

Connecting People: Connecting Support "AHP Blethers" Overview #AHPDementia

"Making changes one conversation at a time"



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Introduction

Dementia Awareness Week in Scotland in 2015 was 1st to the 7th June and the theme was *let's talk about dementia*. We know 90,000 people in Scotland live with dementia and tens of thousands of unpaid carers – usually partners or relations – support people with dementia. That is why Alzheimer Scotland encouraged people to talk about dementia during Dementia Awareness Week.

The week's theme was to encourage local and national decision-makers, health and social care professionals, frontline care staff and members of the public to speak openly about dementia and overcome the stigma that often surrounds the illness. It was also intended to encourage people living with dementia, and those who care for them, to share their own experiences; helping to improve understanding of dementia and highlight best practice. Scotland's allied health professionals collaborated with Alzheimer's Scotland in several events held over the week.

Allied Health Professionals are a group of various health professionals, including art therapy, dietitians, music therapy, occupational therapy, physiotherapy, podiatry speech and language therapy, who are experts in prevention, reablement and rehabilitation approaches. They provide an essential contribution to dementia care, however many people living with dementia and their carer's are unaware of who allied health professionals are what they can do to support them.

Scotland's allied health professionals therefore decided, in keeping with the theme of Let's Talk about Dementia, to hold a range of 'AHP Blethers'. It provided an informal opportunity for the public to find out more about the roles of allied health professionals and an ideal opportunity to launch the *"Allied Health Professionals: Who are they and how can they help you"* leaflet. <u>http://www.alzscot.org/assets/0001/7456/AHP_Leaflet_for_launch.pdf</u>,

Allied Health Professionals supported the week in a number of ways.

- Held a "Market Stall" at the Alzheimer Scotland conference on the 1st June launching our new leaflet, Allied Health Professionals: Who are they and how can they help you".
- Developed an AHP Q&A for the week on our blog site from dietitian, occupational therapy, physiotherapy and speech & language therapy on www.alzscot.org/talking dementia & @AHPScotblog
- Supported "AHPBlether" spots around Scotland from Inverness to Dumfries and Kilmarnock to Edinburgh
- Challenged ourselves to use images and photographs which we shared online with the #DAW2015 hashtag and #AHPDementia.
- We all aimed to sign up 10 new people to our blog site at <u>www.alzscot.org/talking dementia</u> encouraging people to connect with us on social media.



Connecting People Connecting Support

During the week we shared 2,000 AHP leaflets and we are ensuring the leaflet is available in all the Alzheimer Scotland Resources Centres, available through our network of dementia advisors and our Alzheimer Scotland link workers. The aim of the leaflet is to enabling the public to learn a little more about 5 of the 12 AHP professions.

During the week we involved 52 allied health professionals who spoke to over 153 people in a range of locations including coffee shops, Strathclyde Park, Alzheimer Scotland resource centres and bus, Garden Centres and local libraries.



For the week, on social media, we posted seven blogs, answering 22 questions from people living with dementia and their families on access, team working, diet & nutrition, being creative, maintaining hobbies and interests, aids, adaptions & equipment, staying mobile, falls prevention, communication and maintaining conversations. We had over 1,204 views that week on the blog posts. We also shared over 56 photos of friends, family and colleagues supporting the week. All our social media activity can be seen here https://letstalkaboutdementia.wordpress.com/2015/06/18/dementia-awareness-week-scotland/#respond

For every conversation we had during the AHP blethers, we invited the allied health professionals to reflect on four questions.

- 1. What were the themes of the conversations?
- 2. What bits stand out for you or struck you? Why was this?
- 3. What were the positive elements of the conversations?
- 4. What does the AHP blether tell you about what matters?

The reflections were to enable us to consider what worked well and how can we build on the work for next year. This paper summaries the four themes collected from the week's AHP Blethers events.



1. The Role of allied health professionals in Dementia Care

There was a genuine interest in the role of AHPs in dementia care. Many people had heard of the individual professions but many did not know what an AHP was or our role in dementia care. The AHP leaflet proved of interest to people and was very positively received.

2. Living Well with Dementia

Many people are living well with dementia and found general health promotion information useful.

3. Raising Awareness of Dementia

The week was useful to raise awareness about dementia generally.

4. Support for People with Dementia and their Carers

People with dementia and their carers require the right help at the right time. There was strong support and appreciation on the expertise of the allied health professionals to be shared and develop hints and tips in a range of areas.

The Way Forward

- Continue to raise awareness of AHPs and the role of the AHP in dementia care.
- Promote the use of the Alzheimer Scotland AHP leaflet for people to know what we do and when to refer enabling AHP's to be accessible to people in a range of settings
- Develop our role in health promotion to help people live well with dementia
- Continue to raise awareness about dementia generally
- Highlight the need that people living with dementia need the right support at the right time
- Highlight that people living with dementia and their carers, families appreciate hints and tips on a wide variety of topics
- Highlight that people with living dementia and their carers, families want information in a variety of ways, written, face to face, social media, video as a few examples

ACTIONS

- Build on the "AHP blethers" from 2015 during dementia awareness week in 2016
- Making best use of the AHP leaflet, making sure they are accessible to people in a range of settings
- Continued use of technology and social media e.g. blogs to share our expertise, evidence base and specialist clinical skills

Themes of the Conversations

A thematic analysis of all of the conversations which took place was conducted and the following themes outlined below came out most strongly.



1. The Role of allied health professionals in Dementia Care

There was a genuine interest in the role of allied health professionals (AHP) in dementia care. Many people had heard of the individual professions but many did not know what an AHP was or our role in dementia care. The AHP leaflet proved of interest to people.

- Role of AHPs especially specialist skills in relation to dementia
- Knew who the professions were individually but not collectively as AHPs.
- Genuine interest and enthusiasm for AHPs in relation to supporting people with dementia.
- Everyone thought the leaflets were really useful
- Everyone felt that it would be beneficial for people to know more about what the AHPs can offer in dementia and the difference they can make.
- Information provided was going to help someone
- Conversation with GP. She was really enthused about the potential for AHPs to really make an impact if people with dementia could access us earlier.
- The AHP stall always seemed to be very busy and although everyone didn't have specific questions to ask, when conversation was initiated, they always had something they wanted to say or then ask.
- Knowledge is power! Person with dementia spoke eloquently about how AHPs had made a difference to her life, yet people who could refer (e.g. GPs) may not know why they should refer.
- We need to continue to raise awareness of AHPs in dementia care, especially the term AHP
- Need to consider ways to increase the public's awareness of and therefore customer expectation of AHP's
- We need to keep increasing knowledge and understanding of the role of the AHPs in dementia so people can access us at the right time.
- I found that people were reluctant to chat and were more receptive to taking a leaflet
- Themes from the conversations mainly around people being unclear what AHP's offer and how they can access AHP's locally.
- Keen for clarity on referral pathways
- All experience felt positive from all who were involved, great to raise awareness about dementia and AHP's contribution.
- Keen to learn about other AHP professions, although had a general understand of who these professions were.
- Everyone felt that it would be beneficial for people to know more about what the AHPs can offer in dementia and the difference they can make.
- Despite now having materials to share, the work that still needs to be done in terms of AHP's contribution, how do we capture and share this information.
- That people did not know that we have can provide a service to help them as soon as they are diagnosed (and in many cases whilst they are awaiting diagnoses). It seems to me like we are regularly promoting occupational therapy but people are still not aware of our services.



2. Living Well with Dementia

Many people are living well with dementia and found general health promotion information useful.

- Living well with dementia/public health
- Most people were keeping well at the moment.
- There were a number of fun stories about people's lives and the" living well" things that made life okay
- conversation about ageing well generally, how to keep active physically and mentally
- positive health messages about ageing well and living well with various conditions into older age is a conversation worth striking up with people
- That so many people are living well with dementia.

3. Raising Awareness of Dementia

The week was useful to raise awareness about dementia generally.

- People were talking about people they knew or were related to who had had dementia
- Think dementia is more openly discussed than it was previously
- Feeling of stigma and negative attitudes towards people with dementia
- Over publicised in the media and considering does a diagnosis matter?
- All experience felt positive from all who were involved, great to raise awareness about dementia and AHP's contribution.
- The general public are starting to take notice about dementia, people have more of an interest, communities need to be educated and on board with developments. We as AHP's need to be better promoting what we offer, show case examples of good practice, educate GP's, link with schools and community groups.

4. Support for People with Dementia and their Carers

People with dementia and their carers require the right help at the right time.

- There was a lack of information available to people about what support care home staff can offer to people with dementia
- Discussion about ways to support each other within a community in a skill sharing manner, and how it can become increasingly difficult for people with dementia to access these supports as their world shrinks
- There was a need for accessible information for people who need it.
- People want to know how they can make things better for their loved ones
- Strong support for hints and tips
- People need more information about decision making. The middle of the journey delegates appeared better informed. The early stage and the final stages – there were more searching questions.
- As AHP's we need to ensure that the complete journey with dementia need to be addressed.
- Looking for tips as carers, talked about stress and distress and techniques.
- Feeling of isolation for the carers who no longer feel able to access their usual support and social networks



- Protective factors were discussed a few times, keeping well, active, having routines
- It is about people have an awareness of what services are available and how to access these services 'you don't know what you don't know!'
- It reinforces the importance of signposting in that people have some awareness but just need guidance. It also shows that across AHPs, people do have some knowledge of what we do but don't utilise us to our full potential.
- The blethers were a great opportunity to have the opportunity to speak to people before issues arise. Being able to spread a more health promotion message
- Appreciate hints and tips in a range of areas.



Additional questions asked during the week

Dementia Awareness Week

We also invited questions from the public and outlined below is a range of the questions asked and answered.

- How do you know if forgetfulness could be more serious, potentially dementia?
- What can you do when the person won't seek help for GP for memory?
- What activities help maintain everyday skills? Need ideas?
- What are the first symptoms? What support is available? How can occupational therapy help?
- What is dementia? Is there respite for carers, wives, relatives?
- Do you have child friendly leaflets?
- Should the first point of contact be the doctor? Are there any local support groups? Where and when are they held?
- Education, information sessions in schools, community venues, church guilds
- How do I access an occupational therapist or allied health professional
- What is an occupational therapist or allied health professional?
- Should I correct a dementia sufferer when they keep repeating the same story over and over, they have got something wrong?
- What respite support is available?
- Is memory decline always the start of dementia??
- Why are we not told about AHP's?
- Can I self-refer for occupational therapy?
- Do you help support carers?
- Why are there no AHP's routinely in care homes?
- How do I encourage activity for my husband?
- Can I have help from physio for loss of mobility and now confidence?
- Any food ideas to tempt my mum??
- Looking for child friendly material to help educate grandchildren?
- How can we improve community awareness?
- Are there supports and groups in evenings and weekends?
- Is there a family link, I'm worried as strong family history?
- Is there medications to help?
- I get frustrated as a carer what should I do?
- How can I help stimulate my mum at home?
- Why is there such a long wait for occupational therapy and physiotherapy?
- Why are AHP's not offered routinely?
- Sleep has become a problem what do I do?
- What activities are good?



Thank you to all 52 of our AHP's who supported the "AHP Blethers" during #DAW2015

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