

Dementia Action Alliance Secretariat Report

(Second Quarterly Meeting – May 2012)

Introduction

This is the second Secretariat Report of 2012. It provides an update on the activity of the Alliance and the Secretariat since the last report in February 2012.

Overview

The activity of the Secretariat since February 2012 has focused on the following activity:

1. **Membership:** Inviting and inducting new members
2. **Action Groups:** Supporting the development and conclusion of two Action Groups
3. **Quarterly meeting:** Organising the 30th May 2012 quarterly meeting
4. **Newsletter:** Producing four newsletters
5. **Prime Minister's Challenge on Dementia:** Providing briefings to the Prime Minister on the Alliance
6. **Local Dementia Action Alliances:** Launch of Northamptonshire Dementia Action Alliance
7. **Website:** Updating and revamping the website, growing the Ning social networking site and initiating a rebuild of the website

Membership Report

Dementia Action Alliance membership incorporates a range of statutory, private and voluntary sector organisations whose work directly or indirectly affects people with dementia and their carers.

The common bond of membership is a:

- Commitment to fulfilling the National Dementia Declaration for England; and
- Producing an Action Plan to describe how they are progressing the values embodied within the Declaration.

There are now a total of 113 organisations that are members of the Alliance. Two organisations have changed their names, Cross Road Care and the Princess Royal Trust for carers have merged to form the Carers Trust and Counsel and Care are now known as Independent Age.

New members

New members join the Alliance through one of two routes:

- Invited to join by an existing member; and
- Direct approach to the Alliance.

Since the last quarterly meeting on the 15th February, 20 organisations have formally joined the Alliance; signing up to the Declaration and submitting Action Plans.

The new members registered since the last quarterly meeting (February 2012) are:

- Age UK Northamptonshire
- Barnsley Hospital NHS Foundation Trust
- Citrus Training Solutions
- dementia web supported by Guide post trust
- Excelcare
- Frimley Park Hospital
- Ladder to the moon
- Norfolk and Suffolk Dementia Alliance
- Northampton General Hospital
- Northamptonshire Association for the Blind
- Northamptonshire Fire and Rescue Services
- Nutricia
- Richmond Village, Northampton
- Royal Pharmaceutival Society
- Skills for Care Yorkshire & Humber
- Social Care Workforce Research Unit, King's College London
- The Society of Later Life Advisers (SOLLA)
- Southern Healthcare
- The Good Care Group
- Vitalise

Other approaches

A number of organisations, proposed by Alliance members, have also been invited to join during the subsequent quarter to move the membership beyond the health and social care sector.

Table 1 below lists these, those saying no and those still waiting to make a decision:

Table 1: Organisations approached	
Organisation	Status
Red Cross	Still corresponding
National Care Association	Awaiting response
British Dietetic Association	Due to have meeting soon
Dementia Care Matters	Awaiting response
Registered Nursing Home Association	Awaiting response
Saint Francis Hospice	Awaiting response
Missing People	Still corresponding
Colten Care Ltd	Awaiting response
Westminster College	Awaiting response
Trading Times	Awaiting response
ode	Awaiting response
Groupe	Awaiting response
Buddi	Awaiting response

Alliance members: Local / National breakdown

There are two types of membership in the Alliance: national and local.

National members of the DAA

'National members' of the Dementia Action Alliance are organisations which work across England or that have an aspiration to deliver better outcomes across England (and beyond, if organisations work across nation boundaries). They publish an Action Plan on the DAA website. National members of the Alliance take part in quarterly reporting and quarterly meetings.

National members of the Alliance are:

- 360 Forward
- Age Related Diseases and Health Trust
- Age UK
- All-Party Parliamentary Group on Dementia
- Alzheimer's Research UK
- Alzheimer's Society
- Anchor Trust
- Association for Dementia Studies, University of Worcester
- Association of Directors of Adult Social Services
- Barchester HealthCare
- Bradford Dementia Group
- British Association for Counselling and Psychotherapy

- British Geriatrics Society
- British Psychological Society
- Bupa Care Services
- Care Quality Commission
- Care UK
- Chartered Society of Physiotherapy
- Citrus Training Solutions
- College of Occupational Therapists
- Crossroads
- Dementia Adventure
- Dementia Advocacy Network (DAN)
- Dementia Services Development Centre
- Dementia UK
- Department of Health
- Design Council
- ECCA
- Excelcare
- Faculty of Psychiatry of Old Age, Royal College of Psychiatrists
- Four Seasons
- Front
- Gloucestershire Constabulary
- Hawker Publications
- HDRC
- Hft
- Housing 21
- Independent Age
- Innovations in Dementia
- International Longevity Centre UK
- Jewish Care
- JRF
- King's Health Partners Academic Health Sciences Centre (AHSC)
- Ladder to the moon
- Lewy Body Society and Parkinson's UK
- Life Story Network
- LloydsPharmacy
- Local Government Group
- Lost Chord
- Lundbeck
- Mental Health Foundation
- MHA Care Group
- MyAmego Healthcare Ltd
- My Life Software
- NAPA
- National Care Forum
- National Council for Palliative Care
- National Development Team for Inclusion (NDTi)
- National Institute for Health and Clinical Excellence

- National Skills Academy for Social Care
- NHS Alliance
- NHS Confederation
- NHS Institute for Innovation and Improvement
- Nutricia
- Orders of St John Care Trust
- Parkinson's UK
- Pictures to Share C.I.C.
- Priory Group
- RCGP
- Royal College of Nursing
- Royal College of Physicians
- Royal Pharmaceutical Society
- Saga
- Shared Lives Plus
- Skills for Care
- Skills for Health
- Social Care Institute for Excellence
- Social Care Workforce Research Unit, King's College London
- The Society of Later Life Advisers (SOLLA)
- Southern Healthcare
- Stroke Association
- The Good Care Group
- Thomas Pocklington Trust
- Uniting Carers, Dementia UK
- Vitalise
- WRVS
- Young Dementia UK

Local members of the DAA

'Local members' of the Dementia Action Alliance are organisations that work in a specific area of England but do not have national reach. They will have an Action Plan published on the DAA website. They will not have to submit quarterly reports and will not be part of quarterly meetings. Local members will be encouraged to be involved in local partnerships with other organisations to deliver the outcomes for people with dementia and carers described in the National Dementia Declaration.

Local members of the Alliance are:

- Age UK Northamptonshire
- Aspects and Milestones Trust
- Barnsley Hospital NHS Foundation Trust
- Barnsley Independent Alzheimers Aid Dementia Support (BIADS)
- Barnsley MBC
- Blenheim Regal Care Homes Ltd
- Brenalwood Regal Care Homes Ltd
- Coverage Care Services Ltd
- Deja Vu Dementia Centre of Excellence

- Dementia Services Development Centre South East (DSDCse)
- Doncaster Older Peoples Mental health Steering Group (OPMHSG)
- Frimley Park Hospital
- Great Western Ambulance Service
- dementia web supported by Guide post trust
- Kent & Medway Dementia Service User Envoy
- Kirklees Council
- Norfolk and Suffolk Dementia Alliance
- Northampton General Hospital
- Northamptonshire Association for the Blind
- Northamptonshire Fire and Rescue Services
- Northamptonshire Police Force
- Notting Hill Housing
- Nottinghamshire Healthcare Trust
- Richmond Village, Northampton
- Skills for Care Yorkshire & Humber
- The ExtraCare Charitable Trust
- Uniting Carers, Dementia UK
- Wakefield Dementia Strategy Board
- Wellbeing (Adults) & Communities, Personalisation and Commissioning

Action Groups

To enable the Alliance to be more than the sum of its part, the Secretariat has supported three areas of joint activity since our last quarterly meeting in February 2012.

These were:

- Research into access to drug treatments and memory services
- Boosting timely diagnosis rates campaign
- Call to Action to improve hospital care

Research into access to Alzheimer's disease drug treatments and memory services

In March 2012 NICE changed their guidelines on drug treatments for Alzheimer's disease extending access to four anticholinesterase drug treatments to all people with a diagnosis of dementia. One year on the Dementia Action Alliance investigated the impact of these changes on the lives of people living with dementia.

Using survey data from people working with people with dementia, the study demonstrated that despite this change, people with dementia were still struggling to gain access to drug treatments and memory services, with lack of GP awareness the most common barrier given.

The findings were launched on the 11th April and promoted through a series of interviews on local and national radio. The report can be downloaded at:

Boosting timely diagnosis rates campaign

Due to the Age Related Diseases and Health Trust's generous support, the timely diagnosis action group has continued to benefit from a dedicated coordinator. Since the last quarterly meeting an Advisory Group has been established to guide the Alliance's work in this area and identify opportunities to add value to existing and developing programmes of work such as the Prime Minister's Challenge on Dementia.

The Advisory Group met for the first time on Monday 21st May to review the draft recommendations of the All Party Parliamentary Group on Dementia's report on early diagnosis. The Advisory Group has provided constructive feedback on the report and will be coordinating an Alliance response to it following the formal launch 3rd July 2012. This will be focus of discussions at the next quarterly meeting.

'Call to Action: Improving the experience of people with dementia and their families in acute care

At the last quarterly meeting the Dementia Action Alliance endorsed an NHS Institute bid to launch a new Call to Action on the improving experience of people with dementia and their families in acute care. Through breakout sessions members also provided ideas and content for the bid which was submitted to Quality, Innovation, Productivity and Prevention (QIPP) funders following the event.

We are pleased to announce that the bid has been successful and the formal planning stage has now been initiated. Members will have an opportunity to participate in this early stage through either:
Strategy discussions on 24th May
Front line staff workshops on 5th July.

If you are interested in participating in the front line staff workshops please contact the Secretariat for more information.

If as a member you would like to take a lead on any of the Action Groups listed above, or start a new one, and would like support, please contact the Secretariat on: dementiaactionalliance@alzhiemers.org.uk

At the Alliance meeting on the 30th May members will also be discussing the possibility of initiating a joint campaign on supporting carers.

Quarterly meeting / updates

The Second Quarterly meeting of the Dementia Action Alliance in 2012 will occur on the 30th May 2012. It will be held at Directory of Social Change, 24 Stephenson Way, London, NW1 2DP.

The Agenda was set at a meeting of Alliance members on the 24th April 2012 with the elected co-chair, Sharon Blackburn, providing final sign-out. The final agenda for this meeting has been circulated with the link to this document.

The Second Quarterly update report of 2012 has also been completed, with 48 members submitting substantial progress reports this quarter. The report can be viewed at:

http://www.dementiaaction.org.uk/downloads/3/national_dementia_declaration

Newsletter

Since the last quarterly event, three newsletters have been published, with another due in early June after the next quarterly meeting.

The newsletters have been used to:

- Highlight the work of Alliance members;
- Invite Alliance members to fellow Alliance member events;
- For Alliance members to request help from each other;

Newsletters can be downloaded at:

http://www.alzheimers.org.uk/dementiaaction/downloads/1/participating_organisations

If you would like to promote any work, event or research please contact the Secretariat at dementiaactionalliance@alzheimers.org.uk

Prime Minister's Challenge on Dementia

In March 2012 the Prime Minister launched his Challenge on Dementia. The Challenge includes comprehensive commitments on boosting early diagnosis, improving hospital care, increasing research monies and creating dementia friendly communities.

The Secretariat has played an active role in briefing the Prime Minister on the work of Alliance and the impact of its members on improving the lives of people with dementia. This has resulted in Dementia Action Alliance playing a leading role in creating dementia friendly communities through creating Local Dementia Action Alliance.

The Alzheimer's Society will be supporting the initial development of these local Alliances through their area offices. The Chairs have asked for Local Dementia Action Alliances to be a focus of discussion at our next quarterly meeting to ensure that the Alliance is able to maximise the opportunities presented by them and the wider Challenge.

The full Challenge can be viewed at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170

Local Dementia Action Alliances

The last Secretariat report described the growth of Local Dementia Action Alliances. As stated previously, Local Alliances can provide a useful vehicle for delivering the National Dementia Declaration because they can:

- Continue the momentum built up in the regions by the National Dementia Strategy
- Actively involve local members (local authorities, health trusts, police authorities, businesses) and local offices of national member organisations in undertaking joint actions
- Provide an additional route for delivering national Dementia Action Alliance initiatives such as Calls to Action.

Local Dementia Action Alliances have continued to grow with Northamptonshire Dementia Action Alliance formally launching on the 21st May.

Members included branches of existing national members, namely:

- Age UK
- Alzheimer's Society
- Parkinson's UK

And local members:

- Northamptonshire Police
- Northamptonshire Fire Service
- Parkinsons UK
- Northampton General Hospital
- Northamptonshire Association for the Blind
- St Andrews Health Care
- Northants County Council
- Northants Fire Service
- NHFT

The launch was chaired by Jillian Powell from Age UK. Members discussed each others Action Plan commitments, identified areas of joint working and agreed to look in detail at the Declaration and how it relates to the needs of people with dementia in Northamptonshire. The event was covered in the local press and radio.

Alzheimer's Society provided the Secretariat for this initial launch and has received funding from the Department of Health to develop similar Local Dementia Action Alliances across the rest of England. How the national

Dementia Action Alliance wishes to relate to these local alliances will be the focus of discussions at the next quarterly meeting.

Website

The Secretariat has continued to utilise the current Dementia Action Alliance website, uploading Action Plans and updating the news section.

To coincide with the launch of the Prime Minister's Challenge on Dementia, design company Brand Fuel were commissioned to work within the confines of the existing platform to improve the overall look of the website.

The new homepage is now more engaging which, combined with the Prime Minister's Challenge, has resulted in a marked rise in traffic to the website with unique visitors increasing from approximately 450 a week in February to 600 in May.

Building on these improvements, the Secretariat is aiming to radically improve the web-presence of the Dementia Action Alliance and has drawn together the following objectives for the new website:

Primary:

1. Build a social movement of businesses, charities and public bodies that are undertaking action to make radical improvement in the lives of people with dementia
2. To connect members to facilitate collaboration, share good practice and support business planning
3. To create web-space for Local Dementia Action Alliances to store information, upload Action Plans and have regular news section
4. Promote the work of the Alliance and its members to external audiences including stakeholders and people living with dementia
5. Make the site more user-friendly including for people living with dementia e.g. following W3C guidelines

Secondary:

6. To provide information to organisations that want to undertake actions to improve the lives of people living with dementia
7. To present Action Plans and updates in an accessible and engaging format that encouraging further commitment from existing and future members
8. Utilise member existing online-presence i.e. SCIE Dementia Gateway and Alzheimer's Society Factsheets

Members will have an opportunity to provide feedback on these objectives at the next quarterly meeting. The new website will be developed over the summer with the formal launch taking place at the next quarterly meeting in September.

In the mean time if you have any news items that you would like to be uploaded onto the Dementia Action Alliance website, please contact the Secretariat on: dementiaactionalliance@alzheimers.org.uk

The Ning

To support members in contacting each other between quarterly meetings, the Secretariat has established a social networking site known as a Ning. The Ning currently has 91 members and can be used by members to start initial Action Group discussions on boosting early diagnosis for example.

The Ning also has a calendar function so if you have any events coming up, please register them so other members can come along.

To join the Ning please visit: dementiaactionalliance.ning.com

Finance report

The Dementia Action Alliance is funded by its members. All members are invited to make a voluntary contribution based on the turnover of their organisation.

Alzheimer's Society acts as the accountable body for the Dementia Action Alliance. This involves collecting contributions and ring-fencing Alliance monies and expenditure using a separate cost code centre.

Income

Table 2 below provides an overview of the income of the Alliance to date. The total committed has now risen to £124,625.

Table 2: Dementia Action Alliance Income			
Contribution	Committed	Received (as of 23 May)	In kind support
Department of Health	£40,000	£40,000	
Alzheimer's Society	£30,000	£30,000	
BUPA	£5,000	£5,000	
Age UK	£5,000	£5,000	£1,300
Anchor	£5,000	£5,000	
WRVS	£5,000	£5,000	
Lundbeck	£5,000	£5,000	
JRF	£5,000	£5,000	
ExtraCare	£5,000	£5,000	
Social Care Institute for Excellence	£2,500	£2,500	
British Geriatrics Society	£1,000	£1,000	
Dementia UK	£1,000	£1,000	
ARUK	£1,000	£1,000	
National Care Forum	£250	£250	
Annual Event Bupa Sponsorship	£12,000	£12,000	
Annual Event Stalls	£1,875	£1,875	
Design Council			£3,000
The British Association of Occupational Therapists (BAOT) and College of Occupational Therapists (COT)			£1,300
Journal of Dementia Care			£500
Total	£124,625	£124,625	£6,100

Expenditure

Table 3 below provides the original estimated costs and breakdown by budgetary item. It is accompanied by predicted expenditure based on estimated actuals to date.

Table 3: Dementia Action Alliance Expenditure			
Item	Original Forecast	Estimate* to date from 29 June 2011 (to 09 Feb)	Predicted Actual* at end of year (July 2012)
Secretariat staffing	£84,000	£53,048.50	£70,683.60
Venue hire and subsistence for Alliance meetings	£10,000	£1,785.40	£1,785.40
Accommodation and travel costs for people with dementia and carers	£5,000	£4,200.72	£4,200.72
An Annual Report	£2,000	£5,071.72	£5,071.72
An Annual Event	£6,000	£13,149.00	£13,149.00
Website development	£3,000	£3,360.00	£3,360.00
Total Budget	£110,000	£80,615.34	£98,250.44

*These are estimates and maybe subject to revisions

Surplus income

The Dementia Action Alliance is predicted to have surplus of £26,375 in its first year. Approximately £15,000 of the surplus income has been allocated to redeveloping the website. The spending of the remaining surplus income will be discussed by members at the next quarterly meeting.