

**Dementia Adviser Service**

**Client Impact Survey 2017**

**January 2018**



**THE ALZHEIMER**  
**SOCIETY *of* IRELAND**



**Authors:** Miriam Enright Head of Operations

Samantha Taylor National Information and Advice Services Manager

## Introduction

### Purpose of the DA Client Impact Survey

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.

ASI introduced this new service in Ireland in mid-2014 (€460,000 p/a) following a successful pilot in two sites in 2013. Since 2016 onwards HSE have co funded this service. 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, allowing ASI to shift emphasis beyond output measures and introduce a basic impact measure to provide greater insight.
- receive constructive feedback on the various information, advice and supports being provided in order to enhance future service experiences.
- establish if this service investment offers value added support to those affected by dementia.

### Purpose of the Dementia Adviser Role

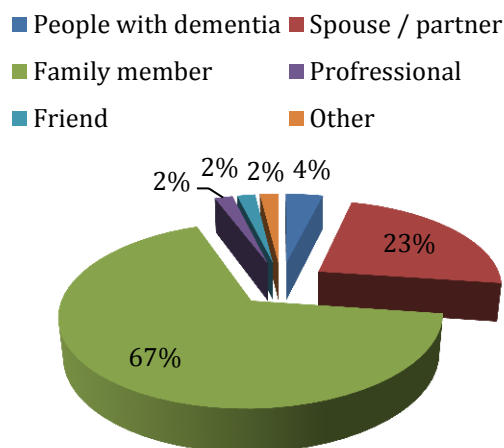
The role of Dementia Adviser (DA) is to provide a locally based, individualised, information, signposting, and emotional support service to people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from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

### Profile of Service Users

This service is available to both people with dementia and their families. The service is targeted to support and empower people as early as possible following a diagnosis with a focus on living life as they wish to in their local community. In 2016 the service worked with 1,708 new clients, 76% are female, 24% are male. Family members accounted for the majority of people availing of the service (90%), people with dementia directly contacting a DA accounted for 4% with the remainder 6% others. The service records the person who contacts the service directly as the client and in 2016 the profile of clients is represented in the graph on next page.

## Service Users



In many cases, while a family member or spouse may contact the DA, the DA will also meet with the person with dementia and other family members during the course of their work. DA's held 2,192 meetings in the year, 47% were first time face-to-to-face meetings.

In 2% of cases the client was recorded as a health/social care professional and 2% a friend as they sought information and advice for a person with dementia from the DA service.

## Methodology

**Instrument development** : ASI reviewed the evaluation undertaken of the Dementia Adviser service in the UK (Healthbridge: 2013) and reviewed the Scottish Post-Diagnostic Support Evaluation Form used with Link Workers and developed with Healthcare Improvement Scotland. It was decided a questionnaire would be the most appropriate instrument to examine the impact of this service due to the geographical spread of this service and the desire to facilitate anonymised feedback. ASI adopted elements of the Scottish approach, however tailored it to suit the DA service and reflect the key deliverables agreed for this role. To ensure accessibility, ASI adopted Plain English guidelines to language and developed two questionnaires: one addressing a person with dementia (12 questions, 4 open 8 closed) and one addressing a family members (13 questions, 4 open, 9 closed) – both were reviewed for accessibility and content by 3 Dementia Advisers

**Distribution of survey** : Individual questionnaire packs were handed to clients at the end of DA meetings over a 6 week period (July and August 2017). 144 anonymous client questionnaires were circulated to clients made up of either people with dementia or family members, representing a sample size of 16% of current service users.

**Method of return** : All questionnaire packs included a self- addressed envelope to ensure ease of response for all concerned. 62 questionnaires were returned, which is a strong response rate of 43%; 54 (87%) were from relatives of people with dementia and 8 (13%) were from people with dementia.

**Method of analysis**: Data from all questionnaire was inputted into a Google forms where an analysis of responses was completed in google sheets.

## Results from DA Client Survey

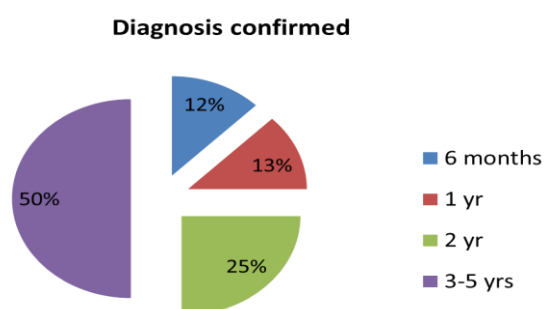
While it is acknowledged this survey is not as scientific as academically produced research, it does provide valuable insight into the value and impact of this service. To assist with our understanding of the needs of both people with dementia and their families, the analysis has been divided into these two areas.

### 1. Client Survey Results from People with Dementia

#### Profile of Participants

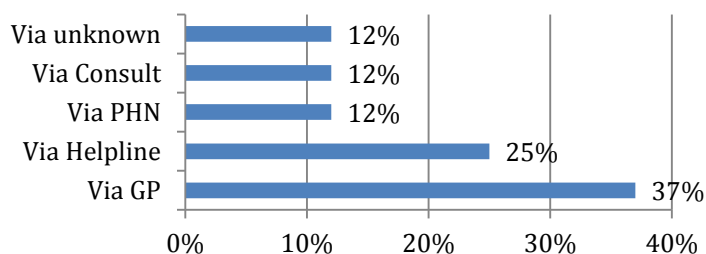
As responses from clients included those earlier in their diagnosis, we were able to capture some direct feedback and measures from a small samples size of people with dementia (8). A good geographic spread across the 8 service users was achieved, with responses from people living in 6 counties broken down as 3 living in Cork and then one response from Kerry, Louth, Sligo, Tipperary and Dublin.

63% of these respondents are female, 37% are male. Interestingly 3 (37%) of the respondents are aged 65 or less with a further 4 (50%) respondents are aged between 66 and 75 years, and one person was over age 76.



25% contacted the service within one year of diagnosis, with half of this group accessing the service within 6 months of receiving a diagnosis. A further 25% within 2 years. 50% respondents have been living with a diagnosis for between 3 and 5 years.

#### Made aware by:



When asked how they heard about the DA service;

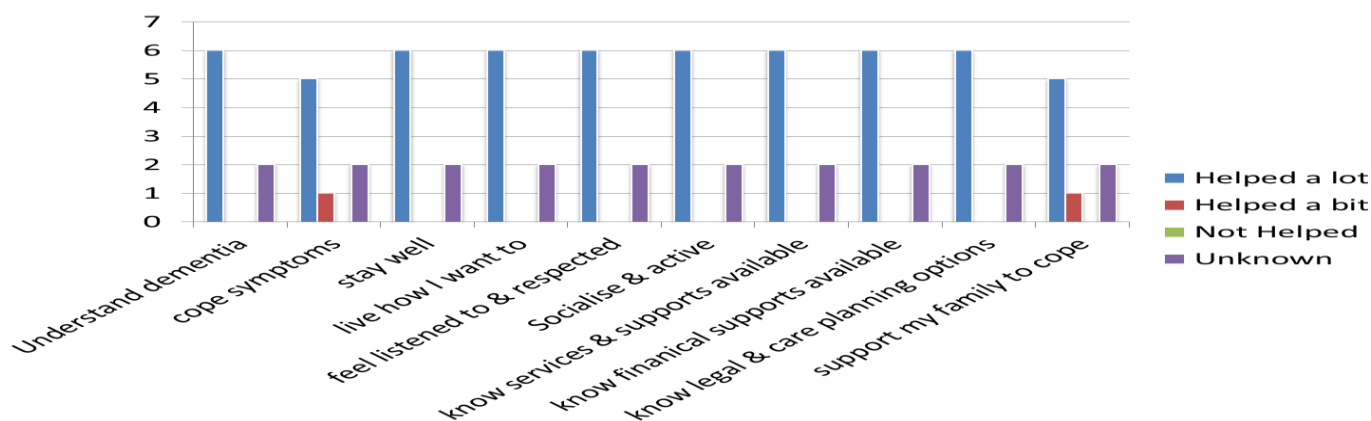
- 3 (37%) people with dementia indicated their GP had told them about it,
- 2 (25%) were signposted by ASI's Helpline Service,
- 1(12%) by a public health nurse,
- 1 (12%) by a consultant and
- 1 (12%) responded unknown.

The profile of respondents provides a strong indication that the DA service is working with people early in their post-diagnosis and has developed a strong referral base by ensuring integration with ASI's Helpline service and by developing links and integrating with health & social care professionals who are highlighting the service to people with dementia directly.

## Feedback about user experience

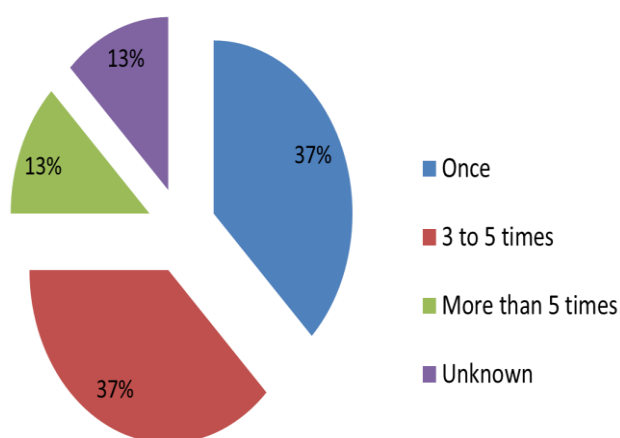
### What was the impact of the Dementia Adviser Service

- When asked how they felt before meeting their Dementia Adviser, people with dementia responded as follows.
  - “my daughter helped me a lot with regular living”
  - “Sad, Upset”
  - “Diagnosis turned my life upside down. Have accepted diagnosis - what will be, will be - plodding along. Day to day- tired sometimes. Lists - organised days- life all about lists”
  - “Worried, doing about ok”
  - “Coping badly”
  - “Got information about my finances (from DA) that I had been worried about”
  - “Not having any information about the help and contact. Not knowing who to call day to day”
- When asked what the support from their DA has meant to them, people with dementia responded:
  - “her support feels more like friendship. She is so calm & friendly. She's good to talk with about anything. She enables people.”
  - “I feel very happy to have someone tell me about my illness
  - “Back up if need be. Someone to call / talk to. Good sound practical advice”
  - “To keep active. Good support available and to use it”
  - “Heaven”
- When asked how helpful they found their Dementia Adviser across 10 key areas (depicted in chart below);
  - 6 respondents (75%) indicated their DA has ‘helped them a lot’ in all 10 areas, the most positive option on the scale.
  - 1 respondent (12%) picked two areas where they indicated the DA had ‘helped them a bit’, the middle option on the scale, for the remaining 8 areas they choose ‘helped a lot’.
  - 1 respondent (12%) did not complete this section of the form and is represented as Unknown.
  - No respondents indicate the DA had not helped them, as confirmed in the chart below.



4. When asked what difference has the service made to you and to your family, people with dementia responded:
  - “Reassurance, calm presence, friendliness. Meeting her feels very relaxed and informal”
  - “Its a break for my wife when I go to Bessbora (Day Centre) and I enjoy going to meet other people”
  - “better understanding”
  - “helps a great deal”
  - “very good”
  - “To me now I know what to do, Cogs clubs to keep active”
5. When asked how many times they contacted their DA, they responded:

**How many times contacted your DA?**



37% of respondents had contacted the DA service once . This is probably related to the fact that the surveys were circulated at a point in time (Summer 2017) and answers reflect that some clients are new and have just had their first meeting.

50% of respondents have had 3 or more contacts with their DA

6. When asked would they use this service again 75% of people with dementia said they would contact their DA again, with 25% leaving this field blank.
7. When asked would they recommend this service to others, 88% of people with dementia said they would recommend the DA service to others, with 12% leaving this field blank.

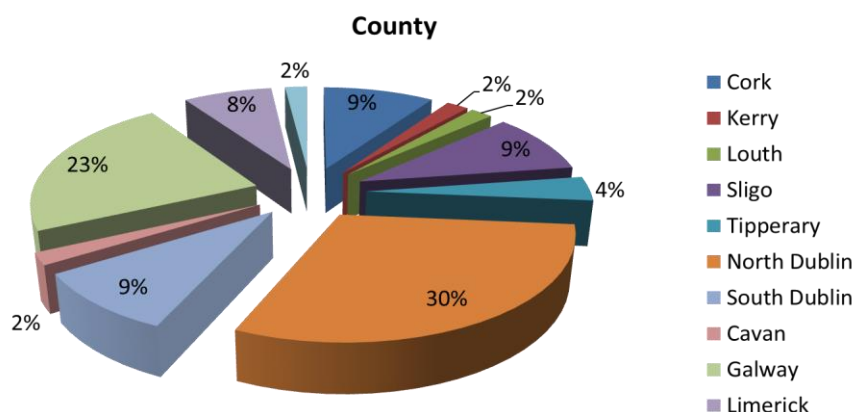
**In summary**, it is clear that people with dementia place a high value on the DA service and that the service has had a positive impact on their lives, with very high levels of agreement that the DA service had ‘helped a lot’ across 10 key information and support areas. Their responses highlight the importance of a dedicated resource providing an individualised service with a number of people highlighting keeping active, better understanding, peer support and knowing where to go for services and support as outcomes from their interaction with their DA, all indicators of a person supported to live well with their condition.

## 2. Survey Results from Family Members of People with Dementia

### Profile of Participants

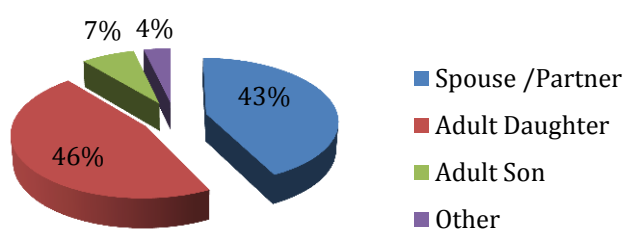
54 clients who are family members of people with dementia completed the client impact survey.

80% of respondents are female, with the remaining 20% being male. The respondents are located across 10 counties as outlined in the chart below:



The survey responses provide a good geographic spread that represents at least one area for each DA. Respondents were also asked to confirm their relationship with the person with dementia, and a strong mix of service users supporting a person with dementia at home was achieved, as outlined in the chart below.

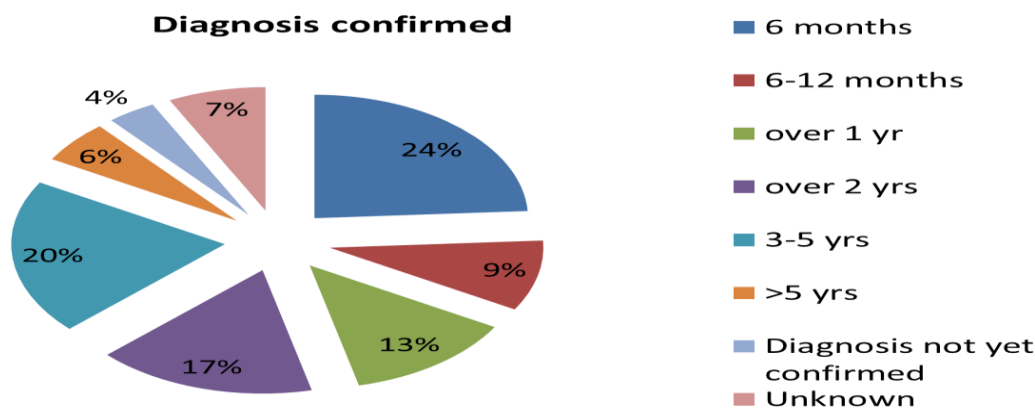
### Relationship



Both spouse / partners (43%) and adult children (53%) contacted the service .

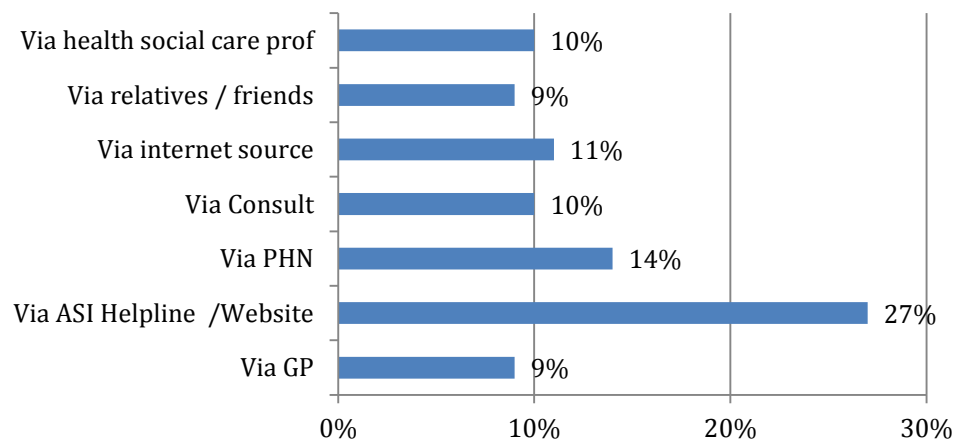
Other is a mix of siblings, adult niece/nephew and friends.

Family members responding to the survey are from all stages of the post diagnostic journey, however 33% are within the first year , and 63% are within the first three years, see chart below for further breakdown.



When asked how they heard about the DA service the respondents gave a wide range of responses (see chart below). There is clear integration with ASI Helpline and website as 27% of respondents were referred to their DA from these sources. Interestingly, 43% of respondents indicated that a health or social care professional told them about the service.

**Made aware by:**



The above profile strongly indicates the DA service has linked well with diagnostic and support service teams within their community and that these professionals see this as a service they will refer patients to. It is also clear they are making these referrals early in the post-diagnostic journey.



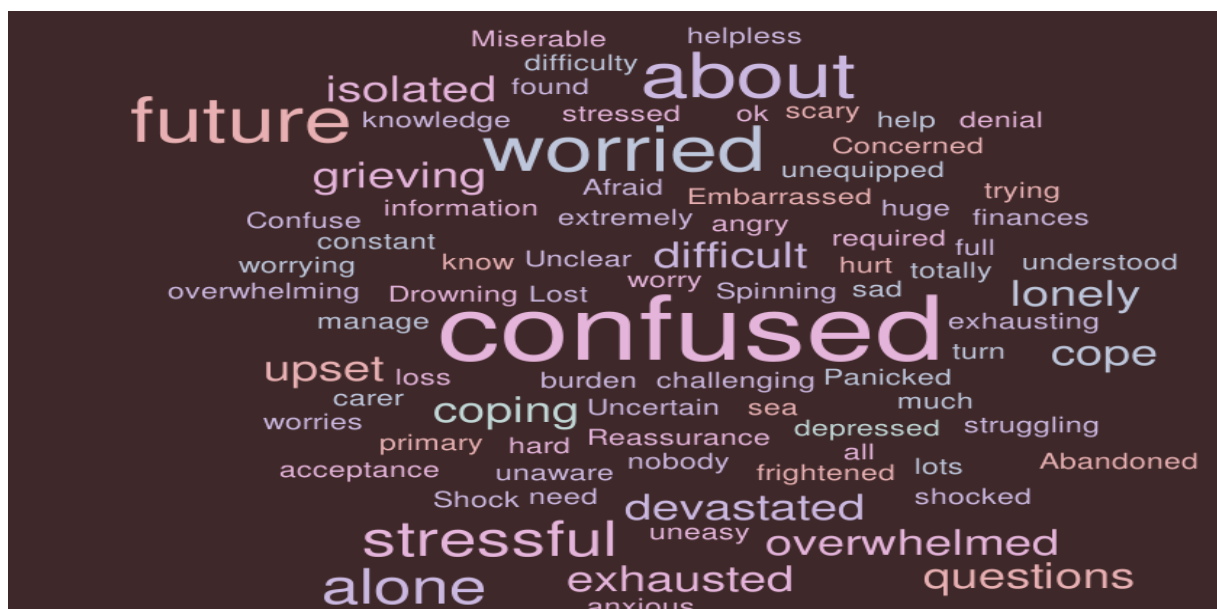
## Feedback about user experience

### Impact of the Dementia Adviser Service

1. When asked how they felt before meeting their Dementia Adviser, family members responded as follows:

Respondents provided details of their emotions before meeting their DA. The responses highlight that most family members were feeling confused, worried, stressed, overwhelmed, grief and alone / isolated prior to using the DA service

The word image below captures these feelings, the more frequently the word appeared in the survey responses, the larger the size of the word in the image below.



The following quotes are a sample which provides further insight to how families felt before accessing the service:

"I was in complete shock. Just getting from one day to the next and trying to help the family come to terms with their Dad's diagnosis"

*"Drowning, spinning, panicked, helpless, frightened, overwhelmed, upset, grieving, struggling"*

"sad, taking each day as it comes, angry, confused, scary"

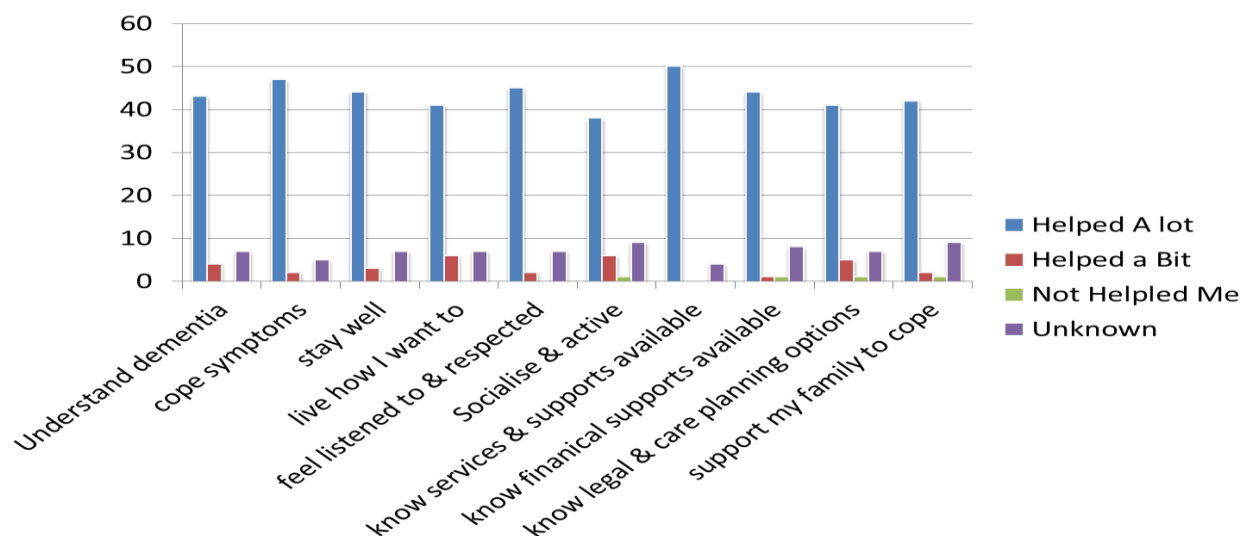
"Felt alone with no help or anyone to talk to that understood. Coped as best I could"

*"the first year I felt so alone and had lots of worries about the future and finances, how would I cope on my own with my husband and a progressive illness"*

2. When asked what the support from their DA has meant to them family members responded as follows: Respondents provided overwhelmingly positive feedback, with responses highlighting support, information, advice, understanding, relief and knowing that they were not alone as very important outcomes to clients. The image below captures this feedback.

3. When asked how helpful they found their Dementia Adviser across 10 key areas family members responded as follows:

- The vast majority of the 54 service users felt their Dementia Adviser 'helped a lot' across the areas. The four areas that have a 'not helped me' had a comment beside them to say either 1) a further appointment had been made with the DA to cover this topic or b) the topic was not relevant to the person. No responses indicated a negative experience with a DA or the service.

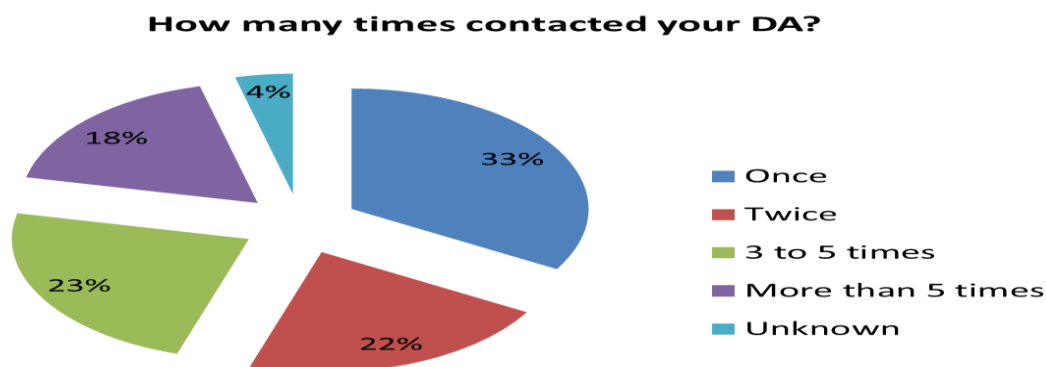


4. When asked what difference has the service made to you and to your family, family members responded as follows:

- There was an overwhelmingly positive response to this question and no negative responses received. Respondents also repeatedly identified that the DA service had been beneficial for the family confirming the impact of the service is wider than the person with dementia and their main carer. This selection of quotes provides an indication of impact of the service:

- "Knowing that there are options, help is available, and helping us to plan for the future."
- "like we are listened to and valued as people. (PWD)...goes to art therapy which has now transitioned well into attendance at day services. willingness to try new things...."
- "We have implemented several suggestions. We are being more proactive. Dad (pwd) is more engaged..."
- "It has helped take the worry and strain away from hard to manage situations. It has helped us know where to get further help for him."
- "No words can describe the difference made to us. She was always there to guide, to listen, to advise and to support us. We were at the most difficult period of our lives and she was our miracle"

5. When asked how many times they have contacted their Dementia Adviser, family members responded:



6. When asked if they would contact their DA again, all 54 of family members said they would contact again.
7. When asked if they would recommend the DA service to others, again, all 54 of family members said they would recommend.

Would you contact the DA again?



Would you recommend DA services to others ?



### Suggestions on how to improve the DA service

Both people with dementia and family members were asked for their suggestions on how ASI might improve the DA service. The following are the suggestions received;

- Earlier access – be told on diagnosis
- More dementia advisers
- Make it available to all PWD & carers
- Signage for a particular ASI office, the person found it hard to locate.
- More for people who are deaf/blind, the person did not elaborate

## Conclusions

1. This survey demonstrate clear evidence that both people with dementia and their families placed a high value on the Dementia Adviser service across all 62 completed surveys received. Many clients took time to not only complete the questions asked but to write additional comments to underline how positive their experience with their DA was and highlight the impact of the service in their lives.
2. It is also apparent that availing of this service has a positive impact for both people with dementia and their families. It appears to be particularly affective at reducing social isolation and empowering individuals to seek further assistance.
3. The survey indicates the DAs are providing high quality information and support with a very high level of respondents confirming that the DA service helps people with dementia and their families to:
  - Understand the condition and manage symptoms,
  - live how they want to, as much as possible,
  - keep active and socially engaged, with focus on connection with peer supports,
  - know about and access supports and services in their community,
  - know about and access financial supports available to them, and
  - know about legal and care planning options and to plan in these areas

It is clear that the majority of the respondents contact their DA a number of times, the reasons for these meetings vary but in the main it is because 1) the service users indicated a need to have information delivered across a number of meetings rather than all at once and 2) a new need emerged due to progression or changing circumstances.

4. The survey also confirms that in 3 years the service has
  - a) integrated well with key internal ASI services such as the Helpline which provides high levels of referrals to the DA service.
  - b) has achieved strong links with relevant health and social care professionals working in the diagnostic and post-diagnostic services that people with dementia and their families engage with and that these professionals are referring people to this service.

It is therefore reasonable to conclude that this has achieved a better experience for people in their post-diagnostic journey by ensuring a streamlined and simple the pathway to the service .

5. One of the core aims of the service is to provide early intervention and prevent crisis, the feedback from clients suggests that the DA service is delivering in this regard. Respondents were in the majority early in their post-diagnostic journey and overwhelmingly indicated that they felt listened to and respected and received the information they needed to empower them to plan and to access services and supports early and to adopt strategies which focus on ability and their individual preferences. It must also be acknowledged that the service does also work with people later in their journey with dementia, some clients received their diagnosis several years before the DA service existed, and so could only access it later in the journey. While needs may be different, It is reasonable to conclude that access to this service has a positive impact for people with dementia and their families and that access to this service contributes to a better quality of life.

## Recommendations

1. ASI recommends that access to a Dementia Adviser should be a core feature in the post diagnostic pathway for all people with dementia and their families in Ireland. It is clear that this early intervention service does empower and inform those affected in a positive manner. To that end, the service should be funded to expand into counties that do not have access to this service and to increase capacity in high density population areas to meet demand.
2. ASI recommends that the Dementia Adviser Service is an intrinsic element of any future county service development plans in order to influence future priorities for dementia funding in particular in the area of post diagnosis dementia services.
3. ASI recommends constructive feedback received is used to ensure ongoing learning and development of information content and delivery to enhance the experience and impact of this service. ASI also recommends developing internal data capture process to enable better understanding of the number of interactions with the service and the needs of service users as dementia progresses, this is currently limited given the short time frame the service has been running and the evolving nature of our data capture systems as we work with clients over time.
4. ASI recommends a more in-depth impact study of the service is completed to better understand the impact of this service not only for service users and their families but also for the health and social care professionals delivering diagnostic and post-diagnostic services in Ireland. ASI recommends a longitudinal approach to understanding the impact of this service as a person with dementia and their family live through the progression of dementia and as their needs change.

## Appendix A – Questionnaire for person with dementia



### Finding out what difference your Dementia Adviser makes to you

We would like to find out about your experience with your Dementia Adviser.  
We would like to understand what difference this service has made to you.

Your feedback will help us to deliver the best possible service and to plan for new services.

**Your Dementia Adviser is:** \_\_\_\_\_ **Location** \_\_\_\_\_ (county)

1. **Are you**    ☐ Male or ☐ Female
2. **Are you between :** ☐ 35-59 years    ☐ 60-65 years    ☐ 66-75 years    ☐ 75+ years
3. **When was your diagnosis made?**  
☐ Within last 6 months    ☐ 6 months to 12 months ago    ☐ over 1 year    ☐ over 2 years    ☐  
3 to 5 years    ☐ more than 5 years    ☐ diagnosis not yet confirmed
4. **How did you hear about your Dementia Adviser?**  
☐ ASI Helpline    ☐ ASI website    ☐ Consultant    ☐ GP    ☐ Public Health Nurse  
☐ Social Worker    ☐ Internet    ☐ Other \_\_\_\_\_
5. **Describe what life was like before you met with your Dementia Adviser?** For example how did you feel about your diagnosis, how were you coping day-to-day? You can write words or short sentences

6. Please tick how helpful your Dementia Adviser was to you for the following topics

<b>My Dementia Adviser helped me</b>	<b>Helped me a lot</b>	<b>Helped me a bit</b>	<b>Not helped me</b>	<b>Comment</b>
To understand dementia and the changes that I am experiencing				
To be able to cope with my symptoms				
To stay as well as possible				
To live how I want to, as much as possible				
To feel I am listened to and respected				
To get to see people socially and keep active				
To know what services and supports are available to me and how to access them				
To know what financial supports may be available to me and how to access them				
To know what legal and care planning options are available and how I can approach this area				
Supported my family to cope with and understand my dementia				
Any topic or issue you want to mention?				



**7. What has the support from your Dementia Adviser meant to you?**

You can use words or short sentences

**8. What difference has this service made to you and your family?**

You can use words or short sentences

**9. How many times have you contacted your Dementia Adviser?**

☐ once    ☐ twice    ☐ 3-5 times    ☐ more than 5 times

**10. Would you contact your Dementia Adviser again?** Yes ☐ Maybe ☐ No ☐

**11. Would you recommend the Dementia Adviser service to other people?**

Yes ☐ Maybe ☐ No ☐

**12. Have you have suggestions on how we can improve the Dementia Adviser service?**

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

The form will be sent to The Alzheimer Society of Ireland, National Office, Temple Rd, Blackrock, Co Dublin.

## THANK YOU VERY MUCH FOR YOUR HELP

**This survey is anonymous; we do not need your name or your contact details. If you would like a response to your comments in your survey, you can fill in your contact details and the manager of the Dementia Adviser Service will contact you.**

Name \_\_\_\_\_ Telephone No \_\_\_\_\_

### ASI OFFICE USE ONLY

Date Received	Received by
---------------	-------------

## Questionnaire for Family Members



### Finding out what difference your Dementia Adviser makes to you

We would like to find out about your experience with your Dementia Adviser.  
We would like to understand what difference this service has made to you.

Your feedback will help us to deliver the best possible service and to plan for new services.

**Your Dementia Adviser is:** \_\_\_\_\_ **Location** \_\_\_\_\_ (county)

1. **Are you** ☐ Male or ☐ Female
2. **Are you between :** ☐ 35-59 years ☐ 60-65 years ☐ 66-75 years ☐ 75+ years
3. **What is your relationship to the person living with dementia?**  
☐ Spouse/partner ☐ Daughter ☐ Son ☐ Sibling ☐ Other \_\_\_\_\_ (please state)
4. **When was the diagnosis made?**  
☐ Within last 6 months ☐ 6 months to 12 months ago ☐ over 1 year ☐ over 2 years ☐  
3 to 5 years ☐ more than 5 years ☐ diagnosis not yet confirmed
5. **How did you hear about your Dementia Adviser?**  
☐ ASI Helpline ☐ ASI website ☐ Consultant ☐ GP ☐ Public Health Nurse  
☐ Social Worker ☐ Internet ☐ Other \_\_\_\_\_
6. **Describe what life was like before you met with your Dementia Adviser?** For example how did you feel since the diagnosis was made, how were you coping day-to-day? You can write words or short sentences

**7. Please tick how helpful your Dementia Adviser was to you for the following topics**

<b>My Dementia Adviser helped me</b>	<b>Helped me a lot</b>	<b>Helped me a bit</b>	<b>Not helped me</b>	<b>Comment</b>
To understand dementia and the changes that have happened				
To be able to cope with symptoms and support my family member to cope with their symptoms				
To stay as well as possible				
To live how I want to, as much as possible				
To feel I am listened to and respected				
To get to see people socially and keep active				
To know what services and supports are available to our family and how to access them				
To know what financial supports may be available to our family and how to access them				
To know what legal and care planning options are available and how I can approach this area				
Supported my family to cope with and understand dementia				
Any topic or issue you want				

to mention?				
-------------	--	--	--	--

**8. What has the support from your Dementia Adviser meant to you?**

You can use words or short sentences

**9. What difference has this service made to you and your family?**

You can use words or short sentences

**10. How many times have you contacted your Dementia Adviser?**

☐ once    ☐ twice    ☐ 3-5 times    ☐ more than 5 times

**11. Would you contact your Dementia Adviser again?** Yes ☐ Maybe ☐ No ☐

**12. Would you recommend the Dementia Adviser service to other people?**

Yes ☐ Maybe ☐ No ☐

**13. Have you have suggestions on how we can improve the Dementia Adviser service?**

--

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

The form will be sent to The Alzheimer Society of Ireland, National Office, Temple Rd, Blackrock, Co Dublin.

**THANK YOU VERY MUCH FOR YOUR HELP**

**This survey is anonymous; we do not need your name or your contact details. If you would like a response to your comments in your survey, you can fill in your contact details and the manager of the Dementia Adviser Service will contact you.**

Name \_\_\_\_\_ Telephone No \_\_\_\_\_

**ASI OFFICE USE ONLY**

Date Received	Received by
---------------	-------------