

The Dementia Action Alliance and National Dementia Declaration for England

Introduction

On 26 October the Dementia Action Alliance was launched. The Alliance is a coalition of 45 organisations committed to improving quality of life for people with dementia and their carers in England by 2014 (the date when the National Dementia Strategy comes to an end). On launch the Alliance published a National Dementia Declaration explaining the outcomes we seek to deliver for people with dementia and their carers. In addition each signatory organisation has published an action plan setting out what their role is in delivering better quality of life for people with dementia and their carers and the actions they intend to take in order to help deliver those outcomes. This paper explains how the initiative came about, how it may develop and the role the Society will play.

How did the Alliance and Declaration come about?

Public and political commitment to dementia has grown significantly in recent years to a position where dementia is now a major strand of public policy discussion. In February 2010, one year into implementation of the National Dementia Strategy and following the National Audit Office report on the National Dementia Strategy and the Public Accounts Committee hearing, Alzheimer's Society instigated discussions with the Department of Health, Association of Directors of Adult Social Services and English Community Care Association. It was agreed that while there had been good early progress on delivery of the Strategy we were about to go into a period of change with the possibility of a new government and significant financial pressures for public services. The Society suggested that the key to ensuring sustainability through a politically and economically turbulent period would be to see the development of a more formal Alliance of organisations that would sign up to delivery.

The Society decided to wait until a new Government was in place before progressing this initiative. In May a meeting of Alistair Burns (National Clinical Director for Dementia), Ruth Sutherland (Interim Chief Executive, Alzheimer's Society), Jenny Owen, Martin Green (Chief Executive, English Community Care Association), Jerry Bird (Department of Health Dementia Strategy Project Manager) and Andrew Chidgey (Head of Policy and Public Affairs, Alzheimer's Society) took place to discuss a proposal from the Society for the development of a National Declaration. A core concept and list of organisations to approach was agreed by the group.

Following the election proposals on the future of the NHS were published setting out plans to reduce central government work on health and devolve further responsibility to local areas. In addition the government made clear its intention to enforce tough public spending restraint to reduce the budget deficit and began setting out more details about the Big Society. All of this augured well for the creation of an Alliance.

Setting up the Alliance

On 26 July a summit was held where people with dementia, carers and representatives from 30 organisations met to discuss the development of a National

Dementia Declaration. There was significant enthusiasm from participants to the proposal and the following was agreed as an approach by the group:

- There was broad support for the concept of a National Dementia Declaration and all organisations attending the event wanted to be involved in its development.
- The group wanted a Declaration which described the key outcomes for people with dementia and carers that we wanted to achieve.
- A strong view from the group was that it wasn't enough for people to simply sign up to the Declaration but that they also had to set out what they would specifically do by 2014 to help deliver better outcomes for people.
- Time was of the essence and we should act quickly.
- Stage one of the initiative should be about developing an inner circle of organisations who see dementia as their core business before the end of 2010.
- Stage 2 of the initiative in 2011 should be about developing an outer circle of organisations who do not see dementia as their core business but which have the potential to help deliver better quality of life for people with dementia within a dementia supportive community. The group felt that a large range of individuals, businesses, civic organisations and professions might be involved in this task. It should be the responsibility of members of the group to bring on board other partners.
- Some additional partners for the group were suggested to be approached.
- The group wanted to share information and monitor progress against commitments over time.

In July a draft National Declaration was sent to participating organisations for comment by 6 September.

In August a template for organisations to fill in explaining their role and proposed actions was developed and sent out for completion by 6 October.

Launching the Dementia Action Alliance and National Dementia Declaration

By the time of launch the following organisations had agreed to be part of the Dementia Action Alliance:

1. Age UK
2. All-Party Parliamentary Group on Dementia
3. Alzheimer's Research Trust
4. Alzheimer's Society
5. Anchor
6. Association for Dementia Studies – University of Worcester
7. Association of Directors of Adult Social Services
8. Barchester Healthcare
9. Bradford Dementia Group
10. British Association for Counselling and Psychotherapy
11. British Association of OTs and College of OTs
12. British Geriatrics Society
13. BUPA
14. Care Quality Commission
15. Care UK
16. Chartered Society for Physiotherapy

17. Counsel and Care
18. Craegmoor
19. Dementia Services Development Centre
20. Dementia UK
21. Department of Health
22. English Community Care Association
23. Four Seasons
24. Housing and Dementia Research Consortium (HDRC)
25. Jewish Care
26. Local Government Group
27. Mental Health Foundation
28. MHA
29. National Council for Palliative Care
30. NHS Alliance
31. NHS Confederation
32. NICE
33. Parkinson's UK
34. Royal College of GPs
35. Royal College of Nursing
36. Royal College of Physicians
37. Royal College of Psychiatrists
38. Skills for Care
39. Skills for Health
40. Social Care Institute for Excellence
41. Southern Cross
42. Stroke Association
43. Thomas Pocklington Trust
44. UK Age Research Forum
45. WRVS

A breakfast stakeholder event was held on Tuesday 26 October for members of the Alliance attended by over 70 people. This was addressed by Peter Dunlop who has dementia, Hazel Leventhal who cared for her sister, Paul Burstow the Minister for Care Services, Tony Robinson the actor and a variety of senior representatives from Dementia Action Alliance organisations.

The event and launch had been arranged to coincide with a Department of Health dementia conference taking place the same day. At the conference Paul Burstow and Ruth Sutherland performed the public launch of the Alliance and Declaration to the 500 delegates from across health and care services. Every delegate received a copy of the National Dementia Declaration and a copy of the action plans.

News of the launch was on the Radio 4 Today Programme and a variety of news bulletins later in the day. It was also on the front page of the Daily Telegraph.

A Dementia Action Alliance website has been set up which can be seen at www.dementiaaction.org.uk

The website includes all of the action plans from Alliance members.

What happens next?

Stage 1 – the inner circle (in place)

Members of the Alliance will meet quarterly to discuss progress and next steps. All organisations will be asked on a quarterly basis to provide updates on their progress in implementing their action plans. An annual report will be prepared on progress, with the first report due in early 2012.

Stage 2 – the outer circle (to be developed, therefore detail at this stage does not exist)

The Dementia Action Alliance has agreed that in 2011 the group intends to begin developing an outer circle of organisations which do not see dementia as part of their core business. This group could include business and civic organisations. The Alliance will agree some key challenge themes to support delivery of the declaration outcomes and then approach other organisations to ask them to take part. A meeting will take place in December 2010 to begin scoping out that work.

Andrew Chidgey, November 2010