



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





Members of the Scottish Dementia Working Group – Archie, Brian, Agnes and Nancy – photographed outside the Museum of Transport, Glasgow.

Foreword: Kate Fearnley, Alzheimer Scotland

Kate Fearnley is Deputy Chief Executive of Alzheimer Scotland, with responsibility for managing and developing services for people with dementia. She has a particular focus on promoting the role of Alzheimer Scotland Link Workers in providing post-diagnostic support.

The eyes of the world are on Scotland's approach to post-diagnostic support. The Scottish Government's commitment to ensuring that people with dementia have a minimum guarantee of a year's support after their diagnosis, and the associated HEAT target, are a transformational step forward. Based on Alzheimer Scotland's 5 Pillars model of post-diagnostic support, the guarantee means that people will have the opportunity to be flexibly supported to learn to live well with their diagnosis, understand their condition and manage their symptoms. They will be supported to maintain or regain their connections to their communities, connections so often lost as people with dementia lose confidence and encounter barriers. They and their partners, families and carers will benefit from the support of their peers, building their resilience and ability to cope with the challenges dementia brings. And they will be sensitively supported to look ahead and plan, both for future decision-making but also for how they will manage their

condition and keep well and connected following their year of support.

Allied health professionals have a huge amount to contribute to the 5 Pillars model. Your therapeutic skills are vital to helping people during this crucial first year, whatever stage of dementia they are at. As AHPs know so well, early intervention is an investment in future wellbeing. And at a wider level, evidence shows that the right support at this key time will help delay people's need for long term care – a vital investment which will contribute to how we can support the rapidly growing numbers of people with dementia.

We know there is work to do in many areas before the links and pathways between link workers, other staff providing this support and AHPs are fully in place. There are still barriers to access to be overcome. But this publication showcases the breadth and depth of progress that has already been made, and the many powerful and creative ways AHPs are already engaged in post-diagnostic support.

It is an inspiring and encouraging picture. Knitting the vital skills and contributions of AHPs into the delivery of the 5 Pillars of post-diagnostic support across Scotland will help to ensure that people diagnosed with dementia, and their partners, families and carers, have the best possible foundation for living well with their condition, and I very much welcome this report and commend it to you. ■



'AHPs have a huge amount to contribute to post-diagnostic support. Your therapeutic skills are vital to helping people during this crucial first year'

Foreword: Henry Rankin, Scottish Dementia Working Group

Henry Rankin chairs the Scottish Dementia Working Group (SDWG), a national campaigning group which is run by people with dementia. The group campaigns for better services and to improve attitudes towards people with dementia.

The Scottish Dementia Working Group are a national campaigning group and the independent voice of people with dementia within Alzheimer Scotland. One of our mottoes is that we campaign not for ourselves, but for those coming behind us. A prime example of this is our campaign work for post-diagnostic support.

I was diagnosed with vascular dementia in 2011. When I was first diagnosed it took me a long time to come to terms with having dementia. It had a big impact on my confidence. In time and with support I began to accept my diagnosis and I learnt to deal with some of the impacts on me and my family. I made contact with East Renfrewshire Carers Centre and then Alzheimer Scotland. They were incredibly supportive and I started to feel more positive for the first time since being diagnosed. I don't know where I would have been without that support.

The Scottish Dementia Working Group has always listed post-diagnostic support as one of its top campaign priorities because we know from first-hand experience how important it is to have help and support following a diagnosis of

dementia. Without it you can feel you are disappearing into a black hole.

The group was so pleased to see the Scottish Government's pledge in its second national dementia strategy to provide a minimum of one year's post-diagnostic support from April 2013. The 5 Pillars model of support outlines exactly what people who are newly diagnosed with dementia need: our new members will now have that vital support to help them live well with dementia immediately after their diagnosis. This report describes the outstanding work being carried out by allied health professionals across Scotland in providing innovative and effective post-diagnostic support. The work of the AHPs is helping deliver the post-diagnostic guarantee in practice. ■



Foreword: Elaine Hunter and Sarah Mitchell

Dr Sarah Mitchell is the programme lead for the National Delivery Plan for the Allied Health Professions in Scotland (2012) for the Scottish Government.

Elaine Hunter is the National Allied Health Professions Consultant based in Alzheimer Scotland.

Our respective roles in the Scottish Government and Alzheimer Scotland involve working in partnership with AHP directors, AHP dementia consultants and AHP leads from NHS boards and local authorities to promote post-diagnostic support. This joint working is supporting AHPs with the practical implementation of action 2.6 of the National Delivery Plan for the Allied Health Professions. Action 2.6 is a commitment that *'AHP directors and AHP leads in local authorities, working in partnership with Alzheimer Scotland, will work to ensure the multisectoral delivery of early intervention and post-diagnostic support for people with dementia and their families and carers, in line with the national commitment.'*

The case studies in this report illustrate the work that is being done in practice to deliver post-diagnostic support and self-management across Scotland. This progress has only been made possible by working across health and social care

boundaries and focusing on the needs of people living with dementia, their families, partners and carers.

The report includes examples of innovative practice across a range of allied health professionals, including occupational therapists in both the NHS and local authorities; physiotherapists; podiatrists; and speech and language therapists. It also demonstrates the transferable skills of an occupational therapist who has taken on a new role as an Alzheimer Scotland Link Worker.

New models of practice are being delivered, including an occupational therapy clinic; partnership working involving GPs and Alzheimer Scotland Link Workers; and the use of interventions such as cognitive stimulation therapy; the Otago Exercise Programme; mindfulness; and home based memory rehabilitation.

We will continue to work with allied health professionals in Scotland to spread and sustain this great practice. At the same time, we will ensure that the work of AHPs reflects local needs and what people living with dementia, their carers, families and partners are asking us to prioritise. The work described is helping to deliver the Scottish Government's commitment of a guaranteed minimum of one year's post-diagnostic support coordinated by a skilled named person. ■



Dr Sarah Mitchell



Elaine Hunter

Building a national picture of the role of AHPs in post-diagnostic support

Alison Groat is an occupational therapist specialising in mental health, based within NHS Dumfries & Galloway. Since June 2014 she has held the post of AHP Project Lead in Post-diagnostic Support, working with Elaine Hunter (Alzheimer Scotland National Allied Health Professions Consultant) to support delivery of action 2.6 of the National Delivery Plan for Allied Health Professions in Scotland.

The main focus of my role is to build an overview of current levels of post-diagnostic support being provided by AHPs across Scotland. I'm also looking at ways of making it easier for Alzheimer Scotland Link Workers and AHPs to link up and provide the most effective post-diagnostic support possible. We feel that service provision and access to services may vary depending on what part of Scotland people live in. In the light of this, a big part of my role is scoping what is already happening and then considering an improvement programme to develop the spread and sustainability of best practice. I am in the process of carrying out a literature review and designing two surveys to identify the range of work currently being undertaken by AHPs, and opportunities to enhance post-diagnostic support.

The first survey is targeting the
Alzheimer Scotland Link Workers. It

explores their understanding of the role of AHPs in post-diagnostic support. The second survey is aimed at AHPs, and for this project we focus on the five specific professions involved in post-diagnostic support: dietitians, occupational therapists, physiotherapists, podiatrists and speech and language therapists. The second survey aims to find out a bit more about what AHP work is currently underway nationally. We want to find information such as what interventions are being offered and how referrals are received. The goal is to see whether people who have dementia have access

'I'm looking at ways that Alzheimer Scotland Link Workers and AHPs can link up to provide the most effective post-diagnostic support possible.'

to AHPs at the right time, and if the right AHP skills are being used at the right time. Moving forward, the focus will be on enabling people with dementia to benefit from AHP support early on in their diagnosis, as this is where we can make a really big impact. During this early stage, AHPs can often help people develop skills which will benefit them further on in their dementia journey.

We are working with identified project leads representing each health board

.....**Building a national picture of the role of AHPs in post-diagnostic support**

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and local authority to identify the AHPs who are potentially working with people in the post-diagnostic support period. We also wanted to make sure that dementia was the primary reason that they are working with the person. The Board Leads are supporting us to look at what is already happening, along with distribution of the surveys.

'The ultimate goal is to raise awareness about AHPs, Alzheimer Scotland Link Workers and the support they provide. We want people with dementia, their families and carers to know what's on offer so that they can access what they need.'

In due course we hope to make recommendations on ways of increasing awareness of AHPs, and making the referral process clearer. The ultimate goal is to raise awareness about AHPs and the support they provide. We want people with dementia, their families and carers to always know what's on offer so that they can access what they need. It's currently not uncommon to visit someone and discover that they didn't know certain types of AHP support were available. We want to rectify that. In November 2014 we are going to produce a report on the findings of the surveys, and this will help us recommend the way forward for raising awareness of the AHP contribution to post-diagnostic support. ■

Staff at Alzheimer Scotland's Dementia Resource Centre in Dumfries, where the link worker survey has been piloted.



Taking AHP expertise out into the community

Joanne Payne is an occupational therapist working for NHS Ayrshire & Arran. She is the local lead for the National Delivery Plan for Allied Health Professions in Scotland, with specific responsibility for the dementia working group. This has introduced a range of measures to ensure people with dementia get early access to AHPs and the support they can provide.

Following the launch of the National Delivery Plan for Allied Health Professions in Scotland in 2012, we set up working groups for each of the different strands of the plan, and I lead on the dementia strand locally. The group is made up of four occupational therapists from the NHS; two AHP Dementia Champions; a physiotherapist; a speech and language therapist; two dietitians; a podiatrist; an occupational therapist working for the local authority; and an Alzheimer Scotland Link Worker. We have specific responsibility for implementing action point 2.6 from the plan. This involves AHPs working in partnership with Alzheimer Scotland to provide early interventions and post-diagnostic support for people with dementia, their families and carers in line with the national HEAT target.

Initially we sat down as a collective to work out a model for delivering more effective post-diagnostic support in partnership with Alzheimer Scotland.

There was a bit of anxiety about how we would make this work in practice, but everyone in the group could see the value of people having access to AHPs as soon as possible after their diagnosis. We came up with two proposals for delivering post-diagnostic support.

In the east of the locality, we piloted a post-diagnostic support group. This was run jointly by an occupational therapist, an Alzheimer Scotland Link Worker and a member of nursing staff. When anyone in

'We sat down to work out a model for delivering more effective post-diagnostic support in partnership with Alzheimer Scotland. Everyone could see the value of people having access to AHPs as soon as possible after their diagnosis.'

the area received a diagnosis of dementia, they were invited to join the group.

We ran the group in weekly sessions over seven weeks. The first week was an introduction, then the middle five weeks centred around Alzheimer Scotland's 5 Pillars model of post-diagnostic support. Week seven was the concluding session and included an afternoon tea. During the course we provided information about dementia, as well as details of peer



'People get really quick and easy access to our expertise at the dementia cafe. It provides an opportunity for us to showcase the benefits we can offer and the role we can play in post-diagnostic support.'

support and other community resources that were available. The whole project worked really well, and we're looking at rolling this out as a regular event commencing again in September.

In South Ayrshire, part of Ailsa Hospital was being converted to a new resource centre, and the nurse who was leading this process set up a dementia cafe at the centre. We used this as an opportunity to ensure AHPs were involved in its development and the nurse was keen to have our help and support in setting up the cafe.

The dementia cafe runs on the first Wednesday of every month. There is excellent professional representation there, with occupational therapists, dietitians, speech and language therapists, physiotherapists, podiatrists, community psychiatric nurses and a consultant all regularly attending. All the AHPs come to the cafe on a monthly basis so that up to 35 people can ask questions and get advice. People get really quick and easy access to our expertise at the cafe, and it provides an opportunity for us to showcase the benefits we can offer and the role we can play in post-diagnostic support.

Both of these projects have been very successful in giving people greater access to AHPs. It's also given us a chance to build relationships with them, with the flexibility of following individuals into the community to offer further interventions if required. Our evaluation of projects like the cafe has suggested it's been having a very positive impact on the experience of those newly diagnosed with dementia and their carers. ■



Occupational therapists from NHS Ayrshire & Arran celebrating publication of the first report in this series, 'Agents of Change'. Pictured (left to right): Jacqueline McComish, June Wilson, Joanne Payne, Sarah Roebuck, Lynsey McCloy and Jacqueline Martin.

Providing specialist advice about swallowing and communication

Rebecca Kellett is a speech and language therapist working for NHS Dumfries & Galloway. She provides specialist advice and support on issues including swallowing and communication. Her role within the local multidisciplinary team is enabling people with a diagnosis of dementia to benefit from a person-centred approach to support, with access to a wide range of AHP disciplines.

I qualified as a speech and language therapist in 1988 and immediately began working with adults with acquired neurological problems, including people with dementia. I came to NHS Dumfries & Galloway in 2008 and started training

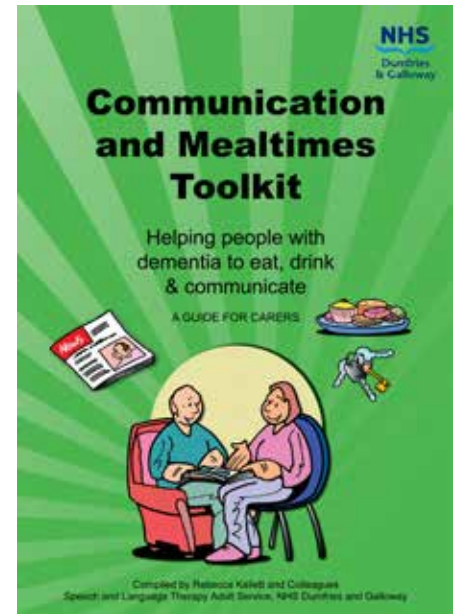
'Solving issues early on and helping people put self-management strategies in place can help reduce demand for services as the person's dementia progresses.'

locally as a Dementia Champion the following year. I graduated in spring 2011. Afterwards I developed a resource called the Communication and Mealtimes Toolkit which we use widely across the board area to support people with dementia.

For the last few years we have been offering swallowing assessments for people with a diagnosis of dementia, and I have recently started getting involved in post-diagnostic support. I'm in the process of building closer links with the local memory clinic so they are aware of the help I can provide with communication. I'm also aiming to work more closely with our Alzheimer Scotland Link Workers so they can refer people if required.

I recently provided support to a gentleman who had been diagnosed with fronto-temporal dementia, and his case illustrates the role I play as part of the multidisciplinary team. He went to his GP because he was having swallowing problems, and this eventually led to a diagnosis of fronto-temporal dementia. Afterwards he was referred to a neuropsychologist at the memory clinic, who built up a clearer picture of other symptoms linked to his diagnosis.

When I met him to do a swallowing assessment I discovered he had stopped taking medication he needed for long-term gastric problems. His dementia meant he was struggling to understand



..... Providing specialist advice about swallowing and communication

the need to take these, but he agreed he would start them again. When I visited a month later his swallowing was worse and his wife was struggling to cope. He had only taken his medication for four days after my first visit. This time we sat down and wrote some notes together about why the medication was important, helping him understand that he might not be aware of his symptoms himself, but that he still needed to take his prescriptions. I was also able to talk to his wife and find out about her support needs, as well as talking her through the different effects that fronto-temporal dementia can have.

Because I was concerned that there might be a second co-presenting illness that was contributing to the gentleman's swallowing problems, I spoke with his GP. This has led to a referral to a neurologist which enabled a full assessment to be carried out. I am continuing to work with the man and his wife and plan to use Talking Mats (a tool to enhance communication) during my next home visit to find out what activities he is interested in doing, and what he is comfortable with. I will also try to give him some visible and permanent information about what his symptoms are and how he can manage them. I'm aware he has lost interest in activities he previously enjoyed, like gardening, and I think this is an area that an Alzheimer Scotland Link Worker or occupational therapist can potentially

help with. Working as part of the local multidisciplinary team means I can talk to other colleagues about ways in which they can help people with dementia address specific issues.

Providing this kind of support early on in a person's diagnosis is extremely worthwhile, as it can really help improve quality of life for a person with dementia and their carer. Solving issues early on and helping people put self-management strategies in place should also reduce demand for services as the person's dementia progresses. ■

Linda Preveet, Rebecca Kellett and Fiona Murchie from the Speech and Language Therapy Adult Team, NHS Dumfries & Galloway.



Helping people with dementia stay 'Fit for Life'

Jackie Hodge is a specialist physiotherapist working within the Older People's Community Mental Health Team in Edinburgh. She has piloted and developed a community exercise programme for people with long-term mental health conditions, dementia and cognitive impairment, called Fit for Life. She has also helped set up a follow-on community-based exercise class to support people to stay independent and remain part of their community.

I have been working as a mental health physiotherapist in the older people's service for five years. Initially my job focused around rehabilitation for frail, older people within their own homes. However, I realised that many of the people I was working with – including those with dementia – would benefit significantly if they could participate in a suitable community-based rehabilitation exercise class.

Joining an exercise class can be very daunting for someone with a mental health problem. They may never have exercised before, or have had negative experiences. I wanted to set up a class that could be a stepping stone, enabling them to make the transition from being treated by the NHS to becoming independent and accessing mainstream groups.

I set up a dedicated exercise programme for people with dementia,

depression and anxiety called Fit for Life. This is a 12-week programme run three times a year, where people attend for an hour each week at a local venue. The class focuses on improving balance and influencing people's own impression of their balance. If they've had a fall and lost confidence, this can be a risk factor



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for further falls. We try and improve their confidence and fitness by enabling them to experience exercise in a safe, supportive and social way.

Referral numbers were small to begin with but have grown dramatically. Roughly half the people who come along have dementia. I initially visit each person who

Physiotherapist Tracy Falconer (left), delivering Fit for Life training.

has been referred to explain the purpose of the group and establish whether they are interested in attending. I do a follow-up visit after they have completed the course to see how they've found the group and what they want to do next. After completing Fit for Life, many people want to move on to something else in the community, such as a seated exercise group or walking group, but this can still be quite a big step.

Because I was finding it difficult to identify appropriate groups for some people to graduate to, I started talking to other local voluntary organisations who had funding available. We worked together to set up a follow-on exercise group, called Keep Moving, located in the same place as Fit for Life. They provide the instructor and market the group to anyone with a long-term condition, including people with dementia. Keep Moving is dementia-friendly and has a similar format to Fit for Life. The only difference is that it's run independently and participants are asked to pay a fee to cover the costs of the class. It launched two months ago in partnership with KICC Active and the Thistle Foundation. If it's a success we plan to roll out more groups in different parts of Edinburgh.

Key to the current service is the fantastic support from the Edinburgh Volunteer Centre who have provided three



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volunteers to assist participants during Fit for Life sessions and any follow-on exercise groups.

Jackie Hodge delivering Fit for Life training.

Fit for Life has been a really exciting project and came about because I had a manager who really trusted me and let me see where the needs were. Things were moving into the community and I saw that physiotherapy had a role to play. We have been able to demonstrate that this type of group work can be of great benefit for older people with dementia and other mental health problems. It also ties in well with post-diagnostic support services as it's about empowering people to regain confidence and remain part of their local community. ■

Providing cognitive stimulation and falls prevention programmes in the community

Pauline Finnegan is an occupational therapist working in older people's day services for the City of Edinburgh Council. Prior to this she worked in adult mental health as a community occupational therapist. The main focus of her current role is to promote a reablement philosophy within day centres, focused around maintaining or improving skills.

This is a relatively new post and has involved working in day services to promote a reablement approach using occupational therapy skills. A major focus for our team over the last two years has been introducing cognitive stimulation therapy (CST) groups across Edinburgh. CST is a brief treatment for those with mild to moderate dementia which is supported by NICE and Alzheimer Scotland's 8 Pillars Model of Community Support. Many of the people who use day services have dementia, and CST offers a really good alternative to some of the activities they have been offered historically.

Over the last two years we have been co-facilitating CST groups with social care staff, enabling them to gain the skills to run their own groups on an ongoing basis. We have been working with staff at council-run day centres, and also centres run by the voluntary sector, and overall have trained around 70 staff. This

has been a great success and groups are now being run at over 20 locations across Edinburgh. We have started to use MoHOST (Model of Human Occupation Screening Tool) as an outcome measure to see what the impact of CST has been on daily life, and have been able to demonstrate very positive benefits following completion of the programme.



Pauline Finnegan and Helen Ryan., occupational therapists at City of Edinburgh Council Day Services for Older People.

CST is particularly suitable for people with mild to moderate dementia. This is enabling us to tie our work in more closely with the post-diagnostic support being offered by the Alzheimer Scotland Link Workers.

'The cognitive stimulation therapy groups have been a great success and are now being run at over 20 locations across Edinburgh.'

..... Providing cognitive stimulation and falls prevention programmes in the community

We have just introduced a new 'Be Able' programme which is being delivered in two council day centres, with two more about to start. Be Able is a 14-16 week programme which offers individualised and group programmes which are tailored to the needs of everyone who participates. There is a particular focus on CST and falls prevention. We believe this service works very well for all older people, including those who have been newly diagnosed with dementia.

All our occupational therapists are trained to deliver the Otago Exercise Programme, which focuses on strength and balance. This involves completing an intensive four-day course. It's a great fit for our community work because people with dementia often also have mobility issues and can be at risk of falls. We have taken steps to ensure that they will be comfortable attending Be Able, for instance by reducing group sizes if required. . We organise transport so we can bring people to the groups and they don't have to self-travel. We have also involved the Alzheimer Scotland Link Workers and did some training with them around reablement and CST, which has led to quite a few referrals to the Be Able days for both Otago and CST.

Be Able is ideal for people who don't necessarily want to come to a day centre long-term but would benefit from the Otago Exercise Programme, working on their own personal goals and attending CST groups. There are currently CST groups running in the longer-term day service (where we run both CST and maintenance CST groups) as well as in the short-term Be Able service. The Alzheimer Scotland Link Workers are aware of both options, and are helping promote the service to people who are newly diagnosed with dementia and may be interested in them. ■

'Many of the people who use day services have dementia, and cognitive stimulation therapy offers a really good alternative to some of the activities they have been offered historically.'

Providing integrated care for people with dementia and their carers

Ylva Champion is an occupational therapist working in an integrated community dementia team as part of Argyll and Bute Community Health Partnership. Her work has included piloting a mindfulness support group for carers, and using a cognitive screening tool to help people with dementia and their carers identify daily activities they can still safely participate in.

Our community dementia team uses partnership working to help meet the needs of people with dementia at different stages of their dementia journey. The team is made up of a social worker, a community psychiatric nurse, an occupational therapist, a consultant psychiatrist and two Alzheimer Scotland Link Workers. Working together across health, social care and the voluntary sector means that people can receive a diagnosis quickly, and get access to the most appropriate post-diagnostic support.

We cover a large remote and rural area including the Inner Hebrides and parts of the Highlands. Often we are providing support and education but then have to find innovative ways to keep these services going, for example by working in partnership with volunteers to run the groups, which helps meet the demands of covering such a large region.

A significant part of my role centres on providing memory and cognitive

rehabilitation to help people maintain their independence with daily living skills. One of the tools I use is from the Cognitive Disabilities Model – the Large Allen Cognitive Level Screening Tool (LACLS). This is a very useful assessment tool to gauge how someone can concentrate and follow instructions.

‘Working together across health, social care and the voluntary sector means that people can receive a diagnosis quickly, and get access to the most appropriate post-diagnostic support.’

It involves asking people to complete a novel sewing activity ranging in complexity. It is a hands-on tool measuring functional cognition – how the cognitive/thinking skills are affected in day-to-day activities. As it’s such a practical tool, both men and women seem to engage with it positively. Based on the results, we can make deductions about their remaining strengths, their level of insight, their memory and their ability to follow instructions.

I use LACLS in post-diagnostic support. We use the results to give the person themselves, their family members and professional colleagues information about

.....Providing integrated care for people with dementia and their carers

how to maintain the tasks they are doing. We can help determine the levels of risk associated with different activities. One of the best aspects of LACLS is that it is a measure of what a person can do, not a measure of what they can't. The person who has been recently diagnosed with dementia, their relatives and carers will often ask 'what activities can we do with them, what can I still do?' LACLS helps us to answer that question. For example, we may conclude that someone only needs a prompt from their carer to start an activity like cooking or washing. Without this intervention, the opportunity to keep being active and involved in their lives is lost, as the carer can take over, albeit with the best of intentions.

We have just finished piloting a mindfulness project called 'Being Mindful of Carers'. This involved the provision of an 8-week course in mindfulness-based cognitive therapy (MBCT) to those living with and caring for someone with dementia. The group gave the carers the opportunity to discuss any issues in a supportive closed setting. During post-research interviews, comments included that they had found more ways to cope with the demands of caring and had realised that caring for themselves helped them care for others. They also mentioned that they didn't know how they would have coped without the mindfulness teachings and the support of the group. ■

'We cover a remote and rural area that includes the Inner Hebrides and parts of the Highlands. Often we provide support and education then find innovative ways to keep these services going, for example by working in partnership with volunteers.'



Ylva Champion carrying out an assessment using the Large Allen Cognitive Level Screening Tool and (right) photographed at Tobermory on the Isle of Mull, part of the area she covers.

Helping people living with dementia develop new memory strategies

Emma Coutts is an occupational therapist working in a rural setting within NHS Dumfries & Galloway. She recently carried out a pilot into home-based memory rehabilitation for people with dementia, and is currently developing resources so that her colleagues can be trained to deliver the programme as well.

I graduated from Queen Margaret University in 2012 and took up this post soon after. My role involves working with older adults, and particularly people with dementia. I'm part of a team that works quite rurally, based in the Stewartry and Wigtownshire.

At the moment the main project I'm involved in is home-based memory rehabilitation (HBMR). This is a four to six week programme that's carried out with the person and their caregiver in their home environment. It was developed in Belfast by an occupational therapist called Mary McGrath to help people with a recent diagnosis of dementia compensate for memory difficulties affecting their everyday function, resulting in reduced demands on caregivers/family/friends. HBMR has been recognised by the College of Occupational Therapists, and also fits in with the National Delivery Plan for Allied Health Professions in Scotland, as well as Alzheimer Scotland's 5 Pillars model of post-diagnostic support.

The HBMR project was introduced in NHS Dumfries & Galloway by Wendy Chambers, occupational therapy team leader (west), and the pilot took place from May to November 2013. It was delivered by me and my colleague Corinna Sidebottom, with lead responsibility by Alison Groat. The programme is structured around visits of 30 minutes to an hour, with one session delivered per week. At the following visit we review what was covered the previous week. It provides a range of memory strategies to help the person compensate for everyday difficulties.

During each week of the programme we focused on a particular memory challenge, such as helping the person remember where they had put something, or remember information they had been

Left to right: Hazel Borland, Executive Nurse Director, NHS Dumfries & Galloway; Emma Coutts; Alison Groat; and Jacqui Lunday Johnstone (Chief Health Professions Officer, Scottish Government) photographed at NHS Dumfries & Galloway's Local Delivery Plan Showcase event. Emma and Alison's poster was runner up in the poster competition.



told. After the pilot we refocused some of the themes, and also added extra elements including tips for keeping the brain active and guidance on the environment and landmarks. We introduced this last element because some people had difficulty remembering their bearings and were sometimes unable to find their way home.

Everyone I have delivered the programme to so far has been very positive about it. People who had completed it were using a greater number of memory strategies, and reported a decrease in the number of everyday memory difficulties they experienced. We also used emotional touch points which gave us additional feedback on the programme.

One of the drivers behind HBMR is to encourage referrals to occupational therapy from people early on in their dementia journey when interventions like this can be particularly beneficial. We have been picking up referrals directly from the Memory Clinics and are continuing to explore ways of improving

access to our service. We're working hard to promote the service as much as we can, for instance by giving presentations, as well as distributing leaflets.

We are working closely with the local Alzheimer Scotland Link Workers who are a valuable source of referrals. After the HBMR programme has finished we can refer the person to a post-diagnostic supported self-management group. We ask everyone on the programme if this would be useful for them. These groups are currently being run jointly by Alzheimer Scotland and the Mental Health Occupational Therapy Service. They enable a person who has been recently diagnosed with dementia to benefit from a further stage of post-diagnostic support, if they wish.

The pilot work for home-based memory rehabilitation has been really encouraging. We are in the process of compiling a manual for this and are hoping to roll out the programme within the next few months. ■

'During each week of the programme we focused on a particular memory challenge, such as helping the person remember where they had put something, or remember information they had been told.'

Creating communities of post-diagnostic support

Sandra Shafii is an AHP Dementia Consultant based in NHS Lanarkshire. She has a national role that includes a specific focus on promoting activity, participation and the environment for people with dementia.

Lanarkshire AHPs have taken a varied approach to post-diagnostic support for people with dementia. Within the community, we co-developed an innovative campaign in partnership with Alzheimer Scotland and others to make Motherwell a dementia-friendly town, including advising shops and businesses on ways they can support their customers with dementia. On the services side, we have built relationships with Alzheimer Scotland Link Workers, informing them of the role of AHPs in dementia care and how to refer people to our services such as Speech and Language Therapy for swallowing problems. We have also produced a suite of leaflets designed by AHPs to assist people with dementia and carers in everyday self-management.

Our work in Motherwell and other Lanarkshire townships aims to enrich the community environment for people with dementia. We believe this is making a valuable difference to their post-diagnostic experience. When we asked people living with dementia – including people at the post-diagnostic stage – what was important to them, they told

us that continuing to live an ordinary life like getting out and about to shops or libraries, and maintaining a sense of citizenship was what mattered. Ultimately we want people who have been diagnosed with dementia to be able to remain part of their communities and feel confident and comfortable in their social environment.

To achieve our goal we approached small and large businesses, and advised

At Scotland's Dementia Awards 2013, North Lanarkshire Partnership won the award for 'Best dementia friendly community initiative'. Sandra Shafii is pictured (centre) holding a certificate.



them on how to treat people with dementia with dignity and respect. We provided hints and tips, audited environments, and provided training to

Creating communities of post-diagnostic support

staff. Every business we approached made the commitment to become dementia friendly, helping people with dementia to live well and maintain their community connections. Using the heading 'Dementia is Everyone's Business' the project has attracted international acclaim and widespread publicity.

We are working towards the government's HEAT target for dementia in 2015/2016, which aims to provide one year of post-diagnostic support and to have a person-centred plan in place at the end of this period. AHPs created a suite of self-help leaflets for distribution to people in Lanarkshire who are diagnosed with dementia. Not everyone in Lanarkshire with dementia will be able to see AHPs like physiotherapists, speech and language therapists or dietitians in the period immediately following diagnosis. Instead, we have made helpful AHP-led information immediately accessible in leaflet format, and on-line via the Making Life Easier website in North Lanarkshire. This means people know about us and what we do, should they need support in the future.

The leaflets provide hints and tips on how to manage some of the practical, everyday problems which dementia may

bring. They cover topics like staying active, communication, and other advice on how to self-manage. It is specialist advice which reaches people with dementia who may not need a referral at the time, but who could live better with such advice. The leaflets can also be used by families and carers.

Our Alzheimer Scotland colleagues, including link workers, have received information about the role of AHPs in Lanarkshire in dementia care and they can provide access to specific AHP support via Community Mental Health Teams (CMHTs). Occupational therapists in CMHTs also provide direct interventions in the post-diagnostic period. If direct AHP support isn't needed, we can provide the AHP leaflets for the person and their carer to take home.

We believe our approach in Lanarkshire is making a real difference to the lives of people who have recently been diagnosed with dementia. ■

'We co-developed an innovative campaign to make Motherwell a dementia-friendly town, including advising shops and businesses on ways they can support their customers with dementia.'

Working in partnership with the NHS, the local authority and Alzheimer Scotland

Fiona Robertson is an Alzheimer Scotland Link Worker with 12 years' experience as an occupational therapist. Her new post is enabling her to support people with dementia at an earlier stage of their journey. This is helping them to develop the skills and resources to live well with their diagnosis and remain independent for longer.

I'm one of six Alzheimer Scotland Link Workers covering Edinburgh and am on a seconded post from NHS Lothian. The link worker role is a true partnership between Alzheimer Scotland, NHS Lothian and Edinburgh City Council. Although my colleagues and I are employed by Alzheimer Scotland, we're based in council or NHS offices and work alongside colleagues from health and social care, which is quite novel and works very well.

As a link worker my role is to provide at least one year's support for people who have been recently diagnosed with dementia and their families. I'm an occupational therapist, so a lot of this fits with my professional background. The whole premise of occupational therapy is enabling people to re-engage with their everyday activities, which can mean re-engaging with life more broadly. The Alzheimer Scotland Link Worker role builds on this.

For all of my career I have worked in care of the elderly mental health, and

mostly with people with dementia. That is my passion. In the past I spent a lot of time supporting people who were a lot further along their dementia journey. I heard about the Alzheimer Scotland 5 Pillars model of post-diagnostic support, and it seemed that the idea behind the model was to catch people early in their diagnosis and build resilience. This seemed like a very appealing approach.

Being a link worker allows you to be absolutely person-centred. You work at the person's pace and on whatever pillar they want to work on. I mostly visit people in their own homes and make sure I have at least an hour set aside per visit. This allows people to relax and open up, and it's often in the last 20 minutes that the real nub of what's worrying them comes out. As a link worker you can make the time to properly sit and listen. That is very valuable and rare.

As this is a new role I'm still building my caseload and am currently working with around 30 people. One couple I'm supporting were quite sceptical about working with a link worker, but following my second visit they agreed to try a peer-support group, and ended up really enjoying it. I had previous experience of the group and knew it was a fantastic resource. The gentleman's wife got to meet other carers and found it a very emotional experience, but also an incredibly positive one.

'Being a link worker allows you to be absolutely person-centred. You work at the person's pace and on whatever pillar they want to work on.'

Right: Helen Hay, Alzheimer Scotland Regional Manager for South East and Central region and Councillor Henderson, Convener of Edinburgh's Health, Social Care and Housing Committee, launching a campaign to raise awareness of the signs of dementia.

Getting NHS staff involved early in the dementia journey

My colleague and I cover south-west Edinburgh so have a good overview of what's going on locally. This includes dementia-specific things, as well as general community resources like bowling clubs and church groups, or what's going on in the local community



centre. Because we have that knowledge we can link people in with activities that matter to them and that they may have become disengaged with.

Both NHS and council colleagues have really bought into the Alzheimer Scotland Link Worker role and have embraced it as complementary to what they do. In this partnership I think we are all making a difference to the experiences of people with dementia, particularly during the potentially difficult period immediately following diagnosis. ■

Jenny Reid is an AHP Dementia Consultant based in NHS Lothian. She has a national role that includes a focus on early interventions and supported self-management. She also produces the Dementia AHPproaches newsletter, which is circulated to colleagues across Scotland.

When I started in post in April 2011, I was given a national remit to focus on early interventions and supported self-management. A few weeks beforehand we had hosted a masterclass involving 40 AHPs from across Scotland looking at how they could use a supported self-management approach with people living with dementia. This was facilitated by Claire Craig, a Senior Lecturer in Occupational Therapy and Senior Research Fellow at Sheffield Hallam University.

Supported self-management has traditionally been associated with people with more physical long-term conditions, such as diabetes or COPD. During the workshop, we looked at how a person with dementia could be supported to self-manage their condition based on Claire's experience and research. She shared different ways of supporting people, what people with dementia had identified as important to them, and how to measure the impact of this approach. The workshop was supported by Scottish Government and NHS NES and involved AHPs from 11 different health boards and staff from Alzheimer Scotland. It is still available to view online as a webcast (at www.video3uk.com/alzheimersresourcelibrary).

'In Lothian feedback from the people we work with found AHPs to be consistent, reliable, and to deliver on what they said they would.'

Getting NHS staff involved early in the dementia journey

Afterwards, I sent a survey out to the people who had come to the masterclass, asking them for feedback and to share how they were taking it forward in practice. Responses revealed staff starting to act as a bridge for introducing change locally; sharing resources with colleagues, and developing self-management groups and information resources for people with dementia and their carers.

Over the following year we organised a series of supported self-management roadshows spanning nine health boards and involving over 330 staff. This was arranged through the network of mental health AHP leads as well as the masterclass participants. The roadshows took the form of a conversation discussing what self-management means for people with dementia, and how AHPs could facilitate this. One of the most striking experiences was how different the board areas were. Each had different strengths and challenges, along with a range of different partnership working arrangements.

When the 5 Pillars model was published by Alzheimer Scotland in 2011, we encouraged AHPs at the roadshows to map what they were currently doing onto the pillars. This was extremely helpful because many people recognised they were already doing some very good work which they

could build on. We spoke about how to measure impact, and shared the Talking Points model to show a personal outcomes approach. In Lothian feedback showed the people we work with found AHPs to be consistent, reliable, and to deliver on what they said they would.

One of biggest challenges for staff has been how they make themselves accessible to a person with dementia earlier in their journey of care. Traditionally, AHPs have often come into contact with people with dementia only when problems arise and a crisis has occurred (or is about to). The workshops looked at how we can be available earlier, allowing more proactive ways of working – rather than responding reactively. During the earlier stages of the illness there is a bigger window of opportunity for people to take on board information and develop new habits which could benefit them in future and help to delay or/prevent problems from occurring.

AHPs are now starting to work more regularly in partnership with Alzheimer Scotland Link Workers and Dementia Advisors, offering in some areas a new, quicker referral route for people with dementia. We hope that in the future we can make access even easier by offering the option of self-referral as a way to make supported self-management even more practical for people with dementia. ■



Jenny Reid photographed at Alzheimer Scotland's 2014 Memory Walk at Dalkeith Country Park.

'The workshops looked at how AHPs can be available earlier, allowing more proactive ways of working – rather than responding reactively.'

Empowering people to live well with their diagnosis using supported group learning

Dorothy Hathaway is a Highly Specialist Podiatrist based at Lynebank Hospital in Dunfermline. She is helping to disseminate information about foot care – and living well with a long-term condition – to a wide range of groups, including people with dementia and their carers. The fun and interactive training sessions she facilitates enable participants to talk about a wide range of subjects in a supportive environment.

My role is focused on empowering people to experience and maintain good health – whatever their circumstances. Although as a podiatrist my main focus is on foot care, we use an innovative ‘map’ approach that enables people to talk about a wide range of issues, including worries or questions about their diagnosis of dementia. The focus is on empowering the people we work with, using the motto ‘No decision about me, without me’.

Last year the National Footcare Guidelines were reissued by the Scottish Government and this led to the publication of the Healthy Footsteps map (see illustration). Unlike traditional training sessions, where a trainer stands in front of a PowerPoint, the map enables groups to discuss and learn about what’s important to them in an informal environment, supported by a facilitator.

The map is a cartoon which is set around a fun fair. Working in quite small groups (no more than 10 people), the sessions involve someone choosing a feature of the map that interests them and talking about it with the other participants, before moving on to another talking point as a group. The facilitator usually eases their chair back and lets the participants take over, but is present if they have a question.

There are several ‘places’ on the map that are particularly relevant to people with dementia, their carers and families. A feature on the map that often gets discussed is the fairground ride which provides opportunities to talk about ill health and emotional ups and downs. At this point, family carers can talk about any difficulties they are having coping, and being in a group with other carers means they talk at the level they want to, thanks to the informal environment.

We take our training sessions out into the community, visiting care homes and carers’ groups, and going to community events. We are also offering training to the Alzheimer Scotland Link Workers so they can deliver it directly to people with a diagnosis of dementia and their carers. People can receive a huge amount of information immediately following a diagnosis, so this might not always be the ideal time to focus on a specific issue

The Healthy Footsteps map (overleaf) provides opportunities to talk about a range of subjects, not just foot care. One example is consent to treatment, which can be very relevant to people with dementia and their carers.



Empowering people to live well with their diagnosis using supported group learning

such as foot care. To help ensure people have the right information to hand, all participants receive a copy of the map to take away, and this has our contact details on the back. This means they know who to contact if they have a question or a problem at a later stage.

Everything we do is based around the principle of helping the person think about how they can help themselves to feel better, and empowering them

to take ownership of their own needs. Following a diagnosis, you don't become 'unable' the next day, and we hope our work can help reduce stigma like this, as well as providing support. We have been delighted with the response we've had to the Healthy Footsteps map, and are certain this approach has a role to play in enabling groups of people to support each other as their journey with dementia progresses. ■

'Following a diagnosis, you don't become 'unable' the next day, and we hope our work can help reduce stigma like this, as well as providing support.'



Promoting self-management and risk enablement for people with dementia

Iona Parkinson is a head occupational therapist working for NHS Grampian. She is involved with a range of projects that are designed to help people with dementia self-manage their condition, as well as manage risks so they can remain part of their communities.

Our occupational therapy team runs various projects which dovetail with post-diagnostic support and help people with dementia maintain the best quality of life they can. We are involved in piloting Dementia Friendly Communities in Aberdeenshire, which will enable people to continue to feel like part of the community, and lead a full life following diagnosis.

We are working jointly with Alzheimer Scotland's Seize the Day Project to deliver information sessions to people who have recently received a diagnosis. People generally come with a relative or carer, and each session focuses on a different topic, with a particular focus on techniques for self-management. Topics vary from tips on memory problems and how to manage them, to information about modifications the person can make to their home environment that will make it easier for them to manage. This includes telling them about telecare options, if appropriate. The project has been running for several years, with support from a range of AHP staff. Most of our occupational therapists have taken part, along with many

physiotherapists and dietitians across Aberdeen City and Aberdeenshire. We receive a lot of positive feedback after every session. A recent development in this project is to run the sessions specifically for adults under 65 who have received a diagnosis of dementia.

Another project we run in NHS Grampian is a supported self-management group called Mind Your Memory. The meetings focus on enabling people with dementia to consistently manage their condition independently, with multidisciplinary input from AHPs and nurses across Aberdeenshire. Group members are at an early stage of their

Staff involved in the Risk Enablement Framework. Left to right: Serena Buchan, Iona Parkinson, Avril Verlegh, Michelle Dunne & Angela Pointon



Promoting self-management and risk enablement for people with dementia.....

dementia journey, although a prerequisite of joining is that they have received a diagnosis and understand it. Each session focuses on a different topic, from keeping yourself physically healthy, to maintaining the activities you enjoy, dealing with emotions and relationships, and coping with memory problems. We found that these sessions were most successful when the group was either all women or all men, in which case participants were far more likely to enter discussion.

The third project is the Risk Enablement Framework (REF), which can be appropriate immediately following diagnosis or later on in the person's journey. The REF is there to support people with dementia so that they can carry on with valued activities which may involve an element of risk. For example, if someone who was recently diagnosed was keen to go to the shops alone but also struggled with spatial awareness, we

would assess the risk of them going out by themselves. If this presented too high a risk for them, we might suggest a buddy system or provide a tool like an adapted mobile phone to mitigate the risk. The REF enables people with dementia to continue enjoying activities that carers or professionals might previously have thought were too risky for them. It is based on the principle that taking a minor risk is often the key to unlocking significant benefits for the person, whereas not taking that risk can seriously compromise their quality of life. We ran the REF last year as a pilot and are hoping to roll it out and also see it adopted by other health boards.

These three projects are giving people who are newly diagnosed with dementia access to the expertise of our AHP colleagues, and equipping them with strategies to manage their condition better and take appropriate risks. ■

'We are working jointly with Alzheimer Scotland's Seize the Day Project to deliver information sessions to people who have recently received a diagnosis. Each session focuses on a different topic, with a particular focus on techniques for self-management.'

Early assessments to help people maximise their abilities and plan for the future

Lynn Dorman is head occupational therapist for the Older Adults Mental Health Service, NHS Fife, managing a team of occupational therapists and support staff across the region. Her team has set up an innovative assessment clinic that has reduced waiting times and enabled staff to provide advice and support to both people with dementia and their carers.

We are working hard to ensure that people with dementia get access to occupational therapy services early on in their diagnosis. Often a GP or other professional will have a concern about a person's memory and refer them to our clinic, where the assessments we carry out can contribute towards a diagnosis. The earlier the diagnosis is made, the sooner the person can access appropriate support and interventions.

The clinic carries out cognitive and functional assessments which were traditionally done in the person's home. This model enables us to see six people each morning and afternoon, resulting in shorter waits for appointments, which has been a really positive outcome. Everyone receives three assessments, each carried out by a different member of staff. One is done by a healthcare support worker, who uses a question and answer based fact-finder to establish what activities the person is still engaged with and which they

would like to re-engage with. Occupational therapists carry out a standardised assessment of functional cognition (part of the Cognitive Disability Model) and an assessment of how the person performs a kitchen task. These assessments help us identify how any cognitive impairment is impacting on the person's ability to carry out everyday activities.

When we ask people to the clinic we also invite their carer or a relative. Often the person being assessed would like



Examples of some of the assessment techniques used by the team of occupational therapists at their clinic in NHS Fife.

.....Early assessments to help people maximise their abilities and plan for the future

them to sit in to support them. Carers are also able to spend one-to-one time with a therapist if they have particular concerns they would like to discuss. They can signpost them to other services that will support them if required.

People who have had dementia for a number of years are often referred for assessment. We're also really keen to assess people who either don't have a diagnosis, but have memory problems, or are newly diagnosed. It's really important to be able to help the person with dementia establish and maintain routines from an early stage of the illness. We can also help them introduce strategies and techniques which will support them to remain as independent and engaged as possible. Once a person is diagnosed with dementia, there is a huge variety of interventions available from the occupational therapy service, including cognitive stimulation therapy, life story work, and community support groups to name but a few.

As a service we are striving to support people at an earlier stage in their illness and provide them with the tools to self-manage their condition and live well with dementia. We undertook a pilot project in partnership with a GP practice in Buckhaven to flag up the benefits of our occupational therapy assessment clinic. As a result they started referring people who presented with non-specific memory problems to us, enabling us to assess them fully. The report we sent back to the GPs then assisted them to make a diagnosis or prompted them to refer the person for additional tests.

At the start of September a new post-diagnostic support project was set up in Fife. Our assessment clinic is building close links with this to try and ensure people receive assessments as early as possible. Our whole ethos is about keeping people active and engaged in their communities. It's about positive risk-taking and helping people plan for the future at an early stage. ■

'As a service we are striving to support people at an earlier stage in their illness and provide them with the tools to self-manage their condition and live well with dementia.'

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Below: Agnes Houston and James McKillop of the Scottish Dementia Working Group.

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Picture courtesy Jo Hanley Photography (www.johanley.com)

This publication is the second in a series of three reports sharing examples of the innovative work that allied health professionals are doing in Scotland to support people with dementia, their partners, carers and families. Much of this work is being actively supported by Alzheimer Scotland.

Alzheimer Scotland wants to make sure nobody faces dementia alone. There are two main objectives that help us achieve this and drive all our work:

- being the foremost provider of support services and information for people with dementia, their families and friends throughout Scotland
- being the leading force for change at all levels of society, protecting and promoting the rights of people with dementia, their families and friends.

Alzheimer Scotland is committed to improving the lives and opportunities of people with dementia, their partners, families and carers. We do this through provision of direct support services, and by raising funds to provide our 24 hour Freephone Dementia Helpline (0808 808 3000), our networks of Dementia Advisors and Dementia Nurses, and our Dementia Research Centre. Our work and campaigning activity is informed by our 7,000 members and delivered by over 1,100 staff and 700 volunteers.

For more information about who we are and what we do, visit www.alzscot.org

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Making sure nobody faces dementia alone.