

The contribution of the Allied Health Professionals to Post diagnostic support in Dementia Phase 1

A National Scoping Exercise 2014-2015

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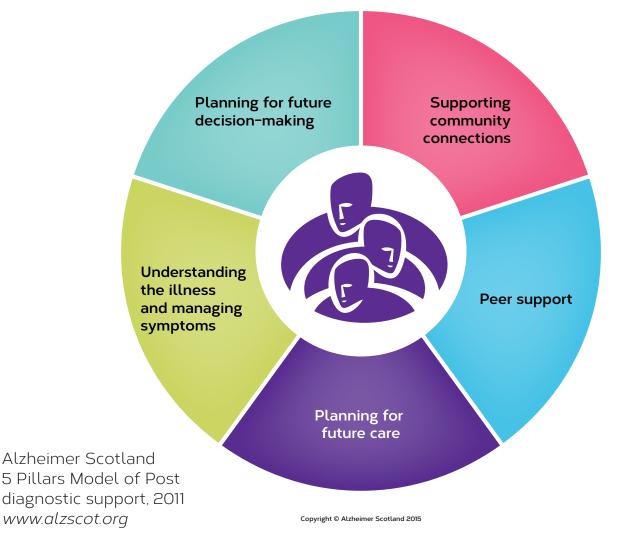
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The number of people living with dementia in Scotland is estimated at over 90,000 and this is continuing to grow. Around 3,200 of these people are under the age of 65 (Alzheimer Scotland, 2015). Therefore there are increasing numbers of people requiring post diagnostic support.

At the time of carrying out this work, we were responding to Scotland's National Dementia Strategy 2013–2016 (Scottish Government, 2013) to improve post diagnostic support with a national HEAT Target designed to ensure people with dementia receive the support they need following diagnosis. The HEAT target was:

"To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Dementia Link Worker, including the building of a person-centred support plan."

The post diagnostic support HEAT Target was designed to give people time and space to access services and receive high quality support in a way that meets their individual needs over the course of a year. The Target was informed by the Alzheimer Scotland 5 Pillars Model of Post diagnostic support, which covers the following domains: Supporting community connections, Peer support, Planning for future care, Understanding the illness and managing symptoms, Planning for future decision making.



High quality post diagnostic support is vital in enabling people with dementia to live a better quality of life and to remain as independent as possible for as long as possible. Allied Health Professionals (to be referred to as AHPs in this report) have the expertise to support people with dementia, their families and carers to live well with the condition. Although it was recognised that the AHPs had a key role in the delivery of post diagnostic support, there was no national overview of what the AHPs were contributing across Scotland. Therefore, the AHP Project in Post diagnostic support was commenced and within the project charter, the problem identified was:

"We have no national overview of the current post diagnostic support that AHP professions are involved in. There is also no clear understanding of the links between Alzheimer Scotland Dementia Link Workers and AHP Services. This could result in potentially an inequitable service nationally with underutilisation of AHP skills in enabling people to live well with dementia."

This report sets out the work completed for Phase One of the AHP Project in Post diagnostic support from 2014-2015. This includes the engagement and promotion work which has taken place as well as reference to current available evidence.

This report will highlight the key findings from the scoping exercise with Alzheimer Scotland Dementia Link Workers and the scoping exercise with the five main AHP groups involved in post diagnostic support (dietitians, occupational therapists, physiotherapists, podiatrists and speech and language therapists). Areas for action will be outlined.



In order to inform this work, it was vital to engage with a wide range of stakeholders across Scotland. This has been carried out in partnership with the Alzheimer Scotland AHP Dementia Consultant.

Extensive dialogue has taken place via attendance and presentations at national events and workshops. Consultation and ongoing expert input from the AHPs in local practice, AHP Project Board Leads and the then Alzheimer Scotland AHP Dementia Expert Group has also shaped this work. The main driver behind this work is what has been informed by people living with dementia, their families and carers, which will be discussed further in the Evidence Section. The following are examples of some of the stakeholder engagement, which has taken place:

AHP Project Leads

An essential part of the Project involved working with AHP Project Leads from the Health Board areas. The AHP Directors were asked to nominate a Lead in each of the Health Board Areas and a Consultation Group was formed with members from 11 Board Areas across Scotland (Appendix 1). The inaugural meeting of this group took place in August 2014 and following this, communication was maintained electronically, via teleconferencing and webex.

National AHP Dementia Expert Group

This Group was led by the Alzheimer Scotland AHP Dementia Consultant and consisted of representatives from all of the AHP Groups, Professional Bodies, and Health Board areas.

Community of Practice

The AHP Dementia Community of Practice was established and linked to wider AHP programmes in Scotland and can be accessed at:

http://www.knowledge.scot.nhs.uk/ahpcommunity/ndp-2012-2015/dementia.aspx The Community of Practice contains the project charter and monthly project updates in the form of Flash Reports. It has also been populated with information from the Board Leads on work happening in their areas in relation to Post diagnostic support. Additional relevant information such as presentations and reports were included on the Community of Practice.

'Connecting People, Connecting Support' workshop

This event was held in September 2014 and focussed on post diagnostic support and selfmanagement in dementia. This one-day conversation involved AHPs and Dementia Link Workers and celebrated the best in supported self-management for people with dementia. The conversation also focussed on the co-creation of the future direction of supported self-management and this conversation is ongoing.

Publications

The 'Connecting People, Connecting Support' event saw the launch of the document 'Allied Health Professionals Delivering Post diagnostic support: Living Well with Dementia'.



Allied Health Professionals Delivering Post-Diagnostic Support: Living Well with Dementia



This document is one of a suite of three publications which raise awareness of the work of the AHPs in dementia. All three publications can be accessed at:

https://www.alzscot.org/our-work/transforming-health-care/ allied-health-professionals-and-dementia/allied-health/ourahp/collaboration-ahp-dementia-policy-evidence

Within this document, the AHP Project in Post diagnostic support is included: 'Building a national picture of the role of AHPs in post diagnostic support'.

Social Media

Social media has been utilised in order to further raise awareness and inform people of the Project. The use of Twitter and blogging has aimed to reach a wide audience in order to enable people to think about the role of the AHPs in post diagnostic support. The AHP Dementia Consultant also hosts a 'Let's Talk About Dementia' Blog www.alzscot.org/talking_dementia. This Blog provides a platform to share the work of the AHPs in dementia care as well as informing and encouraging conversations.



All of the work highlighted above, and the collaborative approach has had an integral part to play in taking the project forward and will continue to do so.

3. Evidence Informing the Project

At the start of this project, post diagnostic support in dementia was still a relatively new concept and the contribution of the AHPs in this area was also a new but expanding area. The information explored in order to inform the scoping work and recommendations will be described in this section. This will focus on four key areas:

3.1 People living with dementia3.2 Policy and Standards3.3 Literature3.4 AHP Professional Bodies supporting materials



3.1 People Living with Dementia

It is known from anecdotal evidence that people are not always receiving access to the expertise of the AHPs after receiving a diagnosis of dementia. The AHP Dementia Consultant, in partnership, has been leading work on engagement with people living with dementia, their families and caregivers. This has been carried out in a variety of different ways including:

- Visiting local board areas to carry out interviews with people living with dementia, their families and caregivers
- Dementia Awareness Week "Ask an AHP"
- What is important to me?
- Appreciative Inquiry conversations

One of the key areas of importance for people living with dementia was having access to services when they needed them. Information on this work can be found on the Alzheimer Scotland website www.alzscot.org/ahp.

3.2 Policy and Standards

This section covers the national reports and policy that are supporting the need for greater post diagnostic support.

• Facing Dementia Together Project 2009-2011 (Gilmour, 2011)

As highlighted within the introduction, Scotland's approach to post diagnostic support in dementia is based on the Alzheimer Scotland 5 Pillars Model of Post diagnostic support. This model evolved from the Alzheimer Scotland 'Facing Dementia Together' post diagnostic support pilot project which took place from 2009–2011. The Scottish Government had made dementia a national priority and launched a National Strategy on Dementia in June 2010 (Scottish Government, 2010). Post diagnostic support for people with dementia and their carers was one of two key areas of this strategy.

The project was funded by Scottish Government and was carried out in partnership with The East Renfrewshire CHPC, Renfrewshire CHP and Renfrewshire Council. It set out to provide support to people who had recently received a diagnosis of early stage dementia and their families. The project offered different levels of input, according to need and there was a variety of different types of support provided including information, advice, signposting, emotional and practical support.

The project found that there is a clear need and demand for post diagnostic support and the following five key areas (pillars) were demonstrated as being essential in a post diagnostic service:

- Supporting community connections
- Peer support
- Planning for future care
- Understanding the illness and managing symptoms
- Planning for future decision making.

It was recommended that a comprehensive post diagnostic support service should be a mainstream part of the support offered to people with dementia and their partners and families immediately after diagnosis. The 5 Pillars Model of Post Diagnostic Support has since been adopted nationally. Full report available:

http://www.alzscot.org/assets/0000/1821/Facing-dementia-together-post-diagnosticsupport-pilot.pdf

• Scotland's National Dementia Strategy 2013 – 2016 (Scottish Government, 2013)

Scotland's second National Dementia Strategy continued to prioritise post diagnostic support and the 5 Pillars Model of Post diagnostic support (2011) informs the post diagnostic support HEAT target.

It was recognised within the Dementia Strategy (2013-2016) that timely health and social care support can enable people to live a good quality life at home for as long as possible. It was also recognised that there is a need to move towards a system of care which maximises and promotes resilience and independence, and which supports and promotes the capabilities of the person with dementia.

The commitments within the Dementia Strategy are interlinked and any work around post diagnostic support will have an impact in other areas. Namely for this project, emphasis must also be placed on the specific commitment for the AHPs where the Scottish Government commissioned Alzheimer Scotland to produce an evidence-based policy document outlining the contributions of AHPs to ensuring implementation of the 8-Pillar Model. This work was led on by the National Alzheimer Scotland AHP Dementia Consultant and was informed by the AHP Project in Post diagnostic support.

Since this original work, Scotland's third dementia strategy has been published – Scotland's National Dementia Strategy 2017 – 2020 (Scottish Government, 2017). The work of the AHPs is embedded in the way forward. Connecting people, connecting support: The allied health professional offer to people living with dementia in Scotland (Alzheimer Scotland, 2017) sets out how the rehabilitation skills and expertise of the AHP workforce can have an even greater impact on the lives, experiences and outcomes of people with dementia.

• Standards of Care for Dementia in Scotland (Scottish Government, 2011b)

These standards were developed to help people with dementia and their carers understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to. The standards recognise the importance of people with dementia being enabled to stay at home, as well as being connected and active participants in their local communities. The Standards of Care for Dementia also state that: People with dementia and their carers will receive treatment that is likely to be of benefit, including a range of non drug-based treatments.

A range of non-drug based interventions are available and include evidence based therapies, such as group based or individual cognitive stimulation, individual reality orientation therapy, art therapy, therapeutic activities and physical exercise programmes.

• Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers (Scottish Government, 2011a)

The Framework was developed by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) in order to support the delivery of the aspirations and change actions outlined in Scotland's first dementia strategy (2010). The Promoting Excellence framework details the knowledge and skills that all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, and carers. This applies to the AHPs and work is ongoing in this area.



3.3 Literature

'The Knowledge Network' was utilised, combining search terms around each of the five AHP Groups and 'post diagnostic support' and 'dementia.' This did not yield any specific results at the time of searching. The author focussed instead on some of the available articles around post diagnostic support and dementia, which will be described. At the time of searching, there appeared to be little focus on the contribution of the AHPs in this area.

In one study on the service-related needs of older people with dementia and their unpaid carers (Gorska et al, 2013), the participants highlighted a need for well-coordinated post diagnostic support. 'The need for increased access to nonpharmacological interventions was highlighted as an essential element of high-quality care for people experiencing dementia in order to support identity and social engagement This included access to services such as occupational therapy, physiotherapy, and speech and language therapy.'

A further study explored the experiences of people with dementia and their families around dementia diagnosis and post diagnostic support (Innes et al, 2014). Within the study, participants discussed three types of clinicians providing dementia care and post diagnostic support after a diagnosis: general practitioners, psychiatrists and community psychiatric nurses (CPNs). Other sources of post diagnostic support were from family, friends, and neighbours with no mention of the AHPs in this area.

Informing this work was also the work by Pentland, 2015, "Dementia: A scoping review of AHP interventions for people living with dementia, their families, partners and carers." This highlighted the positive impacts for people living with dementia when interventions are tailored, individualised and delivered by AHPs and is available at www.alzscot.org/ahp.

3.4 AHP Professional Bodies supporting materials

An exploration of the websites of the five professional bodies (relevant to this project) was undertaken to help establish what information they highlighted around post diagnostic support in dementia. A search of the sites did not result in finding any specific information on post diagnostic support. However, most sites contained factsheets, leaflets or papers on dementia (with the exception of Podiatry at that time). Although the Professional Bodies did not specifically refer to 'post diagnostic support', they highlighted the importance of early intervention. Rehabilitation was a focus, as was training and education. Attention was also drawn to the emerging evidence on what the professional groups could offer.

A leaflet was produced on AHPs: Allied Health Professionals – Who are they and how can they help you? (Alzheimer Scotland, 2015). This leaflet was produced by the AHPs in partnership with the professional bodies and endorsed by the National Dementia Carers Action Network and the Scottish Dementia Working Group. The leaflet advocates making early contact with an AHP if you are worried about your memory or if you or someone in your family has recently been diagnosed with dementia. In addition to providing information on the AHPs, the leaflet also provides details of where to find more information. The leaflet is available at: www.alzscot.org/ahpresources. It can be concluded that, across Scotland, people with dementia and their carers are not receiving equitable AHP input within their year of post diagnostic support. AHP skills are not being utilised to their full potential to enable and support people to live well with dementia in their own homes or homely environments.

Based on the evidence gathered and the scoping work, five key areas for action have been identified. There is a requirement for:

- **Key action 1:** Clarity and consistency around the AHP role in the post diagnostic period
- **Key action 2:** Clear processes and pathways for timely access to the AHPs in the post diagnostic period
- **Key action 3**: Development of AHP knowledge and understanding of post diagnostic support in dementia
- **Key action 4:** Development of the evidence base for AHP led interventions during the post diagnostic period
- **Key action 5:** Development of partnership working and consultation between AHPs and Dementia Link Workers.



Key action 1: Clarity and consistency around the AHP role in the post diagnostic period

The AHPs should begin to identify their role in post diagnostic support and their unique contribution to supporting national strategy and the 5 Pillars model of Post diagnostic support (Alzheimer Scotland, 2011). Promotion of AHP roles in post diagnostic support should be integrated across Scotland and driven forward by the AHPs themselves. Increased promotion and consistency will in turn lead to an improved understanding on the role of the AHPs in post diagnostic support for the Dementia Link Workers; people living with dementia and their carers; and Primary Care Practice Teams.

National AHP Dementia Working Groups could help ensure consistency and take forward the development and sharing of information. There is already a Speech and Language Therapy Dementia E-Network in existence. An Occupational Therapy Dementia Working Group is also currently being developed.

As highlighted in the evidence section, there are already some leaflets and fact sheets around some of the AHPs and dementia. However, it would appear that there is a lack of information shared by the AHPs relating to self-management, which would be beneficial in the post diagnostic period. Production and sharing of self-management information would enable people with dementia to build their resilience and live well with the condition.

The new Alzheimer Scotland leaflet (written by the Professional Bodies) 'AHPs: Who are they and how can they help you?' recommends making early contact with an AHP if you are worried about your memory or if someone in your family has recently been diagnosed with dementia. That way you can get the information, advice and treatment that is right for you and your family as quickly as possible. This leaflet describes how AHPs can help and how to get in touch with them. This leaflet can be accessed at www.alzscot.org/ahpresources. The availability of further information will help to raise awareness of the AHP role.

Joint working, information in induction and shadowing was highlighted by the Dementia Link Workers as the potentially the best ways to help them know more about what the AHPs can offer people with dementia. The AHPs can build on previous work and learning from the conversations with people with dementia and their carers (highlighted within the evidence section).

Key action 2: Clear processes and pathways for timely access to the AHPs in the post diagnostic period

It should be as straightforward as possible for the Dementia Link Workers to access the AHPs whether this be for information, advice or referral.

The Dementia Link Workers could be provided with a list of AHPs in their Health Board/ Local Authority area and contact details. Clearer referral pathways to the AHPs could be defined and shared (with DLWs, Primary Care Practice Teams and between the AHP Groups). Improved communication between the Dementia Link Workers and the AHPs could help make Services more seamless for people with dementia and their carers.

Improved awareness and information on what can be offered by the AHPs would support Key Action 1. This could be targeted at potential referrers in order to promote a timely referral. It is acknowledged by the AHP Project Team that currently the Dementia Link Workers do not always receive referrals for people only in the early stages of dementia which in turn can have an impact on onward referrals.

Direct referrals to the AHPs has been touched upon within the AHP Survey and this is an area for further exploration by the Allied Health Professions.

Key action 3: Development of AHP knowledge and understanding of post diagnostic support in dementia

There is variation in the forms and levels of training in dementia undertaken by the AHPs. This is an area of ongoing development with acknowledgement of a need for a 'dementia ready' workforce in Scotland. One way of achieving this is to link with the Higher Education Institutes around the dementia content of AHP undergraduate programmes. This is a piece of work which is currently being addressed by the Alzheimer Scotland AHP Dementia Consultant. Work is also ongoing around Promoting Excellence and the AHP workforce.

The AHP Groups should increase their awareness of the role of the Dementia Link Workers, where they are located and how they can be accessed. One method of doing so is gathering this information from Alzheimer Scotland and distributing in Health Board/Local Authority areas via the AHP Forum Board Leads. This information could also be gathered and shared from the people providing Dementia Link Worker roles outwith Alzheimer Scotland. Joint working and awareness raising sessions could also have an impact in this area. **Key action 4: Development of the evidence base for allied health professional led**

interventions during the post diagnostic period

It is necessary for the AHPs to build on the evidence base for their interventions in post diagnostic support. This would be strengthened if coordinated on a national basis e.g. selecting a number of AHP interventions which already have some established evidence to build upon. This could potentially be piloted in selected board areas and evaluated nationally. It was evident that the AHPs felt they could be offering more in the area of post diagnostic support, which this would support.

Following the sharing of the draft scoping work, consultation took place around the "best" AHP interventions in the post diagnostic period with the AHP Project Leads and the National AHP Dementia Expert Group. For the profession of Occupational Therapy, the Home Based Memory Rehabilitation Programme was identified (McGrath and Passmore, 2009). There is already emerging evidence around this intervention, which was piloted and implemented in NHS Dumfries and Galloway. The recommendation is that this could be rolled out nationally in a planned and coordinated way in order to ensure consistency and further build on the evidence base.

The other AHP Professional Groups were asked to similarly consider "best interventions" via the National AHP Dementia Expert Group. This could then be taken forward on a national basis via working groups (as available) and in partnership with the professional bodies.

Key action 5: Development of partnership working and consultation between AHPs and Dementia Link Workers.

Further promotion and consideration is required to deliver this Key Action. Pieces of work have already happened or are happening in some areas however there is a requirement for this to be built upon and further evaluated.

Developments in consultation opportunities with the AHPs for the Dementia Link Workers and also people living with dementia and their carers could be considered. Consultancy and capacity building is crucial for the AHPs in moving forward in dementia care.



This Phase One Project has helped inform Scotland's AHP priorities within post diagnostic support in dementia. Improvement work will be carried out around Key Actions 1 and 2. This will be phase two of the contribution of the AHPs to Post diagnostic support in Dementia Project. The additional recommendations highlighted are being led on by the Alzheimer Scotland AHP Dementia Consultant. A driver diagram was created in order to represent the next steps (Appendix III).

Continued consideration will be given to the increasing numbers of people with early onset dementia and the role of the AHPs. Links will also be developed on the area of vocational rehabilitation and job retention with links to the national AHP vocational rehabilitation leads.



Acknowledgements

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- People living with dementia, their families and carers
- Elaine Hunter, National Allied Health Professions Consultant, Alzheimer Scotland
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- Lindsay Kinnaird, Research Manager, Alzheimer Scotland
- Alzheimer Scotland Dementia Link Workers
- AHPs across Scotland
- Allied Health Professional Project Leads

Keep in touch

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Twitter	<pre>@AHPDementia #AHPConnectingPeople</pre>

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Appendix I: Allied Health Professional Project Leads

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Lesley Bodin NHS Lanarkshire

Jenny Reid NHS Lothian

Jennifer Moisey NHS Tayside

Appendix II: Alzheimer Scotland Dementia Link Worker Scoping Exercise

Background: Alzheimer Scotland Dementia Link Worker Scoping Exercise

As highlighted in the introduction there is a National HEAT target "To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Dementia Link Worker, including the building of a person-centred support plan" (Scottish Government, 2013).

Alzheimer Scotland identify a Dementia Link Worker as a named person who has the flexibility to work alongside the person, their partner and family and ensure that over a 12 month period each person is given help and support to work through the five pillars (Alzheimer Scotland 2011).

It is acknowledged by the AHP Project Team that there is variation across the Health Board/Local Authority areas around who carries out the Dementia Link Worker role. It is also recognised that not all Dementia Link Workers are employed by Alzheimer Scotland and that local arrangements are in place for the delivery of post diagnostic support. For the purpose of this project, it was agreed to focus on the Alzheimer Scotland Dementia Link Workers only. This was due to the limited timescale of the project and the enhanced opportunities for access and engagement with the Alzheimer Scotland Dementia Link Workers.

A period of consultation took place with key stakeholders including the AHP Dementia Consultants, Joint Improvement Team AHP, Care Home AHP Consultant and Alzheimer Scotland colleagues. Following this, the Dementia Link Worker questionnaire was designed with support from an Alzheimer Scotland research officer and was piloted with a sample group of Alzheimer Scotland Dementia Link Workers in Dumfries and Galloway. The questionnaire was then finalised and produced on Survey Monkey.

The Dementia Link Worker Survey was designed to scope the Dementia Link Workers understanding of, and access to, the AHPs working in post diagnostic support. The survey was distributed to the 66 Alzheimer Scotland Dementia Link Workers across Scotland along with a covering letter. This yielded a high response rate of 74%, meaning a total of 49 surveys were completed. Responses were received from 11 different NHS Board/Local Authority areas.

Following analysis of the survey results, stratified random sampling was completed. The Dementia Link Workers who were agreeable to participate in further information gathering were divided into groups according to Health Board/Local Authority area. Random samples were then taken from each group and nine Dementia Link Workers participated in semi-structured telephone interviews around key themes.

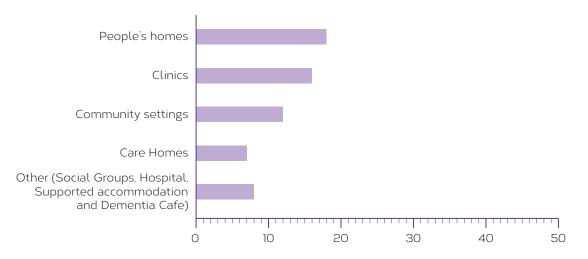
The following results are based on the information gathered in the surveys with the additional telephone interview information incorporated throughout.

Results: Alzheimer Scotland Dementia Link Worker Scoping Exercise

Work Background (N = 44) Voluntary sector Social care Nursing AHP, Occupational Therapy Other (includes Psychology, Legal Executive, Link Worker) гη 0 10 20 30 40 50 Location (N = 44)Community Mental Health Teams Alzheimer Scotland Service Local Authority Other (includes Princes Royal Trust for Carers, Day Hospital, Multidisciplinary team) 0 10 20 30 40 50

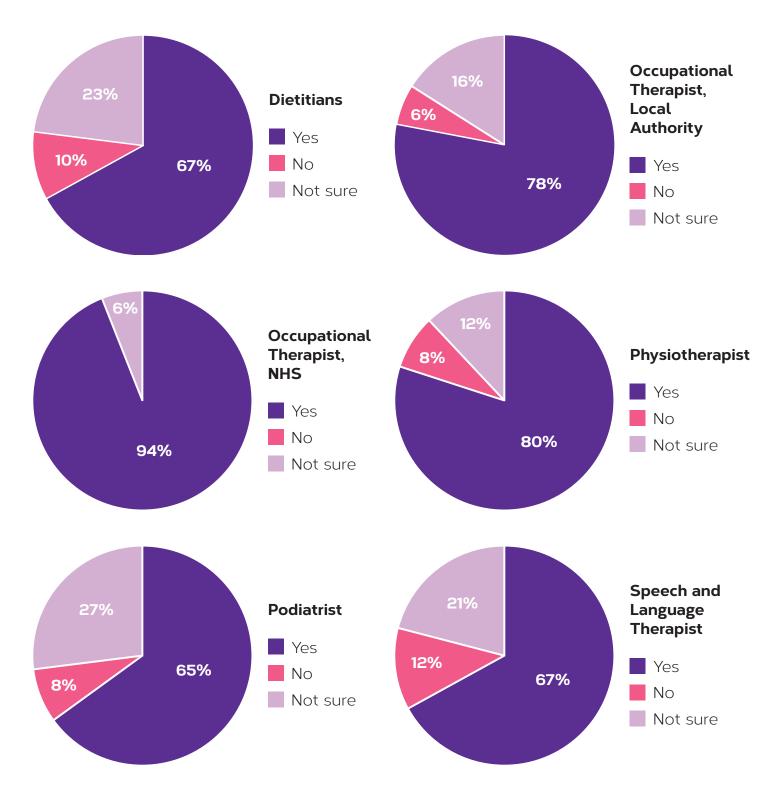
The Dementia Link Workers work in a range of environments. During telephone interviews, the Dementia Link Workers who were part of the CMHTs viewed this as being very positive for joint working and sharing of information.

Where do you carry out your post diagnostic support? (N = 49)



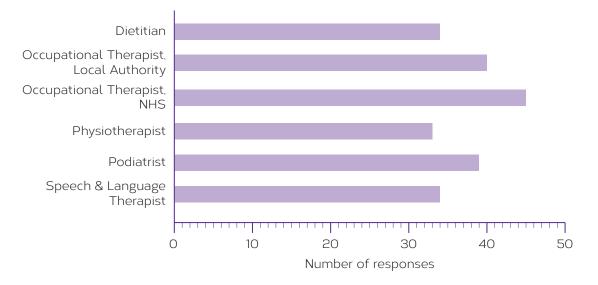
During the Telephone Interviews, 8 out of the 9 repondents reported that less than 50% of their caseload were people in the early stages of dementia journey. Two respondents estimated this to be around 30% and all identified this as an issue when trying to deliver the 5 Pillars model of Post Diagnostic Support. However, the general feeling was that things are slowly starting to change, and more referrals are coming through for people in the early stages of dementia.

Do you know what the primary role is of the following AHPs working in Post diagnostic support? (N = 49)



The majority of respondents stated that they did know what the primary role is of the AHPs working in Post diagnostic support. Around 33% of Dementia Link Workers answered 'No' or 'Not Sure' for Dietitian, Podiatrist and Speech and Language Therapist. Around 25% answered 'No' or 'Not Sure' for Occupational Therapist (Local Authority) and Physiotherapist. Only 6% of Dementia Link Workers were 'Not Sure' for Occupational Therapist (NHS), the rest answered 'Yes'.

If you answered Yes, please can you briefly explain your understanding?



Most of the respondents appeared to have a fairly good understanding of the role of the AHPs but focussed on this more generally rather than specifically within the Post diagnostic support period. It also should be noted that although a high number of Dementia Link Workers felt they understood the role of the Occupational Therapist (NHS) in particular, several people gave explanations around equipment and adaptations only. Several people perceived that the role of the Occupational Therapist (NHS) was similar to that of the Occupational Therapist (Local Authority).

The Dementia Link Workers highlighted a need for a better understanding of the different Allied Health Profession Services and what can be offered.

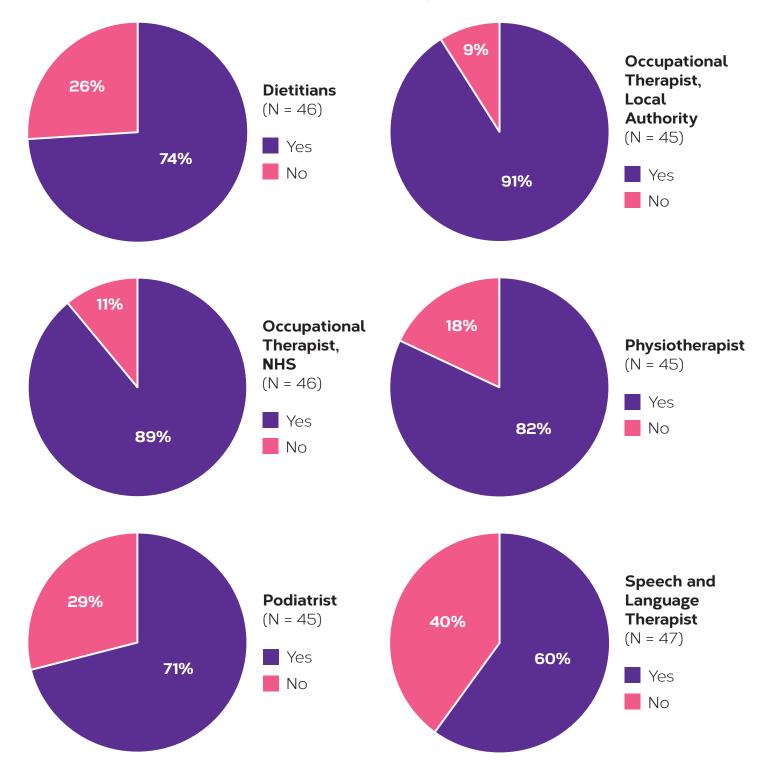
"It would be good to know if Allied Health Professions work to the same Post diagnostic support framework as Dementia Link Workers such as the 5 Pillars and a minimum of a years support provided. Although we know about the Allied Health Profession roles we haven't been told much on their roles in delivering Post diagnostic support." Dementia Link Worker

If you have an understanding of the role of any of the AHPs working in Post diagnostic support, please could you briefly explain how you obtained this information?

Respondents identified that their understanding came from literature such as leaflets and factsheets or the internet. It was also reported that co-location or being part of the same team provided an understanding of the roles of the AHPs. Previous experience of working with the AHPs, as well as communication with them was identified. The Dementia Link Workers have also been provided with information from Community Mental Health Team members, GPs or other AHPs.

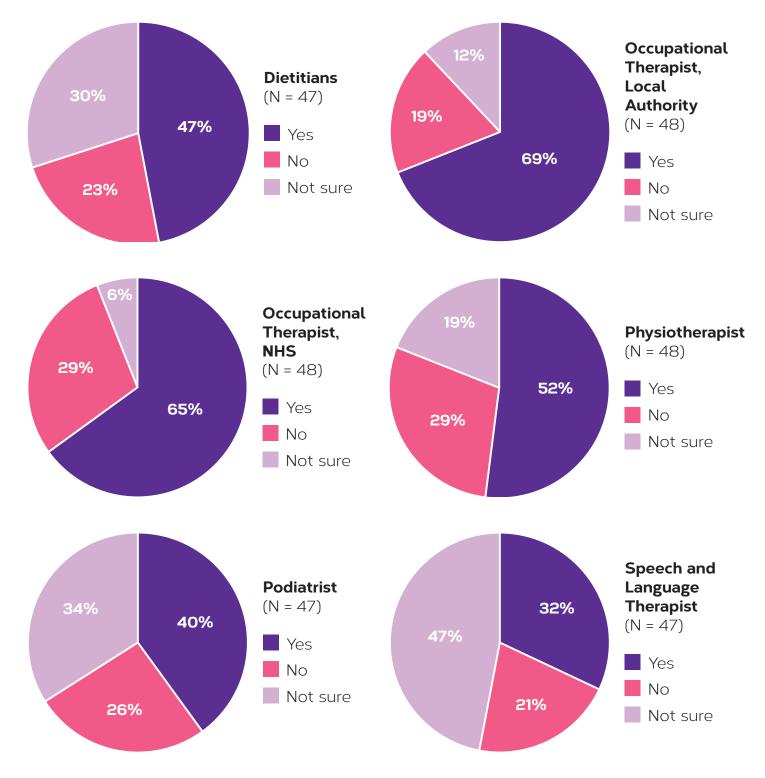
During the telephone interviews, the Dementia Link Workers were asked for their opinion on whether they felt that people with dementia and their carers have an understanding of the role of the AHPs in post diagnostic support. The general feeling was that people didn't have an understanding unless they had received AHP input in the past. It seemed to be a fairly rare occurrence for people with dementia and their carers to highlight the need for AHP input. When this had happened on a few occasions, it tended to be around Physiotherapy or equipment from Occupational Therapy.

Do you know how to refer a person to the following AHPs?



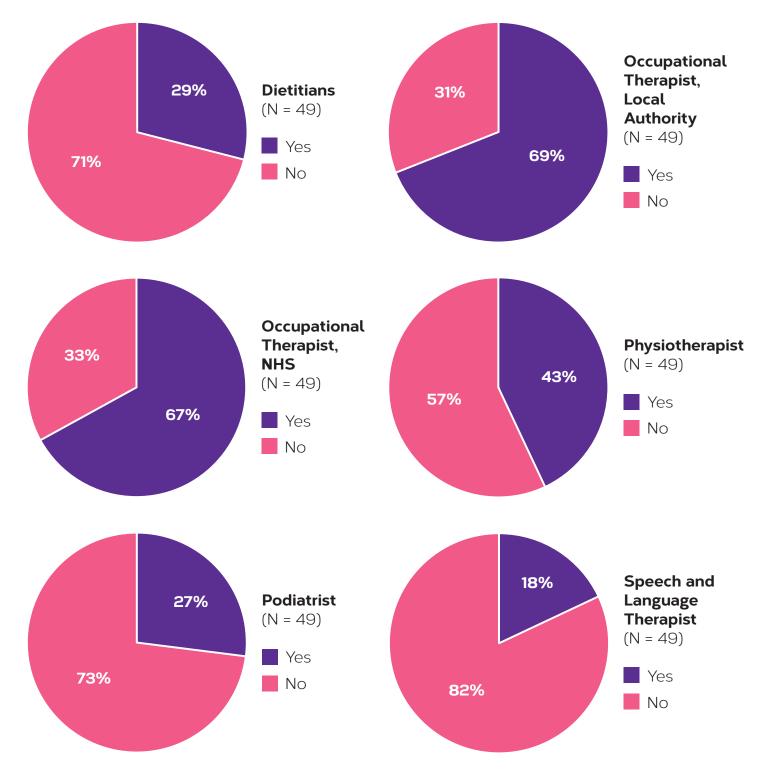
It would appear that the Dementia Link Workers are clearest over how to refer to an Occupational Therapist (Local Authority and NHS). They appear to be least clear on how to refer to a Speech and Language Therapist. It was commented that details of how to refer to the various AHPS can be vague.

Are you able to make a direct referral to an Allied Health Professional?



It would appear that a significant proportion of Dementia Link Workers cannot refer directly to the Allied Health Professions or Don't Know whether they can do this. When the Dementia Link Workers are able to refer directly to the Allied Health Professions, they view this very positively. Those who are unable to refer directly to the Allied Health Professions highlighted that they felt it would be very beneficial to be able to do so. It was commented that it can be very time consuming referring via GP and following up whether this has happened.

Have you ever made a referral to an Allied Health Professional?



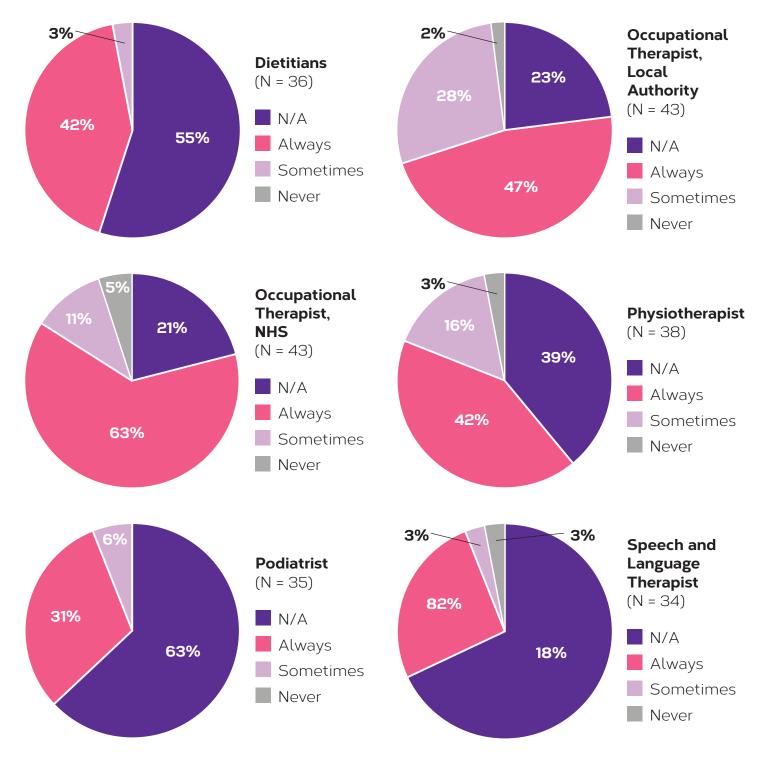
It would appear that the Dementia Link Workers mainly have experience of referring to Occupational Therapy, (Local Authority and NHS). They appear to have least experience of referring to Speech and Language Therapy.

Have you ever encountered any issues when trying to refer to an Allied Health Professional?



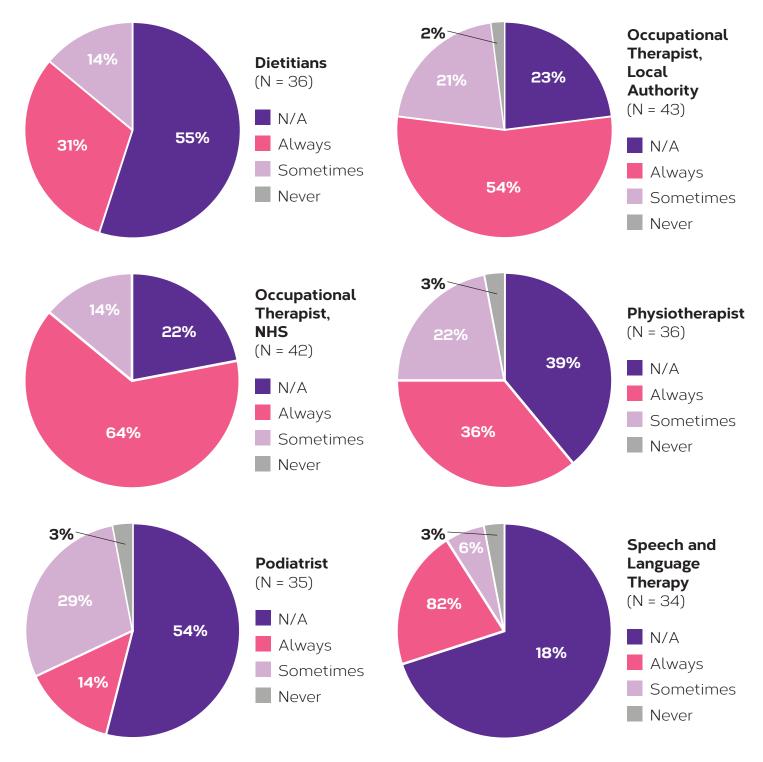
Some Dementia Link Workers reported a lack of clarity around the referral process and also confusion as to which Service they should be referring to. Another difficulty reported was a lack of clarity around referral criteria. Several Dementia Link Workers also commented that they could not make a referral unless the person was open to the Community Mental Health Team.

If you have referred to an AHP, were you satisfied with the referral process?



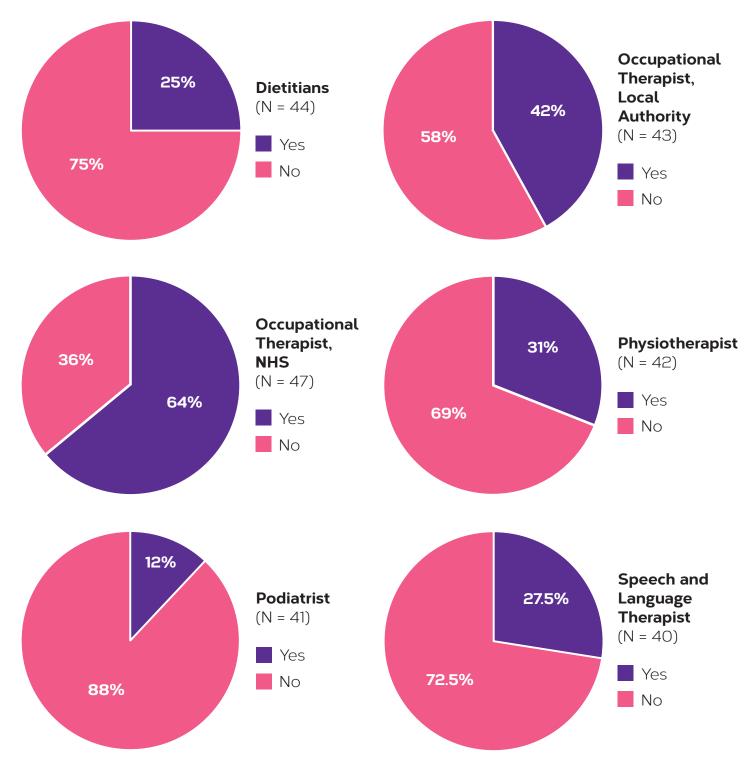
Dementia Link Workers reported that communication is improved and it is much easier to refer when the Allied Health Professions are around to speak to. In one area, the Dementia Link Workers have been provided with a new referral form which covers any of the AHPs and this was viewed as very useful. Waiting lists were identified as an area of dissatisfaction, as were some of the processes.

If you have referred to an AHP, are you aware if the person/people referred were seen?



Several of the Dementia Link Workers reported that they would generally hear from the person receiving the post diagnostic support first. It was commented by one Dementia Link Worker that there can be "hierarchical issues" and that some Dementia Link Workers do not get copied into reports.

Have you ever contacted an Allied Health Professional for advice about a person you are working with (not resulting in a referral)?



Several of the Dementia Link Workers have contacted an Allied Health Professional for advice and on the whole, they were very satisfied with the outcome. Comments reflected that the high quality of the information received meant that a referral did not have to be made.

"[an] excellent outcome. I contacted Speech and Language Therapy as they had been involved with a man with mild Learning Disabilities, aphasia and dementia who I provide Post diagnostic support for. The Speech and Language Therapist sent me communication guidelines which I have incorporated into his person centred plan and with his consent it has been sent to his GP, Dentist, Optician and Social Worker with information on how to communicate with him." Dementia Link Worker Have you carried out any partnership working (e.g. joint visits, groups, development sessions) with any of the AHPs?



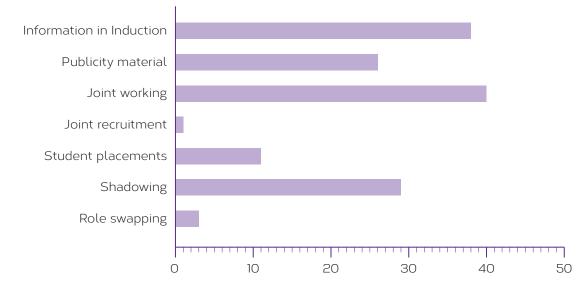
The main Allied Health Professional Group the Dementia Link Workers have carried out partnership working with has been the Occupational Therapists (NHS). There has been limited partnership working with the rest of the Allied Health Professional groups. However the benefits of partnership working are clear:

"The joint working I have undertaken in this post to date has been some of the most rewarding and has ensured better outcomes for the person with dementia. Encouraging a genuinely biopsychosocial approach to post diagnostic work (rather than a medical model), across the board, may take longer depending on how joint working is viewed within a team." Dementia Link Worker Examples of partnership working include joint visits and liaison around interventions. Dementia Cafes, Post Diagnostic and other Groups were also highlighted. People had been involved in piloting Groups in partnership and were hopeful that this could occur again in future.

It was acknowledged that people with dementia and their carers can become overwhelmed with too many professionals involved at the same time. Joint working and strong communication were highlighted as the way to provide people with dementia and their carers with a better Service. This was reported as something people with dementia and their carers ask for. It was commented that people need to receive the right Services at the right time.

There was a strong enthusiasm for continued and increased partnership working between the Dementia Link Workers and the AHPs. The Dementia Link Workers also provided additional examples of partnership working including linking in with local communities and volunteers.

What do you think would be the best way for you to know more about what the AHPs can offer to people with dementia? (N = 48)



Other suggestions were that the AHPs need to be more aware of the Post diagnostic support role, "they need both the freedom and encouragement to engage." (Dementia Link Worker). It was also suggested that something as simple as swapping email contacts would be enough to get communication started.

Additional Information:

During the Telephone Interviews, the Dementia Link Workers were asked for their opinions on what they thought people with dementia and their carers would like from the AHPs. The following themes emerged:

- Improved communication between different services
- Improved information on what could be offered by each service, which would help people identify what they need
- Clarity on how to access services
- Greater availability of AHPs
- Better joint working

These themes were also reflected within the 'Any Other Comments' section of the survey.

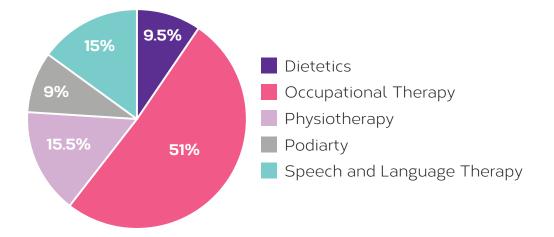
Background: AHPs Scoping Exercise

For the project, it was agreed to focus on the five main AHP groups who work in the area of post diagnostic support in dementia. Based on information from the AHP National Dementia Expert Group, these were identified as: Dietitians, Occupational Therapists, Physiotherapists, Podiatrists and Speech and Language Therapists. It is acknowledged by the AHP Project Team that other AHP Groups provide interventions in post diagnostic support however currently this is less readily available.

A period of consultation took place with key stakeholders including the AHP Dementia Consultants, the AHP Project Leads and Alzheimer Scotland colleagues. Following this, the AHP questionnaire was designed and piloted with a sample group of 10 AHPs. The questionnaire was then finalised and produced on Survey Monkey. The Allied Health Professional (AHP) Survey was designed to scope what the AHPs are currently contributing in relation to post diagnostic support in dementia. The survey was distributed via the identified AHP Project Leads in the following 11 Health Board/Local Authority areas involved in the Project: NHS Ayrshire and Arran, NHS Borders, NHS Dumfries and Galloway, NHS Fife, NHS Forth Valley, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Highland, NHS Lanarkshire, NHS Lothian and NHS Tayside.

The AHP Project Leads were asked to target those who are providing AHP led interventions in post diagnostic support to people with dementia. The survey was mainly forwarded via professional leads and distribution lists. It is acknowledged by the AHP Project Team that potentially the survey will not have reached everyone but for the purpose of the project, this was deemed to be the most effective method.

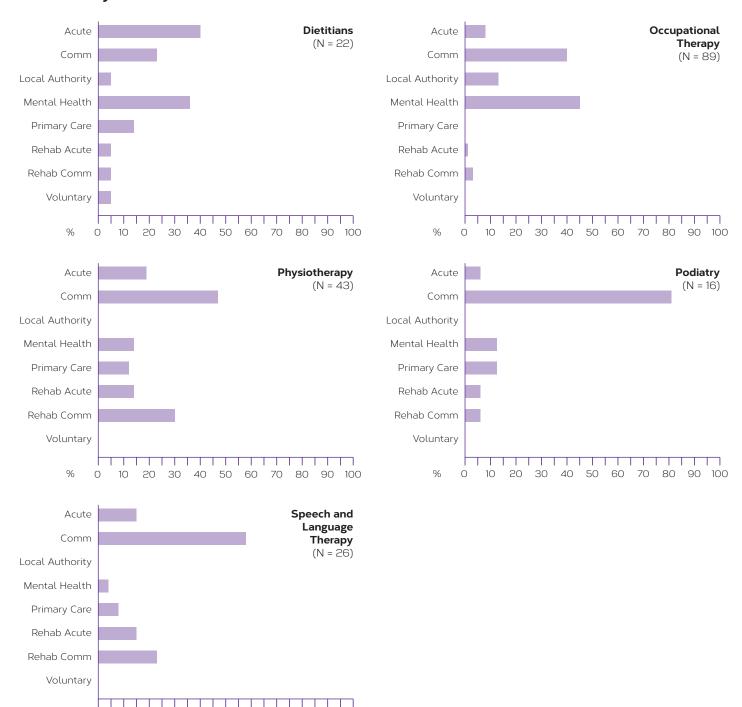
Responses were received from across all 11 of the Health Board/Local Authority areas with an AHP Project Lead. Data has been analysed on a total of 146 respondents who identified that they had a role in post diagnostic support in dementia. This can be broken down into Professional Groups as follows:



Throughout this report, when comparing data (which is in percentages) according to profession, it should be considered that for example, Occupational Therapy had a high number of responses compared to Dietetics and Podiatry. This is what was expected due to what is already known about the Allied Health Professional workforce in dementia within Scotland.

Following analysis of the survey results, stratified random sampling (based on Profession and NHS Board/Local Authority areas) was completed and 7 AHPs participated in semistructured telephone interviews along key themes similar to that of the Dementia Link Worker interviews.

Results: AHPs Scoping



Where are you based?

% 0 10 20 30

40

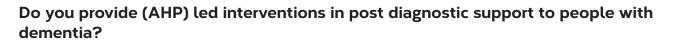
50 60

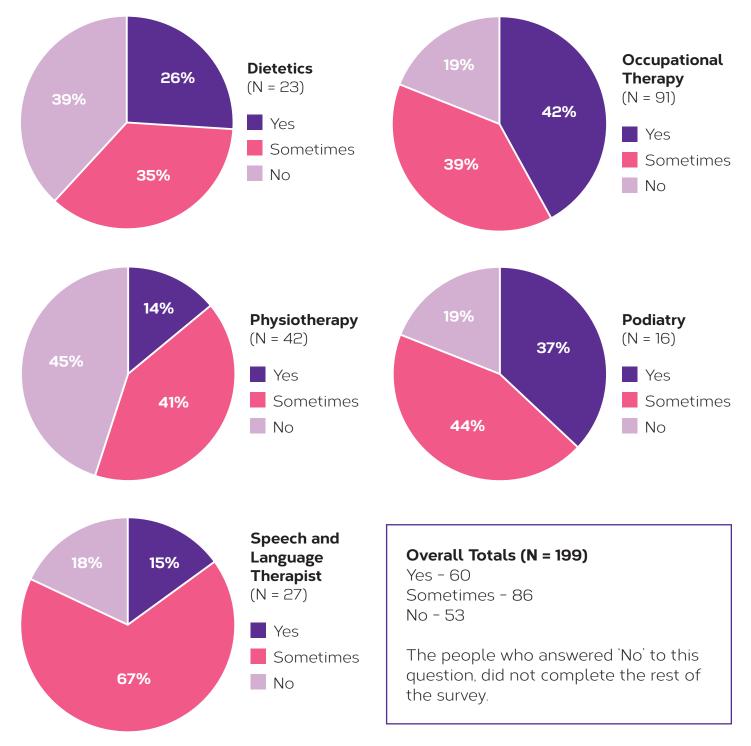
70 80 90

100

The AHPs who completed the surveys work across a variety of settings (some covering several different areas) with the most common being community, mental health and acute.

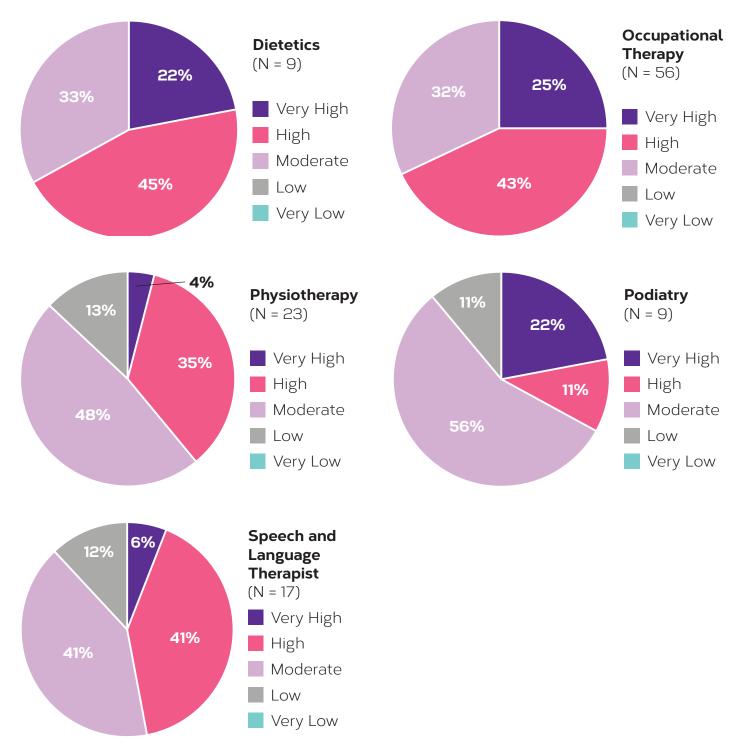
NB: This information around settings also captures the AHPs who do not provide AHP led interventions in post diagnostic support to people with dementia. It had been anticipated that the Surveys may reach some of these people, therefore a specific question was included around this to filter out the people who do not work in this area:





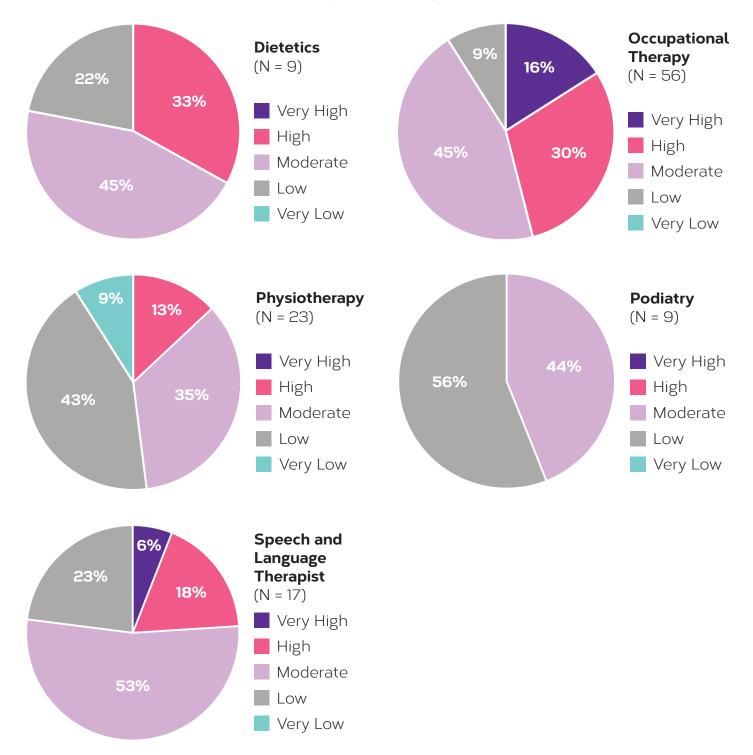
*It should be noted that although 74 Occupational Therapists identified a role in post diagnostic support in dementia, usually around 55 of those responded to the rest of the survey.

How would you rate your understanding of dementia?



Overall the five AHP Groups were fairly confident in their understanding of dementia, mainly rating their knowledge as moderate and high (every profession also had at least one person rating their understanding as very high). However, it is interesting to note that some respondents rated their understanding of dementia as 'Low'.

How would you rate your understanding of Post diagnostic support in Dementia?

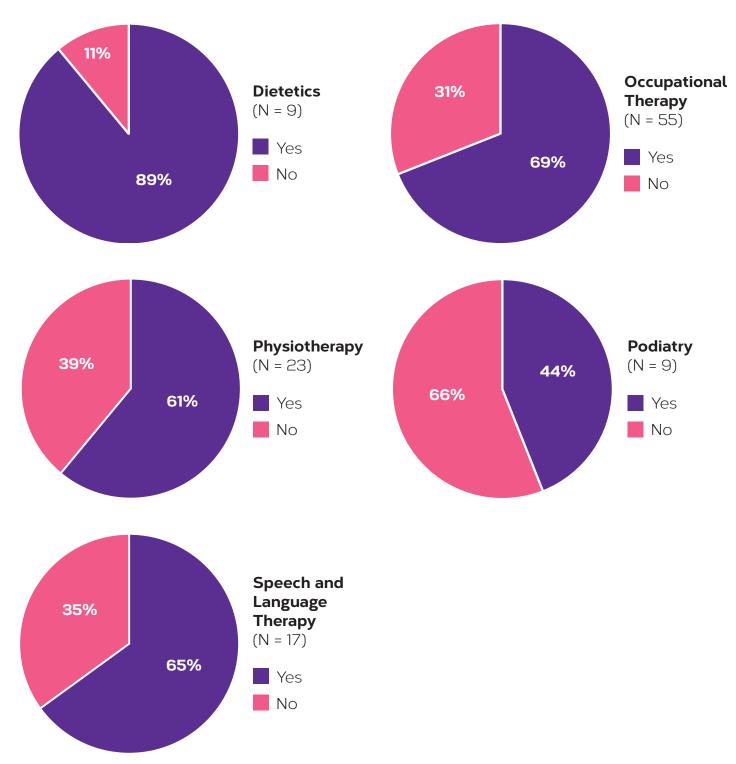


For this question most of the responses are rated as low and moderate (with the exception of Occupational Therapy and Speech and Language Therapy, who are also the only two groups with at least one person rating their understanding as very high).

"I thought that post diagnostic support was just provided by Dementia Link Workers, however am now aware we all do post diagnostic support in a form through referrals from them." Physiotherapist

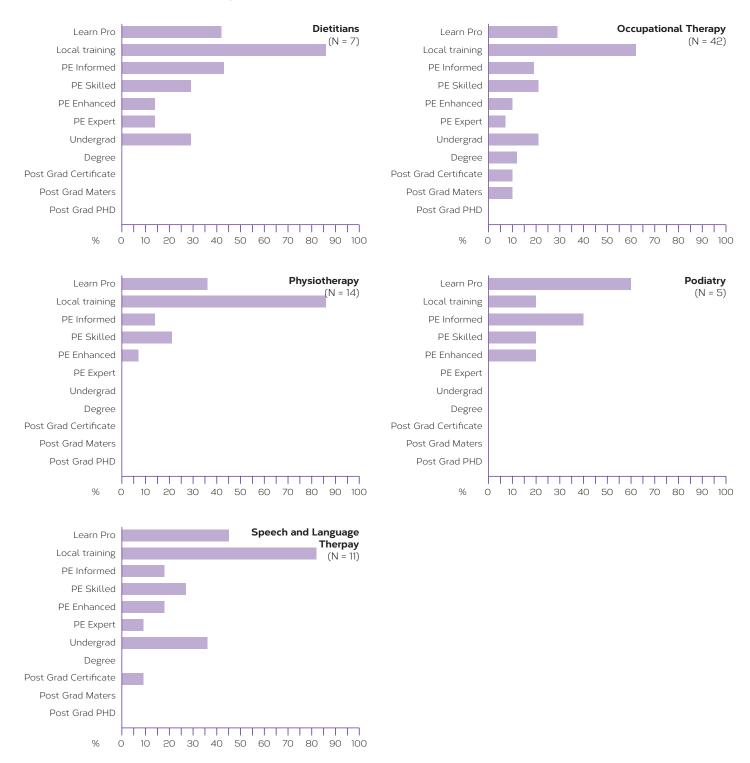
"I understand there is a move to improve post diagnostic support. I'm not sure I'm aware of all that is available or how best to direct patients and carers to this support." Dietitian Some of the AHPs highlighted that they had a good working knowledge of the 5 pillars model. A small number of AHPs mentioned the Post Diagnostic HEAT target and were interested to know how the AHP contribution is captured. It was recognised that dependent on need, AHPs or other professionals could be the main post diagnostic worker and recording systems should support this.

Several people commented that they had attended the AHP post diagnostic event in Edinburgh (Connecting People, Connecting Support) in 2014. Their understanding of post diagnostic support in dementia was also related to having a special interest in this area or in relation to the AHP Dementia Expert Group.



Have you undertaken any specific training in dementia?

Please tell us what training you have undertaken in relation to dementia?

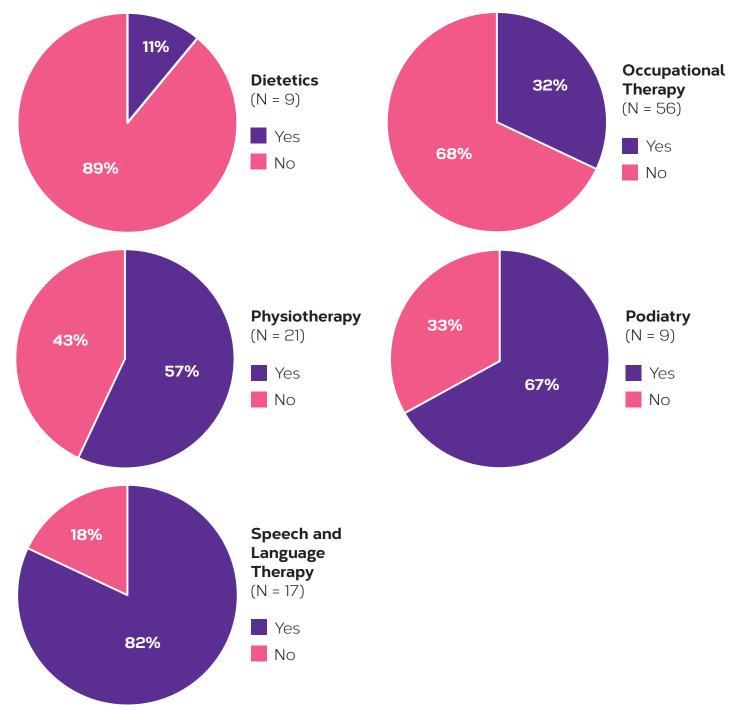


Others

Additional training included Dementia Champions (local and national), SIGNE Study Day, AHP Dementia Masterclass and Dementia Design Course.

The most common forms of dementia training undertaken were learn-pro modules, local training and promoting excellence.

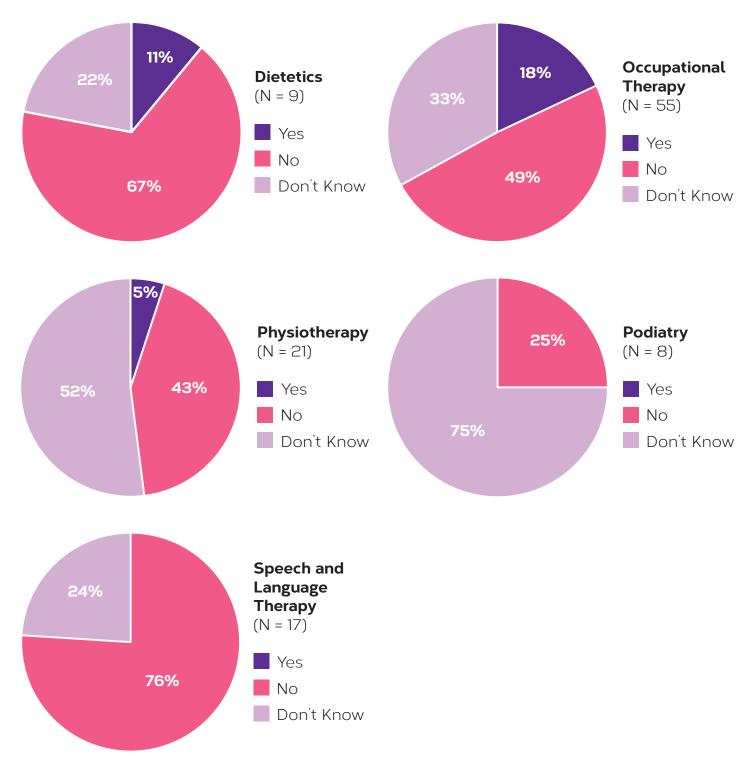
Undergraduate training was undertaken by some of the Dietetics, Occupational Therapy and Speech and Language Therapy respondents but not within Physiotherapy or Podiatry. Occupational Therapy is the only group with respondents who have carried out degree level training and post graduate training (except for one SALT who has carried out a post graduate certificate). When people have undertaken training, difficulties were identified with implementation and development of learning. Reasons highlighted included high clinical demands on time, little admin time and staffing issues.



Are you able to accept direct referrals from the person with dementia or carer?

There are variations around whether the AHPs can accept direct referrals. In some services, people can self-refer if they have received input in the past, if they are already known to the Community Mental Health Team or occasionally for specific groups. Many services require referrals via the GP. This was highlighted as an issue because people have to spend time following up with the GP to ensure this has happened.

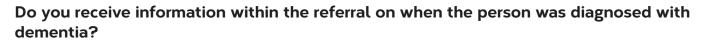
In your opinion, do potential referrers have enough information about what (AHP Group) can offer in Post diagnostic support in Dementia?

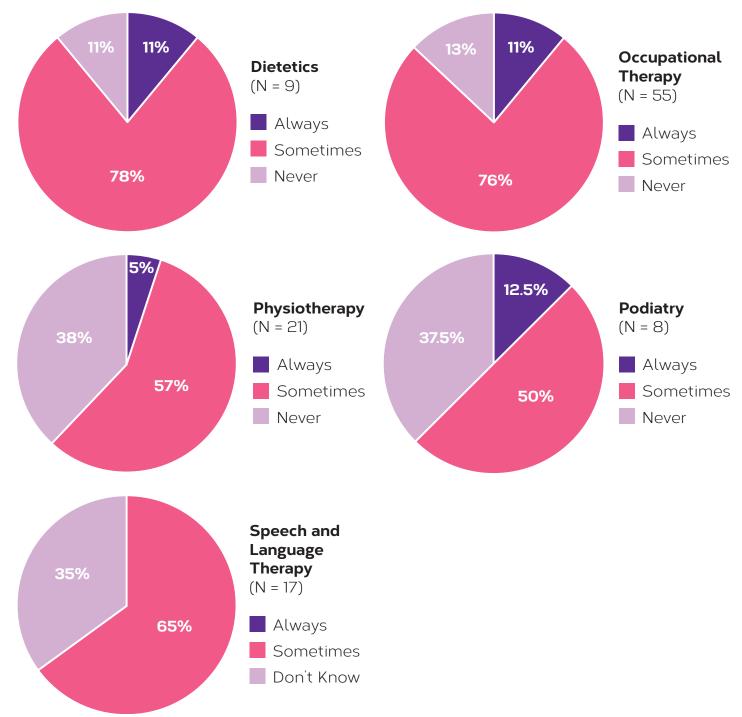


Unanimously, the AHP groups mainly answered 'Don't Know' and 'No' to this question.

"I believe that Occupational Therapy is still an unknown profession, especially in dementia care and management. I currently work with service users who see me as the "equipment provider" which in some essence is Occupational Therapy but there is so much more to offer people with a diagnosis of dementia to live at home and receive the support they require." Occupational therapist

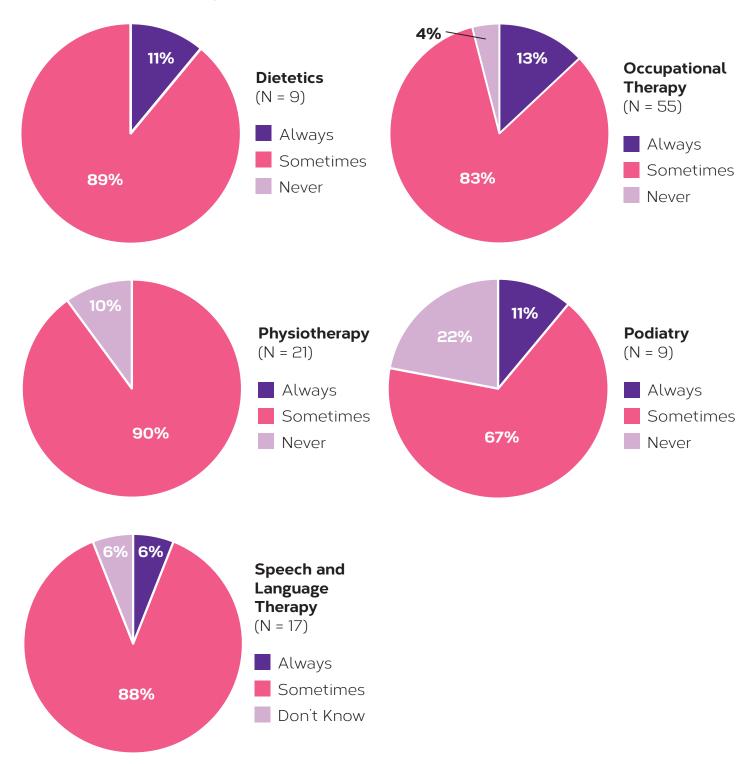
"We (OTs) need to be clearer ourselves about what we can offer. There is a lack of continuity, and subsequently huge variation in what service PWD can expect" Occupational therapist A small proportion of some of the AHP groups perceived that potential referrers do have enough information on what they can offer in post diagnostic support in dementia.





There were reported inconsistencies around receiving information on when the person was diagnosed with dementia or at what stage the person is at.

Are you are provided with adequate referral information to enable you to carry out AHP led interventions in post diagnostic support in dementia?

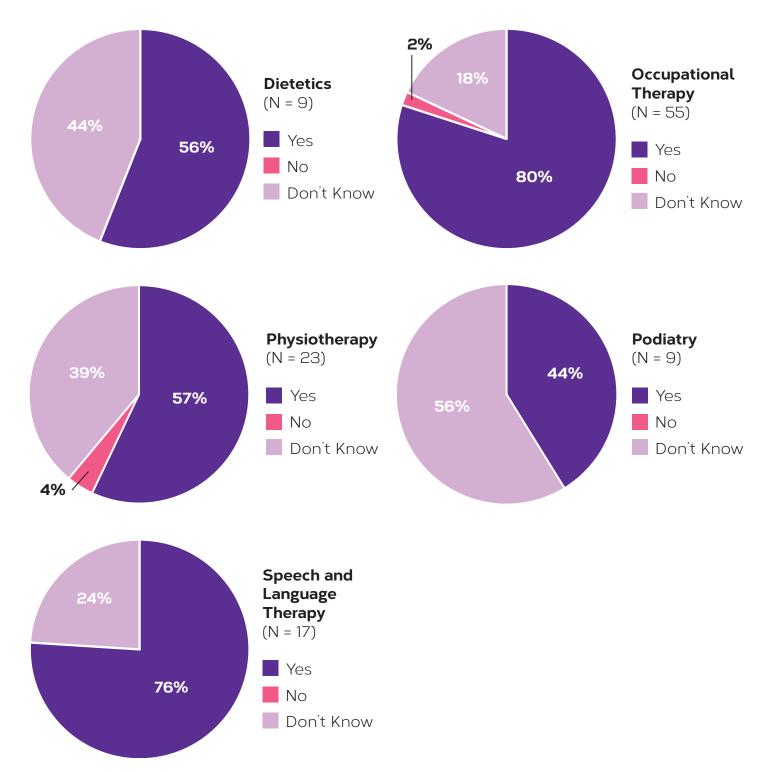


It was reported that there can often be inadequate referral information and often the quality of referral depends on who is referring. It was commented by a dietitan "I get my Sherlock Holmes gear on for every referral."

"Often the referral is not specific, asks for 'support' but is not clear what for, what the issues and impact are for the individual." Speech and language therapist

Much of the time, further information gathering by the AHP is required prior to assessment.

Are there Dementia Link Workers in your locality?



Of the AHP Groups, Occupational Therapy and Speech and Language Therapy had the most awareness of whether there are Dementia Link Workers within their locality (although 18% and 24% respectively, didn't know). Of the other three groups (Dietetics, Physiotherapy and Podiatry), around half of the respondents didn't know if there were Dementia Link Workers within their locality.

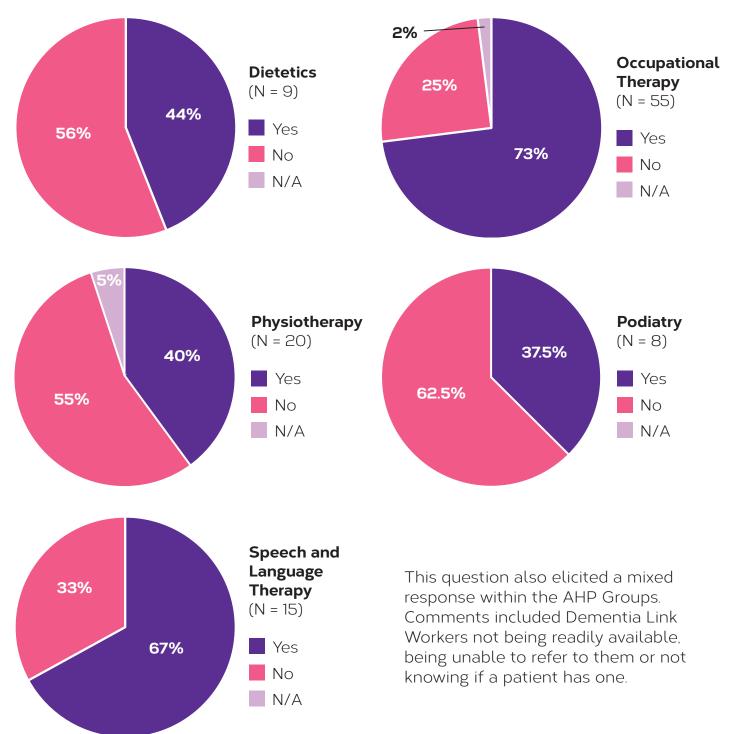
What is your understanding of the role of the Dementia Link Workers?

This question elicited variation of responses. Some respondents (mainly from the Occupational Therapy profession) were able to give comprehensive explanations mentioning the 5 Pillars and 12 months post diagnostic support.

"have full understanding of the role of the Dementia Link Worker, as they are integrated into our teams. There can be some role overlap at times, but through our communication we resolve this without difficulty." Occupational Therapist

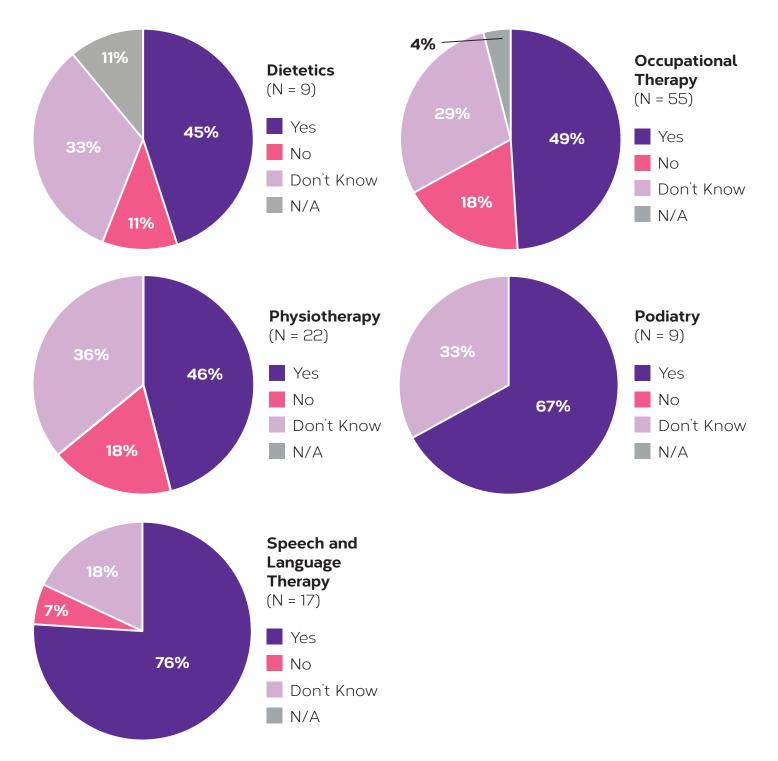
Other respondents acknowledged that they have a limited knowledge. There also was some confusion around the Dementia Link Worker role versus the dementia champions. A small number of respondents reported that they were unclear whether the Dementia Link Workers provided input to people with a diagnosis of Learning Disabilities and Dementia. Many of the AHPs recognised that increasing their knowledge around the Dementia Link Workers is something they need to develop:

"I realise I need to build bridges here but have been unable until recent changes in my workload to enable this to happen. Joint working and training envisaged." Dietitian



Do you know how to access the Dementia Link Workers?

Are you able to accept direct referrals from the Dementia Link Workers?

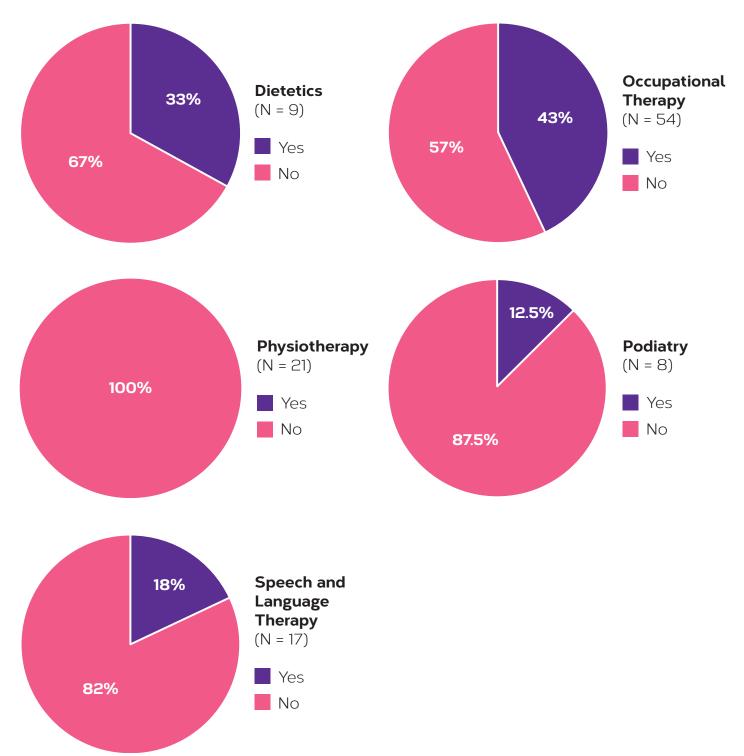


It would appear that many of the AHPs are unclear as to whether they can accept direct referrals from the Dementia Link Workers. Several of the AHPs commented that they would accept referrals if the person was already open to the CMHT. Several AHPs also said they would be willing to accept referrals from the Dementia Link Workers but this has never happened before. They were positive around the potential for this.

"Never had one but do not see why not, if it's appropriate for physiotherapy intervention." Physiotherapist

"We have self-referral forms and these could be filled out on behalf of someone with dementia. This is usually done by a family member or carer. I see no problems with a link work completing one of these forms." Podiatrist "No referrals yet but the Dementia Link Workers would be very well placed to refer to Speech and Language Therapy – I hope that some joint working or training may develop this in future." Speech and language therapist

Do you carry out any partnership working with the Dementia Link Workers (e.g. joint visits, groups, consultation)?



The main AHP group who carry out partnership working with the Dementia Link Workers are the Occupational Therapists followed by the Dietitians. This would appear to be a more limited occurrence between the other AHP Groups. When partnership working does occur, it is viewed in a very positive light:

"I recently did a joint visit with one (Dementia Link Worker) and it was so helpful – she knew the patient so well and it helped me with my treatment plan" Occupational Therapist

The main areas of partnership working between the Dementia Link Workers and the AHPs were joint visits and liaison around interventions. Information sharing and consultation were highlighted by a few respondents. Dementia Cafes*, Post Diagnostic and other groups were also highlighted. Some of the AHPs had attended training sessions held by the Dementia Link Workers or had been involved in joint workstreams, which they felt was beneficial.

*An example of Dementia Cafe was provided as "a multi- disciplinary drop in service. There can be representatives from all AHPs, Nursing, Consultant Psychiatrist, Telecare, Advocacy. People who drop in to the cafe can approach any member of staff for advice/signposting."

Several of the AHPs reported that although they hadn't carried out any partnership working with the Dementia Link Workers, this is something they would plan to do. The majority of the AHPs felt that this would be beneficial however some highlighted issues around capacity. AHPs again reported that often they don't know if a Dementia Link Worker is involved and thought it is likely to be vice versa. This can be due to use of different systems, no written information within the person's home etc. Joint visits and opportunities for consultation were perceived as beneficial:

"I think groups and consultation opportunities would be a great opportunity as I think the SLT role and the Dementia Link Worker role complement each other as quite often in visits I'm asked the kind of questions I think are suitable for a Dementia Link Worker because they come up in conversation and I have to go back to my team and try to find the answer whereas the Dementia Link Worker would be able to answer then and there." Speech and language therapist

"It's beneficial to maintain links to DLW to understand each other's roles/service to ensure the best service for the client" Occupational Therapist

There was also an enthusiasm around joint groups, and in particular the sharing of skills.

Some of the perceived benefits of partnership working include:

- People will repeat less information which avoids duplication
- Maintaining links ensures understanding of roles to ensure best service for the client
- Often the Dementia Link Worker will already have established a relationship and can assist with provision of information
- At times there are so many different people involved but if partnership working occurs, approaches can complement each other
- Things can be done quicker

Throughout the surveys and telephone Interviews, examples of additional partnership working were provided by the Dementia Link Workers and the AHPs, and felt to be beneficial. Examples included partnership working with Carers Services, Home Care Services, Voluntary Services, other AHPs and members of the multidisciplinary team.

What AHP led interventions in post diagnostic support do you currently provide in dementia?

The five AHP Groups provided many examples of the interventions they reported they are carrying out in Post diagnostic support. For the purpose of this report, only the main interventions from each profession have been included taking into account the number of responses.

Dietetics

Nutritional support Attendance at Dementia Cafe monthly where they were on hand to give general advice and support

Occupational Therapy

Memory techniques/skills/rehabilitation including Home Based Memory Rehabilitation, Memory Management Supported self-management approaches and advice Post diagnostic groups and memory skills groups Aids, Adaptations and Telecare

Physiotherapy

Promotion of Physical Activity OTAGO Home Exercise plans Mobility assessments and falls prevention

Podiatry

Health promotion advice to carers Frequent follow up appointments

Speech and Language Therapy

Information on what to expect and how dementia affects language and communication Enhancing the communication environment Maintenance of communication

There were many reported examples of AHP led interventions in Post diagnostic support, however what is available would seem to vary across different Health Board/Local Authority areas.

How do you provide your AHP led interventions in Post diagnostic support in dementia?

Technology

One to One

Groups

% 0 10

Technology

One to One

Groups

%

Technology

Groups

% 0 10 20 30 40

Signposting/Info One to One

Consultation/Advice

0 10 20 30 40

Signposting/Info

Consultation/Advice

20 30 40 50 60 70 80

> 50 60

50 60

80

(N = 17)

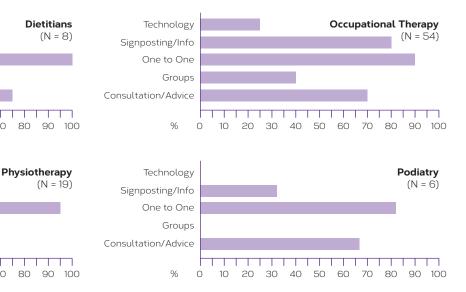
70

Speech and Language Therapy

70 80 90 100

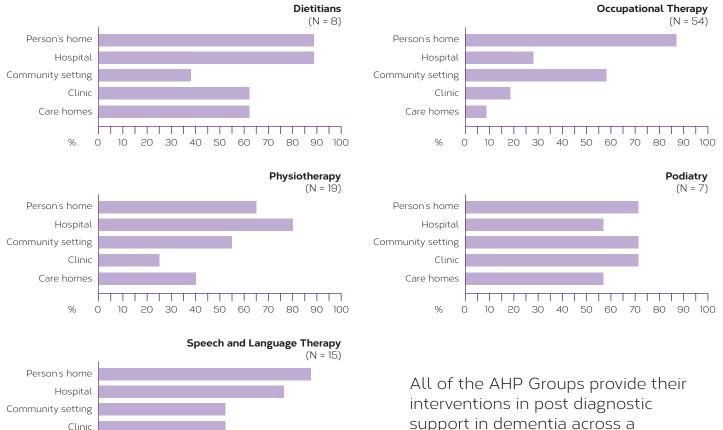
Signposting/Info

Consultation/Advice



One other example was given by a Speech and Language Therapist which was indirect intervention through training for care staff. As highlighted, the main AHP group which utilises technology for provision of interventions are Occupational Therapy.

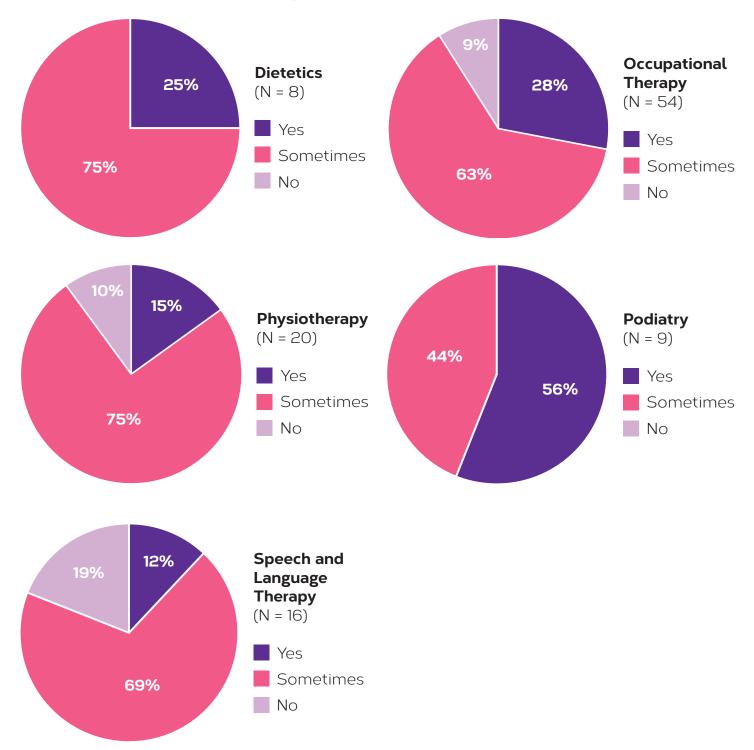
Where do you carry out your AHP led interventions in post diagnostic support in dementia?



Clinic Care homes % 20 30 40 50 60 70 80 90 100 0 10

variety of settings.

Do people with dementia have access to your Service at the right time in order to receive (AHP) led interventions in post diagnostic support?



'Sometimes' is main answer to this question. Across the AHP Groups, it was felt that people are being referred too late on in their dementia diagnosis. People commented that they are often:

"Receiving referrals once a person's skills/function is causing concern/risk rather than when they are newly diagnosed in order for us to do some teaching/education and preventative work." Occupational Therapist

This view was reflected in many of the comments made by the other AHP Groups too.

"Often referrals for specific symptoms come to us when there are significant problems – earlier referral would allow us to have a more preventative approach" Physiotherapist

"I do find sometimes that individuals have often been referred in later stages of dementia and families/carers/GPs have not been aware the feet may be in a bad state. People with memory problems may not realise their feet are too bad and because they are usually covered up, family just don't realise." Podiatrist

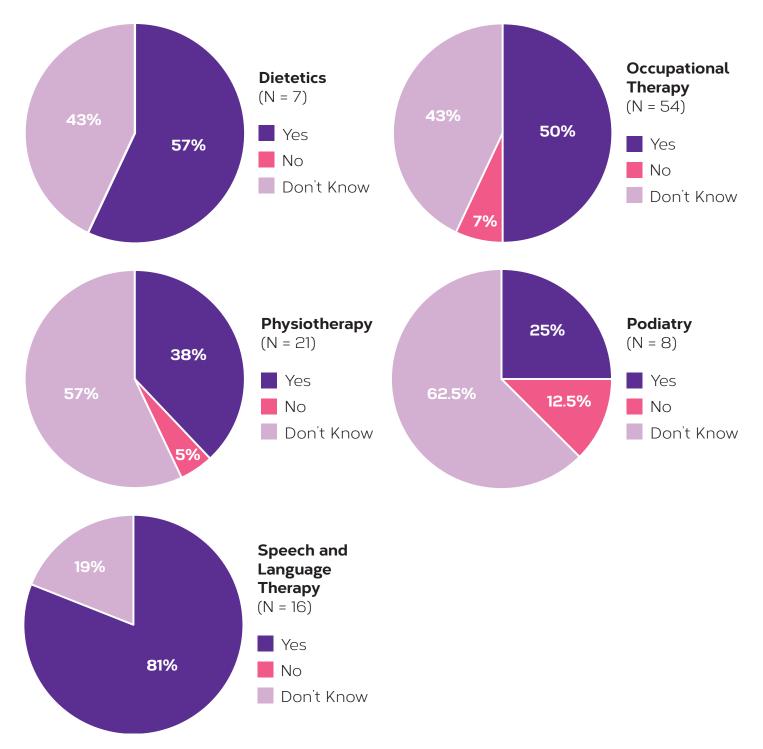
Referrals were perceived to very much be dependent on the referrer's level of knowledge and understanding of AHPs. A few people reported that things are getting better however recognised that there is still a lot of progress to be made. Some of the barriers to early referral were perceived to be:

- A general lack of awareness and understanding of AHP role
- GPs being unaware of AHP role
- Delayed confirmation of diagnosis
- Being unable to accept direct referrals
- Referral routes
- People being overwhelmed with information initially/not being ready to accept support
- Service lacking in capacity, having waiting lists
- AHPs being forgotten about at Memory Clinics.

There were some good examples of areas of practice which were trying to address the inconsistencies around access to Services including:

- Dietetics running education sessions for Hospital and Community Nurses. Also for carers along with Alzheimer Scotland
- Occupational Therapy screening people with Downs syndrome for dementia from the age of 30
- Podiatry completing Dementia Champions training and applying to practice
- Physiotherapy organising CPD sessions for multidisciplinary team in day services and wider mental health services
- Speech and Language Therapy linking with Memory Clinics around earlier referrals for primary progressive aphasia.

Is there anything else your AHP Service could be offering in the area of Post diagnostic support to people with dementia, which it does not already provide?



There is a strong belief amongst the AHPs that they could be offering more in the area of Post diagnostic support to people with dementia. It is recognised that the AHPs are seeing more people with a diagnosis of dementia and are keen to develop their practice in this area. The following are some of the suggestions made by the AHPs:

- Better self-management information and resources
- Education and training for colleagues, people with dementia and carers
- Improved links and joint working
- Improved structure around memory strategies
- Brief consultation opportunities
- Earlier intervention
- Increased focus on communication

Appendix IV: Driver diagram for phase 2

