DEMENTIA ACTION ALLIANCE
ANNUAL REPORT 2012/13

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360 Forward Limited • Age Related Diseases and Health Trust • Age UK • All-Party Parliamentary Group on Dementia • Alzheimer’s Research UK • Alzheimer’s Show • Alzheimer’s Society • Anchor • Arts4Dementia • Aspects and Milestones Trust • Association of Dementia Studies - Worcester • Association of Directors of Adult Social Services • Barchester Healthcare • Barnsley Hospital NHS Foundation • Barnsley Independent Alzheimer’s and Dementia Support • Barnsley MBC and Barnsley’s Older People’s Expert Partnership & Joint Agency Group • Blenheim, Regal Care Homes • Bradford Dementia Group • Brenlwood, Regal Care Homes • British Association for Counselling and Psychotherapy • British Geriatrics Society • British Psychological Society • BSI Standards • Bupa • Care Quality Commission • Care UK • Carers Trust • Chartered Society of Physiotherapists • Chasewater Railway and Museum Company • Citrus Training Solutions • Clairmont Plc • Counsel and Care • Coverage Care Services Ltd • Crossroads Care Association • Déjà Vu Dementia Centre of Excellence • Dementia Adventure • Dementia Advocacy Network • Dementia Services Development Centre • Dementia Services Development Centre South East (DSDCse) • Dementia UK • Dementia web supported by Guideposts Trust • Dendron • Department of Health • Design Council • Diocese of Lichfield • Doncaster Older Peoples Mental Health Steering Group (OPMHSG) • English Community Care Association • Excelcare • Extracare • Falmouth Dementia Action Alliance • Falmouth Memory Cafe • Find • Finer Day • Four Seasons Health Care • Frimley Park Hospital • Great Western Ambulance Service NHS Trust • Guinness Care and Support • Hft • Housing 2 • Housing and Dementia Research Consortium • Independent Age • Innovations in Dementia • International Longevity Centre UK • Jewish Care • Joseph Rowntree Foundation • Journal of Dementia Care • King’s Health Partners Academic Health Sciences Centre • Kent Skills Academy for Social Care • Skills for Care • Skills for Care Yorkshire & Humber • Skills for Health • Social Care Institute for Excellence • Social Care Workforce Research Unit, King’s College London • South Tees NHS Foundation Trust • South Western Ambulance Service Foundation Trust • Southern Healthcare • Springhill Care Group • Tavistock Dementia Action Alliance • The British Alzheimer’s Society • The Stroke Association • Thomas Pocklington Trust • Truecall • Vitalsen • Wakefield District • Wolverhampton City Council • WRVS • YoungDementia UK
Like many of my friends with an early diagnosis of dementia, I find that, since diagnosis, (I have early vascular dementia) I am asked to contribute in many ways to the debates and challenges regarding good care for those with dementia. Those of us able to speak out are very conscious that we also speak for those whose illness has progressed so that they are not able so easily to write or talk about their wishes and problems.

There are those who help people less able to communicate, which helps us reinforce the message. Many family carers are powerful advocates on behalf of their loved ones. And there are those who develop ways of expressing the feelings of people with dementia who they meet and represent, either by assisting communication – like John Killick and others – or by developing activities that stimulate and bring pleasure.

Sometimes we become distressed by organisations who seem to miss the opportunity of hearing about dementia ‘from the horse’s mouth’. My friends and I are often told that having a person with dementia or a carer describing the needs and problems of the dementia journey is the best way of helping others to understand. But too often it feels that discussions become detached from the realities of ‘living with dementia’.

In the Dementia Action Alliance there are now a variety of people and organisations who are concerned to push forward ideas to improve many aspects of care. Early diagnosis is increasingly recognised as desirable, and ways of improving this are being sought by many organisations. Innovation to improve dignity and wellbeing for those with dementia has become an increasingly common goal.

Working with the Design Council earlier this year was not only stimulating, it was also heart-warming that so many were prepared to develop innovative ways of improving the lives of people with dementia, with so much imagination and hard work. As the Alliance grows I hope that the focussed enthusiasm continues in the years to come, with those with dementia ‘part of the team’.

Dr Daphne Wallace
Retired Psychiatrist Ambassador, Alzheimer’s Society
Having been involved in the birth of the Alliance from the drafting of the Declaration to seeing the growth in the last two years, I feel very proud to be part of this social movement.

All members of the Alliance are passionate about improving the experience of people living with dementia – and by that I mean the person diagnosed with dementia as well as the family carers. Yes, we have done well to spread the word and encourage businesses and organisations to join and work collaboratively; but when we look at the scale of what we have yet to achieve, there is a long way to go.

The Prime Minister’s Challenge has given us more opportunities and support to deliver – at a faster pace – the outcomes which people with dementia and carers called for in the Declaration. And we certainly need to move more rapidly.

Last year Barbara Pointon clearly stated what carers need to help them continue caring longer. As a former carer myself, I meet many families still struggling through the maze of local health and care systems, feeling as if they are abandoned. While we have pockets of excellent practice, it is far from the norm. Family carers are the biggest workforce in the country: we cannot afford not to support them in their crucial role.

I am delighted that the Alliance has collaborated in the Call to Action on improving general hospital care for people with dementia. Family carers, when fully involved during the hospital stay, have a major impact in supporting staff to provide quality care for the person with dementia and achieve a smooth discharge home.

Even better, the Alliance recently agreed to develop a Call to Action for Carers – now we’re motoring!

Jean Tottie
Chair, Uniting Carers Dementia UK
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INTRODUCTION

Dementia is one of the greatest challenges facing our ageing society. In October 2010, 41 organisations working in the field of dementia launched the National Dementia Declaration for England. Developed by people with dementia, their families and the organisations themselves, the Declaration set out a radical new vision of how society should respond to this challenge.

The Dementia Action Alliance was formed by these initial signatories to turn the Declaration into a reality. The Alliance is founded on the philosophy ‘I will if you will’ – a call to action to society, but also a promise from its members to make the same commitment.

Each member has published an Action Plan setting out how they intend to deliver on the Declaration by 2014. Quarterly updates are provided and members meet regularly to share good practice and promote joint activity. The Alliance is supported by a Secretariat, which is hosted by Alzheimer’s Society but funded by Alliance members.

This annual report restates both the need for the Declaration and the scale of challenge to which it responds. It reflects on the past twelve months, celebrating some of the many achievements of Alliance members, the rapid growth of its membership, the impact of its joint work – and sets out fresh commitments for the coming year.
THE SCALE OF THE CHALLENGE

There are currently 800,000 people living with dementia in the UK. By 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain. Over time it seriously impairs the person’s ability to live independently. Symptoms can include severe memory loss, mood and personality changes, and challenging behaviour such as serious confusion, agitation and aggression. Many people with dementia also have other medical conditions or develop them during the course of their illness.

Families currently provide the majority of care and support for people with dementia. This can be both tiring and stressful – physically, emotionally and financially. A large number of people with dementia live alone and can be at particular risk of isolation or abuse. But if people with dementia are diagnosed early, and they and their families receive help, then they can continue to live a good quality of life.

The financial cost of dementia in the UK is £23 billion a year and rising. Two thirds of people with dementia live in their own homes and one third live in care homes. One in four people in hospital have dementia, as do two-thirds of people in care homes. Tackling dementia therefore has profound implications for the long term financial sustainability of the health and social care system.

Responding to this challenge will require a whole society response, from funding research into treatments, to employers training staff to support customers and colleagues affected by dementia.
WHY IS THERE A NEED FOR A NATIONAL DEMENTIA DECLARATION?

— Public awareness of dementia is high but understanding about it is still very poor. Fear of dementia also remains high; there is a reluctance to seek help and few people understand that it is possible to live well with dementia. In addition there is limited understanding of the fact that dementia can affect people in many different age groups.
— The Alzheimer’s Society’s Dementia 2012 Report found that large numbers of people with dementia are not living well with the condition, experience loneliness and continue not to be involved in decisions about them or receive services that are designed around their needs.
— NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
— Only 42% of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late. GPs often report being reluctant to diagnose dementia either because they lack the knowledge to do so, do not see the benefits of early diagnosis or because they are aware of the lack of specialist support and services available for people after a diagnosis.
— Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
— Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
— Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
— Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
— The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia. For example the NAO has highlighted the potential for the NHS to identify savings of at least £284 million per year through improving dementia care. In addition to the costs borne by public services people with dementia and carers face high costs for care.
— Due to commitments made as part of the Prime Minister’s Challenge on Dementia UK spending from all sources on dementia research is high by international standards but continues to be low compared to other conditions.
People with dementia and their family carers have described seven outcomes they would like to see in their lives.

01 I have personal choice and control or influence over decisions about me
   — I have control over my life and support to do the things that matter to me.
   — I have received an early diagnosis which was sensitively communicated.
   — I have access to adequate resources (private and public) that enable me to choose where and how I live.
   — I can make decisions now about the care I want in my later life.
   — I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

02 I know that services are designed around me and my needs
   — I feel supported and understood by my GP and get a physical checkup regularly without asking for it.
   — There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
   — I am treated with dignity and respect whenever I need support from services.
   — I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

03 I have support that helps me live my life
   — I can choose what support suits me best, so that I don’t feel a burden.
   — I can access a wide range of options and opportunities for support that suits me and my needs.
   — I know how to get this support and I am confident it will help me.
   — I have information and support and I can have fun with a network of others, including people in a similar position to me.
   — My carer also has their own support network that suits their own needs.

04 I have the knowledge and know-how to get what I need
   — It’s not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.
   — I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.
   — I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.
   — My carer has access to further information relevant to them, and understands which benefits they are also entitled to.
I know there is research going on which delivers a better life for me now and hope for the future. I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I’m receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

I live in an enabling and supportive environment where I feel valued and understood.

— I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.
— I am making a contribution which makes me feel valued and valuable.
— My neighbours, friends, family and GP keep in touch and are pleased to see me.
— I am listened to and have my views considered, from the point I was first worried about my memory.
— The importance of helping me to sustain relationships with others is well recognised.
— If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.
— My carer’s role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

I have a sense of belonging and of being a valued part of family, community and civic life.

— I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.
— Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.
— My carer and I continue to have the opportunity to develop new interests and new social networks.
— It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.
The last year of the Dementia Action Alliance (DAA) has seen it continue to grow rapidly in membership and impact.

The Alliance now has a total of 106 national members and 45 local members. This represents an extra 76 Action Plans and commitment to undertake hundreds of additional actions to progress the Declaration. Our membership now includes architects, FTSE 100 companies, Rotarians, local authorities, police forces, fire brigades even a volunteer run railway – all working to improve the lives of people with dementia.

Alliance members have elected four chairs: Prof Graham Stokes, Director of Dementia Care at Bupa Care Services UK, Gill Ayling Deputy Director at the Department of Health, Jeremy Hughes Chief Executive of the Alzheimer’s Society and Sharon Blackburn Policy and Communications Director at National Care Forum. These Chairs oversee the work of the Secretariat, provide strategic direction to the Alliance and rotate the chairing of Alliance events.

Last year saw the results from our first area of joint work, the Right Prescription. Led by the NHS Institute, this joint programme made a major contribution to reducing the inappropriate prescription of antipsychotics. Now, 60,000 fewer people are experiencing the lower quality of life and higher risk of death that those drugs bring.

March 2012 also saw the launch of the Prime Minister’s Challenge on Dementia – a high level political commitment to transform the lives of people with dementia – and the establishment of three Champion Groups to lead change.

Building on the success of the Right Prescription, and in support of the Prime Minister’s Challenge on Dementia, the Alliance has initiated four new areas of joint work:

— The Right Care: creating dementia-friendly hospitals – a major new call to action led by the NHS Institute and DAA to get every acute hospital trust in England by March 2013 to commit to becoming dementia friendly.

— Campaign to boost early diagnosis – the DAA Action Group on Diagnosis and Post Diagnosis Care, led by the Age-Related Diseases and Heath Trust, has been commissioned by DAA and the Department of Health to review the evidence on the benefits of diagnosis and produce a guide for health practitioners.

— Local Dementia Action Alliances – the Alzheimer’s Society and DAA are bringing together local authorities, emergency services, care providers and local businesses across England to form local Dementia Action Alliances to bring improvements for people with dementia in local areas.

— Carers Call to Action – members working together to ensure that carers are recognised as true partners in care.

The Secretariat would like to thank all our Alliance members.

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WORDS FROM OUR CHAIRS

“The Dementia Action Alliance is playing a large part helping to transform the lives of people with dementia and their family supporters and carers. At both national and local levels member organisations are monitoring developments, and driving forward change to help all people affected by dementia have better lives. And for me, what is most pleasing is to be Co-Chair of an alliance of organisations that doesn’t simply talk about the need to see improvements happen, but goes out and does it. Throughout the country DAA members are doing new things, initiating innovative services, reshaping people’s attitudes and helping to bring about dementia-friendly communities. And that is what is needed: for the National Dementia Strategy must not result in changes that only a statistician can love. Any investment must make the lives of people not only appear better, but be better.

However, there is still much to achieve, so even when we report successes we must never become complacent. If we do, we risk perpetuating the state of affairs where, today, hundreds of thousands of people with dementia – along with their families and friends – still face abandonment, exasperation and incomprehension. Let’s never forget: this is not about dementia, this is about the lives of people.”

Graham Stokes, Director of Dementia Care, Bupa UK Care Services and Visiting Professor of Person-Centred Care, University of Bradford and Co-Chair of the Dementia Action Alliance
“The reason Alzheimer's Society worked with others to set up the DAA two years ago is that we want to see an active alliance of people and organisations collaborating to improve quality of life for people affected by dementia. Because it's a condition that affects each person in so many aspects of their life, no single organisation can tackle the challenge alone. It is excellent that there are now over 150 members of the Alliance who have committed to action.

The Alliance is being watched with interest across government and the wider world as a model for action. I want the Alliance to identify an increasing number of opportunities to work together on joint campaigns and projects. As well as joint action the Alliance needs to find ways to hold members accountable for what they have committed to deliver. Alzheimer's Society has committed to support the development of local and regional alliances across the country and many have already started this vital work.”

Jeremy Hughes, Chief Executive of Alzheimer's Society and Co-Chair of the Dementia Action Alliance
WORDS FROM OUR CHAIRS

"The strength of the DAA lies in the diversity of its members; especially people who have dementia and those who live with and care for them. The DAA has taken the things that are important to people with dementia and influenced policy and practice at the highest level. Each person/organisation plays an important part in making and sustaining change through distinct and complimentary ways.

As one of the Co-Chairs it is my desire to see the pieces of the jigsaw come together so that collectively the sum is greater than the individual parts. As the DAA progresses I believe it has a continuing role in the Prime Minister’s Challenge but also in ensuring the Dementia Strategy objectives are acted on. Together we can make living and dying well with dementia a reality”.

Sharon Blackburn, Policy & Communications Director of National Care Forum and Co-Chair of the Dementia Action Alliance
“Over the two years since the launch of the Dementia Action Alliance, the profile of dementia and the commitment to supporting people with dementia has continued to grow, at a national, regional and local level. The launch of the Prime Minister’s Challenge on Dementia in March 2012 reflects the significance that dementia now has across all areas of society. It is a condition that touches us all in some way, whether as an individual, carer, professional, family member or friend.

I was pleased to chair the last quarterly meeting of the Dementia Action Alliance in September 2012 and was struck by the energy and enthusiasm of Alliance members, people with dementia and carers to work together to make a positive difference to people’s lives. Working together, the Alliance has a much greater ability to deliver change than individual organisations working alone. I was also pleased to welcome a number of new members to the Alliance, reflecting the reach and diversity that the Alliance now has and the way it has grown so significantly since its launch in 2010.

The Alliance has had a number of successes, particularly the call to action on reducing the use of antipsychotic medication. The call to action made a significant contribution to reducing the rate of prescribing of antipsychotics and showed how the Alliance can deliver change in a very practical way. More recently, we have also seen the launch of the call to action on hospital care. My challenge to the Alliance is to keep up this momentum and to identify further areas where Alliance members can work together to make a real difference to the lives of people with dementia and carers. As we continue to implement both the National Dementia Strategy and the Prime Minister’s Challenge on Dementia, the Alliance will have a key role to play and we very much value your contribution”.

Gill Ayling, Deputy Director – Older People and Dementia of Department of Health and Co-Chair of the Dementia Action Alliance
What we did this year

— In October, we started shooting our training film, ‘Lots of Talk and No Conversation; Breaking through Dementia’. It is no ordinary training film: scripted from real life characters, it is the first of its kind to demonstrate the deep conversational skills and sensory acuity needed in those emotional situations that are so heart-wrenching for people and families experiencing dementia. We have been commissioned by SCIE for a large proportion of the money and are fundraising through Crowdfunder to make up the rest.

— We were awarded RCN Accreditation for our 360 Standard Framework in October 2012. We have also delivered a number of diagnostic audits for person-centred cultures, and supported homes to deliver the changes to continuously improve with evidence of outcomes achieved.

Some of our new work-based learning courses delivered include:
— Using pictures to communicate with people with dementia
— Preventing falls
— Optimising abilities to promote independence
— How to lead, manage and develop person centred cultures using the 360 Standard Framework
— Designing, implementing and reviewing action planning

What we will do next year

— Secure RCN accreditation for all 360 Forward work-based learning, all of which supports the delivery of a relationship-activated culture that delivers person-centred outcomes for people in care homes living with dementia.

— Launch the ‘Lots of Talk and No Conversation; Breaking through Dementia’ film, with supporting a learning resource. The film will be an invaluable tool that can be used over and over again as a guide to learn how to communicate better with people in care, giving hope to a relationship that was thought lost.

Deliver further work-based learning courses, including:
— Developing therapeutic conversing with people living with dementia
— Exploring the experience and needs of visiting family and friends
— Introduction to therapeutic conversing with people living with dementia
— Exploring the person’s home life, occupation and environment
— Produce a DVD and learning workbooks providing an introduction to English customs and culture for staff working with older people in England, called ‘Anyone for Tea?’ This will be released next year.
Here is some feedback from staff who have been on our courses:

“A fab way of learning about residents’ feelings. I look forward to working with picture questionnaires in the future, building an insight into our residents’ lives and thoughts.” (Participant who trained in delivering a person-centred culture through action-based learning in the workplace.)

“We were inspired, enthused and energised… and we can now improve care to be more relationship and person-centred in achievable ways – empowering the staff into new ways of thinking and working.”

(Care home manager who completed a course on communicating with people with dementia.)
ART works to improve health outcomes for older people in fields such as dementia by working in partnership with other key stakeholders and acting as a catalyst for change. By carefully staying small and minor we help major and all stakeholders develop effective synergies. We seek to avoid re-inventing wheels and help attach the best ones to effective vehicles. We drive workstreams, organise events, support research and delivery and undertake specific projects as necessary.

What we did this year
ART ran the Alliance’s first Action Group, dedicated to improving dementia diagnosis and post-diagnosis care. As part of this work we:

— produced a major report mapping current work on improving diagnosis, and identifying the major barriers to be overcome.
— conducted a review of how member organisations can exchange best practice.
— co-ordinated the Alliance’s response to the APPG report on diagnosis in July, and are now co-ordinating work to ensure that the APPG’s recommendations are implemented.
— and we are currently working on a report which definitively identifies the key benefits of diagnosis, commissioned by the Alliance and the Department of Health.

We also organised a strategic advisory body for the Action Group, including members from the Department of Health, NHS Institute, SCIE, British Geriatrics Society, RCGP, APPG and BUPA Care Homes, among others.

What we will do next year
In the coming year, through the Action Group we will continue to lead the Alliance’s work on dementia diagnosis and post-diagnosis. Specific outputs in 2013 will be driven by the Advisory Group, but we are already preparing a major piece of work on post-diagnostic support and advice for people with dementia and their families and carers. Another significant project will focus on access to information in primary care to enable people — including health and social care professionals — to make informed decisions about the help options that are available following a diagnosis.
Age UK aims to improve later life for everyone through our information and advice, campaigns, products, training and research. We know that ageing is the main risk factor for developing dementia, but equally that dementia is neither an inevitable nor a normal consequence of ageing.

What we did this year

— Age UK, the NHS Confederation and the Local Government Group established an independent commission on improving dignity in care for older people in hospitals and care homes. This year the commission published its report, highlighting the number of people with dementia in both settings, setting out necessary changes to practice, and making recommendations for action.

— Age UK Training this year focused on offering dementia training as a core product available to health and social care providers.

— Age UK continues to fund a major research project on cognitive ageing: the Disconnected Mind project at the University of Edinburgh. Through our Research into Ageing Fund programme, we fund a variety of projects on dementia and cognitive impairment in later life at UK academic institutions.

— We are developing information and advice resources with and for people with dementia and carers.

What we will do next year

— We will focus on implementing the recommendations from the commission on dignity in care.

— We will support local Age UKs to engage with people with dementia and carers, and make their services more accessible to them. We will be working with Innovations in Dementia on this.

— We will support local Age UKs in their development of services for people with dementia and carers.

— We will publish our information and advice resources for people with dementia and carers.

— We will continue with our dementia-focused research and training programmes.
The APPG on Dementia is a cross-party group made up of MPs and peers with an interest in dementia. Its aim is to raise awareness of dementia among parliamentarians, and to influence legislation and policymaking to improve the lives of people with dementia and their carers.

What we did this year

The APPG ran an inquiry into improving dementia diagnosis rates across the UK. This was prompted by the fact that only 43 per cent of people in the UK living with dementia ever receive a formal diagnosis. This varies greatly across England, Wales, Northern Ireland and Scotland, and overall little progress has been made towards improving rates over the last few years.

In this inquiry, the APPG sought evidence from people with dementia and their carers, health and social care providers and practitioners, and key stakeholder organisations and professional bodies.

The inquiry brought together evidence and understanding about obstacles to improving diagnosis of dementia. It also found good practice examples where services have helped people with dementia get an early diagnosis, and ensured they have proper information and support afterwards.

Nine recommendations were made to health professionals, government and commissioners. The Dementia Action Alliance advisory group on diagnosis are also taking some of the recommendations forward.

The report and its recommendations can be found at: Alzheimers.org.uk/appg.

What we will do next year

The APPG on Dementia undertakes an inquiry each year and is currently in the process of selecting its next topic. This will be announced towards the end of 2012.
Worked towards the launch of a new research strategy to direct our funding towards the highest quality science with the greatest potential to translate into patient benefit. Research will look at the detection, diagnosis, prevention and treatment of dementia.

What we will do next year

— Continue to push dementia research up the political and public agenda.
— Through our role on the Research Champion Group and our parliamentary activity, support government and keep the pressure on to ensure delivery of dementia research commitments from the Dementia Challenge.
— Chair further meetings of the Dementia Research Funders Forum.
— Launch our new Research Strategy.
— Hold further successful public events and our major annual network conference in March 2013 in Belfast.
— Improve access to information about dementia and research, including new patient information leaflets and a new dementia information section on our website.
— Work with other charities to raise awareness of common factors that could help reduce the risk of developing dementia.
Alzheimer’s Society is the UK’s leading dementia support and research charity. We provide services, fund research and advise health and social care professionals. Working nationally and locally, we campaign for improved care and greater awareness and understanding of dementia.

What we did this year

— Supported the work of the Dementia Action Alliance.
— Hosted the 27th International Conference of Alzheimer’s Disease International (ADI), bringing people together to share advances in knowledge and good practice.
— Published Dementia 2012: A national challenge – setting out how well people with dementia are living in the UK. Working with the All-Party Group on Dementia, we held an inquiry into improving UK diagnosis rates.
— Worked with the Department of Health (DH) on new government commitments on dementia – part of the Prime Minister’s Challenge on Dementia.
— Jeremy Hughes, Chief Executive of Alzheimer’s Society, co-chairs the Dementia-Friendly Communities Champion Group as part of the Prime Minister’s Challenge on Dementia. We have been working with the public, private and voluntary sectors to create dementia-friendly communities.
— Worked with the Royal College of General Practitioners to improve GPs’ understanding of dementia. Collaborated with BMJ Learning on an e-learning module on managing behavioural symptoms of dementia.

What we will do next year

— Continue to host and provide funding to support the work of the Dementia Action Alliance.
— Work with the Dementia Action Alliance to develop local Alliances, bringing together people with dementia, their carers and key organisations.
— Publish reports on: the impact of social isolation on people with dementia; end of life care for people with dementia; and experiences of people with dementia in care homes.
— Develop evidence on what makes a dementia-friendly community.
— Work with organisations to support the development of dementia-friendly products and services
— Working with other charities, campaign for the urgent reform of social care funding.
— Raise awareness and understanding of dementia across communities.
— Support the work of the All Party Group on Dementia.
Amore Care is the new name for the older people’s services within the Priory Group of companies. The new brand will highlight the division’s core service strengths by focusing on promoting the individual care services offered within our homes across England, Scotland, Wales and Northern Ireland.

What we did this year

— In October 2012 we launched our new dementia strategy for putting the person with dementia at the heart of their own care.
— Ginny Patterson, Dementia Lead, devised the strategy and developed the Creative Minds programme by developing a learning strategy which supports our staff to provide excellent care.
— The ‘Creative Minds’ programme is an integral part of the Dementia strategy that evokes thoughtful and creative approaches to care practice. It is intended to transform the way in which we improve the lives of residents in our care and their families.
— We have formed a Dementia Service Team to work closely with home managers, care teams, senior managers and quality teams, who will all play a vital role in making this a great success.
— We are focused on creating an impetus for change, building on the work so many people have been developing to date, both nationally and most importantly locally with our services.

What we will do next year

— Priory/Amore Care will continue to implement the Dementia Strategy by focusing on key areas:
— Work with residents’ families and friends to ensure they are supported and actively engaged in all that we do.
— We want to create homely environments that are enabling and promote independence, and which are age appropriate and support care for people with dementia.
— We recognise that specialist training is key to providing good quality dementia care services. Educating our teams is paramount in delivering the change we need to see.
— Measure the success and progress of strategy and service improvements.
— Undertake a systematic and continuous review of antipsychotic medication prescribing in order to minimise use.
— Working with local and national partners, raise awareness of dementia among the communities where we practice.
At Anchor, our passion is giving older people a choice of great places and ways to live. We provide housing to rent for people over 55 at over 700 locations across England, as well as homes for leaseholders in managed estates. Anchor runs around 100 care and nursing homes, including several specialist dementia homes for people with higher care needs.

What we will do next year

— Continue to invest in our employees and develop our services through our Dementia Strategy, which reflects the organisation’s vision to give older people a choice of great places and ways to live. We do this by treating our colleagues and our customers as individuals – and by building meaningful, long-term relationships based on happiness, openness and respect.

— Provide an enhanced suite of dementia training sessions and courses delivered by our dedicated Dementia Consultant and Dementia Specialist Team, which is supported with on-going expert coaching and advice.

— Build on the focus of developing our customers’ living stories. By helping people represent their past, present and their future hope and desires, we aim to provide a truly person-centred approach.

— Continue to support current and future family and friends with free education and information sessions, and one-to-one support as required. We intend to expand this initiative to the wider community.

— We hope to expand our relationship volunteering programme, and will continue our antipsychotic medication review.

What we did this year

— Continued giving our staff specialist dementia training and support, provided by our dedicated Dementia Consultant and Dementia Specialist Team. This investment helps our staff support and care for Anchor customers.

— Extended the development of employees by concentrating on personal learning through value-based leadership and access to expert advice.

— Continued to support our current and future customers’ families and friends with a rolling programme of information and education sessions, along with further support.

— We have expanded our relationship-based volunteer programme that matches individual volunteers to customer’s hobbies and interests.

— Continually reviewed the use of antipsychotic medication for customers in our care homes. The level of usage has continued falling, while the number of active reviews has increased.
Male customer admitted from hospital receiving high dosage of the antipsychotic medication risperidone. He had been prescribed this dose due to high levels of anxiety and distress presenting at late evening and night times, which impacted on the lives of others in the hospital ward.

The care home immediately requested a review of medication with the allocated psychiatrist.

Effects on the individual and others
During the interim period before the review, the situation escalated, resulting in the male customer becoming incontinent and withdrawn from the social activity of the care home, and missing family and friends’ visits because he was sleeping throughout the day.

Care and support
The care team undertook several activities to find out why this individual was so agitated at night and often becoming incontinent and very distressed.

They made a record of his behaviours and carefully monitored to see if there was a pattern, or certain triggers for this behaviour.

The man’s family was encouraged to become involved with the care team in building a life story. It was found that in his own home when the man had got up during the night to use the bathroom – which he did frequently – he arose, walked forward, turned right to the bathroom door, opened it and managed to locate the toilet easily without direction or support.

The team quickly established that the man’s distress and anxiety increased because he was simply looking for the bathroom. Despite being unable to articulate this, he was moving around the care home opening any doors, including into other customers’ rooms.

Having found the reason, the care team helped the man rearrange his room to directly reflect the layout of his previous home. This was then monitored over the following days.

His behaviour changed considerably, and he became less agitated and distressed. There were no more incidents of incontinence, and he did not enter any other customers’ rooms during the late evening and night time.

Case review
At the time of the review the man, although heavily medicated, was now starting to make friends with others and take part in everyday activities.

Conclusion
As the initial anxiety and distress had reduced, it was agreed by all involved – including the reluctant immediate family member – to reduce the antipsychotic medication with a view to stopping it altogether in the following weeks.
The Association for Dementia Studies (ADS) at the University of Worcester comprises a multiprofessional group of educationalists, researchers and practitioners building evidence-based, practical ways of supporting people living with dementia and their families. We do this primarily through research, consultancy, education and scholarship.

What we did this year

— Delivered a wide range of education and practice development programmes to professionals and staff who support people at all stages of dementia. This has included primary care, home care, acute hospital care, mental health teams, extra care housing and care homes. People living with dementia and families have contributed as educators on a number of these courses. We launched our free on-line resource kit for care homes: carefitforvips.co.uk

— Engaged in much research that will have a direct impact on how to provide better care for people and their families. Many of the research projects have simple initials as names, but underpinning them is a serious endeavour to try to unpick the complexity of caring well for people with dementia and their families. Highlights have included:

— Leading the work providing evidence for best practice policy advice on early interventions as part of the ALCOVE European Union programme with the Department of Health.

— Developing a ‘dementia care bundle’ to really improve the care of patients with dementia in acute hospitals, in partnership with the Royal Wolverhampton NHS Trust.

— Undertaking in-depth case studies into the culture of care homes, as part of the CHOICE research project, to help us understand why some homes care well for people with advanced dementia and others do not.

— Starting research into the experience of people in housing with care schemes, as part of the ASSET project.

— Starting research with Alzheimer’s Society to evaluate a practical application of the FITS programme across 150 care homes.

— Evaluated innovative practice such as the intergenerational schools programme.

— Continued developing networks and expertise around creative expression in dementia care. We have been undertaking development work in developing culturally competent support for people with dementia and their families across different communities.

— Been active in helping to move forwards dementia-friendly communities.

What we will do next year

— Start delivering our education programmes at Worcester as open accredited modules, leading to named awards in dementia studies.

— Publish the results of a number of research projects and disseminate the findings.

— Launch our recommendations from the ALCOVE project in March 2013.
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ASSOCIATION OF DIRECTORS OF ADULT SOCIAL SERVICES

ADASS represents the 150 directors of adult social care in English local authorities.

What we did this year

— Extended our input into the dementia strategy. Our president is co-chairing the Prime Minister’s Challenge Group for health and social care, and has joined the programme board.
— Gave evidence to the APPG on early diagnosis.
— We have been a member of the NICE topic expert group on social care standards. Having established an informal network of directors and associate directors across the country, we have supported regional work to progress the strategy.
— ADASS also inputs into national working groups such as on housing, telecare and workforce.

What we will do next year

— Continue to give leadership as part of the Prime Minister’s challenge. We will continue to provide input and a statutory, commissioning, and local authority perspective to the many forums and working groups that exist.
— Improve our ability to measure what we do for people with dementia as part of the Zero Based Review.
— Continue to drive improvement through our regional networks and joint improvement programmes.
What we will do next year

— Further develop staff teams in learning and delivering high quality and meaningful care and support for individuals living with a dementia in a care home.
— Enhance the end of life experience for people with dementia and their families – including asking and finding answers for the ‘difficult’ questions.
— Continue providing individuals with dementia a quality of life, and be able to evidence this.
— Continue monitoring the use of inappropriate medication.
— Continue working in partnership or consultation with other agencies on dementia specific projects.

Barchester is a leading independent provider for nursing and residential care for older people. We also have a diverse portfolio of other services, including complex mental health and learning disabilities.

What we did this year

— Concentrated on developing our ‘Memory Lane’ communities and supporting individuals living with a dementia to continue to live well. This has been achieved by embedding the core philosophy of being person-centred and relationship-focused with our care staff teams, by commissioning the ‘Achieving’ manual, and by re-introducing key workers in line with the personalisation agenda.
— Enabled our care staff teams to evidence that they are becoming more skilled through bespoke and dementia specific train-the-trainer courses, learning in action, and taking learning beyond awareness.
— Explored systems to support staff team in the delivery of person centred care – such as tele-care and tele-health systems.
— Focused on reducing inappropriate medication, and developing skills in staff teams to support and care for individuals whose ‘behaviour’ may be described as challenging.
— Appointed an academic Chair for Dementia Research with the University of Nottingham.
For 20 years Bradford Dementia Group (BDG) at the University of Bradford has been leading the field in dementia research, education, training and practice development – with the aim of enhancing the lives of people with dementia and their families, and supporting the practitioners who care for them.

What we did this year

— Worked with people with dementia and their families in all aspects of our work, including in our carer reference panel and our distance learning programmes on dementia studies.
— Collaborative research including: a participatory video with people with dementia in residential care; and an evaluation of person-centred training in acute care.
— Developed our consultancy services to embed person-centred care.
— Developed our training and education programmes in line with government priorities, including: train-the-trainer programmes in person-centred dementia care; new dementia care leadership courses; and training Care Quality Commission inspectors nationwide to capture the experiences of service users who may not be able to express this themselves.
— Increased awareness of dementia in various ways, including: a stand in the University atrium during Dementia Awareness Week; a public recital of poems written by people with dementia.
— Increased investment in research by making numerous academic and research student appointments.
— Awarded Dr Graham Stokes, Bupa’s Director of Dementia Care, an honorary professorship in person-centred dementia care.

What we will do next year

— Further develop multi-disciplinary research with direct implications for the quality of life and care of people with dementia and family carers.
— Report on the findings of our pilot study on ‘Improving health care in care homes’.
— Further enhance our consultancy service in person-centred care.
— Conduct research on our practice development methodology, Dementia Care Mapping.
— Continue to develop our training and education programmes.
— Deliver the first course of ‘Practitioners with a special interest in dementia’, for which we will seek Royal College of General Practitioners accreditation.
— Optimise the synergy between our research, education, training and practice development portfolios for the benefit of people with dementia and their family carers.
What we will do next year:

Publish ‘The meaning of therapy from the perspective of family carers of people with dementia: An exploratory study’, by Professor John Keady and Dr Ruth Elvish, University of Manchester. This exploratory study will address the emotional and psychological needs of those who support a person with dementia, and how psychotherapy and counselling can be tailored to meet these needs.

What we did this year:

Published ‘Counselling and psychotherapy for the carer’s of those with dementia: A systematic review of the research literature’, by Professor John Keady and Dr Ruth Elvish, University of Manchester. The aim of BACP’s systematic review process is to produce a readable and rigorous overview of the research. The review provides practitioners with evidence to inform practice and adds to the knowledge base of researchers in the field.

BACP is recognised by legislators, national and international organisations, and the public, as the leading professional body and the voice of counselling and psychotherapy in the United Kingdom, with over 37,000 members working to the highest professional standards.
The British Geriatrics Society is a professional association of doctors practising geriatric medicine, old age psychiatrists, general practitioners, nurses, therapists, scientists and others. We are united by our shared interest in the medical care of older people, and the promotion of better health in old age.

What we did this year

Our work in relation to dementia is mostly overseen by our Cerebral Ageing and Mental Health Special Interest Group (SIG), who have achieved the following:

Collaboration, exchange of ideas and advice
— Surveyed geriatricians with an interest in dementia to identify what training they have received, and opportunities for geriatricians to develop a subspecialist interest in dementia.

Education, Training and Research
— Surveyed UK medical schools about their teaching in the area of dementia.
— At our spring meeting, held a session focussing on neurodegenerative disease.
— With the Royal College of Physicians, held a study day on the needs of people with dementia and delirium in acute hospitals.

Policy
— We provide policy advice to the British Geriatrics Society, the Faculty of Old Age Psychiatry and other interested professionals/organisations.
— On early diagnosis, we gave evidence to the APPG and contributed to the Alliance’s Action Group.

Quality and Improvement
— Group members are actively involved in the second national audit of dementia in acute hospitals.
— Many of our other groups also do work relevant to the area of dementia, including on our dignity campaign.

What we will do next year

Collaboration, exchange of ideas and advice
— Publishing regular updates on dementia-related work by the SIG in our society newsletter. We will develop an area on our website which allows members to engage actively in the work of the SIG in relation to dementia.

Education, Training and Research
— We plan to develop an education and training strategy which reviews, advises on and develops undergraduate, postgraduate and subspecialty curricula, to ensure they deliver excellent treatment and care to older people with dementia and associated disorders.

Policy
— We will continue providing expert policy advice and contributing to the Early Diagnosis subgroup

Quality and Improvement
— We will continue to be involved in the second national audit of dementia. Our members will be actively involved in the Call to Action on care of people with dementia in acute hospitals.
What we will do next year

— Launch a paper on psychosocial alternatives to antipsychotic medication for people experiencing emotional and behavioural sign of distress in dementia.
— Continue working with the Memory Services National Accreditation Programme to implement the newly added chapter on psychosocial interventions, moving it towards a mandatory rather than optional quality indicator of memory services.
— Continue collaborating with other organisations and professional bodies (e.g. RCP, RCN, British Geriatric Society) to ensure high standards in dementia care.
— Deliver high quality and affordable training events for psychologists and other professions interested in psychological ways of working with people with a dementia.
— Actively support and participate in the Early Diagnosis Action Group, particularly to highlight issues around pre-diagnostic counselling and consent, engagement, neuropsychology, and post-diagnostic care.
— Liaise with our expert reference group and professional network to provide high calibre speakers for training events and conferences.
— Produce a suite of briefing documents on evidence-based psychological interventions in the context of early diagnosis and aftercare.
BSI delivers best practice solutions through the publication of British standards and related information products and services. As the UK national standards body, we have a globally recognised reputation for independence, integrity and innovation. We are keen to engage with stakeholders to consider the development of standards – in the form of guidelines, best practice, codes of practice, and specification – to support consumers, carers, services and infrastructure related to dementia. As such, we are particularly interested in the use of Standardisation within the emerging areas of Dementia Care, and in particular in response to the Prime Minister’s challenge.

What we did this year

BSI has become a member of Alliance, and are currently renewing a project on Dementia Care Mapping with the Bradford Dementia Care Group at Bradford University following the success of our standard PAS 800:2010 – ‘Use of dementia care mapping for improved person-centred care in a care provider organization’

What we will do next year

The key areas where BSI feel that a Standards based approach, as part of our role in the DAA, and in response to the Prime Minister’s Challenge, could be of value, include:

1. A Standardised approach to the early diagnosis of Dementia (i.e. what do GP’s and others use to early diagnose? EEG’s? Spinal fluid? Pen and Paper tests? Software programmes? All of these and others?)

2. Standards for Care Homes in the level of Dementia Care provided

3. National Standards for training for Dementia Care staff

4. Standards for Dementia friendly communities, retailers etc – e.g. What is a “Dementia friendly Bank or Supermarket or Retailer?” What should “Dementia Friendly” look like?

5. A Standards based approach to integrated services for those living with Dementia, including Assisted Living initiatives and new services for those diagnosed with early dementia.

In terms of deliverables, BSI hopes to achieve the following:

— Initiate a revision of our standard, PAS 800:2010 ‘Use of dementia care mapping for improved person-centred care in a care provider organization’.

— Carry out engagement activities to review the landscape for dementia information and determine whether a standards-based approach can be further applied in the field of dementia care.

— Organise stakeholder workshops and discussions with Alliance members to consider where information gaps exist and areas where standards could provide solutions. This could include aspects such as dementia-friendly retailing, dementia care homes or carer training.

— Consider the need for an overall strategy for dementia standards in the UK by working with key industry stakeholders.

— Where there is a business case, facilitate and publish new BSI standards, and use our marketing support, media alerts and press releases to promote new BSI dementia standards.
In the UK, Bupa provides 215 dementia care communities within care homes, where more than 8,000 people with dementia live, mostly with complex, high-dependency and end-of-life care needs. Some of these communities also provide day and respite care. Bupa also provides advice for people with dementia and their caring families.

What we did this year

— Partnership with University of Bradford’s Division of Dementia Studies is delivering an informed and trained workforce.
— Bupa is the Alzheimer’s Society’s partner in the Memory Walk campaign, which raises both funds and awareness.
— Our antipsychotic reduction programme has resulted in a 34% decrease in prescribed antipsychotics over the past three years.
— Thirteen dementia-friendly refurbishments of our dementia care communities were completed.
— Nine films were produced that provide information on dementia; advice and support for people looking after a loved one with the condition; and information on later stages of the diseases. The films can be seen at: www.bupa.co.uk/understanddementia
— A national partnership with Dementia UK means that Bupa-Admiral Nurses are now based in some of our dementia-care communities.
— The Bupa-Bradford University Dementia Care Scholarship Programme was launched in September. Nine of our senior UK dementia care practitioners and managers have registered for undergraduate and postgraduate courses in dementia care, management and education.

What we will do next year

— Continue implementing and rolling our dementia care training programme and dementia-friendly refurbishments.
— Appoint more Bupa Admiral Nurses.
— More senior dementia care practitioners and managers will be admitted to the Bupa-Bradford University Dementia Care Scholarship Programme.
— Develop and deliver a flexible and responsive day care provision known as ‘pop-in’.
— Deliver a family carers’ education resource in Bupa’s care homes for relatives who are negotiating transitions to a home, and facing difficult conversations about end-of-life.
— Continue driving down the use of prescribed antipsychotics. Bupa will be implementing an antipsychotic screen (currently being trialled) which identifies on admission to a care home whether a person is prescribed an antipsychotic medicine, triggering a review and on-going governance.
— Support more families who are caring for a loved one with dementia in their own homes with face-to-face advice and guidance.
We are the independent regulator of health and adult social care services in England. Our job is to make sure that care provided by hospitals, dentists, ambulances, care homes, along with services in people’s own homes and elsewhere, meets government standards of quality and safety.

What we will do next year

— Conduct a thematic review of the quality of acute care for people living with dementia.
— Conduct an audit of the use of the Short Observational Framework for Inspection (SOFI tool).
— We are consulting on our strategic priorities for 2013 – 16. Depending on the feedback from stakeholders, as well as the findings from work outlined above, the CQC action plan for the Dementia Action Alliance has the potential to be developed further in 2013.
— From April 2013, CQC will bring general practices – often the first point of contact for people living with dementia and their carers – into registration.

What we did this year

— Completed a number of thematic reviews that are relevant to the quality of care experienced by people living with dementia. In March, we published the findings from our review into how health care needs of care home residents are met. We also completed a review into end of life care, focusing on admissions to hospital from care homes.
— Developed the work of the dignity and nutrition inspection programme of 2011 by including 500 care homes this year. Fifty NHS hospitals have also been included in the 2012 programme, a combination of hospitals that raised concerns during the original review and a new sample of other locations.
— Started to analyse findings from compliance inspections to produce a report on the use of Deprivation of Liberty Safeguards.
— Continued preparing to bring other providers into regulation, including dentists and out of hours primary care services, many of which provide care, treatment and support to people living with dementia.
What we will do next year

— Open more new homes, including one in Edinburgh designed by Richard Pollock, Director of Architecture at the University of Stirling’s Dementia Services Development Centre, with grounds designed by Annie Pollock, who specialises in creating safe and stimulating gardens for people with dementia.

— Develop the use of gardens in our homes to create more rewarding and enticing spaces for residents, whether to garden, to walk, to meet — or to reminisce, supported by mood and memory enhancing features.

— Employ three specialist dementia trainers and an expert dementia triage nurse to spread our training, and to visit homes, give advice and support staff in their regions. Next year we hope to appoint more trainers, along with a second nurse, to ensure that our growing number of homes, residents and relatives have the support they need. We will also be supporting our homes to share their expertise and facilities with families in their communities who are caring for someone one with dementia.

We provide tailored care in people’s homes or residential care. We support relatives with training and support networks, and through day centres and respite care. We work to maximise each person’s independence and individuality. Increasingly, we are working with community groups to provide activities for service users and support for relatives, which also helps reduce the stigma associated with dementia.

What we did this year

— This year we looked at both ends of dementia: from supporting those who have been recently diagnosed with our home visit team, to holistic end-of-life care with our participation in the St Christopher’s Hospice ‘Namaste’ project in South London.

— We explored new ways of unlocking memories and cherishing the individual through our work with the culture change group Ladder to the Moon. Our teams have already shown increased creativity and confidence as they help people explore their interests and enable their ambitions: for example, greater ‘self-service’ entertainment, refreshment and amenities throughout the home. Now entering its second year, the ‘Our House’ project has led to greater confidence and creativity among residents as they take on a greater role in the home.

— Opened new homes which have been specially designed to maximise natural light and create a relaxed but stimulating environment. The staff have taken our extensive dementia training.
For many residents, pubs were at the centre of the community during their early life. When Maggie Harrison, the Manager of Care UK’s Collingwood Court asked residents what they wanted to do with a lounge that was rarely used, the answer was unanimous – make it into a pub.

Everyone rallied around to find vintage knick-knacks, optics, a beer hand-pump and old photographs of the original Collingwood Arms (which was on the site of the home) and the maintenance man installed an old bar, an old-fashioned fireplace and he found a paint that looked like nicotine-stained white paint. He then took a great deal of time and effort making it looked distressed as real pub paint work does.

The results have been impressive. Residents enjoy playing traditional pub games during their visits, and darts, played with a board and darts donated by a former resident’s family, is very popular – the resident’s trophies give the bar an authentic feel.

Maggie said: “Residents put on their hats and coats as if they are going out when they come to the pub and they feel that they are actually out in a pub.”

“Many of our residents have lived in the area all their lives. I was delighted when one of our gentlemen declared that he was going to make the Collingwood Arms his local, as he preferred it to the nearby Spring Gardens pub which had been his regular pub for many years.”

Apart from providing fun and a meeting place, the pub has had tangible health and wellbeing benefits for residents. Being in the pub often triggers thoughts and memories. Reminiscing helps to make connections with a person – their past, present and future – and life stories can help unlock the ‘voice’ of a person with dementia.

Residents have pub lunches in the bar. As well as being enjoyable, it means that they can have a change of scene and personalities. Living and eating with the same 23 people all the time would leave anyone looking for an occasional change and the pub has been invaluable there.
What we will do next year

— Review progress against carer-specific clauses in the Dementia Declaration.
— Promote collaboration by our networks at local level to meet the aspirations of the Declaration and encourage participation in regional Dementia Action Alliances.
— Ensure our Primary Care and Community links project raises awareness of dementia carers’ rights and support services along with all carers.
— Conduct a research project to identify carer needs and crisis points on the dementia carer journey, producing outcomes including guidance and recommendations on how best to support dementia carers, involving DAA colleagues where possible.
— Support the DAA Carers Action Group in its campaigning.
— Promote and develop the Triangle of Care project to ensure dementia services supporting carers are incorporated.
— Encourage the use of dementia care mapping by network partners.

What we did this year

— Crossroads Care schemes continued provision of home share and a range of initiatives to improve the quality of life of people living with dementia while allowing carers time to themselves.
— The successful dementia crisis intervention service in West Kent has prompted investment in home treatment crisis intervention in East Kent. Our first schemes have joined their local Dementia Action Alliance (East Midlands) and found this a positive experience.
— Our action plan is being revised to reflect that, on 1 April 2012, Crossroads Care Association merged with the Princess Royal Trust for Carers to become Carers Trust.
— Our Primary Care and Community Links project is helping improve GP awareness of carers and people living with dementia among the range of conditions which require people to become carers. Carers Trust is committed to supporting the DAA Carers Action Group, and is currently starting a research project on the needs of carers of people living with dementia.

Carers Trust supports local network partners in the provision of breaks and practical support for carers and those relying on them, information, advice, peer support and more. Carers Trust also provides grants, online support, research, development, consultation and lobbying.
Clairmont plc manufacture products to help preserve and prolong independence among people with dementia. These include Choices for Alzheimer’s, a simple communication tool to help identify peoples preferences about food, clothes and daily activities; award winning day/night dementia clocks; braille and tactile ‘dementia doors’; projecting and directional signage; and communication boards which promote communication among carers, relatives and residents of care homes and hospitals.

What we did this year

— Introduced a new range of Braille and Tactile (3-Dimensional) signs which greatly improved independence and quality of life for people living with dementia. We expanded our range of Menu Boards and Activity Cards, and improved the graphics for our Day/Night dementia clocks. We introduced a range of framed famous paintings to improve the environment in care homes and hospitals; these complement our prints of famous places, buildings and people, which are often used to assist wayfinding.

— We introduced a new range of Clairmont governance boards. These streamline the handover event; enable staff to readily see the needs of service users; provide a real time update of care requirements; and are easily transferable. The Care Assistant Report Data Set (C.A.R.D.S) board has been devised to enhance the quality and accuracy of the handover event. Carers can clearly and quickly see details relating to the key care components of the resident’s needs package. When completed, this board accurately allows nurses, care staff and managers to instantly see which service users are in a risk category and require additional support for nutrition, sores management, and so on. The information on the C.A.R.D.S reinforces service users’ care plans with an easy, at a glance précis of the most relevant critical information. The C.A.R.D.S. Board is an additional medium for publicising information and does not replace care plans which are an integral part of personalised care.

— The Staff Nurse Priorities Reporting System (StRePS) board details the clinical needs of service users, and again assists with information handover by being a single point of information for clinical staff.

What we will do next year

— Next year we intend to continue developing our existing range of products and introduce more new products.

— The management team at Clairmont have a background in engineering, manufacturing and design. We are currently in collaboration with a professional occupational therapist and between us we hope to identify areas where our combined expertise would enable us to design new products to help improve the quality of life of people with dementia.
This year we worked with Jo James at the Royal Free Hospital in London. Jo has done a magnificent job in educating the staff about dementia, and we were lucky to be allowed to work with her. Although many other things were achieved, we wanted to use signage to help the person with dementia to know where they are. At the end of the project the only complaint was from the psychologist, who could no longer ask the question "Where are you?" in the assessment pack.
What we did this year

For UK occupational therapists:
— Developed clinical briefings and online resources on aspects of care for people with dementia.
— Provided training on aspects of care for people with dementia, such as assessments, creating dementia friendly environments, and driving.
— Kept members updated on examples of best practice, policies and initiatives in dementia care through print and online news. For example: news article asking occupational therapists to consider their work environment – is it dementia friendly, what changes could be made?

With partners:
— Hosted a quarterly meeting of the Dementia Action Alliance.
— Supporting the Call for Action for dementia-friendly hospitals facilitated by the NHS Institute for Innovations and Improvements.

What we will do next year

— Host and facilitate a networking day for occupational therapists working in memory services to explore assessments, interventions and best practice examples.
— Facilitate a master class on a ‘whole homes’ approach to dementia care.
— Complete and launch a resource and campaign entitled: ‘Living Well Through Activity in Care Homes: The toolkit.’
— Host a quarterly meeting of the Dementia Action Alliance in 2013.
— Continue developing resources and training for occupational therapists working with people living with dementia.
Dementia Adventure is a multi-award winning social enterprise specialising in connecting people living with dementia with nature and a sense of adventure. We provide training, research and consultancy services as well as designing and leading adventure breaks and holidays – all with nature in mind.

What we did this year

Since joining the DAA at the start of 2012, Dementia Adventure has provided a range of nature based adventures in the UK for people living with dementia. This has included a weekly programme of park walks in Essex, sailing holidays in Cornwall and Essex, an activity holiday on the Isle of Man, and a research residential in the Lake District. We also trained and supported staff in care and hospital settings on how to include nature in supportive, thriving and enabling environments. We supported staff working in organisations with a primary focus on nature conservation, travel and tourism to make their services more dementia friendly. We carried out more research into the benefits of ‘green exercise’ for people with dementia as well as supporting research on Dementia Activism. We also expanded the reach of our website. In May 2012 we launched a new website (www.dementiaadventure.co.uk) enabling us to showcase our films and resources, and substantially grow our online community.

What we will do next year

— Expand our adventure provision by sharing our successful park walk programmes in more locations across the UK and beyond. We will also expand our range of holidays and short breaks by working in partnership with DAA members, and with organisations in the leisure and travel sector.
— Deliver more dementia friendly training and consultancy services to green space leisure organisations, so that many more of our beautiful parks, woodlands and nature spaces are accessible and welcoming for people living with dementia.
— Directly support health and social care staff with training and facilitation. By sharing our nature-based approaches, we will work to bring about positive health outcomes for the people living with dementia in their care.
— Continue research-related work into dementia activism, and dementia and green exercise, using our successful ‘research residential model.’
On the 24th July 2012, Dementia Adventure led a Woodland Celebration day at Lochore meadows with VisitWoods Scotland, in partnership with The Woodland Trust. Dementia Adventure convened 77 people, including 38 people living with dementia, who enjoyed a day of activity out in nature. Participants came from a variety of backgrounds and included family members and carers from residential and nursing homes, as well as active younger groups of people with dementia. The day was delivered in collaboration with Alzheimer Scotland’s Facing Dementia Together Group and the Scottish Dementia Working Group. An individual living with dementia participating in the day said, “I loved seeing it all… sun on my skin for the first time in ages.”

Please share this inspirational film about the day: www.youtube.com/watch?v=cFgFn3f4DqU&feature=plcp
The Dementia Advocacy Network (DAN) is a national support network for independent advocates working with people with dementia. DAN provides networking and training events, and an informative website.

What we did this year

— Held three training events in dementia advocacy.
— Facilitated three networking events and one conference.
— Developed three ‘Memory Books’ for people with dementia.
— Produced the publication ‘Taking Their Side: Fighting Their Corner’, a collection of advocacy stories showing the difference an advocate can make to the lives of people with dementia.
— Secured funding for a further three years to manage and develop the network.

What we will do next year

— Support London-based advocacy schemes to improve their evaluation schemes so they can show the difference they make to people’s lives.
— Develop good practice for independent advocates working in care homes.
— Develop advocacy skills for supporting people with learning disabilities who develop dementia.
— Continue to provide quality training on how to advocate for people with dementia: ensuring their voices are heard, their rights upheld and their quality of life improved.
Dementia Action Network (DAN) collected 16 stories from dementia advocates around the UK which demonstrate the difference that having someone to speak up and fight their corner can make to the life of someone living with dementia. Here are some of them:

— Reducing antipsychotics dramatically changed Andrew’s world and allowed him to communicate, to make his own choices and experience a good quality of life.

— Bertram was supported through homelessness and multiple debts to get a diagnosis for his dementia, bringing some stability and hope to his chaotic life.

— Frances and Betty are part of a close-knit family. But well-meaning social workers misunderstood this, and they were threatened with being broken up until their advocate listened to their views and took up their cause, recognising their fundamental rights under the Human Rights Act.

— Kim was in financial and emotional chaos until his advocate helped him to manage his own finances and care plan, get legal advice, set up a lasting power of attorney, manage family conflict, and prevent further financial abuse by a family member.

— Poor communication and service from several services and professionals meant that Samira and her daughter were struggling. The advocate supported them to challenge poor practice and get much needed services.

Each story is placed in its wider context by being linked to current legislation, good practice in dementia care, or relevant statistics. Reviews say the collection is ‘inspiring’, ‘punchy’ and a ‘powerful read’. The stories show how a highly skilled, sensitive and persistent advocate can make a tangible difference to a person with dementia’s independence and quality of life. It is free to download from: www.advocacyplus.org.uk/dan
What we will do next year

— Increase our potential and participation in joint working, at strategic and service delivery level, to improve the quality of support and information for people affected by dementia.
— Work with local clinical commissioning groups to provide information and support for people throughout pre-assessment, diagnosis and post diagnosis.
— Build on models of support being established in Oxfordshire across other local dweb areas, including: MCI support group, Empowerment Group and Creative Arts support group.
— Produce local Handy Guides across our local dweb areas to enable people to receive hard copy local information in both concise and more in depth formats, covering different aspects in individual booklets, which can be requested as appropriate.

What we did this year

We have been working towards improving the support available to people within their local areas by:

— Further developing our local online information.
— From May 2012 we introduced a 24-hour helpline, seven days a week.
— Introduced a personalised information prescription, which anybody in any part of the country can request based on their postcode, diagnosis and any additional local or dementia specific details they may require.
— Invested in additional staffing to manage our growing online dementia resources information, and associated activities.
— With the Research Institute for the Care of Older People (RICE), we have produced a post-diagnosis Handy Guide, a hard copy resource based on information from our website.

National and local websites and 24-hour helpline offering impartial information and support to anybody affected by dementia.
Elaine's two aunts (who were sisters) both had dementia, but lived 100 miles apart. Elaine made regular trips, bringing the more mobile of the two to visit the other, who was in a care home. Elaine's family criticised her for this – they didn't see any point when the aunts forgot the visits afterwards. But she persisted.

Elaine saw the joy of her aunts' reunion at each visit. She saw the pleasure they got from the little time they had together – reliving past times and shared memories – and felt it was the least she could do. Even if they could only live in the moment, she was determined to give them some good moments.

Elaine contacted the DSDC for advice. She felt instinctively that she was doing the right thing, and was looking for vindication. We helped her with research and writings by the leaders in the field of dementia care, and gave her ideas for recording her sessions with the aunts using her mobile phone, both to remind them of their visits, and to show her family the pleasure the aunts got from each other's company. She did this, and it made the effort worthwhile and rewarding. Elaine didn't give into family pressure; she did what felt right, with compassion and generosity of spirit.
Dementia UK is a national charity that seeks to improve the quality of life for all people affected by dementia. Dementia UK is responsible for Admiral Nurses, specialist mental health nurses working in communities, hospitals and care homes. Dementia UK Training delivers training and educational programmes for health and social care staff working with older people and people with dementia and their families. Uniting Carers is a national involvement network for carers and former carers.

What we did last year:

— Developed new Admiral Nurse posts within the NHS and with independent sector organisations including the Royal British Legion, Bupa, Order of St Johns Care Trust, Brunelcare, Avante, Dementia Forward, Making Space and Age UK Norfolk.
— Expanded Admiral Nursing DIRECT
— Broadened the charity’s educational and training programme, to include delivery of the QCF Dementia Award at Levels 2 and 3 and the ‘Bee Inspired Leadership Programme’, in partnership with Jackie Pool Associates.
— Delivered a comprehensive programme of activity through Uniting Carers, including contributions to government consultations, involvement in research studies, carer presentations at conferences, influencing commissioning strategies and decision making.
— Delivered specific projects including: ‘Carers as Educators’ a DH funded Uniting Carers project; ‘Butterfly Scheme’ Uniting Carers partnership project; ‘Training for Carers’ DH funded project; ‘Dementia: Carers and Workers Together’ publication produced for Skills for Care.

What we will do next year:

— Continue to build capacity in Admiral Nursing by increasing the number of Nurse posts, both within the NHS and with independent sector organisations
— Appoint a Chief Admiral Nurse and invest in the Admiral Nurse Academy
— Increase the scope and availability of Admiral Nursing DIRECT, to include a research study on the potential of a ‘casework approach’ for carers
— Continue to develop and broaden training and educational provision for health and social care staff working in all sectors
— Widen the influence of family carers through Uniting Carers
— Seek research opportunities in order to strengthen the evidence base underpinning all aspects of the charity’s work
— Strengthen external communications to promote awareness of the charity’s models, approaches and achievements
What we will do next year

— Increase our potential and participation in joint working, at strategic and service delivery level, to improve the quality of support and information for people affected by dementia.

— Work with local clinical commissioning groups to provide information and support for people throughout pre-assessment, diagnosis and post diagnosis.

— Build on models of support being established in Oxfordshire across other local dweb areas, including: MCI support group, Empowerment Group and Creative Arts support group.

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National and local websites and 24-hour helpline offering impartial information and support to anybody affected by dementia.
CASE STUDY
DEMENTIA WEB GUIDEPOSTS TRUST

Here is some feedback from people who have used our services:

“I really can’t begin to tell you how much your support has helped me today. I just wanted to drop you a quick email to say many thanks for your support. Dad moved into XXXXX in July and is doing great. He has settled really well into what is a real family home and we are very pleased with his progress. Thank you so much for your support, our chats and the information you supplied were of great help and comfort. Keep up the good work. You provide a very valuable service.”

“Thank you – at midnight I was on the ceiling and talking to XXXXX for half an hour really calmed me down..... when somebody called me back the next day I was helped to get all the information I needed.”
NIHR DEMENTIA AND NEURODEGENERATIVE DISEASES RESEARCH NETWORK (DENDRON)

DENDRON is hosted by University College London (UCL) and Newcastle University and is part of the National Institute for Health Research (NIHR) Clinical Research Network (CRN), supporting research to make patients, and the NHS, better.

We support the development, set up and delivery of clinical research in the NHS in the dementias, Huntington’s disease, motor neurone disease, Parkinson’s disease, and other neurodegenerative diseases.

What we did this year

DENDRON has a core purpose to support dementia research, and has had great success in past year, including:

— Supported researchers working on funding bids in the governments ‘Dementia Themed Call’.
— Conducted a large national review to better understand the landscape of research, and reorganised resources to provide improved consistent support for research across England.
— Worked with the Royal College of Psychiatrists (RCP) to bring about new research standards. As a result, all memory services with RCP accreditation will in future promote local research opportunities to patients.
— Launched a new tool kit (www.DENDRON.nihr.ac.uk/enrich) to support researchers, care homes, residents and carers to work together to support the delivery of dementia research.
— Supported the set-up of 56 studies (of which 24 were dementia-related).
— Supported 16,455 people to be recruited into research studies (of which 9,277 were on dementia).

— Overseen a 12% growth in the number of research studies open to recruitment.
— Supported a further 22 NHS Trust to become involved in dementia research.

What we will do next year

In addition to working towards our core objectives around improving the quality of clinical research, DENDRON will continue to support delivery of the Prime Minister’s Challenge on Dementia by:

— Establishing a patient research register system that enables patients to register their interest in participating in dementia research, both inside and outside the NHS.
— Working with third sector and government agencies to promote participation, improving the ability of people with dementia and carers to easily access and participate in research. For example, working with Alzheimer’s Society to ask ‘Dementia Friendly Communities’ to be ‘Research Friendly’.
— Continuing to establish the ‘Research Ready Care Home Network’ to ensure that the 260,000 people living with dementia in care homes have equal information and access to participate in dementia research.
Over the past year, the Department of Health has made significant progress in delivering its Action Plan. The Department has also continued its work to implement the National Dementia Strategy and has renewed its focus on dementia through the Prime Minister’s Challenge on Dementia, launched in March 2012.

Prime Minister’s Challenge on Dementia

— The Prime Minister’s Challenge on Dementia, launched on 26 March 2012, is an ambitious programme of work designed to make a real difference to the lives of people with dementia. Building on the achievements of the National Dementia Strategy, the ambition is to secure greater improvements in dementia care and research so that people with dementia, their carers and families get the services and support they need.

— The Challenge is one to the whole of society, as well as to government, the NHS and social care. It focuses on three areas: driving improvements in health and care; creating dementia friendly communities that understand how to help; and better research.

Health and Care Champion Group

— The Challenge sets out 14 commitments across the three areas, together with further supporting actions. A Champion Group has been established for each area, bringing together key leaders and organisations to support delivery of the commitments and to mobilise wider engagement across society. The Champion Groups reported their progress to the Prime Minister in November 2012 and will report again in March 2013.

— The Prime Minister’s Challenge Health and Care Champion Group is being led by Sir Ian Carruthers and Sarah Pickup. The Champion Group has met three times to date and reported its progress to the Prime Minister in November. Having sought views from the public, the Champion Group has developed an action plan setting out 15 priority work areas. The action plan widens the Challenge to encompass social care and integration issues including, for example, work on end of life care, rehabilitation, reablement and housing. The priorities for the next phase of the Champion Group’s work include commissioning effective high-quality care; timely diagnosis; high-quality compassionate care in hospitals; high-quality compassionate care in the community; supporting health and care professionals; and the right treatment.
NHS Operating Framework

— The Operating Framework for the NHS in England 2012/13 sets out a systematic set of actions relevant to dementia care which will require organisations to work together. These include:

— commissioners should ensure that providers are compliant with relevant NICE quality standards and ensure information is published in providers’ quality accounts;

— commissioners should work with GP practices to secure ongoing improvements in the quality of general practice and community services so that patients only go into hospital if that will secure the best clinical outcome;

— ensuring participation in and publication of national clinical audits that relate to services for older people;

— initiatives to reduce inappropriate antipsychotic prescribing for people with dementia to improve quality of life with a view to achieving overall a two-thirds reduction in the use of antipsychotic medication; and improving diagnosis rates, particularly in the areas with the lowest current performance.

— PCTs were also required to continue to work with their local authorities to publish dementia plans which set out locally the progress being made on implementing the National Dementia Strategy.

NHS Outcomes Framework

— The NHS Outcomes Framework 2012/13 includes a placeholder on enhancing the quality of life for people with dementia. A placeholder represents a commitment to developing an indicator in this area, recognising that this may take time. We will use the NHS Outcomes Framework 2013/14 to measure progress on diagnosis rates.

Reducing the use of antipsychotic medication

— The national audit to measure progress towards the goal of achieving a two-thirds reduction in prescribing of antipsychotics for people with dementia was published on 17 July 2012. The audit showed a 52% reduction in the level of prescribing of antipsychotics for people with dementia between 2008 and 2011. The audit also highlighted regional variations in the level of prescribing, which the Department is working with the call to action to understand and address. The Department will be re-running the national audit to continue to monitor the level of prescribing and the regional variations.

Improving hospital care

— The NHS Operating Framework 2012/13 announced the Dementia Commissioning for Quality and Innovation (CQUIN) goal to improve awareness and diagnosis of dementia in an
acute hospital setting. The CQUIN came into operation on 1 April 2012, supported by a new data collection. On 15 October 2012 there was a national learning event to assess implementation of the CQUIN and look at how we can develop it next year to include measures of quality and support for carers.

— The call to action on dementia care in acute hospitals was also launched on 15 October 2012, setting the goal that by 31 March 2013, every hospital in England will be committed to becoming a dementia friendly hospital.

Awareness campaign

— On 21 September 2012, the Department of Health, in partnership with Alzheimer’s Society launched the latest phase of its dementia awareness campaign. The campaign will run until the end of January 2013 and aims to help raise awareness of the signs and symptoms of dementia and encourage people to visit their doctor if they are concerned.

Workforce education and training

— On 8 June 2012, e-learning for Healthcare published an e-learning package, funded by the Department of Health, to train health and social care staff in recognising, assessing and managing dementia and providing high quality dementia care.

— The Department of Health has commissioned Skills for Care to support the delivery of a national learning and development programme for the adult social care workforce supporting people with dementia. Skills for Care announced on 26 July 2012 that they would make up to £2.4m available to employers through the Workforce Development Fund to support the completion of relevant accredited qualifications by social care workers who support people with dementia.

— The Department will continue to commission a wide range of projects on dementia education and training for health and social care staff, including training in life story work and reminiscence.

Support for carers

— The Department of Health report ‘Innovation, Health and Wealth’, published on 5 December 2011, emphasised that without better support for carers of people with dementia, such as the provision of carer breaks and access to a range of psychological therapies, an increasing number will be unable to continue caring and pressure on the health and care system will continue to grow.

— ‘Innovation, Health and Wealth’ identified six high-impact innovations that genuinely improve the quality and experience of people’s lives, as well as delivering productivity improvements. One innovation that all NHS organisations are working to deliver is that for every person who is admitted to hospital where there is a diagnosis of dementia, their carer will receive information to help and support them, and be signposted to relevant advice.
EU Alcove project

— In December 2011, the Department appointed a permanent project lead for the UK-led contribution to the EU Alcove project on dementia. Alcove is a joint action funded by the European Commission and made up of 30 partners from 19 member states. The UK work programme will continue until March 2013 and involves an assessment of national recommendations for the diagnosis of dementia, in order to access to a common definition, and formulating recommendations for improving early diagnosis, based on an evaluation of healthcare systems.

Innovation

— On 26 April 2012 the Design Council, in partnership with the Department of Health, launched the project outputs from the innovation challenge ‘Living well with dementia’. For further information on this, see the Design Council’s website.

Research

— The Prime Minister’s Challenge Research Champion Group is being led by Dame Sally Davies and Sir Mark Walport and reported its progress to the Prime Minister in November. On 10 October 2012, the government brought together representatives from across the UK’s research system to showcase the country’s specialist dementia research and resources at a major industry event.

— The National Institute for Health Research (NIHR) has completed a £17m call for applied health research on dementia, as part a programme to push further and faster on progress in the prevention, treatment and care of dementia. This builds on a significant body of dementia research previously funded by the NIHR and has exceeded expectations. Projects range from work on better diagnosis, to improving care in a range of settings. A full list of successful research bids will be announced in Autumn 2012. On 9 July 2012, up to £13m funding was made available through the Economic and Social Research Council (ESRC)/NIHR call for research proposals “Dementia: prevention, intervention and care”.
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DESIGN COUNCIL

The Design Council is a charity, incorporated by Royal Charter, which places design at the heart of creating value by stimulating innovation in business and public services, improving our built environment and tackling complex social issues. We inspire new design thinking, encourage public debate and inform government policy to improve everyday life and help meet tomorrow’s challenges today.

What we did this year

In partnership with the Department of Health, the Design Council ran a national design Challenge competition which funded and supported the development of five innovative design solutions to improve the quality of life for people living with dementia and their carers. Key achievements have been:

— In November 2011, five ideas were selected and supported through early development with funding, mentoring and skills. These were then launched as working prototypes at an event in April 2012.
— Over 150 people attended the breakfast launch, and the series of afternoon talks were attended by over 50 people each, with an additional 409 people engaging remotely via livestream.
— A series of video ‘adverts’ showing the story of each prototype was launched via social media. To date these videos have been watched a total of 8,395 times.
— The programme attracted a large amount of media interest, including national and regional broadcast media, and national and international and print and online coverage.

— A website displaying the five prototypes from the project can be seen here: www.livingwellwithdementia.com.

What we will do next year

— Continue offering support to the five funded projects as they develop their working prototypes into saleable and scalable products and services.
— Continue to disseminate information learned throughout the process of the programme about how to best design and innovate to support people with dementia and those who care for them.
— Continue in our role on the Prime Minister’s Champion Group on Dementia Friendly Communities.
— With auditors Baker Tilly, we have undertaken a forecast analysis of targeted social impacts using Social Return on Investment (SROI). Early indications are for an SROI of over 40 times the original programme funding, while the potential values brought by the five project finalists are projected to be £500 million. We will be further evaluating the impact from the programme over the coming year.
— We are actively seeking new opportunities to develop further design and innovation challenges relating to dementia. Get in touch with us if you’re interested in collaboration.
ENGLISH COMMUNITY CARE ASSOCIATION

What we will do next year

— Continue our commitment to supporting people with dementia, and developing a range of new approaches.
— ECCA Members have commissioned Ipsos Mori to develop a standardised user experience questionnaire that can be used across the system.
— Work hard to encourage take-up of the Prime Minister’s Dementia Care and Support Compact.
— Encourage our members to publish action plans on how they will improve dementia care.

What we did this year

— Raised the profile of the Dementia Strategy and the Dementia Action Alliance. We encouraged our members to make declarations of intent around improving services to people with dementia and their carers.
— Worked with the Social Care Institute for Excellence on an innovation exchange of models of good care.
— Supported the Dignity Commission in developing an approach to dignity for people in health and social care.
— Worked with the Great British Care Awards to champion good dementia care, and wrote extensively in the trade press about how to improve care and support.
— Worked with the Gold Standards Framework, and became members of the Dying Matters coalition to improve end of life care for people with dementia.
We provide nursing and residential care in care homes throughout the South East of England. We also provide domiciliary care and continuing healthcare in the community.

What we did this year

— Forty staff completed the Dementia Care Matters Diploma in-house, and have cascaded their knowledge throughout the company.
— Introduced a new therapy called NAMASTE, which is being pioneered in two homes. It’s having positive effects in the later stages of dementia and at the end of life.
— The introduction of My Life units to most of our services has improved the wellbeing of residents and we are taking part in a trial to validate this.
— Improvements have been made to lighting and environment. Locked doors have been reduced to only those that would otherwise compromise the health and safety of residents. Decoration is ‘homely’ and themed areas have been introduced, bringing the outside in.
— Continued reducing antipsychotics, whose prescription is monitored monthly.
— Enhanced our care in the community for people with dementia by improving our training.

What we will do next year

— Introduce observational audits into our quality monitoring system. These will be used as a training tool for staff and to monitor the quality of life our service users experience.
— Residents, their friends and families will be encouraged to create life stories on the ‘My Life’ units.
— Continue developing our feelings-based approach to dementia care, and explore different technologies for improving the lives and wellbeing of people.
— Introduce new methods of quality monitoring to ensure that we maintain our standards and improve the quality of our residents’ lives.
— Update our dementia strategy to plan for the next two years of improvement.
Across the UK, we oversee training in old age psychiatry and support old age psychiatrists to maintain best standards in delivery of service.

What we did this year

— An exciting development was the introduction of a bespoke memory assessment service across the UK, including working age dementia services led by old age psychiatrists.
— Faculty members helped to reduce use of antipsychotics in dementia.
— Our members contribute to several national research networks in dementia.
— Conducted national audits of dementia services in general hospitals, and the use of antipsychotics in dementia.
— Thirty-three memory services were accredited by the Memory Services National Accreditation Programme (MSNAP), of which 20 were accredited as “Excellent”.
— Members in various NHS Trusts took lead in mapping services as per dementia quality standards; appoint dementia liaison nurses and “dementia champions” to help in early diagnosis and support carers.
— Gave evidence to the APPG inquiry on dementia.
— Published a report, ‘Invisible addicts’, on alcohol and drug misuse in older people, including alcohol induced dementia.
— Our online forum for young onset dementia services continues to be active and popular.

What we will do next year

— Continued to foster links with other professional organisations and royal colleges, and support members in assisting Clinical Commissioning Groups to develop dementia services.
— Continue delivering good psychiatric practice nationwide to improve the health and well-being of people with dementia and carers.
— Review our Dementia Action Alliance agenda regularly at Faculty executive level.
— Complete a second audit of antipsychotics in patients with dementia and disseminate the results nationally.
— A cross-faculty working group on elderly substance misuse will produce an information guide on alcohol-induced dementia and alcohol related brain damage (ARBD). This will include a resource of services and guidelines for managing people with ARBD.
— The Royal College of Psychiatrists is planning a campaign to reduce hypnotics use for people with dementia.
— In collaboration with Alzheimer’s Society, the Faculty and College research unit will study the impact of the National Dementia Strategy to determine the relationship between referral and diagnostic rates.
— Set up an email group for the National Audit of Dementia
What we will do next year

— Develop and launch free online life stories.
— Develop and launch free minority language capabilities (Urdu and/or Punjabi).
— Extend Our Yesterday reminiscence content for people with dementia and activities staff and family.
— Develop a variety of remote care, healthcare, safety and sensor solutions for people with dementia and their carers.
— Develop and launch free FinerGroups for formal and informal care networks.
— Work with local authorities and Dementia Action Alliance partners to develop dementia-friendly environments.

What we did this year

— Increased user numbers to over 60,000.
— Engaged with several new local authorities and county councils to develop and launch joint initiatives.
— Extended the intergenerational school volunteering initiative for care homes – Go ON Adopt.
— Launched ‘Front Door’ – a care home front door and communications system.
— Launched ‘Our Yesterday’ – a free reminiscence website for individual, group and family activities.
— Launched (November 2012) video messaging – free video messages – which can be viewed when the person wants to see or share the video.
— Partnered with BT to deliver digital inclusion for older people in housing schemes.

FinerDay is the free, secure, intergenerational networking platform. It offers two things: one, a safe messaging, video messaging, diary, photos and memories; and two, a portal which can be personalised for people with dementia living at home or in care – and their carers – offering life stories, remote monitoring, reminders, coping strategies and more.
FOUR SEASONS HEALTH CARE

What we will do next year

— Continue rolling out the PEARL programme to other dementia care homes in our organisation.
— Continue to review PEARL and the criteria to ensure it is current, and reflects the needs of our residents and staff.
— Review the policies and guidelines in our Dementia Care Manual and ensure these continue to support the PEARL criteria while reflecting best practice.
— Continue to deliver and review the training needs of our staff to ensure training is current and beneficial.
— Members of our dementia care team will continue to expand on their knowledge and share this information.
— Continue to collect data on the benefits of PEARL, which have included significant reductions in antipsychotic drugs.
— Continue to use Dementia Care Mapping, and provide support and mentorship for existing Dementia Care Mappers.

What we did this year

— Continued to use DCM (Dementia Care Mapping – a specialised observational assessment tool) to establish the views of people living with dementia, and two team members are now approved trainers.
— Trained 2,689 staff in dementia-related courses.
— Carried out the annual review of the PEARL criteria, which has now extended to 158 criteria and been aligned to latest government recommendations, i.e. National Dementia Strategy and CQC Outcomes.
— We have now 54 homes accredited with the PEARL award and 76 homes are currently working towards the project.
— Developed two in-house dementia development programmes – aligned to the QCF dementia modules – for new care staff and nurses working in our dementia care homes.
— We have been shortlisted for the finals of two awards by the Nursing Times and the Guardian Public Service Awards.
— Our dementia team has expanded to 12 staff members.
The HDRC is the largest UK network of Housing with Care (HWC) providers, commissioners and other interested parties. It brings together those that are committed to achieving timely, appropriate high quality research – focused on ‘what works’ – to directly influence policy and practice on housing and care for people with dementia in the UK.

What we did this year

In-house research
— Conducted a small-scale study to assess support for people with dementia within Housing with Care. The report – ‘Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers’ – was emailed to HDRC members and published on the HDRC and Housing LIN websites.

Funding bids
— NIHR School of Social Care Research 4th wave call proposal, ‘Developing best practice in social care and support for adults with concurrent sight loss and dementia within different housing settings’: successful; project set-up has commenced.
— Submission to The Dunhill Medical Trust, “The impact of interaction with the outside community on the health and wellbeing of older residents in extra care and continuing care settings”: unsuccessful; alternative funding will be sought.
— Dementia: prevention, intervention and care ESRC/NIHR research initiative. HDRC has collaborated on a proposal for a large research programme with a number of workstreams. Outline proposal submitted in September.

What we will do next year

— Expand our in-house research and apply it at a larger scale across all HWC schemes in the HDRC. A 4-month project with Bournemouth University Dementia Institute has been planned and funding is now being sought.
— Seek alternative funding for ‘The impact of interaction with the outside community on the health and wellbeing of older residents in extra care and continuing care settings’ project proposal.
— Seek external funding for continuation of our research coordinator’s post.
— Work on the full proposal for the ESRC/NIHR dementia initiative call.
— Generate further proposals, in line with HDRC research priorities, in response to appropriate funding calls / for submission to suitable trusts or foundations.
— Fulfil commitments to the Sight Loss and Dementia project (NIHR SSCR funded).
— Continue to influence policy relating to dementia and housing through work with the Dementia and Housing Working Group.
Hft is a national charity that supports people with learning disabilities. We proactively source information and training to ensure quality support for people as they age. Our ‘Valuing Ageing Network’ shares good practice and finds peer support for specific issues, and has become involved in national research projects on dementia and ageing.

What we did this year

— Some of our services are now supporting older carers in the community.
— Four senior staff members are on the Dementia Leadership award programme. As part of this process they are placing Dementia Link workers within our services.
— The Cardiff Health Check list is to be used in all Hft services. Where it has already been used, the list has improved the service to individuals.
— Hft services are booking longer appointments with GPs and using accessible health passports to work with GPs. Some of our services are meeting regularly with GP practices to improve communication and understanding of people with learning disabilities.
— One Hft service won the Linda McEhill Award for end of life care, while another is working towards a ‘dignity and respect’ award in their locality.

What we will do next year

— Hft are developing a new organisational strategy. One strand of this is to further develop services which need specialist skills: for example, ageing and dementia for people with learning disabilities. Right now, we are exploring areas of focus such as staff learning and knowledge, and partnership working with local authorities, families and health professionals. Our estates department will be trained to give advice on dementia-friendly environments, not only for new developments but also for existing services as individuals’ needs change. We are also considering having an ‘expert’ staff member to ensure information and learning is devolved in each service.

Hft received the Linda McEhill award for supporting an individual with downs syndrome and dementia at the end of their life. Full information is available here: www.pcpld.org/real-life-stories/supporting-tim.
What we will do next year

— Build upon our Portable Care Project by replicating the model in a range of other settings so we can support more people with dementia whilst they are in hospital.

— Review the progress of our Dementia Strategy, published in November 2011. We plan to accelerate a number of actions, including expanding our successful dementia/palliative care ‘Dementia Voice Nurse’ service – currently operating in Westminster – to more localities across the country.

— Carry out a holistic dementia design review so that all our housing developments benefit from the latest research and best practice.

— Continue to work with the Housing and Dementia Research Consortium.

— As part of the Care and Support Alliance, we will continue striving to ensure ensuring that care funding reform is at the top of the political agenda.

What we did this year

— Opened Beeches Manor, a £3.8 million state of the art specialist dementia care and supported living scheme in Wokingham.

— Worked with the Mental Health Foundation on a London-based project called ‘Self Help’. This involves creating, facilitating and evaluating three peer-support groups for people with dementia living in supported housing schemes.

— Early findings from our ‘Portable Care Project’ in Bristol indicated positive outcomes for people with dementia, including better discharge planning. The project involves extra care staff supporting residents when they are admitted to hospital. It was developed because people with dementia often experience deteriorating health when in hospital.

— We are one of seven European partners working on ‘My Life’, a touchscreen application for computers or mobile phones. This will give access to common online functions – such as email – but will feature an easy to use format for people with dementia.

We are a social enterprise specialising in older people’s care and housing services. We are a leading developer of extra care housing and the largest not-for-profit care provider in England. We manage over 18,000 properties, including specialist care facilities for people with dementia.
We run innovative and creative projects that demonstrate what people with dementia can do, and test out innovative ways of engaging with people with dementia. Our work is underpinned by our belief that while a diagnosis of dementia might be life-changing it need not be life-ending.

What we did this year

Our work this year included:

— MyLife project – developing accessible internet-based services and applications for people with dementia.
— The DEEP project (Dementia Empowerment and Engagement), a scoping project looking at how people with dementia across the UK want to be engaged in influencing services and policy.
— In partnership with NDTi (National Development Team for Inclusion), continued with ‘Circles of Support’ for people with dementia.
— In partnership with SWAPs (South West Adult Placement Scheme), a national project to develop ‘shared lives’ opportunities for people with dementia.
— ‘Our House’, a user engagement project in care homes, in partnership with Care UK and MHA.
— Produced guidelines and a toolkit for the Local Government Association on developing dementia-friendly communities.
— We provided support to Alzheimer’s Society Ireland to develop their work around dementia friendly communities.

What we will do next year

Most of the projects above will run into 2013.

— ‘Dementia Without Walls’, a Joseph Rowntree Foundation-funded project to make York a more dementia-friendly city.
— Age UK – working with 15 local services to ensure their mainstream services are dementia-friendly.
The International Longevity Centre UK is the leading think-tank on longevity and demographic change. It is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. We develop ideas, undertake research and create a forum for debate.

What we did this year

— The ILC-UK are looking at dementia and the prevention agenda. This project aims to:
  — understand trends in the levels of known risk factors of dementia and establish the implications for the future;
  — establish the awareness of these risk factors for dementia in the general population;
  — identify appropriate health responses aimed at raising awareness and understanding of these risk factors;
  — develop specific recommendations and interventions aimed at raising awareness of dementia and dementia risk factors
— The study combines a mixed method approach of quantitative analysis with a policy and evidence review, and is anticipated to be published in January 2013.
— We have also written several peer reviewed articles on the disproportionate impact that dementia will have on women globally, including an article in Maturitas, available from this website: http://www.ncbi.nlm.nih.gov/pubmed/22877688

What we will do next year

We are planning next year to explore cultural perceptions of dementia at the global level from a multidisciplinary perspective.
JEWISH CARE

**What we will do next year**

Jewish Care will undertake a training needs analysis over the coming months with staff and volunteers across the organisation. From this we will devise a strategy of dementia training and development from January 2012.

We will develop a life story project across our homes and day centres. My Life Software (Digital Reminiscence Therapy Software) will be used to enhance this work.

In collaboration with Ladder To The Moon, we will set up a project called Creative Hubs. This will provide networking opportunities to link people living in our care homes with the local community.

Jewish Care will actively support the movement for dementia-friendly communities within the Jewish community – which is a religious and cultural one, rather than a geographical one.

Jewish Care commits to supporting the Alliance’s calls to action on early diagnosis and supporting carers.

**What we did this year**

— In April 2012, Jewish Care began hosting a ‘Singing for the Brain’ group at Otto Schiff in Golders Green, North London.
— We launched a dementia cafe (Memory Way Cafe) in April 2012.
— Jewish Care and Dementia Adventure jointly ran an “adventure” for people living with dementia from nine homes and two day centres
— Innovations In Dementia provided training courses for staff and volunteers on the new online assistive technology guide for people living with dementia.
— Two senior staff attended a ‘Train The Trainer’ course for the Department of Health-funded Your Story Matters project. They have gone on to train a further 18 people to do life story work with Jewish Care service users.
— Twenty dementia champions in our care continue to meet bi-monthly.
— Dementia care maps and follow-up plans have been used in all of our care homes
— The Dennis Centre for People Living with Dementia moved into a remodelled, refurbished, state-of-the-art premises in Redbridge.
Jewish Care's Memory Way Café (MWC) in Golders Green

Solly is 90 and has vascular dementia. He is a wheelchair user. Freda, his wife, is 88 and has hearing loss. They live in Selig Court, the extra-care flats in Jewish Care’s campus in Golders Green. Solly is originally from Vienna and he met Freda in South Africa where they lived until coming to London 20 years ago. They employ Penny as their full-time carer.

Through an enquiry from their daughter, Freda and Solly initially came to the MWC with Penny in attendance to support Solly. Freda wanted Solly to come on his own, with Penny in attendance, but we encouraged them that the Café aims to be enriching for the person with dementia and their family carer.

At the first session, Freda found it difficult to hear, because the acoustics in the Café can echo and Solly was totally unengaged with the activities. She was not sure if it would be right for them. Talking with them we found that Solly loves singing. We maintained contact with them and we invited them to attend when a visiting chazzan (cantor) was booked for a session, in advance of the Jewish High Holydays.

They accepted the invitation and during the session liturgical melodies were being sung and the group was enthralled when a very sleepy Solly woke up and then sang together with the chazzan. For the rest of the afternoon he was much more alert and then Freda proudly told us that Solly not only had sung in a synagogue choir, he had also been the conductor.

Solly and Freda have subsequently come to the MWC and this time, without Penny being in attendance. When they have arrived, on greeting, Solly responds with a beaming smile. He has also started to attend the Singing for the Brain group which he very much enjoys. Freda has formed a connection with another couple at the MWC from South Africa and they have shared reminiscences of happy times whilst living there.

Their daughter has subsequently been in touch with us to ask whether the chazzan could visit him on a one-to-one basis – unfortunately this is not possible, but other options are being explored.
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JOSEPH ROWNTREE FOUNDATION / JOSEPH ROWNTREE HOUSING TRUST

We are two charities, working together for social justice, and sharing trustees and directors. Joseph Rowntree Foundation is an endowed foundation funding a UK-wide research and development programme. Joseph Rowntree Housing Trust is a registered housing association and provider of care services, managing around 2,500 homes.

What we did this year
— Our one-year scoping programme Dementia & Society is complete. We can report:
— DEEP (Dementia Engagement and Empowerment Project) found that people with dementia want support in capacity-building, networking and learning from each other so they can influence attitudes, policy and services. Final report will be launched on 24 October 2012.
— ‘York: Dementia without Walls’ will be published on 4 October 2012. There has been huge interest in the project both nationally and locally.
— Held dementia roundtables around the UK. Published ‘Perspectives on Ageing with Dementia’ by the Scottish Dementia Working Group.
— In addition to our routine care service and activities, JRHT has:
— Successfully piloted dementia awareness workshops for WRVS in Sheffield
— Delivered knowledge workshops for North Yorkshire County Council’s Dementia Champions project.
— Launched the ‘Unique Ambassador’ programme for our own care staff. This includes completion of an accredited dementia care qualification at a higher level than that previously offered to frontline care staff.
— In June 2012 our Trustees committed £1.5 m to a major new programme of work called ‘Dementia Without Walls’. Our long-term aim is that the UK is a good place for those of us who have dementia to live, and live well.

Next year
— Our DEEP project will continue through a partnership with Innovations in Dementia. Our goal is to influence the development of a collective voice of people with dementia through investing in emerging and established groups.
— We will continue to support the development of dementia-friendly communities across the UK. We will support York to become a dementia-friendly city, and are currently discussing how we can support dementia-friendly communities in Bradford.
— We will commission projects in Wales, Northern Ireland and Scotland to build evidence on dementia-friendly communities, and stimulate local action.
— Finally, we propose a short seminar series (or similar) with commissioned papers in 2013 to foster thinking and debate on current issues surrounding the representation of dementia in society.
We provide the widest range of NHS mental health services in the UK. We work closely with the Institute of Psychiatry, King’s College London, and are part of King’s Health Partners Academic Health Sciences Centre. We have 4,800 staff and serve a local population of 1.1 million people. We have over 100 sites and provide support to around 39,000 in the community.

What we did this year

— In September, South London and Maudsley NHS Foundation Trust (SLaM) delivered a care home training event to share current innovations and practice that support safe and effective outcomes for residents who have dementia. This was held for care home owners, managers and senior staff in Lambeth and Southwark. SLaM clinical experts and academics explored various themes including evidence-based interventions for challenging behaviour in dementia; local care pathways, national policy and regulation; and the use of Namaste principles for people with advanced dementia. There was an opportunity to share successes and discuss challenges around dementia care facing care home staff. We plan to hold similar events across south London. At the end of this event we set up a peer support forum.

— In June, SLaM delivered a learning event for 25 Lambeth GPs focussed on understanding dementia, evidence-based prescribing, brief memory assessment and care pathways. This was facilitated by senior clinicians from SLaM’s Mental Health of Older Adults and Dementia CAG including Professor Robert Howard. A similar event is planned for Southwark GPs in early 2012.

What we will do next year

— At the end of the year, SLaM will launch the Dementia Training Centre (www.dementiatrainingcentre.co.uk – website currently under construction) which aims to provide high quality education and training about dementia across all sections of the health and social care workforces. The centre is delivered through a virtual platform and will provide blended learning and bespoke programmes on request. The launch will coincide with the release of our first e-learning module about Non-Cognitive Symptoms of Dementia. The package consists of four modules, which include: understanding cognitive and non-cognitive symptoms of dementia; working with people living with dementia; psychological intervention; and pharmacology. The programme is suitable for professionally trained staff and will take approximately 8 hours to complete.
Ladder to the Moon offers innovative and powerful ways to improve the quality of care by developing practice using creativity, coaching and wellbeing. We are a social enterprise that helps care services to be more productive and enjoyable places to live and work. We use artists, coaches and trainers to develop staff, build a strong sense of community, and shift the care culture to one focused on delivering a high-quality, wellbeing-focused service.

What we did this year

— Our flagship Wellbeing Studio programmes ran in over 23 care services. By unlocking staff and leadership potential, these programmes helped staff communicate and engage with residents in new ways. They also promoted a focus on the wellbeing of the whole care community, improving the quality of care services and producing outcomes for everyone involved.

— Aimed at care managers and their teams, the programme brings creative practitioners and coaches together with care staff and residents, transforming the care setting into a Hollywood film studio. For more info visit www.laddertothemoon.co.uk

What we will do next year

Continue to work in partnership with providers to develop creative care cultures focused on wellbeing.
LEWY BODY SOCIETY

The Lewy Body Society is the only charity in Europe exclusively concerned with Lewy body dementias (LBDs). The charity supports research into these dementias and raises awareness among the general public, the medical profession and policymakers to ensure that people affected by LBDs get the best possible treatment, care and support.

What we did this year

— Funded two pieces of research – one to spot genetic changes associated with dementia with Lewy bodies (DLB); the other to use nerve cells made from stem cells to test potential drug treatments for DLB.

— Worked with Parkinson’s UK to increase our campaigning and influencing, collaborating on Dementia Awareness Day, the All Party Parliamentary Group on Dementia’s consultation on early diagnosis, and the NICE consultation on the Dementia Care Standard. Our focus is to ensure that health and social care professionals and policymakers take the distinctive needs of people with Lewy body dementias into account when designing dementia awareness campaigns and services.

— We have been building up a group of ‘experts by experience’ – carers and people affected by LBDs – who can advise us on messaging and strategic priorities. New people have joined our Facebook community almost every day, and we have extended our website content (www.lewbody.org) throughout the year to provide information resources that will help them gain the best possible care and support.

— Participated energetically in Dementia Action Alliance activities at national and regional level.

What we will do next year

— Raise awareness and provide leadership on Lewy body dementias within the dementia arena by setting up a multidisciplinary advisory committee of expert health and social care professionals, and by continuing to grow our ‘experts by experience’ group. With their advice and guidance, we will work to influence health and social care policy on behalf of people affected by LBDs. We will also seek opportunities for them to share their insights first-hand, to increase understanding of the lived experience of LBDs.

— Extend our collaboration with Parkinson’s UK, and seek new partnerships with other relevant organisations, to explore how best to increase support for people living with LBDs. We will identify how best to respond to the demand for peer-to-peer support, and access to leisure and support activities and opportunities in the community, for people affected by LBDs.

— Continue actively to respond to the Alliance’s calls to action.
What we will do next year

— The LSN has joined the Care & Support Compact to support care organisations delivering their commitment to the Compact.
— DH have sponsored LSN for another phase of innovative training, ‘Your Community Matters’, enabling us to work with care homes, registered social landlords and home care organisations.
— Building on the initial pilot from the ‘Your Story Matters’ programme on working with family carers, we are creating a bespoke training resource for family carers, ‘Family Carers Matter’, funded by Skills for Care in partnership with the Tyne & Wear Care Alliance.
— Continue working with Skills for Care to develop bespoke modules for the Qualifications & Credit Framework. We aim for accreditation by April 2013.
— Continue working with an expanding number of organisations to achieve the transformational cultural change needed to fully embed life story work into daily practice.

What we did this year

— Successfully delivered the DH-funded ‘Your Story Matters’ project. Over 5 months, the LSN trained 500 people in life story work embedding a human rights-based approach. We also established a national network of trainers.
— Gave awareness training in life story work to corporate leaders in the statutory and independent sectors, with the aim of bringing about sustainable cultural change. The training enables them to support front line staff in ensuring that life story work underpins person centred care. We ensure that each individual with dementia is seen as an individual person, in the context of their relationships with others, preserving their unique identity and enabling their rights as individuals to be respected and valued.
— Ensured that the LSN, a new community interest company, is developed into a sustainable organisation.
CASE STUDY
THE LIFE STORY NETWORK CIC

A member of staff from Anchor participated in our ‘Your Story Matters’ training course, and went on to train six activity coordinators in Anchor care homes.

One activity coordinator who had been trying to do life story work prior to receiving this training had difficulty in engaging family carers in the process. However, after the training he felt confident in his new knowledge and skills to work with a resident who did not normally participate in any activities. He had learned about building relationships and rapport with people who do not always communicate by spoken language.

He quickly found an interest and, by talking to the family who visited, found out more about her life. He was able to build a relationship with the resident so that she fully participated in gathering information and photos of her life to put in a memory book. She seemed to come to life. The family were so pleased to see her engaged. They had found something they could talk about with her, and contributed to the whole project. A party is planned for family and friends to launch the memory book.

“How can anyone argue with the principle that we should know as much about the people we care for as possible, and celebrate their individuality?” said the care coordinator.
A leading innovation-driven company, Lilly makes medicines that help people live longer, healthier, more active lives. Lilly has a long heritage in discovering medicines for conditions that affect the human brain. We are applying the latest research in the fight against conditions such as Alzheimer’s, Parkinson’s, depression and schizophrenia.

What we did this year

— Lilly works with the world’s best scientists across industry and academia through a number of forums and initiatives. Our research continues to evolve as our neuroscience portfolio moves through key stages of development; this includes our work in the area of potential disease modifying treatments.

— Of note, people with dementia and their doctors have been involved in Lilly’s clinical trial programme at multiple locations across the UK.

— Lilly is proud to have partnered with Alzheimer’s Society on the national ‘Worried About your Memory’ campaign, making significant inroads into raising awareness of symptoms and reducing the stigma associated to dementia.

— In addition, we continue to invest resources in furthering our understanding of the UK dementia landscape, and in particular the needs of people with Alzheimer’s disease and their carers.

What we will do next year

— Lilly is committed to its innovation strategy, and to developing new medicines and diagnostics for the next generation of treatments to improve the lives of people with dementia and their carers.

— Lilly is an active participant in the European Innovative Medicines Initiative (IMI); a series of joint public/private funded programmes designed to address key healthcare problems. Lilly is working with several other pharmaceutical companies and academics to share data and run joint studies aimed at improving our basic understanding of Alzheimer’s disease.

— Lilly continues to partner with Alzheimer’s Society to support their early diagnosis campaign.
What we will do next year

— Continue to raise the profile of dementia services through our suite of resources on adult social care, and in our responses to the government’s Care and Support White Paper and draft Bill.

— Resolving the future of adult social care is the LGA’s top campaigning priority. Between our ongoing policy and lobbying work and our ‘Show us you care’ campaign, we will continue to work hard to secure both funding for, and reform of, the care and support system. We have consistently argued that funding and reform go hand in hand, and that both are needed to create a modern, stable and properly resourced system that can meet the challenge of our changing demography.

— Select a councillor ‘champion’ for dementia from the group of senior local government figures who make up the LGA’s Community Wellbeing Board.

— Examine ways to publicise the work of the Alliance, including the development of local Dementia Action Alliances, and a recognition system for those authorities and communities who are memory aware and/or dementia friendly.

What we did this year

— In May 2012, the LGA launched the Developing dementia-friendly communities toolkit; a practical resource for councils wishing to support the wellbeing of those with dementia who are trying to live normal lives in their communities. This is part of the essential work that councils across the country continue to do to prepare for an ageing society and to work to meet the needs of people with dementia and their carers. For more information and the toolkit, visit: http://www.local.gov.uk.

— Continued to support the Ageing Well group on the LGA’s Knowledge Hub, which exists for council staff and decision-makers to share good practice and innovation in the field of adult social care, including services for those with dementia. (Visit: https://knowledgehub.local.gov.uk/home).

— We were also proud to host the quarterly meeting of the Dementia Action Alliance in September.
CASE STUDY
LOCAL GOVERNMENT ASSOCIATION

DemenShare.com – Cheshire East

Almost 5,000 people throughout Cheshire East have been diagnosed with dementia, and this figure is predicted to rise significantly. Cheshire East Council wanted to provide comprehensive information and increase support as part of its dementia care strategy.

With funding from Local Government (LG) Improvement and Development, the council set up a pilot project – DemenShare.com. This social media website encourages independent living by offering friendship and mutual support.

Meri Yaadain – Bradford MDC

The City of Bradford Metropolitan District Council recognised that South Asian people were not getting the necessary support to help them cope with dementia. Part of the problem was that there is no concept of dementia in Pakistani and other Asian cultures. However, there is a concept of memory loss, so the team called the project ‘Meri Yaadain’, which means ‘my memories’.

Meri Yaadain runs mostly bilingual events with lots of pictures and discussions about what dementia is and what can be done about it. The team uses religious, cultural, and ethnic organisations, and Radio Ramadan, to raise awareness of dementia and Meri Yaadain’s support services.

Communication is mostly face-to-face and verbal, rather than written, but Meri Yaadain has a website and has published some leaflets to support their work. Leaflets have been produced in Urdu, Punjabi, Bangla, Hindi and Gujarati.

Meri Yaadain also offers:

— home visits to ensure that individuals are getting the right homecare, which meets cultural and language needs;
— a monthly support group where carers and people with dementia can share information, take part in activities, relax and get a bite to eat; and
— a telephone advice for those who need to talk or find out about something, which can often help speed up referrals to appropriate agencies.
Lost Chord is a charity that organises therapeutic interactive musical sessions, in residential homes and day centres, for people with dementia. Using highly trained professional musicians with a variety of musical instruments and styles, we attempt to improve wellbeing, quality of life and self-esteem.

What we did this year

So far we have concentrated on people in the later stages of dementia. However, the results of a local survey in Dementia Cafes indicated that clients were very positive about the effect of Lost Chord sessions on their wellbeing. So working with the local Alzheimer’s Society, we managed to secure funding of £10,000 from Awards for All to give therapeutic interactive sessions in Dementia Cafes across the region. In doing so, we have been:

— Encouraging more people to attend the cafes, giving better access to improved information about early diagnosis and treatment.
— Helping with problem solving and signposting.
— Encouraging the concept of exercising the brain with greater stimulation.
— Reducing social isolation by sharing problems and experiences and giving peer support/friendships.
— Giving renewed purpose in life by improving fitness, wellbeing and self-esteem.
— Giving an appropriate activity that carers and the people they care for can still do and enjoy together, in a happy and relaxed environment. This helps reduce levels of confrontation and improve relationships.

What we will do next year

We are planning further promotion of Lost Chord sessions in Dementia Cafes, which will hopefully lead to stronger communities by:

— Promoting volunteering and raising awareness of living well with dementia, particularly in a community environment.
— Drawing whole families together to help them come to terms with the disease and its impact on their relative with dementia.
— Encouraging community support by fundraising activities.

Lost Chord and Alzheimer’s Society are promoting tea dances for people in the early stages of dementia. The aim is to make a significant difference to their lives immediately after diagnosis: offering them a positive approach and a reason to be more optimistic about planning future care while they remain able to do so.

Carers often become exasperated in their role. The strain this puts on relationships can exacerbate the behaviour of a person with dementia. Lost Chord sessions create a relaxed environment where people with dementia and their carers can interact and discover again the person they once knew.
CASE STUDY

LOST CHORD

Donald had great difficulty getting his wife along to a Dementia Cafe after her diagnosis. She had been a maths lecturer at the local university and was really struggling to come to terms with her condition. She had always loved music and been a member of a choir, but the disease had robbed her of that. We managed to persuade her to attend one session where Lost Chord was performing, on the pretext that it was a concert she and her husband could appreciate together. She enjoyed the experience so much, singing and dancing along to the music, that she came to the cafe on a regular basis. She even became a client representative on the staff/client board. It transformed her life, giving her renewed purpose and greater sense of achievement.
Lundbeck is an ethical research-based pharmaceutical company dedicated to becoming a world leader in the development of medicines for psychiatric and neurological diseases. We currently market medicines in the UK for depression and anxiety, schizophrenia, bipolar I disorder, Alzheimer’s and Parkinson’s disease, and have drugs in development for other central nervous system disorders.

What we did this year

— Lundbeck are the marketing authorisation holders for one of the four licensed treatments for Alzheimer’s disease recommended by NICE. The recommendations from the updated NICE guidance published in 2011 mean clinicians now have pharmacological options available on the NHS, for treating patients with mild, moderate and severe Alzheimer’s disease. Up until 2011, pharmacological options were limited to the moderate stage of the disease – this is the first time that clinicians have a pharmacological treatment recommended for severe Alzheimer’s. These treatments are also endorsed for behavioural and psychological symptoms of dementia (BPSD) in the new Department of Health guidelines for BPSD.

— Lundbeck has been working in partnership over the last year to support local NHS Trusts implement both the new NICE recommendations and the reduction of inappropriate antipsychotics prescriptions for people with dementia (one of the four key priorities of National Dementia Strategy). Specific examples include Lundbeck’s provision of support with a data extraction tool which has been used by a number of organisations.

— Through our work with the DAA, Lundbeck has also, as one of the stakeholders whose views were sought, contributed to the All Party Parliamentary Group Enquiry (APPG) on diagnosis of dementia. Lundbeck also supported an independent expert report on how to deliver improved treatments for Alzheimer’s patients in local PCTs, a report launched in parliament in the summer. Further support via an educational grant was also provided to the Age Related Diseases & Health Trust project ‘Determining and Achieving Better Dementia Diagnosis and Care Pathways’.

What we will do next year

— Make our current tools available as a service to medicine, to help enable NHS Organisations to undertake reviews and carry out implementation in line with national guidance and objectives, e.g. reducing inappropriate prescribing of antipsychotics in dementia patients.

— Our Antipsychotic Review Programme supports PCTs/CCGs in the identification of people with dementia who are prescribed antipsychotic medication. In addition our Alzheimer’s NICE Implementation Review Programme (ANIR) contains a number of modules which can support NHS organisations in implementing NICE guidance TA217 both quickly and effectively.

— Lundbeck has a promotional company website www.lundbeck.co.uk as well as information websites for healthcare professionals and non-healthcare professionals & general public at www.adbehaviours.co.uk.
CASE STUDY
LUNDBECK

This case study demonstrates how partnership working can effectively address a specific national issue in dementia care that is of immediate value to patients. The National Dementia Strategy’s main objectives include ‘Improved quality of care for people with dementia in care homes’, and the NICE guidance states that people with dementia must receive care from appropriately trained staff.

Lundbeck sponsored and helped the Norfolk and Suffolk Dementia Alliance (NSDA) to develop a series of conference/workshop events for the owners and managers of care homes and nursing homes across the two counties. The first two events (one per county) took place in February 2012, the second in April 2012. Each event attracted over 100 delegates.

The conferences brought the care home sector together with NHS and social services professionals to discuss key issues including: reducing the use of antipsychotic drugs, managing behavioural and psychological symptoms of dementia (BPSD), and adapting the care environment. Emphasis was placed on the need to improve communications between care sectors.

For Willie Cruickshank of the NSDA, the primary goal of the care homes interventions was to overcome the isolation of the independent care home sector. The first conferences established that care home managers felt there was a poor level of communication with the acute care and social care sectors. The later conferences aimed to raise awareness on all sides of “what other partners in a different sector are doing around the same condition” and to “try and improve communication streams”.

The feedback from the independent sector care home managers, Cruickshank says, “was right up there with the best conferences I’ve ever been to” – because care professionals who “feel very isolated in their own setting” were being given real opportunities to learn and to share their experience.

For Cruickshank, the key lesson of the project was that good communication between all care providers along the dementia care pathway is crucial to the “integrated whole-system working” required to implement the National Dementia Strategy recommendations. “By improving communication channels across the settings, from independent care to social care, to acute hospital care, and to GP and mental health provider care, you start to build up a system of integration that means we can look after people with dementia in a much more effective and efficient way.”

Cruickshank praises the commitment of the Lundbeck team to achieving the project’s goals. “What I liked about the Lundbeck involvement was that there was no hint at any stage of them trying to market their products,” he notes. Rather, they recognised that the partners had different priorities, but “unless we all come together to raise awareness, improve communication, develop the network, then overall the whole system collapses and isn’t effective.”

Lundbeck’s approach to partnership working, Cruickshank says, reflects the principle of shared responsibility that was at the heart of the project’s aims and outcomes: “They’ve brought a wider perspective rather than a myopic pharmaceutical perspective.”
What we did this year

— The Dementia Engagement & Empowerment Project (DEEP) was successfully completed in October, with the publication of the project report and films by the Joseph Rowntree Foundation. The project was led by the Mental Health Foundation, in collaboration with Innovations in Dementia and the Alzheimer’s Society. We identified a growing number of groups led by, or actively involving, people with dementia influencing services and policies affecting their lives. Further outputs included a comprehensive survey and two national events for people with dementia. For more information: www.mentalhealth.org.uk/deep

— We published a summary report of our Home Improvements grant-making schemes, which awarded four grants to organisations doing innovative projects for people with dementia in care homes: http://www.mentalhealth.org.uk/publications/home-improvements/

— We completed an evaluation of an educational programme run by Dementia UK for family carers of people with dementia.

What we will do next year

— We will provide expert consultancy and support to the next phase of DEEP, in collaboration with Innovations in Dementia.

— We will continue with the self-help project for people with dementia. If initial findings are positive, we will consider how we can roll this out more widely.

— We plan to develop work to support the Prime Minister’s challenge on dementia-friendly communities.

— In spring/summer 2013, we will publish a report on a research project that has looked at direct payments for people who lack capacity to consent, including people with dementia.

— We will continue to support good decision-making and mental capacity practice for people with dementia in health and social care.

We are a UK charity that does social research, service improvement, training and evaluation, and policy work. We provide public information on mental health and wellbeing, and on issues affecting people with mental health problems, dementia, and learning disabilities across all ages.

To view the DEEP films and see people with a dementia diagnosis talk about the groups and projects they have been involved in go to: www.mentalhealth.org.uk/our-work/research/dementia-engagement-and-empowerment-project
MHA is a charity providing care, accommodation and support services for older people throughout Britain. As one of the largest charitable care providers in the sector and among the largest charities in Britain, we have been providing services to older people for nearly 70 years.

What we did this year

— MHA home managers and staff have continued working with pharmacists and medical practitioners to effectively review the use of antipsychotic medications.
— A new training programme has been developed in conjunction with the Bradford Dementia Group (BDG). This will form part of a wider dementia resource box, currently being finalised. Facilitators co-trained by MHA and BDG have started rolling out this new training, comprising six modules, at homes delivering care to people living with dementia. Individuals who complete the modules receive a certificate from MHA and BDG. The ‘Dementia Resource Box’ also provides staff with further opportunities for professional development.
— Continued to offer alternative therapies – including music therapy and reflexology – to residents. This forms part of the wider delivery of care that remains committed to placing the person at the centre.

What we will do next year

— Continue rolling out our dementia training, using the facilitators we have trained with BDG.
— As MHA has established a broader scale of music therapy service than other organisations in older persons’ care, we will conduct precedent research to evidence the effectiveness of the existing music therapy service, while establishing MHA’s expertise in providing music therapy as a psychosocial intervention.
— Continue using our trained dementia mappers as a part of our continuous improvement, with particular emphasis on driving up care quality for people living with dementia.
— Continue working with pharmacists and medical professionals to reduce antipsychotic use in our care homes.
Albert was admitted to a MHA care home in December 2010. His wife visited the home weeks before he was admitted and described the desperation of their situation. Albert was living with dementia and being cared for at home by his wife. He had undergone surgery and required assistance with a colostomy bag. After the surgery he lost his zest for life, no longer wanting to eat, drink or mobilise. In the months that followed, Albert’s wife watched him lose weight and deteriorate, becoming a shadow of the man he once was.

Albert’s wife consented to the introduction of a PEG tube to help with his nutrition, stating that she knew her husband wasn’t ready to give up, and she wasn’t ready to give up on his behalf. Albert was only accepting a small spoonful of thickened liquid every few hours. His wife spent hours on end trying to encourage him to eat again.

Albert was being nursed in hospital in bed for 24 hours a day. The hospital staff told Albert’s wife that they had done all they could and now it was time for her to find a care home.

On his admission, Albert was withdrawn and drowsy. The day after arriving in the home, staff decided to try taking Albert into the home’s lounge to meet other people. Albert sat in his chair looking at the other residents and staff around him. The staff tried Albert with oral intake but he just wasn’t interested.

On the third day, while sat in his chair during lunch time, Albert suddenly piped up: “Where’s my dinner?”

The staff took a meal to Albert, and with the help from staff he began to eat it. The home involved Albert’s dietician, who as impressed with his weight gain. While removing the PEG is still a long way off, Albert is beginning to improve.

On admission Albert was assessed as bedridden, unable to eat, use the toilet or communicate independently. Now Albert and his wife are looking forward to what the future may hold.
MyAmego provides nurse call, personalised monitoring and electronic care planning to care organisations. We collect data on individuals which support decision-making for care staff. MyAmego also has a full reporting system for safeguarding. The system is passive so it reduces shadow care, and maximises independence and dignity.

What we did this year
— MyAmego continued to sell its personalised monitoring system into care organisations, increasing the number of customers and residents being proactively supported.
— Our nurse call system was successfully launched. This has significantly improved care home environments by delivering alarms and alerts directly to staff, which reduces noise and disturbance.
— We have introduced electronic care planning, creating an end-to-end solution for the care home environment.
— And we have expanded into assisted living, learning difficulties and mental health environments.

In today’s challenging environment, we have been able to work with customers and produce critical data. Three examples are:

1. A 10% reduction in staff costs thanks to less attrition and more productivity.
2. Evidence that supports improved care delivery per person and changes the relationship with local authorities.
3. Access to information that allows families to see the activity of residents on the internet.

In twelve months, MyAmego has proved how care delivery can be changed by supporting all care staff in their roles.

What we will do next year
MyAmego has three objectives for the next year that will directly impact the person with dementia in a positive way:

1. Continue to expand our customer base as we push to achieving 100 sites in the UK as soon as possible.
2. Take out prototype products for domestic homes and hospital wards, and launch both with our customers.
3. Continue working with customers to test the incorporation of vital sign monitoring into the MyAmego platform, as we seek to demonstrate that creating an integrated community platform is realisable.

In support of the initiatives outlined above, MyAmego will produce data demonstrating the benefits of our system. The analysis is to show the benefit to cost, time and effectiveness.
What we will do next year

— Continually support the cause by evolving our systems and linking not only with the clinical establishments, but also with charitable, voluntary and liaison groups and networks.
— Planning and scoping is currently underway for an online application, as part of our ongoing development and commitment to improvement.

What we did this year

— Worked with a number of NHS hospitals and care homes, large and small, and in the community working with occupational therapists seeking alternative resources for helping people with dementia. As a member of the Alliance working to help frontline clinicians and hospital staff respond to the Call to Action, we have embarked on a NHS acute hospital trial to help achieve:
— Improved patient satisfaction, mood and wellbeing. Mood and wellbeing outcomes are available as part of the DRT and ‘Life Story Book’ sessions.
— Reductions in BPSD (behaviours and psychological symptoms of dementia), feeding into the patient satisfaction and antipsychotics audit, which also measures outcomes of distraction therapy.
— Improved care for patients with dementia.

We are provide touchscreen technology that enhances the lives of people with dementia. This is achieved through digital reminiscence and life story work that engages the individual, stimulating them and helping to reduce agitation. Digital reminiscence therapy (DRT) is a form of cognitive stimulation therapy that has been proven to help with cognitive decline.
CASE STUDY
MY LIFE SOFTWARE

Admiral Nurses are specialist mental health nurses who work with families, carers and people with dementia, helping people to develop skills and maintain relationships. Across the country Admiral Nurses have been involved with MyLife software in trialing the technology and providing useful feedback.

An Admiral Nurse has worked very closely with full-time carer Helen in providing care for Helen’s mother, who has had vascular dementia and Alzheimer’s disease for three and a half years. Formerly the head teacher of a primary school, Helen’s mother finds it very difficult to communicate. The Admiral Nurse provided Helen with MyLife’s “Digital Reminiscence Therapy Software” (DRTS), opening up a whole new world of communication and reminiscence for Helen and her mother.

“I love the range of media, Helen said. “The wide selection means I can choose from lots of time periods and go to different parts of mum’s life.” Helen has taken DRTS to Alzheimer’s Cafes with her mother. “A man with the same disease used DRTS with my Mother and they got on really well,” she said. “Different capabilities can sit together, and have fun for a few minutes and chat. It’s good for all the elderly.”

The Admiral Nurse also pointed out the use of the software for grandchildren and younger carers. “Grandparents can look at old photographs, videos, music, even personal memorabilia, and reminisce with their grandchildren, and they can learn about each other,” she said.

She added that among carers is frequently an issue, with the difficulty involved in effectively communicating with residents who have dementia and similar cognitive disorders and is one of the most common problems. Carers struggle to maintain relationships with residents and tools to help are often nonexistent.

“The ease of communication provided by MyLife’s DRTS is therefore beneficial to both carer and resident, taking some of the pressure off and encouraging engagement, communication and wellbeing.”
NAPA helps care staff support older people to live in the way that they choose, with meaning and purpose. Things to do, people to see and places to go – these are vital to us all at every stage of life.

What we have done this year

— Focused on ensuring that activity providers have access to training, in order to develop their knowledge and skills around activity provision and dementia.
— Worked closely with Skills for Care and the National Open College Network to develop a qualification that is now on the Quality Curriculum Framework.
— We are now advocating that ‘Supporting Activity Provision in Social Care’ should be regarded as the minimum national qualification for activity staff. One of the four assignments is about understanding dementia, and how activity contributes to wellbeing. NAPA has developed distance learning course materials that offers the course in a format that activity workers seem to find easier to complete.
— To address the commonly-held perception that staff being away on training means that residents lose out, we have been campaigning for a cultural shift so that care staff recognise that activity should be seen as integral to care, and the responsibility of all staff: not just a nice extra when it can be fitted in or when a dedicated activity coordinator is on hand.
— Our single day training courses have focussed on: the ‘Whole Home Approach to Activity’; ‘Making the Most of Mealtimes’; and ‘Spontaneous Activity in Dementia Care’. We also offer manicure and hand massage training in conjunction with the Red Cross. This training is particularly popular with staff working in dementia and end of life care.
— Worked more closely with businesses developing computer software programmes. We are trying to encourage greater access to modern technology, to support more varied ways of engaging with people with dementia.
The National Care Forum (NCF) was established to promote quality care and support services and provide a voice for not-for-profit care providers. Our membership reflects the wide diversity of the care sector including home care, housing with care, day care, intermediate care, outreach services, residential and nursing care and specialist provision including for people with dementia.

What we did this year

— NCF Annual Managers Conference 2012 – dementia is central to the agenda.
— Several NCF members have appointed Admiral Nurses in their organisations
— NCF members continue to win awards for their innovative contributions to the field of dementia care.
— It is not possible to name all our members’ achievements, however organisations such as St Monica Trust; Brunel Care; CiC; Extra care Charitable Trust and Housing 21 will give some insights into the pioneering approaches to design; models of care and the use of technology which enhances peoples quality of life.

NCF have continued to work in partnership nationally and internationally to influence the quality of care and support provided to people with dementia (and their carers) by:

— Promoting awareness and best practice to members through information, guidance, events and activities – a key component of this is the NCF members weekly newsletter.
— As members of EAHSA (European Association of Housing and Services for the Ageing), NCF arranged for three members to present at the EAHSA 2012 conference in Malta.
— Working with the National Skills Academy for Social Care; SCIE; NCPC and National End of Life Care Programme, to achieve better outcomes for people who use services, and to inform staff development and leadership approaches.
— Working with the Department of Health to improve medication management in care homes.
— NCF continues to work with MHL and has jointly presented at events regarding living with dementia.

What we will do next year

NCF will continue to contribute to the Dementia Action Alliance, building on the work that has been ongoing across the NCF membership. Sharon Blackburn, Director of Policy and Communications at NCF, serves as one of four Chairs of the Alliance.
NCPC AND THE DYING MATTERS COALITION

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, hospice and end of life care in England, Wales and Northern Ireland. NCPC leads the Dying Matters Coalition to raise awareness and change behaviours around dying, death and bereavement.

What we have done this year

— A major priority has been the Prime Minister’s Dementia Challenge. We are delighted that, although not referred to in the challenge when it was first published in March, end of life care is now seen as a key aspect of the agenda. Our Chief Executive, Eve Richardson, is a member of the Health and Care Champion Group, and we will be working into 2013 to deliver real change for people with dementia approaching the end of life, and their carers.
— In July, we hosted a successful meeting of the All Party Parliamentary Group (APPG) on Hospice & Palliative Care on the Dementia Challenge. A key message was that societal change towards both dementia and dying is urgently needed.

— Responded to the APPG on Dementia’s inquiry into dementia diagnosis rates, and the Dementia Action Alliance’s work mapping the benefits of early diagnosis.
— Our 7th Annual Conference on Dementia & End of Life Care is happening in London on 4 December 2012. The event brings together the three key aspects of the Dementia Challenge and showcases good practice in relation to end of life care.

What we will do next year

— Work hard to make the Dementia Challenge a reality by producing pain guidance and mapping current areas of good practice, with the help of our Dementia Working Group. Working with the Dying Matters coalition, we will be developing a training DVD to help GPs initiate end of life care conversations with people with dementia and their carers.
— Continue to champion the voice of people with dementia and carers with experience of end of life care and bereavement; and relentlessly communicate the profound impact a poor death has on individuals, families and society as a whole.
The National Development Team for Inclusion (NDTi) is a not-for-profit organisation concerned with promoting inclusion and equality for people who risk exclusion and who need support to lead a full life. We have a particular interest in issues around age, disability, mental health and children and young people.

What we have done this year

— Continued developing and implementing the ‘Circles of Support’ for people with dementia project, including:
  — Setting up and running Circles of Support, with 20 now set up or about to start.
  — Working national and local organisations and groups such as CSV, WRVS, CVS and community mental health teams.
  — Trialling different methods of involving people with dementia.
  — Continued to involve people with dementia in our work, ensuring that all developments lead real improvements in wellbeing and inclusion.

For example:

— Researching how older people with high support needs, including people with dementia, give and receive support.
— Launching ‘Older Leaders for Change’, a project designed to raise the profile of older people’s mental health and wellbeing; and to enable older people with mental health problems to lead and influence change.

What we will do next year

In ‘Circles of Support’:

— Continue working with all involved to support developments towards meeting individuals’ goals.
— Recruit new people with dementia to develop their own Circles, towards meeting our goal of working with 40 people with dementia by April 2014.
— Continue working with other organisations and groups to promote and develop person-centred planning approaches.

We will also:

— Continue developing ‘Older Leaders for Change’, and complete both coproduction projects.
— Work on more projects which support people with dementia to live positive, inclusive lives.
— Continue challenging ageism and the stigma around dementia.
What we did this year

— Set up the dementia and housing working group with the Department of Communities and Local Government to identify and promote the work of housing providers in improving the lives of people with dementia. The working group includes representatives from Foundations, CIH, HCA, Care and Repair England, Housing LIN, Alzheimer’s Society and ADASS. The working group feeds into and supports the work of the champion groups on dementia-friendly cities and health and social care, taking forward the Prime Minister’s challenge on dementia.

— More broadly, NHF is working closely with the Department of Health to ensure that the health and social care reforms maximise the potential for securing more effective and efficient provision for communities by working for a more holistic approach to care, support and housing – including for those with dementia.

What we will do next year

— Publish a report on housing and dementia, looking specifically at the role of housing providers in early diagnosis of dementia. The report will set out the positive impact of good housing and related services on people with dementia in terms of: delaying a move into care, supporting of relatives and carers, and supporting people to continue living independently in the community for as long as possible.

— Hold seminars to increase dementia awareness in the housing sector, and improve understanding among the health and social care commissioners of the importance of integrating housing with health and social care.
Housing with care helps people with dementia to live in the community, delaying a move into a care home. Beechwood Court, an extra care scheme recently opened by Willow Housing and Care, has care workers and scheme managers trained in dementia awareness, and incorporates aspects of dementia-friendly design to help people with dementia continue living independently in the scheme.

Housing-related care and support, as well as home adaptations and telecare services, reduce the pressure on acute services such as accident and emergency departments. Rochdale Boroughwide Housing operates an assistive technology service to help tenants with dementia live independently. Fall detectors and lifting cushions have reduced the frequency of paramedic call-outs and A&E admissions, resulting in estimated savings of £392,288 a year.

The nature of the dementia challenge means it cannot be met by specific care and support services alone. Housing staff working in general needs accommodation are helping to increase the rate of diagnosis and signposting to packages of support. Riverside Housing Association runs a health check service for older tenants called LiveTime. The service has encountered a number of cases of people living with dementia, resulting in specialist training for staff. The service has helped to get some people a diagnosis of dementia through contact with their families, GPs and social services.

Elsewhere, the Accord Group has worked with local partners such as Age UK Walsall to set up an information service with trained dementia advisers to advise people with dementia, as well as providing a dementia cafe for people to access information on diagnosis and available support.
What we will do next year

— In April 2013, NICE will change its name to the National Institute for Health and Care Excellence to reflect the new remit for social care.
— We are currently tendering for a collaborating centre for social care, who will develop additional guidance starting in 2013/14 (the complete list includes some topics for children). Quality standards will follow on from the guidance, which will include:
  — The transition between health and social care, including discharge planning, admission avoidance, reducing readmissions and reducing unnecessary bed occupancy.
  — Mental wellbeing of older people in residential care.
  — Management of physical and mental co-morbidities of older people in community and residential care settings.
  — Medicines management in care homes.

For information about dementia, and other health and social care topics please see:

www.nice.org.uk/socialcare
pathways.nice.org.uk/pathways/dementia
www.nice.org.uk/newsroom/news/

NICE hosts a database of examples of where guidance has been put into practice to facilitate shared learning. Visit www.nice.org.uk/sharedlearningexamples and search for dementia to find relevant entries.
What we will do next year

— NSASC has a particular interest in building support for registered managers in care home and home care settings, as they are commonly the lead professionals in their areas.

— Build on the findings of our nationwide survey of registered managers – published in the report ‘Everyday Excellence’ – to strengthen the support and information available to registered managers so that they can, in turn, improve the services they provide for people living with dementia.

— Continue with our employer and stakeholder engagement programme, expanding our membership base to include more employers that support people with dementia and their carers.

— Continue working with our members to identify how best to support them in their leadership capacity.

— Work closely with our partners, such as the Social Care Institute for Excellence, to provide a unified voice in the social care employment sector. This will be greatly aided if our current merger talks with Skills for Care come to fruition.

— Launch a Leadership Qualities Framework and a Leadership Strategy for Adult Social Care, which will illustrate the essential leadership qualities and behaviours needed to deliver best practice in social care, including care for people with dementia.

— Following the proposals in the recent white paper, ‘Caring For Our Future’, we will be establishing a leadership development forum to collate and promote best practice in leadership from around the world.
The NHS Confederation is the membership body for all organisations that commission and provide NHS services. We are the only body to bring together and speak on behalf of the whole of the NHS.

**What we did this year**

— Our jointly established Commission on Dignity published its final report, ‘Delivering Dignity’ which made recommendations on how to improve dignity in care for older people in hospitals and care homes. We also held an event to share some of the good practice the commission collated, and started engaging people in what we need to do next as part of our action plan.

— Published a briefing on new approaches to integrated falls prevention services, which made recommendations to push for greater national and local drive to address falls and fractures in older people.

— The NHS Confederation Community Health Services forum is running a one day conference on the future of commissioning and delivering services for frail older people. The event will explore quality benchmarking and tariffs, patient and carer involvement in commissioning, and local integrated commissioning for falls prevention and dementia.

**What we will do next year**

— Continue working in partnership with Age UK and the Local Government Association to look explore how we can support hospitals and care homes to forward the recommendations in the Commission on Dignity’s ‘Delivering Dignity’ report.

— Publish a report into integrated commissioning for frail older people.
The NHS Institute transforms good ideas into workable solutions for an improving NHS. Our purpose is to support the transformation of the NHS, through innovation, improvement and the adoption of best practice.

What we did this year

On the ‘Right Prescription’ call to action:

We brought together a senior leadership taskforce team who have been able to deliver a recognised key contribution to the improvements in prescribing (IC audit 2012), including:

— A clear narrative to motivate people to undertake clinical reviews of people with dementia who are taking antipsychotics.
— Products to support this process, including the RPS resource pack, junior doctors’ education resource; a doctors.net GP education microsite; online community; and an expert webinar series.
— Shared best practice across England and internationally.
— Increased engagement through the call to action: 6,000 GPs, 40,000 pharmacists, and 25,000 nurses.

On ‘The Right Care’ – creating dementia friendly hospitals:

We brought together a national senior leadership taskforce to deliver:

— A national launch of this call to action on October 15th – fully supporting the National CQUIN review and the Prime Minister’s challenge.
— A self assessment resource for all hospitals that sign up to be able to benchmark their progress towards dementia friendliness
— All acute hospitals signing up, by March 31st 2012, to becoming dementia friendly – and to join the Dementia Action Alliance as part of this commitment.
— An online community for sharing best practice and for hosting expert webinars.
— Content support for the CCG development programme run by the NHS Institute (and to move to the NiB)

What we will do next year

The role of the Institute as an enabler for all of the above work comes to an end in March 2013. To ensure that the work is hosted beyond this date, we are now setting in place a robust transition plan for all aspects of the calls. For the ‘Right Prescription’ call, this includes the RPS resource, MIQUEST guideline development, and GP education. For the ‘Right Care’ call, this includes: acute hospital self assessment implementation; local eporting mechanisms to include CCGs; and case study exemplars.
NUTRICIA ADVANCED MEDICAL NUTRITION (NUTRICIA LTD)

What we will do next year

Through the Health Awareness programme run by Nutricia Homeward, the Care Quality Commission registered home enteral feeding service operated by Nutricia, the company will continue to raise awareness of dementia during key times of the year.

Nutricia will support the activities of the Alliance, such as the commitment that every hospital in England will become dementia-friendly by 31 March 2013. Nutricia will play an active part in the Alliance’s carers task force, and will continue actively to support dementia-friendly communities both within Nutricia and throughout its locality. The company will achieve this through voluntary work, training and education, in particular during Dementia Awareness Week in 2013.

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In partnership with Carers UK, Nutricia will continue training carers to better understand acceptable standards of nutritional care. This helps them understand in which circumstances they should demand better nutritional care for themselves, their loved ones and those they look after.

What we did this year

Having joined the Alliance in May 2012, Nutricia demonstrated its commitment to supporting people with dementia, as set out in the Declaration. It has done this by focusing on fostering a dementia-friendly community both within the company and locally to its Trowbridge head office. The company has striven to remove the stigma associated with dementia by raising awareness of dementia and helping carers enhance their knowledge of good nutrition. Nutricia has campaigned for better support for people with dementia, their families and carers. Finally, Nutricia demonstrated its ongoing commitment to funding research into Alzheimer’s disease, for example, by recently sharing data from a highly relevant clinical trial.

Nutricia specialises in the delivery of advanced medical nutrition for the very young, the old and the sick. As well as being the largest specialist nutrition company in Europe, Nutricia is the market leader in the UK. Nutricia’s mission is to improve people’s health through nutrition by supplying high quality feeds, systems and support services to patients and health care professionals. The Nutricia Homeward service can deliver nutritional feeds, enteral feeding systems and nursing care directly to patients’ homes. www.nutricia.co.uk
CASE STUDY

NUTRICIA ADVANCED MEDICAL NUTRITION (NUTRICIA LTD)

Training Nutricia nurses

Over 100 registered nurses work for Nutricia’s CQC-registered homecare provider, Homeward. A specific cohort of nurses have become Nurse Dementia Champions. Having sat the Alzheimer’s Society Foundation Certificate in Dementia Awareness examination paper (which had a benchmark pass of 80%), Nutricia is delighted to report that all of the nurses passed the exam with flying colours and were awarded certificates in June. The next phase is to cascade dementia awareness throughout all Nutricia Nurses. The objective here is to provide insight and knowledge of dementia, including the implications it may have on the nutritional status of the individual. These sessions are now being delivered by the Nurse Dementia Champions. Finally, ‘Lunch & Learn’ sessions will start at our head office in Trowbridge from October 2012, which will provide customer service employees with an overview of dementia, thereby further raising awareness of the condition.

World Alzheimer’s Day

This year, on World Alzheimer’s Day (21 September 2012), members of the Nutricia senior management team volunteered their time to ‘tidy up’ the Alzheimer’s Support Wiltshire community garden. Others pitched in to help out on a boat trip with a group of carers and people with dementia. Also, a ‘Lunch and Learn’ session was organised in our Ealing office, with the local Ealing Carers Group sharing experiences with Nutricia staff.
OSJCT provides high quality person-centred care for older people in the counties of Lincolnshire, Oxfordshire, Gloucestershire and Wiltshire. Our services offer personal care, nursing care, specialist dementia care, intermediate care, respite and day care, and extra care housing.

What we did this year

— Developed our dementia strategy in line with the 17 objectives in the National Dementia Strategy – it will be completed by the end of the year.
— Developed a specific dementia audit tool which aids the assessment of our care homes working towards the Trust Dementia Accreditation, which is endorsed by Dementia UK. To date four homes have achieved their accreditation, with many other homes working towards it.
— With the aide of capital grant funding, three homes purchased a Digital Reminiscence Therapy unit (DRTS). The units can be used by individual residents or groups of residents to reminisce, play games and create life stories incorporating personal photographs and music. We have also applied for lottery funding through ‘Awards for All’ for further DRTS units.
— In conjunction with Dementia UK we have appointed a second Admiral Nurse.
— Appointed a second Trust Advisor to give additional support to the Trust Admiral Nurses.
— Working towards the development of therapeutic environments, particularly creating destination areas in the homes. Progress continues with developing a ‘street theme’ along whole corridors.
— Each of our homes has a dedicated Dementia Lead who is supported by the Trust Admiral Nurses and Trust Dementia Lead. They hold quarterly meetings in each county, which gives the care home Dementia Leads the opportunity to network with peers, discuss challenges and get updated on new research and initiatives in dementia care.
— The Trust continues to be committed to reducing the use of antipsychotic drugs through a robust system of monitoring and review.
— The work with the Design Council has been completed. Use of flip cameras during this project was valuable in capturing real-time feedback from staff, residents and relatives.

What we will do next year

— Continue to measure our service against the National Dementia Strategy.
— The Trust Dementia Lead will continue to support and advise individual care homes with the development of therapeutic environments in our dementia communities.
— Strive to reduce the number of beds per dementia community when planning new care homes, and ensure each community has an appropriate therapeutic environment.
— Continue to support each care home with a dementia community to achieve Trust Dementia Accreditation.
— Consider further ways of developing the Dementia Leads, both in their knowledge base and leadership skills.
— Review our dementia training programme.
Parkinson’s UK works to ensure that no one has to face Parkinson’s alone. Our focus on the Lewy body dementias (Parkinson’s dementia and dementia with Lewy bodies) touches all areas of our work, including campaigning, local group support, a free confidential helpline, specialist nurses, information services, training for health and social care professionals, and research.

What we did this year

This year we have been working in partnership with the Lewy Body Society to:

— Influence policy and service development, particularly around timely diagnosis, carers’ issues and the NICE Dementia Social Care Standard;
— Build our reference group of people affected by Lewy body dementias, to inform our information products, campaigning, education and research priorities;
— Enable two research projects that will increase understanding about the genetics and possible treatments for Lewy body dementias. We also contributed to the James Lind Alliance Dementia Research Priority Setting process, to ensure the distinctive priorities of people affected by Lewy body dementias are recognised;
— Provide training on Lewy body dementias to health and social care professionals through our conference and local education programme;

What we will do next year

Next year we will continue to collaborate with Lewy Body Society to:

— Support the growth and impact of the Dementia Action Alliance by actively participating in the DAA Early Diagnosis Steering Group, website development forum, and the emerging DAA regional networks.
— Extend our network of regional and local dementia champions; participate in local Healthwatch and other health and social care bodies; and contribute to local plans for dementia-friendly communities;
— Develop a training resource for health and social care professionals on advanced Parkinson’s, including Parkinson’s dementia, to improve treatment, care and support – including assessments for NHS continuing care;
— Revise our information materials in line with the Information Standard, guided by the priorities of people affected by Lewy body dementias;
— Establish and resource a specialist advisory committee of health and social care professionals to lead on issues related to Lewy body dementias;
— Provide a new training course on Lewy body dementias for our community-based staff to support them in their advice and awareness-raising work;
— Continue to create and seize opportunities for people with Lewy body dementias and their carers to influence policy and service development.
What we will do next year

— Deal with the difficulties of surviving in a harsh economic climate.
— Try to encourage a better care culture by educating the families of those with dementia about good care, and what they should be expecting from all care providers.
— Try to encourage a better culture of care by providing our high quality resources to as many care homes, day centres and hospitals as possible.
— Try to help family carers by providing them with high quality resources that make a difference.

What we did this year

— Developed our product range and provided resources for many hospital wards.
— Set up a clinical research project in Limerick, Ireland, in conjunction with the senior clinical psychologist at St Camillus hospital. This project will report on the difference that various new visual media have had on staff behaviour and patient wellbeing in a long-stay dementia care ward.
— Faced the challenges created by public spending cuts to libraries, and the negative impact they are having not only on the wellbeing of those with dementia – especially those who cannot afford to buy our products – but also on our ability to help people with dementia across the UK.
CASE STUDY
PICTURES TO SHARE CIC

Mary is 68 and has mid-stage, early onset dementia. For some years she was cared for by her husband, but this situation became impossible due to his deteriorating health. Agency carers and a day centre both failed to help due to Mary’s ‘independent’ personality.

Mary was recently admitted as a voluntary patient to an NHS assessment ward. Her family were initially pleased with the apparent high quality of this ward, with its new building, high staff-to-patient ratio, and well-qualified staff. They soon became disillusioned, however, when they saw the care that was offered and the effect it was having on Mary.

Mary’s family were prevented from putting a name sign outside her door to help her recognise the room. Nothing was provided in the lounge for Mary or her visitors to do. ‘Activities’ only took place when an activity organizer was on duty. The rest of the time there was only the television, which Mary had ceased to understand or enjoy a long time ago. Despite a high staff ratio, staff seemed to spend little time talking to patients. Even at meal times, staff were often seen carrying on conversations with each other and ignoring the person they were feeding.

Personal care was often brutal. Three staff physically restrained Mary and forced her to have showers in a large open shower room, with no attempt to provide privacy or dignity. Only the help of the family (which was not requested) put an end to this practice.

Mary’s condition deteriorated. Her physical health, continence, posture, speech, anxiety levels and behavior all became dramatically worse.

Relatives took in ‘Pictures to Share’ books specifically designed for people with dementia. This provided Mary with a calming and reassuring activity. The books proved an effective way for her family to temporarily alleviate Mary’s psychological suffering and distress.

Mary has now been moved into a wonderful care home. Her condition has improved dramatically, and she continues to enjoy and benefit from the books.
As architects we support the National Dementia Declaration. Through our designs, we create enabling and supportive environments for people with dementia.

What we did this year

— We have hosted visits to our completed care projects to share our experiences of designing for people with dementia, and to obtain feedback from residents, their families and care staff.
— With a housing association, we are exploring an opportunity for providing dementia care in several small properties in the community, rather than one large facility.
— With a care provider, we are exploring designing for a user group with very specific cultural requirements.
— We have been part of a team bidding for funding for a research programme on dementia-friendly housing.
— We have given presentations on dementia design at several conferences.
— Our post-occupation evaluation of a large extra care scheme was accepted as a presentation to the UK Dementia Congress.
— We have attended several conferences, seminars and roundtable discussions on design for dementia and older people.
— We have contributed features to the care press on dementia design.
— We are very pleased to have been voted best design company at the Laing & Buisson Independent Specialist Healthcare awards.

What we will do next year

— We will continue our commissioned projects, including good dementia design within our designs.
— We will continue to host visits to our completed schemes, sharing our experiences with others.
— We will further our own knowledge by visiting other schemes and attending events.
— We will do post-occupation evaluations of our completed schemes, and our involvement with academia and research programmes.
— We will contribute to the ‘Dementia Friendly Communities’ group.
— We will continue to contribute to the care press.
— We will inform construction and property professionals outside of the care sector about the benefits of dementia design.
Belong Care Villages

Belong Care Villages embrace the latest research, international care models and ongoing resident consultation to create vibrant contemporary homes that provide a positive future for people with dementia – one that differs from traditional care homes: visually, operationally and culturally.

These are environments where life revolves around purposeful activity, and each day has meaning. Belong is a place where life happens, people have fun and individuals have made an active choice to live in the village. Every day is different, rather than governed by tasks and time constraints. Opportunities are created for the older person to give care and support to others as well as receive.

The Belong Care Villages provide high-dependency care and independent living with community facilities open to the wider neighbourhood. The care home element of the Villages typically comprises six self-contained households of 12 people. This supports an ‘extended family’ environment that meets the personal needs of individuals. Each resident has a private bedroom with en-suite toilet, basin and shower. The houses are safe and secure, with access to a garden or balcony. Homely open-plan kitchen, lounge, dining and external areas maximize independence and aids orientation, while promoting discreet support. Bedrooms are visible and accessible from the lounge areas. The kitchen is the vibrant heart of each household – enabling and encouraging residents to take part in daily living skills.

The Independent Living apartments combine a self-sufficient lifestyle with specific care packages to suit individual needs. This is all within easy reach of the full facilities of the community.

An intergenerational approach encourages the wider neighbourhood to use the village facilities, which include a bistro, beauty salon, community room, wellbeing suite, gym and internet cafe. The Belong Villages and the people who live there are part of their wider neighbourhood and community.

The principles of designing for people with dementia have been integrated into the households. An orientating, understandable, and domestic interior design maximises independence and subtly compensates for impairments.

Best use of natural light and ventilation ensure a bright fresh environment throughout, which boosts wellbeing for people with dementia.

Flexibility is key. Floor areas exceed national minimum standards, and two bedrooms can be combined to create one-bedroom apartments. The design of the building compliments the mantra that it is support, rather than the person, which should be moved when their needs change. An accessible, valued environment has been created, enabling staff to work flexibly and imaginatively. Staff effectively live and work as a large family; teams are encouraged to self-manage, develop leadership skills, think creatively and have fun during the day.
PRESTIGE NURSING + CARE

Prestige Nursing + Care provide domiciliary care and support services to individuals with dementia and their carers. This service offers people a chance to remain in their own homes and to be independent within the community.

What have we done this year

— Commenced a dementia training programme, aligned with the QCF Dementia Pathway Award. Our trainers attended a train-the-trainer’s course, and now we are starting to train our care workers nationally. We have also made our ‘Dignity in Care’ and ‘End of Life’ training compulsory for all our care staff.
— Implemented training modules – including dementia awareness, person-centred care, and promoting independence – into our training plans, which are being rolled out across our network of branches. We have training modules in place to continuously develop our workforce.
— Received accreditation with the ‘End of Life: Six Steps to Success’ programme, which follows the care pathway laid out in the National End of Life Care Strategy, and incorporates a dementia module.
— Highlighted best practice branches for dementia care and champions within Prestige.

What we will do next year

— Compiled a sign-posting database designed to provide details of other networking and support groups linked to dementia for individuals with dementia, their carers and families.
— Provided high quality person-centered care and support services to individuals with dementia and their carers.
— Continue rolling out our ‘Dementia Care Pathway’ training programme nationwide to all our care workers.
— Ensure our care staff undertake all relevant training modules to continuously develop our workforce.
— We are required to renew our ‘Six Steps to Success’ accreditation annually, so we will work towards maintaining this accreditation.
— Continue to provide high quality person-centered care and support services to individuals with dementia and their carers, in their own homes and in the community. We will continue to look at how we can improve and develop these services.
What we will do next year

— Research, plan and build the OpenMinds dementia community project.
— Explore collaboration with potential partners, including DAA members, to obtain support and invite involvement.
— Print and distribute the 2012 DAA annual report free of charge.
— Launch OpenMinds in summer 2013 with the following features for dementia professionals, carers and person with dementia:
  — Practical content and moderated forums for people with dementia, carers and professionals
  — Educational tools and resources
  — Database of all published literature on every aspect of dementia, including science, research and personal experience
  — Peer reviewed online journals.

What we have done this year

OpenMinds – the dementia community: We have been researching and developing a new digital resource to help build a community of all those concerned with improving the well-being of people with dementia and their carers. It will provide information, education, opportunities for collaboration and mutual support.
REPoD (Rotarians Easing Problems of Dementia) is a nationwide network for Rotary Clubs and Rotarians who believe that it is time to take direct action within their own communities to provide practical help and support to families who are living with dementia.

What we have done this year

— Raised the profile of the dementia strategy among Rotary Clubs by ensuring that clubs received regular updates and information on how Rotarians can support local projects. We also provided speakers at regional and national Rotary conferences.
— Encouraged Rotary Clubs to initiate or join existing Dementia Alliances with a view to creating a dementia-friendly community in their town, village or city. We have already been involved with the setting up of the Tavistock Dementia Action Alliance, the first Rotary-initiated community action group aimed at creating a dementia-friendly community in the town. We are currently working with the Falmouth and Wadebridge Rotary Clubs in Cornwall to develop similar initiatives, while encouraging other clubs across the UK to follow suit.
— Encouraged Rotary Clubs to increase community awareness and understanding of dementia through publicity and marketing, using local media, businesses, schools and civic groups.
— Helped Rotary Clubs to identify volunteer projects that offer practical support in the home to local families living with dementia.
— Linked with Rotaract (Young Rotary) to investigate ways of supporting young people who are living with a loved one with dementia.
— Worked with other community organisations and national groups to develop a strong volunteer network of local support for people with dementia and their carers. We are currently working with Devon Senior Voice to organise a West Devon Dementia Awareness Day on November 23rd, at which we hope to have Angela Rippon as our keynote speaker.
— Donated ‘memory boxes’ to hospital wards across the UK
— Helped several Rotary Clubs across the UK to open up new Memory Cafes in their towns.

What we will do next year

Continue with the above, plus:

— Organise training for Rotary volunteers to improve their understanding of dementia, and develop effective ways of supporting people living with the condition.
— Explore how we can provide additional volunteer support to local groups like Care & Repair for practical support, and Age UK for home and hospital visiting.
— Work with Young Carers groups and early onset dementia support organisations to find ways that Rotary Clubs can help them to develop their services.
— Working with Alzheimer’s Disease International we will be linking up with other Rotary led dementia projects around the world to compare experiences and work towards creating a global Rotary support network for dementia. Rotary International represents 32,000 Rotary Clubs overseas.
What we will do next year

— An RCGP clinical update course on dementia (January 2013) with plans to repeat annually if there is demand.
— RCGP/DH Dementia Toolkit: a key resources kit summarising essential knowledge on dementia for GPs and nurses. This will cover: early identification and diagnosis, drug and non-drug management, carer support, information and end of life care. The information will be summarised as a ‘road map’ — see below.
— Dementia Road Map: an essential collection of key information for GPs.
— National network of GP dementia champions to work with the RCGP dementia champions.
— ‘Key points to consider’ guidance for people commissioning for dementia.

What we did this year

— In April 2012, the RCGP appointed a National Clinical Champion in Dementia to continue the work of the RCGP Ageing Champion (2009-2011). This post is shared by Dr Jill Rasmussen and Professor Louise Robinson.
— The RCGP Dementia Champions are already working closely with the Dementia Action Alliance and the Department of Health’s National Dementia Lead, Professor Alistair Burns. Through these collaborations, outputs this year include:
— E-learning resources, with BMJ Learning team, for clinical primary care staff on dementia, especially the use of antipsychotic drugs. These resources also include quality improvement projects targeted to improve quality of primary care.
— Dementia end of life care think-tank group: established multi-disciplinary group which will develop resources on ACP in dementia; pain/distress management, etc.
— Research and statement about diagnosis of dementia at an earlier stage of illness.
— Recommendations for a cognition screening tool.
— Input into and comment on the NICE Commissioning Guidance for Memory Service and End of Life Care.
What we will do next year

— Continue to build on previous work to increase understanding of dementia and support improvements in care.
— Deliver a development programme for staff in acute care settings, supported by the RCN Foundation. This will aim to evaluate the impact of improvements through partnership working with people with dementia and carers.
— Develop a community of practice / network to cascade initiatives, share good practice and identify models that promote continuity and coordination of care across different settings for people with dementia and their carers.

What we did this year

— Continued to raise awareness and share information about dementia via the RCN website, and promote the ‘Commitment to improve care for people with dementia in general hospital settings’, launched in 2011. We continue to work collaboratively with other organisations to help drive forward improvements in care for people with dementia and their carers.
— New resources have been developed this year to support practitioners in implementing the Commitment, including a film and a practical ‘how to guide’. See: www.rcn.org.uk/dementia
— Regional workshops on hospital care are being delivered between October 2012 and January 2013. See: http://www.rcn.org.uk/newsevents/event_details/rcn_eventsms/older_people_exeter
— The RCN is currently exploring the role and contribution of nursing, and in particular dementia nurse specialist posts,
— We are also working with the National Institute for Health Research (NIHR) Dementias & Neurodegenerative Diseases Research Network (DENDRON) to set up a Dementia Nursing Research Taskforce (in partnership with Dementia UK and Alzheimer’s Society).
Royal College of Physicians is an independent membership organisation that engages in physician development and raising standards in patient care.

What we did this year

This year we hosted the launch of ‘Right care: Creating dementia friendly hospitals’, a call to action to transform the acute hospital experience for people with dementia and their carers. Hospitals across England are being asked to commit to becoming dementia friendly and undertake a series of actions, from improving the design of wards to establishing dementia champions.

What we will do next year

— Continue to promote development of dementia friendly hospitals.
— Continue to promote dementia in undergraduate and postgraduate medical curricula.
What we will do next year

Our next steps will be determined by the actions of the Dementia Action Alliance. We will keep promoting the work of the alliance to our members to make sure that pharmacists understand the importance of their role in reducing the prescription of antipsychotic drugs for people with dementia.

What we did this year

— Promoted the ‘Right Prescription: A Call to Action’ report to our members using all available communication channels.
— Promoted the Right Prescription webinar held on the 13th September to our members using all available communication channels.
— Howard Duff, Director for England at the RPS, and Jonathan Mason delivered the webinar.
— Created a page “Dementia (The Right Prescription): Pharmacy and the call to action” on our RPS website to raise awareness among our members of the issue of over-prescribing of antipsychotics drugs for people with dementia.
What we will do next year

We wish to build on the success of this year, continuing to strengthen our local relationships and contacts. Our aim will be to deepen the knowledge and understanding of dementia within our workforce, and support Alzheimer’s Society to raise the issue of dementia in the media.

What we did this year

— This year Saga Homecare sponsored the Alzheimer’s Society Dementia Awareness Week.
— As an organisation committed to high quality care for all individuals and their families, we wanted to ensure, firstly, that the week was a success: that we could support the society to reach as many people as possible to raise awareness of dementia. And secondly, that we created a legacy from the week, with our regional branch network being able to establish links with other local regional DAA groups.
— Across 13 sites, events ranged from tea parties to supporting a number of local Alzheimer’s Society awareness events – helping to make a big impact, raise funds and increase the profile of dementia in our communities.
— The week attracted significant media interest and parliamentary support.

We provide care and support to people living in their own homes, including people with dementia.
SHARED LIVES PLUS

We are the network for shared lives, home-share and microenterprises in social care, which are all micro-scale and family-based approaches to care, support and inclusion, used by thousands of older people. We help our members work together to survive, thrive and influence decision makers, providing support, training, events, resources, access to insurance, research, and campaigning.

What we will do next year

— Attempt to develop Shared Lives for people with dementia in Scotland and Wales.
— Disseminate resources produced by the ‘National Shared Lives and Dementia’, hosted by Shared Lives South West and Innovations in Dementia.

What we did this year

— Supported the dissemination of learning from the ‘National Shared Lives and Dementia’ project, hosted by SWAPS Shared Lives service.
— Kent University is researching the outcomes of Shared Lives with older people, working with three of our member Shared Lives schemes.
— There was an article about Shared Lives and dementia in the Journal of Dementia Care.
— We have been working on a major funding bid for development of Shared Lives for older people and those with dementia.
CASE STUDY
SHARED LIVES PLUS

Community Care examined a breaks service in Scotland, under the headline “Helping dementia patients with a wider family circle”. “Celia is generosity itself. She and Roy get on like a house on fire,” says Mary Willis of the relationship between her husband and their Time to Share carer, Celia McKechnie. “She includes Roy in everything the family do; he gets a front seat at the Highland shows they go to. Her husband is a good musician and Roy plays the African drums so there is a connection there. Celia takes him out a huge amount and he is treated like one of the family.” Roy currently visits McKechnie three or four times a year, and although Mary says this may increase as she gets older, she adds: “I hope to put off residential care forever.”

Full story: www.communitycare.co.uk/Articles/2010/10/28/115701/good-practice-time-to-share-scheme-for-dementia-patients.html
SCIE improves the lives of people who use care services by sharing knowledge about what works. We are an independent charity working with adults, families and children’s social care and social work services across the UK. We also work closely with related services such as health care and housing.

What we will do next year

— Launch the redesigned Dementia Gateway in the spring, including new content on support after diagnosis, advanced dementia, working in partnership with carers, and dementia and sensory loss.
— Add information to the Dementia Gateway on getting involved with research, how the content links to the Qualifications and Credit Framework, and what research tells us about each topic.
— Continue to support the Alliance’s action group on diagnosis and post-diagnosis care.
— Support the publication and implementation of the NICE pilot Social Care Quality Standard on the care and support of people with dementia.
— Work with TLAP to undertake an investigation into how personal budgets are working for older people, and particularly those with dementia.
— Continue work to support the workforce to understand and implement the Mental Capacity Act, including guidance on the deprivation of liberty safeguards in health settings.
— Undertake further work on safeguarding and end of life care.

What we did this year

— Added a new section to the Dementia Gateway on early signs of dementia and getting a diagnosis, and contributed to the Dementia Action Alliance’s action group on diagnosis and post-diagnosis care.
— Started work with people living with dementia, carers and care staff to inform the redesign of the Dementia Gateway for a wider audience.
— Contributed to the APPG enquiry ‘Unlocking diagnosis’.
— Published a research briefing ‘End of life care for people with dementia living in care homes’ together with SCTV films.
— Published guidance to help local authorities commission care homes which provide safe, abuse-free services, including information on common safeguarding challenges.
— Continued a programme of work to support the implementation of the Mental Capacity Act, including developing training materials and a toolkit. We also delivered workshops and training, particularly to domiciliary care providers.
— Published the report ‘Co-production and participation: Older people with high support needs.’
We are a research unit situated at King’s College London, conducting empirical research and secondary research in the area of social care. A significant work stream is research into social care for people with dementia and their carers.

What we did this year

— We became members of the Dementia Action Alliance this year – a source of pride for us as it means that we are potentially able to enable our research to have a bigger impact on dementia policy.

— Completed our five-year programme of research on the Mental Capacity Act (funded by the National Institute of Health Research) and its relevance for people with dementia and carers, and practitioners who work with them.

— Secured funding for a three-year study into service development for older homeless people who have dementia, due to start by the end of the year.

— Systematically presented our work at local, national and international conferences and in academic and trade journals.

— Worked on research into practice with carers and social care work with people who have dementia and other disabilities.

— Launched a Twitter account to showcase our work (@scwru), and started to blog.

What we will do next year

— Continue publishing and presenting findings from our five-year NIHR-funded Mental Capacity Act study.

— Begin our study into service needs and experiences of older homeless people who have dementia through a systematic review of existing research in this area, and empirical research through assessments and qualitative interviews with hostel staff, GPs and older homeless people themselves.

— We will also specifically aim to include the views of people with dementia and current carers in our study Advisory Group.
Southern Healthcare comprises four nursing homes in Devon, providing a range of support levels to quite complex and/or end of life nursing care needs. The number of our residents affected both by dementia and with other conditions is increasing, as is the general trend.

What we did this year

— This year we have been campaigning on going beyond person-centred care, focussing upon the teachings of Carl Rogers. The emphasis is on building an environment in which ‘unconditional positive regard’ is the norm, and the quality relationships between people is at the very heart of our homes.

— From our dementia studies at Stirling University we have developed our training programmes in dementia, relationship centredness and positive cultural development. We have had our progress evaluated externally by Investors in People and St Monica’s Trust, a leader in the field of dementia care.

— Three senior personnel have undertaken training with 360SF Ltd, towards attainment of the 360 Standards Framework beyond person centred care. Two of our senior managers have also become trained as associates with the ‘Eden Alternative’, a philosophy designed to deliver higher quality of life through developing a vibrant human habitat, creating opportunities for residents to give as well as receive care, and imbue daily life with variety and spontaneity.

What we will do next year

— Continue to build our training and knowledge in dementia, develop strategies to better meet people’s needs with dementia, and support a much higher quality of life. The 360 Standards Framework is a major programme in this initiative, as will be developing the Eden Alternative philosophy throughout our homes.

— Work increasingly with the local authority, NHS and other providers through a new local dementia initiative to ensure faster learning, improvements in the transition between services, and improved multi-professional support for people with dementia.

— Focus on meeting people’s fundamental human, spiritual and psychological needs by creating more:
  — certainty about life with care and support
  — variety, spontaneity and meaningful activity
  — quality in all relationships – with loved ones, ourselves and others
  — inclusion, involvement and participation
  — growth in new ways of building meaningfulness
  — contribution to others.
Springhill Care Group is a provider of quality nursing, residential, rehabilitation, dementia, day care and supported living services for adults. It operates three care homes, two in Lancashire and one in Bristol, and Affinity, a supported living service.

What we did this year

— The Springhill Care Group has invested significantly into dementia care during 2012.
— A specialist care centre officially opened its doors in 2012 at Springhill Care Home in Accrington. This facility is a three storey, 24,000 sq ft development, which includes 46 beds over five separate facilities dedicated to caring for people with dementia. The centre is a separate, dedicated service from the rest of the home, with its own entrance, reception areas and specially trained staff. It provides specialist facilities and care for people with dementia, and promotes mental wellness. The development, which brings the number of beds at Springhill Care Home to 110, is made up of self-contained community living suites of between eight and 10 beds each. As part of the development, a sensory garden was also established with support from Dr Garuth Chalfont, a recognised expert in the field.
— Meanwhile, at Riversway Care Home in Bristol, we have invested in a dedicated 17-bedroom centre to care for people with dementia. The facility has trained support staff, and a redesigned lounge and dining area.

What we will do next year

— In addition to the specialist care centre, ongoing work at Springhill Care Home includes a new extension which will add two eight-bed facilities for younger adults with complex healthcare requirements, including physical disability, brain-injury, neurological and degenerative conditions.
— Springhill home has so far undergone two major programmes of work. Phase three is now underway – the final stage – and will see the older, Victorian parts of the building remodelled and refurbished.
— New facilities will be developed for residents including lounge and dining areas, balcony, ‘lifestyle’ kitchens, a quiet room, chapel and a new reception and entrance to the home.
— The final stage of development will cost £500,000, including new furnishings, fittings and equipment, bringing the total value of the recent work to £5million.
Stroke Association is the leading charity in the UK changing the world for people affected by stroke. We conduct research, run campaigns and provide support services for stroke survivors and their families.

What we did this year

— On World Stroke Day on 29 October this year, we launched a major campaign on “mini-strokes”, otherwise known as transient ischemic attacks (TIAs). Over 46,000 people will have a TIA every year in the UK. Our campaign is to raise awareness of the symptoms of TIAs and spread the message that symptoms should be treated as an emergency. Multi-infarct dementia, the most common type of vascular dementia, is caused by a series of TIAs, which often go unnoticed. TIAs result in only temporary, partial blockages of blood supply and brief impairments in consciousness or sight. Over time, however, as more areas of the brain become damaged, the symptoms of vascular dementia begin to appear.

— Our ongoing ‘Know Your Blood Pressure’ campaign, aims to increase understanding of the link between high blood pressure and stroke and TIAs; help to identify people with high blood pressure; and encourage those whose blood pressure is normal to understand the importance of having their blood pressure checked regularly.

— Local ‘Know Your Blood Pressure’ events are being held across the UK to offer free blood pressure tests, and:
  — explain the link between high blood pressure and stroke, and why it’s important to know your blood pressure;
  — raise awareness of the risk factors for high blood pressure and other contributing factors (age, ethnicity, family history, health conditions, etc);
  — inform individuals of their own blood pressure reading and offer guidance based on their readings;
  — offer information on FAST and other prevention campaigns, such as Ask First;
  — collect essential, confidential data on blood pressures nationally for use in campaigning.

— There is not yet a known cure for vascular dementia, so prevention is important. The best way to prevent vascular dementia is to lower the risk of stroke.

What we will do next year

The Stroke Association’s is currently developing a policy on dementia, TIA and prevention. Our campaigning work will continue to focus on the prevention of TIAs and stroke.
83
THE ALZHEIMER’S SHOW

The Alzheimer’s Show is the first national exhibition, conference and meet-up dedicated to people with Alzheimer’s and dementia, their carers and families, as well as professionals dealing with dementia on a daily basis. The show will run in April 2013.

What we did this year
Following the launch of the show, a key focus this year has been to gain support from the national dementia charities, government and leading voices. We have worked on securing a wide range of exhibitors from leading businesses and organisations within the sector. And we have enlisted the support of high profile speakers and experts to talk at the event.

To make the event accessible across the UK, we have developed a partnership with the Great British Care Shows, a series of regional events showcasing excellence in social care. This will allow key features of the Alzheimer’s Show to be present at nine regional locations during 2013.

What we will do next year
In 2013, the Alzheimer’s Show will take place over two days (19-20th April) at London’s ExCel Centre.

It will offer visitors immediate access to in-depth conference sessions, practical workshops, one-to-one professional consultations. There will be over 60 suppliers of products and services, including residential and home care, telecare, legal advice, financial advice, mobility equipment and assistive technology. The event will feature the Great British Care Shows, who will bring exciting speakers, light bulb sessions and innovative product demonstrations for the care sector visitor.

The Alzheimer’s Show is being held in partnership with Alzheimer’s Research UK, who will be telling visitors about how to take an active part in dementia research, as well as sharing the latest developments from their scientists.
What we will do next year

— Continue to invest in company-wide dementia training, ensuring leadership from the very top as well as additional resource at a grass roots level.
— Reduce care managers’ case loads, creating a more personalised service for clients and additional face-to-face support and supervision for professional carers.
— Continue to work closely with the Contented Dementia Trust in our pioneering application of The SPECAL Method. We hope to have statistical evidence of the success of our dementia strategy in 2013.
— Continue to monitor antipsychotic usage, with the aim to having this down to <2% by the end of 2013.
— Work to reduce antipsychotic usage by working with clients’ GPs to safely reduce prescriptions of these drugs while implementing psychosocial approaches to understanding and managing distressed reactions.

What we did this year

— In 2012 we launched our specialist dementia service.
— Invested in additional advanced training at all levels in our company, from our professional carers right through to senior management and board of directors. Our care managers have recently started a one-year training course with the Contented Dementia Trust.
— We are pioneering the application of The SPECAL Method in a domiciliary care environment, working in partnership with the Contented Dementia Trust.
— We regularly audit antipsychotic prescription among our clients and have maintained a threshold of <6% of our clients taking these medications.
— Implemented initiatives to further support our professional carers in the field, including the introduction of senior professional carers to act as mentors; the development of a 24-hour support desk; and performance-related pay increases and company shares. These measures have improved staff retention, which provides better continuity of care for our clients.
CASE STUDY
THE GOOD CARE GROUP

Former military pilot Steve, in his eighties, was taking antipsychotic drugs for two years before he came under the care of the Good Care Group. He was a threat to himself and his wife – often aggressive and violent.

Using the SPECAL method, which focuses on past memories and uses them to 'build a bridge' to the present day, a new approach to his care began. Soon, his pattern of care had settled.

SPECAL is best applied when the individual is at an early stage of the condition, as the information that can be gathered from the person is richer. However, through close observation, it became clear that while it had been a long time since he had piloted a plane, thoughts of flying and Steve's military career were still vivid in his mind.

Steve was storing information sporadically and did not understand where he was, or what he should be doing – a huge source of anxiety. Working with cues, both verbal and visual, stemming from flying, helped to provide him with context, purpose and pride.

However, this alone did not help persuade such an independent person to accept help with everyday actions such as washing and dressing. Another context had to be found to get him to accept some level of dependency.

Steve had always had issues with blood pressure and has intact memories about this. However, unlike his dementia, this condition did not dent his self-esteem. Bringing these two themes together allowed the carer to move fluidly from one context to the other – using blood pressure checks, for example, to persuade him to remove his shirt – while not implying he was unable to do things. This allowed the carer to help with the activities of washing and dressing with no stress involved for Steve.

Now Steve is no longer a threat to himself, his wife or others, and has ceased to take antipsychotic drugs. He is now calm and free from agitation, which has improved his overall wellbeing.
Pocklington works to enhance the lives of people with sight loss. We aim to increase knowledge of sight loss, empower people with sight loss, provide and inform effective housing and support, and sustain our own services for the long term.

What we did this year

— Continued raising awareness and informing practice about the concurrence of dementia and sight loss.
— As a member of the Vision 2020 UK Dementia and Sight Loss Interest Group, we have worked on a range of issues, including cataract surgery and developing information for the SCIE Dementia Gateway.
— With partners in ARUP and SCIE, we ran a consultation event about care for people at the end of life who have dementia and sensory impairment.
— Commissioned research by Stirling University into the design of domestic environments to support people who have both dementia and sight loss.
— Worked with the College of Optometrists to inform research proposals about the prevalence of concurrent sight loss and dementia; eye examinations for people with dementia; and spectacle wearing among people with dementia.

What we will do next year

— Our work with the ILC-UK to address the need for equity in the provision of eye examinations and support for good eye health in care homes has addressed the particular needs of people with dementia.
— Supported people who have dementia and sight loss to contribute to the JLA Dementia Priority Setting Partnership.

— Continue working in partnership with other organisations to increase knowledge of concurrent sight loss and dementia, and empower people who are affected by both conditions. The findings of the Dementia Priority Setting Partnership will inform our ongoing work.
— Continue our commitment to research that leads to knowledge and appropriate services, with priority given to housing design, eye health and – where possible – the correction of sight loss among people with dementia.
— Continue working to address the needs of people at the end of life who have dementia and sensory impairment.
What we will do next year

— WRVS will continue rolling out our training plan to have all staff and volunteers trained in basic dementia awareness, to support them in their roles and delivery of service.

— Learning from the independent evaluations of the WRVS on-ward pilots will be applied to support future WRVS on-ward services.

— Any new WRVS service provision will be underpinned by design principles that are dementia friendly.

What we did this year

— Developed an online training module on basic dementia awareness, which is mandatory for all new staff and volunteers. WRVS is managing the continued roll-out of the training across our 40,000 volunteers and 2,000 staff.

— Worked closely with a design company to support the roll-out of design across the WRVS portfolio of services, to ensure we embed dementia-friendly principles into our designs.

— WRVS has several on-ward pilots in hospitals which are being independently evaluated to inform wider roll-out across the NHS/hospital board estate.

— Facilitated the training of a staff member to champion the design principles.

WRVS is a registered charity that provides services to older people in the community. We also support hospitals by delivering a range of services including on-ward support, cafés and retail outlets.
YoungDementia UK enables younger people and their families to live well with dementia. We provide tailored, consistent support and a welcoming community for people in Oxfordshire and adjoining counties – from diagnosis to beyond bereavement. We promote a better understanding of young onset dementia among professionals and the public.

What we did this year

We have continued to develop our services for younger people and their families, and our work was recognised with an award from the European Foundations’ Initiative on Dementia. Our pilot programme with the regional Cognitive Disorders Clinic gives newly diagnosed individuals access to our services much earlier. Alongside this we have established a peer support group for those in the early stages of their dementia. We have recruited new support staff to meet the growing demand for our services, together with a fundraiser and communications coordinator tasked with raising awareness of young onset dementia and the importance of our support; and stimulating community fundraising. We are supporting members in their ‘dementia activism’ and encouraging them to discuss with us how best to meet the needs of younger people with dementia.

What we will do next year

We are redeveloping our website so that it gives our members, their families, and health and social care professionals the information they need. This includes people outside our region so that we move towards being a ‘UK’ organisation. As part of this, we will connect with the scattered groups and services specialising in the support of people with young onset dementia.

We are expecting a rise in demand as a result of efforts to diagnose more people and the increasing awareness of the possibility of dementia in mid-life. We will continue working with YoungDementia UK Homes to develop the case for the right place to stay and live for younger people.

We will look for manageable ways for our team and members to play a part in creating positive and enabling local communities. We recognise the huge difference that a change in attitude, environment and awareness would make in enabling people with dementia – of any age – to make the most of their lives.

We will actively participate in the Dementia Action Alliance, offering a young onset dementia perspective where possible.
Larry is 60 and has had symptoms of vascular dementia for the last 10 years. It has meant he has had to give up his job. His marriage came to an end and he now lives apart from his children.

‘Before I was being supported by YDUK, the chaos in my life was overwhelming,’ he says. ‘Before there was any support for me, I couldn’t really get my head around doing very much. I was feeling very depressed and I was often very agitated.’

Larry receives one-to-one support from Sandy, a YoungDementia UK support worker, who visits him each week. They get on extremely well and she has helped him to deal with a huge amount of personal paperwork, as well as making life fun again.

‘It’s difficult to describe the difference it has made to have a one-to-one support person,’ Larry says. ‘I suppose it’s just that I feel everything is altogether more manageable. Sandy has helped me to feel much calmer and in control of my situation. I can also share the things I enjoy with her; the things that matter to me.’

Our support has also given Larry a role and purpose that has tremendously improved his quality of life. Having already become a columnist in our newsletter, we are encouraging Larry’s efforts to develop a group for ‘dementia activism’. Meanwhile, he now often acts as a spokesperson for us in media interviews.
RIGHT CARE: CREATING DEMENTIA FRIENDLY HOSPITALS

2012 could be a landmark year for people with dementia, their families and carers. It has the potential to positively change the way people with dementia experience care, the outcomes of that care, and the way that communities view caring for people with dementia.

On 15 October, the Dementia Action Alliance, in partnership with the NHS Institute for Innovation and Improvement, launched a Call to Action for the improvement of care for people with dementia in acute hospitals.

The goal of this work is that by March 2013 every hospital in England will have committed to becoming a dementia friendly hospital, working in partnership with their local Dementia Action Alliance.

Why is this work important? Will it benefit people with dementia, families and carers who use acute hospital services?

We know plenty about the challenge that dementia poses to the NHS, and why it’s a key priority. An estimated 25% of acute beds are occupied by people with dementia. We know that when they enter acute care, people with dementia spend longer there than people without. We know they are vulnerable to potentially avoidable complications like dehydration and falls. And we know they are often subject to delays in leaving hospital and returning safely home.

We have been listening to people with dementia, their families and carers about what good care looks like. We all understand the transformation that can take place when we have the shared purpose of enabling people with dementia to experience high quality care in acute hospitals, and when we support them, their families, carers and staff to have the confidence to champion best practice and create a culture of excellence.

Clinical, academic and managerial colleagues have all told us that we should focus on improving five key areas:

— The environment in which care is given
— The knowledge, skills and attitudes of the workforce
— The ability to identify and assess cognitive impairment
— The ability to support people with dementia to be discharged back home
— The use of a person-centred care plan which involves families and carers.

By making improvements in these areas we are able to reduce readmission rates and prevent over 6,000 falls across the country. In turn we can reduce the mortality rate of people with dementia in acute care, and lift the sense of pride and wellbeing among acute hospital staff who care for people with dementia.

To find out more about the Call to Acton, please contact the Secretariat on dementiaactionalliance@alzheimers.org.uk.
Local members have already started to look at specific areas of work. In Northamptonshire, members are looking at how they can work with employers to raise dementia awareness. Having decided to pool resources and develop a training and information pack, they are also planning to go into some larger employers to talk about dementia, and hopefully get them involved in the DAA.

In Leicestershire, members have been sharing information and best practice. At a recent meeting, they looked at how Leicestershire police support people with dementia, and what they could do in the future.

Meanwhile, across the East Midlands local alliances and the regional board have been supporting the development of Dementia Champions, a role that helps promote the DAA and help a community become dementia friendly.

The Dementia Action Alliance has grown and developed considerably over the last year. One area of progress has been the development of local dementia action alliances involving local organisations from across the public, private and voluntary sectors. Across the East Midlands, different organisations have come together to radically improve the lives of people with dementia. The last year has seen the development of one regional board, along with five local alliances in Northamptonshire, Leicestershire, Lincolnshire and Nottinghamshire. The regional board has been set up for organisations that have coverage across the whole of the East Midlands or more than one county; the local alliances consist of members from an individual county.

The overall aim of the local alliances and regional board is to allow organisations to sign up – and commit – to a national initiative, but then get involved and make a difference locally. The local alliances aim to support organisations and towns to become dementia-friendly, increase awareness of dementia, and encourage local communities to respond to the challenge of dementia.

So far over 40 organisations across the East Midlands have signed up to the Dementia Action Alliance. We are also working with a further 30 organisations, who have yet to sign up.
The DAA Action Group on Diagnosis and Post-Diagnosis Care

In July 2012 the All-Party Parliamentary Group on Dementia concluded that lack of awareness of the benefits of diagnosis was a significant factor in keeping dementia diagnosis rates at unacceptably low levels in the UK. The report challenged the Alliance to produce a clear statement of the benefits of diagnosis which could be used to improve understanding.

As a result, the DAA Action Group on Diagnosis and Post-Diagnosis Care asked the Department of Health and the DAA itself for funding to carry out a study of the benefits of diagnosis, focusing on outputs aimed at primary care practitioners in the first instance.

This work began in September 2012, and we hope to have an initial report available by the end of the year. The main elements of the work include:

- A qualitative survey of DAA members (76 responses received)
- Structured interviews with key stakeholders
- A consultation with members of the Royal College of General Practitioners
- A literature review

It is not our intention to produce an academic study which will stand peer review; that work is already being done by others, and we hope to collaborate with them so our study and theirs' are as joined up as possible. Our aim is to produce a guide to the main benefits claimed for dementia diagnosis, and signposts to the evidence to support those claims, where that evidence exists.

As outlined above, the purpose of this project is to create an output aimed at GPs. Studies (including the Action Group's own consultation with GPs earlier this year) suggest there are a number of reasons why GPs might hold back when they encounter patients with possible symptoms of dementia. These include 'therapeutic nihilism', lack of confidence in their ability to correctly identify the symptoms, and a lack of faith in the quality of local post-diagnosis pathways. Many of them stem in part from an incomplete understanding of the potential benefits of diagnosis. We believe that shining a bright light into this dark corner could potentially make a significant difference to patient referral rates in the UK, and hence to diagnosis levels.

However, although the main output we are producing is aimed at GPs, the work that underpins it has the potential to be repurposed, by our group and by others, to help raise awareness of the benefits of diagnosis among many other key audiences, including commissioners, social care practitioners, secondary health specialists and, of course, the public at large.
The Dementia Action Alliance is jointly funded by its members, with the Alzheimer’s Society acting as the accountable body and host to the Secretariat.

In another challenging year of budgetary constraint, member organisations have continued to respond generously to the call for support and committed to contributing even greater resources to the work of the Alliance.

**Income**

Table 1 below provides an overview of the predicted income of the Alliance from 29th June 2012 to 28th June 2013. A total of £196,253 has been raised through a combination of £113,050 of direct member contributions, £12,000 raised from sponsorship of the Annual Event, £52,000 of member support to Action Groups, and in kind support from members worth £19,203.

Member support to Action Groups and in kind contributions include:

- £52,000 from the Age-Related Diseases and Heath Trust to establish the Action Group on Diagnosis and Post Diagnosis Care Action Group;
- £10,603 hosting costs for Secretariat by Alzheimer’s Society;
- £3,000 design expertise on Annual Report by Design Council;
- £3,000 for publishing and printing of the Annual Report by Radcliffe and Speechmark Publishing
- £1,300 venue and event management for Second Quarterly meeting of 2013 by the Local Government Association; and
- £1,300 venue for First Quarterly meeting of 2013 by The British Association of Occupational Therapists (BAOT) and College of Occupational Therapists (COT).

Thank you to the Alliance members listed below who have so far contributed/committed to the running cost of the Alliance.

**Expenditure**

Table 2 below provides the actual expenditure of the Alliance, by item, for the 29th June 2012 to 29th October 2012. It is accompanied by committed annual expenditure based on estimated spend to date.

Spend for 2011/12 includes work that the Alliance committed to develop in the previous financial year but is now delivering on, such as the redevelopment of the website and work to boost early diagnosis.
Chart 1: Financial and in kind contributions

Table 1: Dementia Action Alliance Income

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contribution</th>
<th>Event Sponsorship</th>
<th>Action Group support</th>
<th>Total Finance</th>
<th>In kind support</th>
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Chart 2: Predicted expenditure by type

- Secretariat staffing
- Venue hire and subsistence for Alliance meetings
- Accommodation and travel costs for people with dementia and carers
- An Annual Report
- An Annual Event
- Website development

Table 2: Dementia Action Alliance expenditure

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<tr>
<th>Item</th>
<th>Spend 2011 / 2012</th>
<th>Estimate(^{a}) to date from 29th June 2012 (to 29th Oct)</th>
<th>Predicted Actual(^{b}) at end of year (29th June 2013)</th>
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The design and printing of this Annual Report was made possible thanks to the kind support of our sponsors.