

# Dementia Action Alliance



## DAA Quarterly Meeting

The Dementia Action Alliance held its first meeting of 2016 on 23 March at the College of Occupational Therapists and was attended by around 65 delegates. Our thematic Quarterly Meetings in the past have included psychosocial therapies, co-morbidities, safeguarding, and creative therapies.

This meeting focussed on unspoken and contentious issues in dementia. We wanted to cover topics that are not often talked about and perhaps not even thought about and so we had a fantastic range of speakers informing the audience about LGBT issues, intimacy, and cultural perspectives.

For the session on LGBT issues, we heard from York LGBT Forum, a Health Psychologist and a lady whose same-sex partner was in a care home with dementia. A playwright consequently wrote a play about her experience looking at both the issue of dementia and same-sex relationships. As an aside, the [DAA will be putting on this performance](#), entitled Don't Leave Me Now in April for DAA members. Dr Joanna Semlyen stated that "LGBT older people experience double stigmatisation, firstly because of their sexual and/or gender identity and secondly because of stigma associated with old age. This experience of double stigma leads to a cumulative health inequality".

We heard from a doctor about her research into intimacy and followed this up with group work looking at various case studies around intimacy.

Lastly we heard about the different cultural perceptions of dementia from the South Asian, African Caribbean and the Irish communities.

"Fascinating insights into issues I hadn't thought about. I've gone back to the office today and my colleagues have all been really interested hearing about the issues raised - things they hadn't considered either".

The DAA wants to continue concentrating on meaty and contentious issues at further meetings, hoping that we can shine the spotlight on areas of dementia that people so often forget about.

## Dates for your diaries

- 18<sup>th</sup> April – Agenda Setting Meeting: London
- 19<sup>th</sup> April – Board Meeting: London
- 27<sup>th</sup> April – Don't Leave Me Now play: London
- 22<sup>nd</sup> June – Quarterly Meeting 2: London
- 14<sup>th</sup> September – Quarterly Meeting 3: Bradford

## Action update of the month:

### Bournemouth University Dementia Institute

We continue to have a strong commitment to carrying out high quality research and to contribute to the evidence for non-pharmacological interventions and innovations in practice. We continue to work locally, nationally and internationally with stakeholders.

Please remember to regularly provide a Quarter Update for each of your online Actions. For a reminder on how to do so, please read the website [user manual](#).

## Members

We warmly welcome our newest members

### Local:

There were 113 new Local members in March.

### National:

There were no new National members in March.

## DAA at a glance

March 2016

Total membership = 4040

Total actions = 14579

Total Local Dementia Action Alliances = 217

*We spoke to Martin and asked him a few questions....*

### **1. What has been your career path to date?**

The majority of my career has been in the voluntary sector and I have been chief executive or Five British charities and I was a trustee of age concern England. I also worked for several years in Africa on HIV/AIDS projects and the two areas I have concentrated on in my career are older people's care and HIV.

### **2. What is Care England doing to improve the lives of people affected by dementia?**

Care England has done many things to improve the quality of services for people living with dementia. I wrote the Prime Minister's compact for the independent care sector and secured the signatures of over 3000 care services. In order to sign the compact, care providers had to make a public statement about how they intended to improve services to people living with dementia

### **3. What is a project that you have really enjoyed being involved in?**

I was particularly pleased to work on a project in Uganda supporting older people who were the main carers of children with HIV. This project developed new opportunities for older people to become part of co-operatives and to share caring responsibilities and also to generate income that will sustain the families

### **4. What do you see as being the key strengths of the DAA?**

I think the main strength of the DAA is the connection between people who are living with dementia, their families and carers, and the people who provide services. By understanding the needs of people living with dementia care providers are much more able to understand what

their services need to do to improve the quality of life of the people who are using the services

### **5. What more needs to be done to support people affected by dementia?**

One of the major challenges that people living with dementia face is ageism. The health and social care system is very ageist and the amounts of money that are allocated to people who are living with dementia, compared to younger people with other disabilities, is vastly disproportionate. Ageism is evident in every aspect of health and social care, from needs assessment to services packages. People living with dementia are discriminated against compared to younger people with other disabilities. People living with dementia and their families need to be given far more community support, and there needs to be much greater focus on the role of GP surgeries and how they can support people living with dementia and their families.

### **6. What would be your one ask of DAA members?**

I would ask all DAA members to focus on challenging ageism in the health and care system

### **7. Tell us something interesting about yourself.**

I was once interviewed on TV by Jeremy Kyle

#### **About the DAA**

The Secretariat is based at Devon House, 58 St Katharine's Way, London, E1W 1LB and can be contacted at [dementiaactionalliance@alzheimers.org.uk](mailto:dementiaactionalliance@alzheimers.org.uk)

To visit the Dementia Action Alliance's website, please go to [www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)

Follow us on twitter @dementia\_action

# Member Activity

## British Geriatrics Society Spring Meeting 2016

The BGS Spring meeting at ACC, Liverpool on 11-13 May 2016 will cover the latest scientific research and the best clinical practice in care of older people. Our ageing population is stimulating extensive NHS service redesign to deal with the challenge of caring for larger numbers of older people both in and out of hospitals. This conference will cover core areas of interest to all specialists responsible for the health care of older people in the United Kingdom.

Who should attend:

- Consultants and specialist doctors in geriatric medicine
- Researchers in geriatric medicine
- Doctors training in related specialties
- GPs wsi in Older People and GP trainees
- Nurses and allied health professionals
- Core medical trainees considering a career in geriatric medicine

Why participate:

- Understand more on the key areas & challenges faced in geriatric medicine
- Hear focused presentations on core areas of the geriatric medicine
- Present the latest scientific research to British Geriatrics Society members and elected officers
- Attend small, focused group workshop sessions
- Network & socialise with other healthcare professionals over 3 days

Please [register here](#) for BGS' meeting.

**Action: Read the [programme](#) for the day**

## Coping with personal hygiene

How can you cope when a person with dementia refuses to wash or change their clothes? It's not an easy subject, but there are things you can do without the issue becoming an unpleasant confrontation. Christina Macdonald at The Alzheimer's Show has written an article on this that includes the following abstract:

A person with dementia can appear to lose interest in how they look, even if they used to take great pride in their appearance. It can be upsetting for family members and loved ones of the person to see their appearance slide, and observe them walking around with dirty clothes or unruly hair.

It's a sensitive subject of course, and not an easy one to bring up with the person. Firstly, consider why it might be happening. It could be for a variety of reasons. The person might be depressed (and need to see their GP), or find it hard to get washed and dressed. Alternatively, they may not even realise they are putting dirty clothes on.

[Read the full article online.](#)

**Action: Read more about [The Alzheimer's Show](#).**

## Upcoming Arts4Dementia Workshops

### Music at St Mary The Boltons

Starting 19th April, there will be eight sessions on Tuesday mornings in the idyllic church of St Mary the Boltons with fantastic musicians from the [Jacquin Trio](#), Jessie and Charis. These sessions would not be happening without the incredible generosity of Edwina Sassoon and St Mary the Boltons.

### Opera Aboard the Angel Canal Boat

Starting 19th June, there will be a series of four free opera trips on Thursdays sailing down the Regent's Canal. This is a wonderful opportunity to sing some famous arias as the canalboat glides along the Regents Canal and rises and falls in the lock.

Contact A4D to [register](#).

**Action: Find out about the work of [Arts4Dementia](#)**

### How can we improve support for carers?

Informal carers (also called unpaid carers) are people who look after family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or care needs related to old age. This does not include any activities as part of paid employment.

Carers freely give their time and energy to support friends or family members and many rightly take pride in providing essential support for those close to them. Caring for others should not be to the detriment of the carer's own health and wellbeing and carers can receive support in a number of ways – including from social services, the NHS, or the benefit system.

Department of Health think that we need a new strategy for carers setting out how we can do more. One which reflects their lives now, the health and financial concerns they have, and gives them the support they need to live well whilst caring for a family member or friend.

To help DH develop the strategy, they want to hear from carers, those who have someone care for them, business, social workers, NHS staff and other professionals that support carers.

It's a simple question but it can have a lot of different answers – how can we improve support for carers?

Complete the survey on [DH's website](#).

**Action: Read Dept. of Health's [other consultations](#)**

### Consulting People Living with Dementia and Their Carers about Engaging with the Natural Environment

A new report published recently highlights how engagement with nature and the great outdoors could be improved for the benefit of people living with dementia and their carers.

Spending time in the natural environment has been shown by many studies to have a beneficial effect on people's overall sense of wellbeing. Less research has been carried out about its effect on people living with dementia. The 'Is It Nice Outside?' report builds on DA's previous 'Greening Dementia' report that Dementia Adventure worked on with Natural England and the Woodland Trust in 2013 which provided a helpful summary of the evidence into the benefits and barriers to engagement with the natural environment for those living with dementia. However, it was felt that this research could be built on to include the direct feedback of both people living with dementia and their carers.

[Read Dementia Adventure's report](#).

**Action: Find out about the work of [Dementia Adventure](#)**

### Is the telly good for older people with dementia?

"Is TV an escape from the world or a window into the world?" Watching TV is often portrayed as a passive and unhealthy pastime. In relation to elder care, the use of TV in care homes is often associated with poor care. Most research in this area focuses on the negative impact of TV consumption on the lives of older people, especially in care home settings.

A recent Dutch study looked at how viewing patterns changed in complex ways in response to personal experience. For example during a period of loss we can find television plays an important part in helping us adapt to our new circumstances. This will also be

true for carers facing the perceived loss of the person they are caring for as the effects of dementia progress. Tastes also changed with some types of programme becoming more important and older people themselves reflecting a wide range of views about the value of TV to them.

To read Prof June Andrews' full article [click here](#).

**Action: Learn about the work of [DSDC, Stirling](#)**

### **PHE launches One You**

PHE have launched 'One You', a ground-breaking new campaign to help adults across the country avoid future diseases caused by modern day life.

Living healthily in midlife can double your chances of being healthy at 70 and beyond. 'One You' aims to encourage adults, particular those in middle age, to take control of their health to enjoy significant benefits now, and in later life.

Latest figures show that life expectancy at older ages is at record levels, yet many are spending their retirement living in ill health. Currently 15 million Britons are living with a long-term health condition, yet studies show living healthily in middle age can double your chances of being healthy when you are 70.

The new campaign from Public Health England will help adults to move more, eat well, drink less and be smoke free. One You will also provide information on how people can reduce their stress levels and sleep better.

It will encourage adults to start by taking a new online health quiz called 'How Are You'. This innovative quiz provides personalised recommendations based on your results and directs people to tools and advice to help them take action where it's most needed. Over half

(56%) of 40 to 60 year olds taking the 'How Are You' quiz said they were likely to change their lifestyle to improve their health because of the feedback it gave them.

Take the '[How Are You](#)' online quiz.

**Action: Read more about '[One You](#)'.**

### **Recruitment:**

#### **National Development Team for inclusion**

*NDTi is a social change organisation delivering practical support, policy advice & research to promote inclusion.*

#### **Research & Evaluation Officer**

Minimum of two years' experience. This is a fantastic opportunity for a dedicated individual to undertake research and evaluation projects in the not for profit sector and to join a passionate and vibrant organisation.

Salary up to £27,000 per annum  
Full time, Permanent

Further info visit NDTi's [recruitment](#) page.

*Closing date: Monday 11th April 2016.*

#### **Programme Lead - Mental Health**

You will lead NDTi's work to ensure that people living with mental health conditions can live a good life in their communities. With expertise in delivering service change, you will be well connected in the field and capable of generating income/ funding to make things happen.

Salary up to £54,000 per annum

Further info visit NDTi's [recruitment](#) page.

*Closing date: Monday 15th April 2016.*

## PM's Challenge on Dementia 2020

*The DAA are going to be shining a spotlight on the Prime Minister's Challenge in every newsletter as we want to help DoH help implement this important piece of work. This month we look at developments in Health Education England's Dementia Education and Training Project*

The *Prime Minister's Challenge on Dementia 2020 Implementation Plan*, published in March 2016 requires Health Education England (HEE) to work with NHS Trusts to ensure availability of (a) tier one dementia awareness training to all staff and (b) more in depth role-based training (outlined in page 45 of the [Dementia Core Skills Education and Training Framework](#)) for all staff who treat NHS patients and work regularly with people with dementia.

Underpinning this requirement is the [Dementia Core Skills Education and Training Framework](#).

The Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health, Health Education England, Skills for Care and an expert advisory group that ensured multi-organisational and multi-stakeholder representation. It uses key learning outcomes and essential skills and knowledge for individual roles to support the development and delivery of quality dementia education and training. Designed for everyone working in health and social care settings – regardless of whether they provide clinical care, offer information or provide support and assistance in other ways – the Framework sets out the skills and knowledge required to recognise the signs of, and provide appropriate care for, people living with dementia. It's structured into three tiers, from effective basic training, to continuous professional and vocational development aimed at experts and those leading and influencing dementia services.

To support widespread availability of tier one resources, HEE's e-Learning for Healthcare (e-LfH) programme has updated its [dementia e-learning programme](#), available free of charge for the NHS workforce. HEE continues to monitor delivery of dementia awareness training via a biannual survey to NHS trusts.

Supporting the wider rollout of tier two dementia education and training programmes, the Dementia Education and Learning Through Simulation (DEALTS) training package, which has been evaluated very positively, has been rolled out nationally, and screenings of Nottingham University's film 'Inside Out of Mind' have been promoted. As the Framework embeds, HEE looks to support further tier two and three education and training initiatives and will work with the Dementia Expert Advisory Group to facilitate working across the health and social care systems.

To investigate the components that form the most effective approaches to training health and social care staff about dementia, the Department of Health have commissioned Leeds Beckett University to produce 'What Works?', a longitudinal study into dementia education and training. A literature review looking at evidence of the most effective features of training and what leads to the best outcomes for patients is currently underway. The recommendations of this review will be tested through a case study approach and the final report will be published in summer 2017.

In addition, HEE is producing two films to raise awareness of dementia in two specific settings. The first focuses on awareness in African Caribbean communities and the second on dementia care in social care settings. The films will be available later this year for health and social care providers to use in training sessions.