviser communicates well						
The Dementia Adviser is responsive						
The Dementia Adviser is knowledgeable						
The Dementia Adviser demonstrates professionalism						

13. How helpful is it to your role to be able to contact the Dementia Adviser Service?

Very Unhelpful ○ Unhelpful ○ No Difference ○ Helpful ○ Very Helpful ○

14. What, if anything, has the Dementia Adviser Service meant to your role?

15. Would you be open to receiving a referral from the Dementia Adviser Service?

Yes ○ No ○ Maybe ○

If you answered No or Maybe, please state why you did so?

16. In your opinion, should the Dementia Adviser Service be able to refer directly into the primary healthcare services — including GPs, PHNs, Allied Healthcare Professionals?

Yes ○ No ○ Maybe ○

If you answered No or Maybe, please state why you did so?

17. In your opinion, should the Dementia Adviser be present at any of the following?

	Yes	No	Maybe
Community Multidisciplinary Terrri Meetings			
Memory Clinics			
Residential Care 'Local Placement Fora			
Other Please state in the space provided below):			

18. Please indicate your opinion, by ticking the appropriate response, for each of the followingstatements:

	Yes	No	Maybe	D t Know
a) Health & Social Care Professionsts are aware of the Derrientia Adviser Service				
b) People with derrientia are aware of the Derrientia Advise r Se rvice				
c) Carers 'Farriily of those with derrie ntia are aware ofthe Derrientia Adviser Service				

If you answered No or Maybe, what could be done to improve the visibility of the Dementia Adviser Service?

19. Do you know if the Dementia Adviser Service liaises with other voluntary or community organisations?

Yes O No ☐ Don't How O

20. Do you think the Dementia Adviser Service duplicates other services available for people with dementia?

Yes ☐ No ☐ Don't How O

21. What impact, if any, has the Dementia Adviser Service had on dementia services overall?

____

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22. Please tick to indicate your opinion for each of the questions below:

a) In your knowledge, does the Dementia Adviser engage with the following services?

Medical Centres /GP Surgery
Yes O No O Don't How O
Community Based Allied Health Care Professionals
Yes O No O Don't How O
Acute Hospital Team
Yes O No ☐ Don't How O
Voluntary Organisations
Yes O No ☐ Don't How O

b) In your knowledge, does the Dementia Adviser refer clients to the following services?

Medical Centres /GP Surgery
Yes O No O Don't How O
Community Based Allied Health Care Professionals
Yes O No O Don't How O
Acute Hospital Team
Yes O No ☐ Don't How O
Voluntary Organisations
Yes O No ☐ Don't How O

23. What, if any, are the challenges to the Dementia Adviser Service?

24. What, if any, are the resources that help to support the Dementia Adviser Service?

2S. Please rate your level of agreement with the following statements in terms of yp¡iji interaction with the Dementia Adviser Service?

	Strongly Disagree	Disagree	Somewhat <ree	free	Strongly Agree	Don't Know
Ove rail, the Dementia Adviser Service met with the client and 'or family 'c aregive r in a timely manner after the refe rral was made						
The Dementia Adviser Service supports existing healthc are services.						
The Dementia Adviser Service provides regular updates to you on any issues identifie d						
The well-being of the client improved after contact was made Dementia Adviser Service						
I are usually not aware when a client 'family has made contact with the Dementia Adviser Service.						
The Dementia Adviser Service works collabo ratively with other he althc are services.						
The Dementia Adviser Service does not add value to existing he althc are services.						

26. In your opinion, what are the advantages of the Dementia Adviser Service?

27. In your opinion, what are the disadvantages of the Dementia Adviser Service?

28. Please suggest how the Dementia Adviser Service can beimproved.

29. Have any of your clients provided you with feedback with regard to the Dementia Adviser Service?
Yes ☐ No ☐ Don't How ○

30. If so, how satisfied were your clients with the Dementia Adviser Service?
Very Dissatisfied ○ Dissatisfied ○ Mixed ○ Satisfled ○ Very Satisfled ○

Please return the completed form in the envelope provided. The postage has been paid for on this envelope.

This survey is anonymous; we do not need your name or your contact details.

Thank you very much for your help.

Appendix 9. Letters of support

THE ALZHEIMER
SOCIETY of IRELAND

27 October 2017

Re: Evaluation of the Alzheimer Society of Ireland (ASI) Dementia Advisor Service

To Whom It May Concern

The Alzheimer Society, ASI, fully supports the evaluation of our Dementia Adviser Service being carried out by UCC/UL.

ASI will facilitate access to appropriate staff for interview and will gate-keep of all service user data, ensuring only de-identified data is shared with the evaluation team.

Yours sincerely

Samantha Taylor
National Information & Advice Services Manager

The Alzheimer Society of Ireland
National Office
Temple Road, Blackrock,
Co. Dublin, Ireland.

PHONE +353 (0)1 207 3800
FAX +353 (0)1 210 3772
EMAIL info@alzheimer.ie
WEBSITE www.alzheimer.ie

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

National Dementia Office
Leadership, integration and Innovation

23/10/2017

Re: Evaluation of the Alzheimer Society of Ireland (ASI) Dementia Advisor Service

To whom it may concern,

I wish to confirm that the HSE fully support the evaluation of the ASI Dementia Advisor Service being carried out by UCC/UL, and will facilitate access to appropriate personnel for interview as part of the evaluation process.

Yours sincerely,

John Linehan

John Linehan,

Specialist, Older Person Services

APPENDIX 10
DA Job description and Role and Governance and Leaflet

THE ALZHEIMER SOCIETY of IRELAND

JOB DESCRIPTION & PERSON SPECIFICATION

For Dementia Adviser

Dementia Adviser Leaflet

JOB DESCRIPTION	
Job Title: Dementia Adviser	**Job Holder:**
Job Location: South Dublin and Wicklow	**Reports to: National Information & Advice Services Manager**

Purpose of Position:

The role of Dementia Adviser is to be a local point of contact on an outreach basis for people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life. Their purpose is to share information and signpost people with dementia and their carers to appropriate services and supports enabling them to take control of their own lives.

Main Duties and Responsibilities:

1. <u>Grow demand for service</u>

- Promote and build relationships with other health and social care professionals and community based organisations who may provide referrals for the DA service including primary care health professionals, public health nurses, memory clinics etc.
- Proactively find opportunities to engage with clients and their families with particular emphasis of engaging with new or early diagnosed clients
- Liaise with ASI services including the Helpline, for direct client referrals.

- Regularly review process of engagement with potential clients and their carers to ensure that the changing needs of this population are being adequately catered for by the Dementia Adviser and the services of The Alzheimer Society of Ireland.
- In conjunction with the National Advice and Services Manager and other colleagues, identify gaps and new opportunities in provision of support services for people with dementia and their carers, avoiding duplication of existing services.

2. Provide Information and support

- Act as a local resource for people concerned about their cognitive health and those with a diagnosis of dementia and for their carers and family members as needed throughout their journey with dementia.
- Provide information and support and signpost people to the relevant services in their community. Ensure that the information and signposting provided is in the individuals preferred style and format, working in partnership where necessary with other organisations, to ensure that the service provided responds fully and effectively, promotes control and choice, and meets a wide range and diversity of need.
- Provide individual support at key transition times, including visiting people at home when necessary and carry out regular reviews.
- Signpost and empower people concerned about their cognitive health and with a diagnosis of dementia, their carers and families with information to enable them to plan ahead, particularly in relation to money and legal matters and their wishes for their future welfare.
- Promote independence, self-help, well-being, choice and control by assisting people to better understand their situation and to assist them in developing coping strategies

3: Engage and network within local Community

- Identify and liaise with ASI services and supports (support groups, social clubs, café's, home and day care etc) and other services & community resources to support people concerned about their cognitive health and with a diagnosis of dementia and their carers to connect with appropriate service and supports.
- Liaise with and promote The Alzheimer Society of Ireland's information services such as the Helpline as a resource for people for their journey with dementia and for their carers, families and professionals working with them.
- Initiate, develop and maintain effective working relationships with other professionals working in the field of dementia, in the voluntary statutory and private sectors in the area
- Provide ongoing support to volunteer dementia advisers, where appropriate.
- Act as an ambassador for The Alzheimer Society of Ireland when dealing with the public.

4: Maintain Quality and standards

- Achieved agreed KPI relating to dementia adviser role on an annual basis
- Record and monitor all work undertaken and produce regular progress reports to enable effective monitoring and evaluation of the Dementia Adviser service.
- Develop an evolving database of local information, contacts and experiences.
- As part of a learning organisation, is personally committed to on-going development and continuous improvement.

- Adhere to ASI’s policies and procedures and other external legislative and regulatory requirements.
- Protect the security of client information, in both paper and electronic formats, from unauthorized access
- Ensure that information, both in paper and electronic formats, is of a high quality.

The above statements are intended to describe the general nature and level of work required from this position. They are not intended to be an exhaustive list of all responsibilities and activities required. This Job description outlines the main duties. However, in an organisation such as The Society, it is inevitable that tasks may arise which may not fall within the remit of the above list of main duties. Employees are therefore required to respond with a flexible approach when tasks arise which are not specifically covered in their job description. Should an additional responsibility become a regular part of an employee’s job, the job description will be amended to reflect this

PERSON SPECIFICATION:

Knowledge/Experience :

- 3rd level qualification in health or social care or equivalent is expected, **qualification in dementia care desirable**
- **Considerable experience in dementia care**
- Experience in the community care sector.
- Knowledge of the legal aspects of working with vulnerable adults, Enduring Power of Attorney, Ward of Court etc. is desirable

Skills/Competencies:

- Excellent communication (written and verbal) and interpersonal skills
- Strong active listening skills and facilitation skills
- Ability to organise and ensure quality administration
- Ability to self manage
- A full clean driving license will be required as the post will involve travel.

Other Requirements:

- Commitment to excellence
- Motivated self starter
- Empathy and patience
- Reliability and flexibility
- Personal drive and commitment

KEY RELATIONSHIPS	
Internal	External
ASI Information & Advice Services Manager and team, including ASI Dementia Advisers	Local diagnostic services – GPs, consultants, Memory clinics.
ASI local services and supports and Operations Manager	Local primary and secondary care support services - GP's, PHN's, PCT's, Consultants and members of multi-disciplinary teams, LHO's etc
ASI Communications Manager	
ASI Advocacy Officer	Local community care service providers.
ASI Advocacy Engagement and Participation Officer	Local CIC's & other statutory &voluntary organisations.
ASI Fundraising team	HSE Understand Together Campaign

CERTIFICATION

I certify that I have read and understand the responsibilities assigned to this position. Signed: [Insert Job holder’ Job Title] [Insert Job holder’ name] Date	I certify that this job description is an accurate description of the responsibilities assigned to the position. Signed: [Insert Managers Job Title] [Insert Managers name] Date:

Dementia Adviser Service

Description of Role

The role of Dementia Adviser (DA) is to provide a locally based, individualised, information, signposting, and emotional support service to people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life. Their purpose is to

- provide information, advice and support to understand the condition, manage symptoms, support activity and maintain / encourage participation in their community
- signpost/connect people to appropriate services and supports to assist in supporting independence and well-being and to maximise quality of life,
- provide early intervention and prevent crisis.

Description of services

The service is for people with dementia and their families / friends. There is no age restriction. The DA meets people in their own home, in a local ASI office or at an agreed meeting point. DA's also work with people by phone and email.

DA's deliver an individualised, tailored information, advice and signposting service. Service users are supported to identify their current and future needs and their DA will develop an Action Plan and focus on empowering the person with dementia and their families to take the next steps.

The DA service has an open referral policy, people with dementia and their families can self-refer into the service. The service is integrated into ASI's national network - the helpline and ASI staff /volunteers actively highlight and refer into the service. In addition, the service proactively works with allied health and social care professionals (GP's, PHN's, Social Workers, OT's, Consultants, etc) to support referrals from point of diagnosis, primary, and secondary health care settings. The service has a referral form to assist this process.

The service is delivered by 8 Dementia Advisers working across 13 counties.

Working relationship with HSE

Both ASI and the DA service have strong working relationships across the HSE, including throughout the Community Healthcare Organisations (Primary Care and Social Care) and Acute Hospital Settings. A number of DA's work directly with diagnostic services as part of the post-diagnosis support provided and with public health nursing and social care teams. ASI, including Dementia Advisers, also actively support the National Dementia Strategy's HSE led public awareness campaign *Understand Together* and work with the National Dementia Office on key projects.

KPI's

KPI 1: Grow DA Service: Agreed number of client meetings per month, with particular emphasis on meeting newly diagnosed and those who are not already in receipt of dementia specific services.

KPI 2: Deliver Information Service: DA service is a recognised point of information, advice and support within community. DA's provide individualised, tailored information and signposting service and deliver talks / host stands for key stakeholder groups in the community

KPI 3: Community engagement and networking: establish and develop relationships with key health and social care professionals and community groups. DA proactively link people into relevant services and supports in community and develop links with post-diagnostic support teams (clinical and social).

KPI 4: Quality & Standards: deliver, record and monitor service in line with ASI policy, procedures and processes. Engage with ongoing monitoring, evaluation and continuous learning / improvement opportunities.

Governance/monitoring/performance review process

Governance: DA's comply with ASI's organisational policies and procedures which comply with the Governance Code for community and voluntary organisations.

Monitoring and performance review structure:

- Bi Monthly team meetings: (6 per annum). Agenda includes:
    - Peer sharing and support
    - Expert speakers and learning opportunities
    - Updates from ASI nationally
- Quarterly individual meetings with Line Manager and monthly phone contact / activity report.

- Quality Control measures:
    - Standardised Action Plans for Client meetings
    - Standardised data collection and reporting system, including compliments, comments and complaints system.
    - 1 client meeting attended by Line Manager p/a for review
    - 1 client feedback survey p/a circulated to 10% of client base
    - Centralised information repository managed via Helpline Service to ensure access to up to date and accurate information
    - Group email system for sharing information, updating
    - Identified mandatory training areas and minimum knowledge areas for delivery of service.

Reporting relationships

All DA's report to ASI's National Information & Advice Services Manager who reports to Head of Operations in ASI.