

# **Delivering the National Dementia Declaration for England**

## **Second Quarterly Progress Report June 2011**

**A list of organisations that we have received a Second Quarterly Progress Reports from are as follows:**

1. Age UK
2. All-Party Parliamentary Group on Dementia
3. Alzheimer's Research UK
4. Alzheimer's Society
5. Anchor
6. Association of Directors of Adult Social Services
7. Bradford Dementia Group
8. British Association of Occupational Therapists and College of Occupational Therapists
9. Bupa
10. Care Quality Commission
11. Care UK
12. Craegmoor
13. Counsel and Care
14. Department of Health
15. English Community Care Association
16. Local Government Group
17. MHA
18. Mental Health Foundation
19. National Care Forum
20. National Council for Palliative Care
21. NHS Confederation
22. Royal College of GP's
23. Royal College of Nursing
24. Royal College of Physicians
25. Social Care Institute for Excellence
26. Thomas Pocklington Trust
27. University of Stirling: Dementia Services Development Centre
28. WRVS

## Contents

### Introduction

### Progress Reports

|   |     |
|---|-----|
| AGE UK.....   | 6   |
| ALL-PARTY PARLIAMENTARY GROUP ON DEMENTIA .....   | 8   |
| ALZHEIMER'S RESEARCH UK.....  | 9   |
| ALZHEIMER'S SOCIETY .....   | 12  |
| ANCHOR.....   | 17  |
| ASSOCIATION OF DEMENTIA STUDIES, UNIVERSITY OF WORCESTER.....                                 | 21  |
| ASSOCIATION OF DIRECTORS OF ADULT SOCIAL SERVICES .....                                       | 24  |
| BARCHESTER.....   | 26  |
| BRADFORD DEMENTIA GROUP.....  | 28  |
| BRITISH ASSOCIATION OF OCCUPATIONAL THERAPISTS AND COLLEGE OF<br>OCCUPATIONAL THERAPISTS..... | 35  |
| BRITISH GERIATRICS SOCIETY .....  | 39  |
| BUPA.....   | 40  |
| CARE QUALITY COMMISSION .....   | 43  |
| CARE UK .....   | 50  |
| CHARTERED SOCIETY OF PHYSIOTHERAPY .....  | 55  |
| COUNSEL AND CARE .....  | 56  |
| CRAEGMOOR.....  | 57  |
| DEPARTMENT OF HEALTH.....   | 61  |
| ENGLISH COMMUNITY CARE ASSOCIATION .....  | 66  |
| FOUR SEASONS HEALTH CARE .....  | 70  |
| HOUSING AND DEMENTIA RESEARCH CONSORTIUM .....  | 72  |
| JEWISH CARE.....  | 74  |
| LOCAL GOVERNMENT GROUP .....  | 78  |
| MHA.....  | 79  |
| MENTAL HEALTH FOUNDATION .....  | 82  |
| NATIONAL CARE FORUM.....  | 85  |
| NATIONAL COUNCIL FOR PALLIATIVE CARE.....   | 88  |
| NHS CONFEDERATION.....  | 90  |
| ORDERS OF ST JOHN CARE TRUST .....  | 92  |
| PRIORY GROUP.....   | 94  |
| ROYAL COLLEGE OF GP'S.....  | 96  |
| ROYAL COLLEGE OF NURSING .....  | 100 |
| ROYAL COLLEGE OF PHYSICIANS.....  | 104 |
| ROYAL COLLEGE OF PSYCHIATRISTS.....   | 105 |
| SKILLS FOR CARE .....   | 107 |

|   |            |
|---|------------|
| <b>SKILLS FOR HEALTH.....</b>   | <b>109</b> |
| <b>SOCIAL CARE INSTITUTE FOR EXCELLENCE .....</b>                         | <b>113</b> |
| <b>SOUTHERN CROSS.....</b>  | <b>117</b> |
| <b>STROKE ASSOCIATION.....</b>  | <b>120</b> |
| <b>THOMAS POCKLINGTON TRUST .....</b>                                     | <b>121</b> |
| <b>UNIVERSITY OF STIRLING: DEMENTIA SERVICES DEVELOPMENT CENTRE .....</b> | <b>123</b> |
| <b>WRVS .....</b>   | <b>126</b> |

## Introduction

The National Dementia Declaration for England, published October 2010, declares a serious commitment to change the experience of living with dementia in England for good. It has been developed by people with dementia, carers of people with dementia and key national organisations who seek radical change in the way that our society responds to dementia.

There are 750 000 people living with dementia in the UK now, by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain that over time seriously impair a person's ability to live independently. The majority of care for people with dementia is provided by family members, who are often subject to considerable emotional, physical and financial stress.

The 48 national organisations signed up to the National Dementia Declaration have formed the Dementia Action Alliance. The Alliance calls on all families, communities and organisations to work with them to transform the quality of life for the millions of people affected by dementia.

All organisations included in the Dementia Action Alliance have completed a template detailing their plans for delivering the outcomes from the National Dementia Declaration for England between 2010 and 2014. These plans can now be viewed on the Dementia Action Alliance website. **In May 2011 members of the Alliance submitted their second quarterly progress reports on their plans, which are set out in this document.** Specifically members were asked to update on their plans as an organisation to respond to the challenges to delivering better outcomes for people with dementia and their carers between March 2011 and May 2011. This document also includes the first quarterly progress report of those members of the Dementia Action Alliance who submitted them in March 2011.

## **Age UK**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Support local Age UKs and Age Concerns to influence the development of local approaches to services for people with dementia and carers, and to share good practice.
- Publish examples of services offered by local Age UKs and Age Concerns which contribute to improving life for people living with dementia and carers.
- Continue to fund existing research projects into dementia and cognitive decline and consider proposals for new research.
- Work in partnership with a range of external organisations to influence public sector research priorities, with an aim of securing greater priority and funding for ageing-related research, including dementia.
- Offer training to people working in health and social care to improve their understanding of dementia and of effective ways of supporting people with dementia.
- In partnership with the My Home Life programme, produce a DVD for care homes on living with dementia, publish and disseminate information on best practice in dementia care for managers and staff working in care homes, and publish a special edition of the My Home Life bulletin on dementia for health and social care professionals and carers.
- Starting with information and advice, consider practical ways in which our services can be adapted to ensure that they meet the needs of people living with dementia and carers.

### **First Quarterly Progress report**

- The North West region Service Development Group held a day focused on dementia which enabled local Age UKs and Age Concerns to hear more about the priorities for implementation of the National Dementia Strategy, to share examples of positive practice and to hear from people with dementia and carers about the difference these services had made to their lives.
- A new Age UK publication, Living Life with Dementia, sets out a range of community-based services provided by local Age UKs and Age Concerns, often working in partnership. The document highlights how these services contribute to objectives in the national dementia

strategy and to achievement of quality outcomes for people with dementia and carers.

- Age UK is continuing to fund three research projects on dementia for which grants were awarded in or before 2009. In 2010, we awarded grants for a further two projects on dementia and both projects began in October 2010. We have continued to fund Phase 1 of The Disconnected Mind and are now working towards renewal of funding for Phase 2, which will span the five years 2011 to 2016. This is a major research programme on cognitive ageing at the University of Edinburgh.
- Age UK continues to be represented in the Ministerial Advisory Group on Dementia Research. We continue to work with other organisations interested in age-related research through the UK Age Research Forum. We are a member of UKARF's Steering Committee and Dementia Working Group.
- An update on action under the My Home Life programme will be included in a future progress report.
- Age UK Training (a nationally accredited training provider) offers a range of courses including dementia awareness, behaviour that challenges, therapeutic activities in dementia care, and person-centred planning. The full training current training brochure can be found at:
- <http://www.ageuk.org.uk/work-and-learning/further-education-and-training/age-uk-training/>
- Age UK Training is also developing a new QCF accredited Award, Certificate and Diploma in dementia care.

## **Second Quarterly Progress report**

- Age UK has nothing to report for the past quarter.

## **All-Party Parliamentary Group on Dementia**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- The APPG will work to ensure there is an effective voice for people with dementia in parliament by contributing to debates and questions in the house on issues affecting people with dementia and their carers.
- The next meeting of the APPG on Dementia in December 2010 will cover the National Dementia Declaration. Members will have opportunity to discuss the action plan of the Group and contribute new ideas to delivering outcomes.
- The APPG will conduct its next inquiry into the delivery of good quality and efficient dementia care services, reporting by summer 2011.
- The APPG will conduct an inquiry every year from now until 2014 that focuses on issues key to quality of life for people with dementia.

### **First Quarterly Progress report**

- The APPG on Dementia updated members on the launch of the National Dementia Declaration and Dementia Action Alliance at its meeting on 15 December 2010.
- The APPG launched its inquiry for 2011 on 31 December 2010 into the delivery of good quality and efficient dementia care services, which is due to report by summer 2011. People with dementia and their carers, health and social care commissioners, providers, and stakeholders are being asked to submit evidence explaining what they see as the opportunities for saving money and making the most of existing resources on dementia, whilst also ensuring quality of life for people with dementia. The inquiry will seek to identify good practice examples that providers and commissioners of dementia care in the UK can draw on.

### **Second Quarterly Progress report**

The APPG's inquiry 2011 on cost savings in dementia care received over 200 pieces of written evidence. Parliamentarians also heard from expert witnesses on the subject at oral evidence sessions on 15 and 16 March. The report, which is due to be published in July 2011, will provide findings and recommendations based on the evidence received, and will highlight good practice examples. The report will be essential reading for commissioners, providers of dementia care services and others with an interest in dementia on the opportunities to deliver better care for people with dementia in the current financial climate.



## **Alzheimer's Research UK**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Our record £4.3 million investment launches our new strategy to increase our research spending and supports 37 new projects including pioneering work on diagnosis using brain scans, further research on unravelling the genetics of the disease, and research into biomarkers which play a crucial role in diagnosis and understanding disease progression.
- We will continue to fund the best laboratory and clinical research put forward to us, with a marked increase in calls for grant applications and specific funding streams to boost capacity in important areas.
- We will continue to work with the government to stress the need for dementia research and to secure a more proportionate share of funding - for example through the Ministerial Advisory Group on Dementia Research.
- In 2011, we will be able to provide even more information on a new website for people with dementia and their carers to improve understanding and access to information.
- We will be undertaking a project working with scientists in our network to better understand research capacity in the field looking at encouraging more people into this area.

### **First Quarterly Progress report**

- Alzheimer's Research UK launched in February 2011 and with that, launched our new research strategy. Already funding more dementia research than any other charity, our pledge to double our commitment in five years is well underway with 2010 being a record year for investment in new projects at £4.3m. To date, we have funded over 350 research projects across the UK with a value of over £37 million and right now we are supporting 109 projects worth over £17 million. As Alzheimer's Research UK we are aiming to raise this even further.
- As Alzheimer's Research UK we have reaffirmed our ambition to raise more funds for dementia research to help us invest in the most important dementia research and encourage more researchers into the dementia field. Funding calls will focus on our research priorities - to discover and understand the primary causes of Alzheimer's disease and related dementias and to develop diagnoses and interventions to help with prevention, control and ultimately a cure.

- Alzheimer's Research UK continues to be an active participant in the Ministerial Advisory Group on Dementia Research, co-chairing a working group on 'Raising public awareness'. The group will meet for a final time in March 2011 to report on actions going forward. Our Westminster launch in February 2011 marked our move to Alzheimer's Research UK and the launch of a new 'Blueprint for defeating dementia'. This document sets out a renewed call to action for government to address what has become a national health crisis by prioritising dementia research within medical research budgets, encouraging more researchers into the dementia field and helping to raise awareness of dementia as a national health priority. Visit <http://www.alzheimersresearchuk.org/blueprint-defeating-dementia/> to read more and sign up.
- Alzheimer's Research UK launched its new website in February 2011 – [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org) – which provides easy to access information for a range of audiences, including people with dementia and their carers, researchers and policy makers.
- Work on understanding research capacity in the dementia field is ongoing. Preliminary research has indicated there is just one person working on dementia research compared to at least six on cancer research. This data helps to make the case that we need to encourage more Scientists into the field if we are to tackle dementia with the same efforts as other disease areas.

## **Second Quarterly Progress report**

- Alzheimer's Research UK has been promoting its grant programmes more widely among researchers to increase grant applications and boost capacity in important areas. Much of this has been directed through increased digital communications. We have a record number of applications going forward for review by our Scientific Advisory Board this May. These include relatively new programmes that have attracted applications and got off the ground far sooner than expected, for example our Travelling Research Fellowship and Senior Research Fellowship.
- Following on from the Ministerial Advisory Group on Dementia Research (MAGDR), there will be a new public health information campaign linking dementia with wider public health messages, which ARUK will help to lead. The final report of MAGDR, a 'Route Map for Dementia Research' is due to be published later this year. Alzheimer's Research UK has also been publicising the NIHR's themed call for research on dementia through its website and communications with researchers. It was extensively promoted at our annual scientific conference in March. This is the largest event of its kind in the UK and

was attended this year by 250 leading dementia research scientists from the UK and overseas.

However, we continue to stress the need for increased public funding for basic research with more flexible criteria for translation into impacts for patients.

- We continue to expand the information provided on our website for people with dementia and their carers. Most recently, we have added a section on taking part in clinical trials.  
<http://www.alzheimersresearchuk.org/clinical-trials/>
- Our work on understanding research capacity is still ongoing. The Ministerial Advisory Group on Dementia Research found that while the quality of dementia research is excellent in the UK, there is a need to increase numbers of scientists and clinicians working on it from bench to bedside. We are continuing to collect data on this area to make the case for more scientists being encouraged into dementia research.

## **Alzheimer's Society**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We will champion public understanding of dementia through national and local awareness campaigns, and by supporting people with dementia to speak out and tell their own stories.
- We will continue to develop quality information and support services for people with dementia, their carers and families through local information and support services, our website and help lines.
- We will use evidence from the demonstrator sites on dementia advisers and peer support networks to develop more and better services for people with dementia and their carers.
- We will improve the skills of the dementia care workforce by developing and delivering high quality education programmes to staff across a range of dementia care settings and through the use of our approved trainer scheme.
- We will work with people with dementia, their carers and families to campaign for a fairer deal on the issues that matter to them - early diagnosis, access to the right care and treatment, and investment in dementia research - and ensure their needs are recognised by decision makers at national and local level.
- We will fund a programme of research into prevention, cause, care and cure of dementia. We will increase the amount of money we spend on dementia research by 20 per cent per year.
- We will develop 150 local community dementia forums which will bring together people with dementia, carers, health and social care professionals and others to understand the local experience of people with dementia and work out solutions.
- We will work with a range of partners to develop evidence about cost effective interventions for people with dementia and their carers.
- We will work with partners to develop and publish evidence about dementia supportive communities.
- We will provide the secretariat for the Dementia Action Alliance and, working with the Alliance, publish an annual report on progress.

## **First Quarterly Progress report**

### *1. Public understanding.*

We have run major national press stories around our reports 'Support, Stay, Save' (January 2011) and 'Mapping The Dementia Gap' (March 2011) which reached millions of people throughout the UK. We are working with the Department of Health on an awareness raising programme as well as investing in our own Worried About Your Memory campaign, planning for this year's Dementia Awareness Week and investing in a fleet of vehicles which will take mobile community roadshows around the UK to raise awareness and understanding. We have increased our e-campaigners network from 600 active volunteers to over 2,000 as well as recruiting scores of new volunteers for our local campaign and media groups, while our panel of media volunteers - people living with dementia and their families and carers, who sign up to tell their own stories to the media - is now 300 strong.

### *2. Information and support.*

The Society's National Helpline service has been awarded quality accreditation with The Helpline Association (THA). This quality mark covers all aspects of managing and delivering a helpline service and takes in more than 100 markers of effective practice. The review process involved a complete review of Helpline policies and operating procedures, underpinned by a new service specification. The National Dementia Helpline has offered an excellent service for many years and this external quality accreditation reinforces its strong reputation.

In other developments, the Society is piloting a groundbreaking Carers Information Programme with plans to offer this new service to carers around the country in the coming year. Delivered by trained facilitators, the course covers key topics identified as important by carers and staff.

### *3. Dementia advisers and peer support*

The Society continues to work with local authorities across England on the delivery and evaluation of Department of Health-funded Dementia Adviser and Peer support services in 30 demonstrator sites across England. The Society has also completed its own evaluation with service users, which is helping to inform future service development and expansion. The Society's Dementia Adviser service is now offered in South Staffordshire and East Lancashire and has increased capacity in Worcestershire and Shropshire, extending service provision to 32 sites. Since July 2009 over 8500 people have accessed the Society's Dementia Adviser services.

### *4. Dementia workforce.*

We have continued to deliver dementia education programmes to staff in care home and acute settings. We have increased our training reach through our train-the-trainer work. The desire for quality recognition has boosted

applications for our approved trainer scheme We are developing new courses to address specific issues on the dementia pathway and have launched some accredited courses.

#### *5. Campaigns and influence.*

We are actively campaigning against service cuts where they can be shown to be both real and substantial, and in every case we are involving people with dementia, their carers and families Our campaign 'Mapping The Dementia Gap' highlights the importance of getting an early diagnosis and the current inequality in diagnosis rates in different parts of the UK; this will run for three years We are supporting the Care And Support Alliance in their campaign on a fairer deal for charging in care and have submitted evidence to the Dilnot Commission on funding.

#### *6. Research*

We are taking part in the Ministerial Advisory Group for Dementia Research to increase dementia research quality, capacity and relevance We have changed the name of our Public and Patient Involvement programme from the Quality Research in Dementia network to Alzheimer's Society Research Network and increased the number of active volunteers in the network We are working in partnership with DeNDRoN to develop research projects that meet the gaps identified by Alzheimer's Society Research Network volunteers We are working in partnership with NIHR to provide lived experience expertise in the development of research projects submitted to the themed dementia call in May 2011 We worked in partnership with Bupa foundation to increase the funding of clinical dementia research in 2010 We have commissioned additional critical reviews addressing the need for a better evidence base on prevention of dementia.

#### *7. Community dementia forums*

Community dementia forums are under development in every part of England, Wales and Northern Ireland. Work is being done to test and understand different models with a view to further roll out and development.

#### *8. Evidence on cost effectiveness.*

Alzheimer's Society is working with the All Party Parliamentary Group on Dementia which is conducting an inquiry into how to save money in dementia care and deliver better quality of life. The Society is also working with colleagues in the NHS Institute to create a campaign on the use of antipsychotics under the Quality, Innovation, Productivity and Prevention programme.

#### *9. Dementia friendly communities.*

We supported an event held by the Department of Health in February on dementia capable communities. We are gathering evidence about projects

relating to dementia friendly communities in the UK and abroad. We intend to publish this along with a call for evidence from people with dementia and their carers in June to ask for views on the definition of a dementia friendly community.

#### *10. Secretariat to the Dementia Action Alliance.*

We held a meeting in December to discuss next steps for the Dementia Action Alliance with a group of members who had volunteered to take part and have prepared a discussion paper for the 9 March meeting. We have asked all members for quarterly updates which we are compiling into a quarterly report. We held a meeting in February to plan the first quarterly meeting of the Alliance on 9 March. We have updated the website with new members and also advised a number of organisations who want to join the Alliance.

### **Second Quarterly Progress Report - May 2011**

#### **Dementia Action Alliance**

To support the development of the Dementia Action Alliance we have organised and funded:

- A meeting for Alliance members to discuss the NHS Reforms with Sir Stephen Bubb on 17 May.
- A meeting on 13 May to discuss next steps for the Alliance and to plan the agenda for the 8 June meeting.
- A meeting on 27 May to discuss how to measure outcomes for people with dementia and their carers.
- The second DAA quarterly meeting on 8 June.
- The recruitment for 2 stakeholder relations staff who are likely to start work in July. How much of this resource is devoted to the Alliance depends on the outcome of funding discussions with the Alliance on 8 June.

The Society is also in discussions in a number of regions of England about supporting the development of regional alliances and has led the development and launch of the Plymouth Dementia Action Alliance.

#### **Dementia research**

To support the NIHR themed call on dementia research the Society worked with over 30 bid teams to strengthen bids in relation to patient and public involvement and dissemination.

#### **Antipsychotics call to action**

- We have organised the antipsychotics call to action commitment group for people with dementia, their carers and voluntary organisations.

- We have designed and produced booklets for people with dementia and carers and for GPs on the call to action
- We have organised and funded the stakeholder event for the launch of the call to action.

### **All Party- Parliamentary Group inquiry**

The Society has worked with the All-Party Parliamentary Group on dementia to deliver an inquiry into how to save money in dementia care and deliver better quality of life. The report of the inquiry will be published in the second week of July.

### **Dementia Awareness**

The Society is about to launch a UK roadshow with a tour of vehicles visiting Tesco stores across the UK to raise public awareness about dementia.

### **Workforce development**

200 people have now completed the 'caring for people in acute settings' course.

### **Dilnot commission on funding of care**

We have responded to the Commission on Funding consultation, organised a visit for Commission staff to talk to people with dementia and carers and gathered evidence on people's views about social care insurance which will be published soon.



## **Anchor**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We show absolute commitment to supporting and empowering all our customers living with a dementia by supporting all staff, not only direct care staff with information and education.
- We achieve this by structured training courses tailored to the needs of all staff and services; these courses range from awareness sessions to more advanced courses leading to dignity champion status. All cover an extensive variety of dementia related topics and we have a dementia knowledge development plan. We aim to empower people living with dementia by educating staff and effectively and enabling staff to signpost customers and family to community sources of additional support and information.
- We build on the training by providing a rolling programme and supporting and coaching staff and provide debriefing sessions to enable them to identify approaches and solutions to improve the lived experience of people with dementia wherever that person lives.
- We support current and future family and friends and with free education and information session and one to one support as needed.
- We positively encourage people with dementia to influence the services we provide with residents forums across the different settings in which they live. We regularly reflect, review and amend as needed our services and systems of support for people with dementia and Anchor staff.
- Continue to build links with organisations in the local community and national networks to add value to our service and support for people with dementia and our staff.
- Employment of volunteer coordinator to support individual's interests.
- Supporting skills and knowledge of individual roles such as activity coordinators in our care homes
- Review the use of antipsychotic medication in our care homes.

### **First Quarterly Progress report**

*Progress supporting and empowering employees through information and education during the period of November 2010 to February 2011:*

- 166 employees attended the one-day introduction to dementia session, 49 who have previously completed the awareness progressed to the intermediate session, improving dementia care session, and 21 attended the five-day advanced dementia course Developing Dementia Care.
- 78 employees took part in the Mental Capacity Act 2005 session and 125 employees attended a bespoke to service need session, such as sexuality and intimacy.
- To ensure all Anchor employees possess an understanding of the illness and recognise empathy for the person living with a type of dementia, 54 non-direct care staff attended the “Dementia – dispelling the myths” session.
- 129 employees attended 17 debriefing and information sharing sessions.
- 24 mapping and observational visits to different service areas were made to ensure outcomes of support and training were being put into action.
- 9 sessions of the Family and Friends rolling programme of information and education were held and 69 attended and provided 1-1 support and information as needed.
- Forums continuing formally and on an ad hoc basis – individual service areas developing customer survey feedback pictorial questionnaire
- We have been talking and building links with GPs and commissioners – ongoing
- Following extensive preparation and marketing, we are now in the process of matching volunteers to individual customers to enhance their living experience.
- We continue to support all roles including activity co-ordinators and link to Dignity Champion role and Dementia. There are currently 676 registered champions who are commencing the dementia knowledge development plan comprising of specific areas of dementia care and support such as life story and transitional sock.
- We commenced a review of anti- psychotic medication in our care homes in May 2009. We see this as a continuous process and are currently collecting supporting data that demonstrates a fall from 12%, and this is ongoing through the review and support process.

## **Second Quarterly Progress report**

- Since the last action plan we have continued to invest in our employees to support and care for Anchor customers by continuing with the delivery of specialist dementia training and support by our dedicated team.
- 59 employees have completed the dementia awareness session Introduction to dementia care.
- 47 employees have attended the intermediate session.
- 29 employees completed the 5 day advanced course and attained Dignity Champion status to join our internal network.
- 132 employees attended Mental Capacity Act 2005 awareness training.
- 131 employees attended a wide range of dementia knowledge development sessions including life stories. Transitional shock and understanding communication as behaviour.
- Launched Dignity Champion newsletter to provide platform for sharing new initiatives and share good practice.
- Ongoing review and development of new training materials that are tailored to meet individual care home requirements, such as mental health awareness sessions, depression and dementia, effective communication techniques and rarer causes of dementia.
- We support current and future family and friends with free education and information session and one to one support as needed: 10 sessions were held and 41 people attended.
- Attending evening family forums to develop relationships with relatives and friends and offer 1:1 support if required. Individual work has included supporting families in understanding difficult and unusual behaviours and finding solutions in maintaining relationships and friendships.
- Attending organisational events to build links with other organisations and establish what other services are in the area that would support people living with dementia.
- Working with staff in setting up community art project encouraging and supporting customer's involvement.
- Significant progress made in this area having completed the supporting process 57 volunteers have been supported and 15 have completed an induction and have been matched and are being supported to meet individual interests, hobbies and develop life stories.

- Attending area Activities Co-ordinators meetings to facilitate the sharing of new initiatives such as making links with local schools.
- Working with and supporting activity coordinators to make links with local schools and colleges which affords the opportunity for activity (schools – share IT skills/ colleges – beauty therapy). Encouraging activity coordinators to share ideas for different types of activity/meaningful occupation and generally encouraging ‘doing something’ such as everyday household tasks.
- On going review, next stage collation of evidence shows a reduction of 2% to approximately 9% of people living with dementia receiving antipsychotic medication in our 96 care homes. As this support review is ongoing it is anticipated a further small but significant reduction in following progress reports should be anticipated.

## **Association of Dementia Studies, University of Worcester**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Make a difference to the experience of people living with dementia by working proactively at the interface between the experience of those living with dementia, those developing care practice and those undertaking research to ensure real knowledge transfer and translation between these different world-views.
- Ensure that we work actively to include people living with dementia and their carers in all our endeavours.
- Identify centres of excellence in person-centred dementia care in primary care, early intervention, care at home, day services, intermediate care, personalisation, acute hospital care, housing with care, care homes and palliative care.
- Provision of research and development in the delivery of person-centered dementia care through funded research grants and PhD studentships.
- Provision of commissioned research and evaluation of new service models, innovative interventions and commissioning.
- Provide a range of specialist accredited dementia education and training opportunities for those involved in delivering care at all points along the pathway including early interventions, primary care, care at home, acute hospital care, intermediate care, care homes, specialist housing and end of life care.
- Deliver professional accredited leadership development programs for those directing, managing and commissioning dementia care services.
- Provide evidence-based consultancy to improve practice directly for providers of health, social care and housing.
- Contribute to the skills development of those working in training and education in dementia care.
- Contribute to the dissemination of the body of knowledge in person centred dementia care through journal publications, books, media appearances and conference presentations.
- Provide multi-disciplinary seminars, conferences, workshops and networking events.

- Actively support the work of Dementia UK in the West Midlands.

### **First Quarterly Progress report**

- Completed work on “Stand by Me” DVD training resource on good communication between health care staff and people living with dementia and their families. This has brought together a wide range of front-line staff, young film makers, people with dementia and their families and our academic staff. Great knowledge transfer!
- Peter Ashley and John Suchet were awarded Honorary Masters Degrees in Worcester Cathedral in recognition of their work in raising awareness about dementia. This was a fabulous public platform in front of over a 1000 graduates and their families
- Continuing work with 4 national care-home providers, a city council and a county council, large acute hospital trust, housing with care provider and hospices in working towards service excellence.
- Submitted final report on NIHR programme grant on the development of an observational tool to evaluate the experience of people with advanced dementia living in care homes.
- Successful NIHR application with Universities of East Anglia, Stirling and Cardiff on in depth case studies of organisational factors in abuse and neglect in care homes (PANICOA final study) PhD studentship exploring personalisation, dementia and rural issues commenced. Commissioned evaluation of dementia friendly acute hospital continues. Successful tenders for evaluating i-pad applications for people with dementia
- Bespoke education courses delivered over this time period on early interventions, care homes, specialist housing and end of life care.
- Bespoke leadership in person centred dementia care delivered across two local authorities and a national care provider in this time period.
- Continuing expert consultancy on the dementia friendly acute hospital and development of care bundles for people with dementia in acute hospitals.
- Successful tender for development of person centred care home tool kit. Developing network of trainers and educators in dementia care in West Midlands. Member of the national Work-force advisory group.
- Contributions continue to the SCIE Dementia Gateway.

Brooker, D. (2010) Person Centred Dementia Care: Making services better Published in Japanese Conference presentations on Life Story work,  
The Enriched Opportunities Programme: Translational research; End of life care & transcultural care.  
Contributions to NHS West Midlands blog on dementia.

- Seminars delivered on person centred dementia care; Enriched opportunities, leadership, dementia fundamentals; person centred care for Health Care Support workers.  
Conference provided on end of Life dementia care
- Kate Read – senior lecturer employed to lead on Dementia UK in West Midlands
- New Admiral nursing posts appointed.
- Supported West Midlands networks on Memory Clinics and Liaison Psychiatry
- Successful bid with Dementia UK West Midlands on palliative care and dementia

## **Association of Directors of Adult Social Services**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Sharing good practice among its members, encouraging people to see what is possible for people with dementia to live full lives, and helping them to think through how to make this happen locally.
- Including dementia in its support to members about personalisation, so that people with dementia and carers benefit from this national policy.
- Supporting members to think through how to use existing investment to re-shape services in order to deliver better outcomes.
- Promoting the views of service users and carers
- Offering information and advice to other organisations
- Presenting to policy makers the views of service users, carers, and those who commission or provide services
- Working with health partners at a local, regional and national level to promote integrated planning and delivery of health and social care.

### **First Quarterly Progress report**

- Continued membership of the national implantation group and programme board, so that ADASS is influencing both policy and implementation
- Speaking, especially through its Champion and Lead roles, at a range of conferences and seminars in order to raise awareness and knowledge
- Promulgating through the Older People's Network and through the ADASS Bulletin any specific important pieces of information, such as the work on risk sharing and on specialist/generic home support
- Making dementia part of the overall developing use of resources work in ADASS and especially looking for evidence of cost effective solutions to meeting people's needs
- Giving evidence to the APPG on using resources well for people with dementia
- Linking with the policy work on personalisation in order to ensure that choice and control are offered to people with dementia and their carers



## **Second Quarterly Progress report**

- ADASS has nothing new to report for the past quarter.

## **Barchester**

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- To continue to work collaboratively with health commissioners and providers on establishing better dementia care pathways, refining Quality Accounts to produce information on outcomes, quality of life issues and costs.

*Progress: Quality Accounts refined with Lincolnshire*

- To build on our training frameworks, incorporating the Qualifications and Credit Framework and new guidelines and offering staff training focused on the importance of choice, care planning, activities, collaborative work with therapists and work with relatives.

*Progress: Continues. Developing Barchester specific dementia training in line with QCF framework*

- To continue to work collaboratively with local GPs and other health team members on early diagnosis, the reduction in use of anti-psychotic drugs and the avoidance of unnecessary hospital admissions.

*Progress: Discussions continue with GP dementia Leads.*

*Use of supportive telecare system to reduce perceived behaviour challenges*

- To continue to develop approaches for improving the quality of life of all residents (including those living with later stage dementias) through dementia mapping and matching to appropriate environments, communication activities and techniques.

*Progress: Continuance with observational quality of life methods and action plans to enhance the lived experience within a care home*

- To work on the development of audit tools that ensure we facilitate the highest quality of life, can demonstrate delivery of clearly defined outcomes for our residents and that we involve residents and relatives in planning and managing change.

- To support individuals and family members through our charitable organisation The Barchester Foundation and to continue to work collaboratively with carers and local organisations representing people with dementia in order to develop community links and offer support and advice through dementia cafes, in-reach and out-reach work.

*Progress: Residents and family members involved in evaluation of the lived experience*

- To develop a capacity to help people living with dementia and their relatives manage personal budgets, maximise their effectiveness and report back on outcomes to health commissioners.
- To work collaboratively with health sector employees to improve communications around outcomes and quality reporting for people living with dementia and to offer training and work experience to health personnel where appropriate.

*Progress: Projects underway across the country*

- To continue our joint work with groups representing people living with dementia, their relatives and professional development within the sector, expanding collaborative projects and developing our joint lobbying capacity.

*Progress: Discussions with Admiral Nurses and other organisations on working collaboratively*

- To continue to join in the public debate about dementia, to vigorously demonstrate that a high quality of life is possible for everyone living with dementia and to stand against the stigmatisation of the illness at a local and national level.

*Progress: Responding to APPG and CQC*

## **Bradford Dementia Group**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We are committed to further developing the engagement of people with dementia and family carers in the design, delivery and evaluation of our education and training, research and consultancy projects.
- We will actively engage with our key health and social care partners to ensure our strategies related to Dementia Care are aligned and will seek to establish shared projects that will impact on the self worth and sense of control of people with dementia and carers.
- We will actively engage in positive action with our students, people with dementia and carers, community groups and staff to reduce the stigma that can be associated with dementia.
- Dementia Care will remain a key research focus for the University and we will invest in staff time to allow our researchers to create new knowledge that will translate into improved outcomes for users and carers.
- We will further develop of our education and training in order to widen access to all strata of the health and social care workforce, working in partnership with people with dementia and their families.
- Bespoke consultancy service will be further developed to assist organisations and individuals to transfer research into practice in a timely and appropriate manner.
- We will seek out opportunities for our key academics and researchers to collaborate on research bids and ensure we disseminate research in a timely and effective manner.
- To maximise the accessibility of education and training programmes we will ensure our pricing and costing methodology means we can offer affordable education and training to the full range of employers and individuals.
- We will continue to provide a forum for public and professional engagement and debate regarding the best approaches to meeting outcomes of direct relevance to people with dementia and their families.

- We will support our key academics to work alongside people with dementia and their families to influence national and international policy in dementia care.

### **First Quarterly Progress report**

- We have appointed a 1.0 FTE consultant trainer with expertise in the area of user and carer involvement.
- We participated in Meri Yaddain event. Meri Yaadain aims to raise the awareness of dementia in the South Asian communities in Bradford, and help those who have dementia and their carers to understand the condition and seek appropriate support and advice. We continue to work with a number of national care providers to prepare their staff with adequate knowledge and skills for person-centred dementia care and to develop a model of excellence in dementia care.
- In response to the Ombudsman report on acute care, we have contributed a 'profile' piece in the Yorkshire Post on combating dement-ism and promoting person-centred care in the hospital sector.
- We continue to support our PhD student in researching general practitioners and stigma.
- We are working with care providers to promote person-centred care in their care community.
- We are the first university to sign up to the 'Face Equality' ensuring that our marketing materials include people with facial disfigurement.
- We have hosted a meeting with representatives from the NHS and from different Schools throughout the University in response to the NIHR themed call on dementia.  
We have worked with providers to design and evaluate a new range of furniture for people with dementia.
- We have developed new short courses in Leadership and Management in Dementia Care and End of life care for people with dementia and their families.
- In collaboration with colleagues in the acute sector, we are developing a model for knowledge transfer in person-centred dementia care in these settings.
- We are actively working on a promotional campaign to ensure that potential customers know that we have a suite of training and education available for all strata of the workforce ranging from foundation degree to PhD in dementia care.

- We have expanded our practice development consultancy team to include 2 additional FTEs.

## **Dissemination**

We have hosted an exhibition at the University's art centre disseminating results in cartoon form from an ESRC-funded study exploring Campaigning through social action. We have been successful in securing additional funding from the ESRC to create a national touring exhibition of this work.

## **Research bids**

We have submitted a Programme Development Grant on reducing inappropriate hospital admission from care homes.

We have collaborated with our colleagues at the Bradford Institute of Health Research in a research bid to the Research for Patient Benefit Programme to develop a tool for practice development in acute care settings.

We have developed a range of flexible costing models for organisations

We have engaged in a public question time with industry (care providers, estate agents and finance) on the future of long term care.

With the Department of Health and the Alzheimer's Society, we co-hosted a think tank on Dementia and the Big Society at the Design Council in London.

We are engaging with the School's public lecture series to ensure that dementia is well represented.

We have awarded a PhD studentship in user involvement in education and practice development.

## **Second Quarterly Progress Report**

### **USER INVOLVEMENT - RESEARCH**

We have been involved with service users in the following ways:

- We've attended the 'Meri Yaddain' user and carer group meeting and have enlisted their agreement to provide expert input into the development and conduct of a research project re improving the experience of dementia diagnostic services for the South Asian community.

- We presented a poster at the Bradford Institute for Health Research's conference on user and carer experiences of being involved in a randomised control trial of reminiscence.
- We have met with Bradford Older People's Forum to discuss ideas for developing research.
- One of our PhD students is studying user involvement in practice development in dementia.
- A person with dementia is a co-applicant on a grant submission we have made to the NIHR's Health Technology Assessment programme under the dementia themed call.
- We participated in the recent Alzheimer's Society PPI event in London regarding carer and user involvement in research bids for the NIHR dementia research themed call.
- We are working with Methodist Homes at Bay Tree Resource Centre/Moor Allerton Care Centre, Leeds, on a pilot of methods for promoting social inclusion and involvement for people with severe dementia and/or limited verbal communication. A Pioneer Projects arts group for people with dementia in North Yorkshire is also involved in this work.
- We have begun a dialogue with Bradford District Care Trust about how we can work together to improve quality of life for people with dementia.

## **ACCREDITED EDUCATION**

- Two people with dementia and two carers took part in the teaching and assessment of students on our MSc Dementia Studies (Training in Dementia Care) pathway.
- An abstract has been accepted for us, alongside people with dementia and their families, to present on the progress of our 3-stage approach to service-user involvement in education at the UCLan service user involvement conference in June.
- We participate in the monthly management committee meetings of the Bradford & Airedale Mental Health Advocacy Groups.

## **CONSULTANCY in PRACTICE DEVELOPMENT**

- We have been working with people with dementia and their family carers to make digital audio recordings of their life stories for use in our practice development work.

## **JOINT STRATEGIC PLANNING**

- We continue to work in partnership with Nightingale Home to design and develop a model of excellence in care homes.
- We continue to work with Cannon Care Homes to support their continuous quality improvement. Specifically we will be working to trial Enriched Care Planning profiles with input from people with dementia and their families. We will also be seeking feedback on our well and ill-being profile.
- We continue to work with BUPA UK in developing and implementing training in person-centred dementia care. Our work with BUPA was highly commended in the University's recent Excellence in Knowledge Transfer Awards.
- We continue to work with the Care Quality Commission on updating the SOFI observational tool for use in care home regulation, and have also submitted a response to their tender regarding excellence in dementia care. We are also working with the Scottish Commission for the Regulation of Care and the Care and Social Services Inspectorate Wales.

## **REDUCING STIGMA - EDUCATION**

- All of our modules actively challenge stigmatising views.
- Our postgraduate students have been involved, as one of their coursework exercises for the module 'Practice Development and Organisational Change', in the creation of an 'old culture phrase book'. This includes examples of negative and stigmatising language related to dementia that students have identified during the course of their work.

## **TRAINING**

- Our short courses actively challenge stigmatising views held by participants.

## **RESEARCH**

- One of our PhD students is exploring the stigmatising views held by GPs with respect to dementia. An abstract on this work will be submitted to Alzheimer Europe.

## **OTHER**

- We have been invited to serve on an advisory group for the World Health Organisation regarding public attitudes to dementia.



- Our education and training programmes continue to challenge professional and practitioner thinking regarding the value afforded to, and place of, people with dementia in our society and care systems. In particular our 'Understanding Experiences of Dementia' module supports staff in directly acknowledging and addressing the concerns and outcomes of relevance of people with dementia.

## **RESEARCH**

- In collaboration with colleagues we have submitted bids under the following NIHR dementia themed call streams: Health Technology Assessment, Service Development & Organisation, Public Health, Programme Development Grant. We have also submitted a bid to the NIHR School for Social Care Research.
- We have been awarded the University's prestigious Vice Chancellor's Award for Knowledge Transfer in recognition of our work in translating knowledge such that it directly affects the quality of life of people with dementia.
- We continue to host monthly meetings with NHS and University colleagues on dementia research.

We continue to serve on the following bodies:

- Joseph Rowntree Foundation Advisory Group for People with High Support Needs
- The Alzheimer's Society Research Executive Council
- The Dementia and Neurodegenerative Diseases Network Clinical Studies Group
- The Enabling Research in Care Homes Project Board
- The Joint Programme on Neurodegenerative Diseases
- The National Dementia Strategy Workforce Development Committee

## **Education and Training**

- We continue to work in partnership with organisations to tailor our range of training and education provision to meet the needs of individual organisations and sectors.
- Our new Postgraduate Dementia Studies Workforce Development pathway has had its first intake of students. This course was developed in response to the National Dementia Strategy, and has been marketed to NDS implementation groups and other target groups with a view to increasing student numbers in September 2012.

- In collaboration with our colleagues in the acute sector we are developing a training package for staff working with people with dementia in general hospitals.
- As we are academic sponsors of the 2011 UK Dementia Congress our students will be entitled to a 50% discount on the conference fee.

### **Consultancy**

- We continue to develop our consultancy service transferring research into practice and are exploring innovative approaches to this end.

## **British Association of Occupational Therapists and College of Occupational Therapists**

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

COT will be supporting the Dementia Declaration through a number of key actions.

- Promoting awareness and understanding of dementia to occupational therapy staff working within acute, medical and community services. Action: A resource consisting of a series of documents that will cover areas of care ranging from assessments, delirium, feeding, homes visits and discharge planning. Each document will contain a summary of evidence and standards and signpost further reading and resources. To be completed by December 2011.

*Progress: First drafts expected to be completed by April*

- Promoting the National Institute for Health and Clinical Excellence (NICE) Public Health Guidance 16. Occupational therapy interventions and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care (2008) through the Activity Matters Toolkit. The toolkit will be available electronically on the College of Occupational Therapists website with resources and ideas for implementing the guidance for older people, including people with dementia.

*Progress: Activity Matters Toolkit is on the College of Occupational Therapists Website*

- Review existing or produce new resources to advise carer's on different aspects of daily care with partners from other organisations. For example: In collaboration with the Chartered Society of Physiotherapy, the College of Occupational Therapists intends to produce a resource for carers of people with dementia, to support them to identify strategies to manage seating, postural support and the physical management of their family member or client safely and effectively.

*Progress: Currently liaising with the Chartered Society of Physiotherapy regarding a resource for carers on seating and posture.*

- Promote an understanding of the nature of occupation and its importance to health and wellbeing and the contribution that occupational therapists make to services for people living with dementia.

Actions:

- Designing and publishing leaflets for the public outlining the role of occupational therapy working with people living with dementia- December 2010.

*Progress: Leaflet designed jointly with the Dementia Services Development Centre*

- Involvement in the Memory Services National Accreditation Programme through Membership of the Standards Development Group and Accreditation Committee.

*Progress: Ongoing*

- Producing a resource document on commissioning and planning occupational therapy services for people with dementia

*Progress: Planned for summer 2011*

- Develop resources for occupational therapy staff to implement recommendations within the End of Life Care Strategy for people with dementia. Action: Produce an electronic document by 2012.
- Support occupational therapy practitioners to extend the scope of their practice beyond the boundaries of statutory health and social care services to meet the wider occupational needs of individuals living with dementia. For example: within care homes. Actions to be developed and completed by 2014:
- Explore joint working with National Association for Providers of Activity (NAPA).

*Progress: Initial meeting on 23.02.11*

- Exhibiting at conferences (for example: the DSDC Coming of Age: Dementia in the 21st Century conference) and facilitating seminars

*Progress: Exhibited at NHS Alliance  
Co-chaired session at the British Geriatric Society  
Seminar at the Care Homes Exhibition (Birmingham) on the  
Need to be active does not diminish with age*

## **First Quarterly Progress report**

The following has been agreed;

1. A work plan with target dates.
  2. Design and purpose of the documents
  3. Volunteers to write and edit each topic.
- COT Briefing linking policy guidance on end of life care to practical application, ensuring that this covers all four UK countries.
  - Developing a publication -‘Route to Success’, explaining how to implement the steps on the end of life care pathway and the role of occupational therapy. Incorporated within this are references to working with people with dementia, including a case study.

## **Second Quarterly Progress report**

COT will be supporting the Dementia Declaration through a number of key actions.

- Promoting awareness and understanding of dementia to occupational therapy staff working within acute, medical and community services.  
Action: A resource consisting of a series of documents that will cover areas of care ranging from assessments, delirium, feeding, homes visits and discharge planning. Each document will contain a summary of evidence and standards and signpost further reading and resources. To be completed by December 2011.

*Progress: First drafts are currently being collected for editing.*

- Promoting the National Institute for Health and Clinical Excellence (NICE) Public Health Guidance 16. Occupational therapy interventions and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care (2008) through the Activity Matters Toolkit. The toolkit will be available electronically on the College of Occupational Therapists website with resources and ideas for implementing the guidance for older people, including people with dementia.

*Progress: Activity Matters Toolkit is on the College of Occupational Therapists Website*

- Review existing or produce new resources to advise carer's on different aspects of daily care with partners from other organisations. For example: In collaboration with the Chartered Society of Physiotherapy, the College of Occupational Therapists intends to produce a resource for carers of people with dementia, to support them to identify

strategies to manage seating, postural support and the physical management of their family member or client safely and effectively.

*Progress: Outline of the leaflet has been agreed and work allocated.*

- Promote an understanding of the nature of occupation and its importance to health and wellbeing and the contribution that occupational therapists make to services for people living with dementia.

Actions:

- Designing and publishing leaflets for the public outlining the role of occupational therapy working with people living with dementia- December 2010. Achieved.
- Involvement in the Memory Services National Accreditation Programme through Membership of the Standards Development Group and Accreditation Committee.

*Progress: Ongoing*

- Producing a resource document on commissioning and planning occupational therapy services for people with dementia.

*Progress: Ongoing.*

- Develop resources for occupational therapy staff to implement recommendations within the End of Life Care Strategy for people with dementia.

Action: Produce an electronic document by 2012.

- Support occupational therapy practitioners to extend the scope of their practice beyond the boundaries of statutory health and social care services to meet the wider occupational needs of individuals living with dementia. For example: within care homes.

Actions to be developed and completed by 2014:

- Explore joint working with National Association for Providers of Activity (NAPA).

*Progress: Plans to update joint publication with NAPA entitled: Activity Provision. Benchmarking good practice in care homes.*

- Exhibiting at conferences (for example: the DSDC Coming of Age: Dementia in the 21st Century conference) and facilitating seminars

*Progress: None to report.*

## **British Geriatrics Society**

**What are your plans as an organisation to respond to these challenges between now and 2014?**

- Delirious about Dementia document relaunch
- Regional and devolved nation representation on SIG committee

*Progress: Achieved to fair degree*

- Consultee to NICE on the Drugs for Dementia Guideline 2010

*Progress: Fully Achieved*

- Document on Pain assessment in the older patient (BGS, BPS, RCP) –

*Progress: Useful to consider promotion again this year*

- Document on Pain management in older people should include dementia

*Progress: In progress*

- BGS statement on mental capacity 2010

*Progress: Achieved*

- Regional study days to facilitate local hospital leads for dementia

## Bupa

### What are your plans as an organisation to respond to these challenges between now and 2014?

- Continue to improve public understanding through press, TV and web advertising, information on our website and the distribution of our booklet "Caring for someone with dementia".
- Encourage people to plan for their future by providing printed and on-line materials to enable life-story work and Advance Directives.
- Continue to work with Alzheimer's Society to train a Dementia Champion for every dementia specialist community (currently 192 trained) and encourage the NHS and other care providers to follow this example.
- Use our newly launched suite of dementia training modules (developed with the University of Bradford and others) to train every staff member in our dementia specialist communities in the basics of Person First care ; senior members of staff in more advanced care ; and specialist staff in appropriate skill areas e.g. nutrition, activity provision, palliative care etc. Complete this in 2011, maintain and develop it thereafter and extend training to non-specialist units by 2014.
- Establish the concept of Meaningful Moments to encourage brief but positive engagement with residents by all staff at every opportunity.
- Create internal and external environments that preserve privacy, enable quality of life and support activities of daily living.
- Ask the prescriber to review the use of anti-psychotics soon after admission and regularly thereafter, if continued.
- Ensure continuity of care by involving the family, local community and primary care and by maintaining the same care setting until the end of life.
- Ensure that each resident has a respectful and dignified death in line with the principles of Person First and that families are re-assured by this.
- Engage with policy-makers at national level to support the implementation of the National Dementia Strategy.
- Continue to lead practice in care homes and be evangelists for best practice in person-centred care.



## First Quarterly Progress report

- New ageing “hub” on website, active in social media e.g. Facebook regarding dementia care and creation of “Ten glorious seconds” site to promote this film and its message.
- Created Life Story file and distributed these at special “Your Memories Matter” events in five large, regional shopping centres. Working with AS and Dementia UK on possible development of pack of materials for those newly diagnosed.
- Courses being held every quarter to replace leavers and provide a Dementia Champion to every new or newly registered dementia specialist community. Benefits outlined regularly at conferences.
- More than 700 people already completed or underway with The Essentials basic training. First cohort of Person First Coaches has commenced their training to deliver the core modules of more advanced or specialist care skills.
- All residents’ rooms (>6,300) in dementia specialist communities now have a memory box. Specialist activity staff have been trained in the concept of Meaningful Moments at their annual conference. One of the priority modules for Person First Coaches (see above) is Meaningful Activities.
- Paper on dementia appropriate environments by Graham Stokes has been signed off and is being trialled in two typical specialist communities.
- Third six-monthly review of prescribing levels identified further improvement but pressure on GPs to review continues and urgent need for reduced prescribing in hospitals.
- Project planned for later in year.
- Working closely with NCPD and Marie Curie to adapt end-of-life pathways for dementia specialist units and to give homes confidence to follow them, avoiding hospital admission whenever appropriate.
- Providing evidence to APPG on Dementia on cost-effectiveness, DoH on anti-psychotic prescribing and pioneering work on case identification.
- Leadership in training, workplace leadership and meaningful activity and sharing these developments regularly at conferences, in articles etc. Also drawing on experience in our international care homes to learn lessons which can be implemented in the UK.

## Second Quarterly Progress report

- Our social media work continues with the recording of video blogs posted on our Facebook page and You Tube, as well as Q&A in response to the video blogs.
- Courses being held to replace leavers and provide a Dementia Champion to every new or newly registered dementia specialist unit.
- More than 7,359 people already completed or underway with The Essentials foundation training. 4 cohorts of Person First Coaches have been trained (as at 13th May 2011) to deliver the Excellence core modules of more advanced or specialist care skills and knowledge.
- The first specialist dementia care unit with enhanced dementia-friendly lighting, prosthetic features and destination points will be completed in June.
- Fourth six-monthly review of prescribing levels of antipsychotics is scheduled in June to be followed by research to identify the most effective care methodology to reduce prescribing.
- Continuing to work closely with NCPC and Marie Curie to adapt end-of-life pathways for dementia care and to give homes confidence to follow them, avoiding hospital admission whenever appropriate. Collaborating with the Marie Curie Dementia Research Programme to improve end of life care in advanced dementia.
- Provided written and oral evidence to APPG Inquiry on Dementia on cost-effectiveness and better clinical outcomes including pioneering work on case identification.
- Continuing to share developments and demonstrate healthcare partnership at national and international conferences, in articles etc. Also drawing on our international care homes businesses to learn lessons that can be implemented in the UK, e.g. destination features, meaningful moments, dementia-friendly gardens.
- Co-applicant on two proposed NIHR research projects looking at sensory interventions in advanced dementia care and the value of person-centred care training.

# Care Quality Commission

## What are your plans as an organisation to respond to these challenges between now and 2014?

Whilst the position statement and action plan covers what CQC will do over five years, in the first year following publication of the plan we will focus on the following as priorities:

- Getting the basics right through registration - ensuring that regulated services for older people and people living with dementia meet essential standards of safety and quality. There are specific regulations and standards which cover a number of areas which are of particular importance in defining what good quality care for people with dementia will look like, such as:
  - 1 - Care and welfare of people who use services (Regulation 9) - in our standards document we promote a person centred approach to care and treatment
  - 2 - Respecting and involving people who use services (Regulation 17) - we describe expectations about how people will be involved in decisions about their care and treatment and how privacy and dignity will be respected
  - 3 - Safeguarding vulnerable people who use services (Regulation 11) - we describe what services must do to respond to and prevent abuse and ensure that restraint is only used in appropriate circumstances
  - 4 - Meeting nutritional needs (Regulation 14) - including encouraging and supporting people to receive adequate nutrition and hydration
  - 5 - Management of medicines (Regulation 13)- including the requirement for complex drug regimes to be reviewed and to monitor the effect of medicines and take action in relation to adverse effects
  - 6 - Requirement relating to workers (regulation 21 ) - we have made specific reference to staff in social care services that support people with dementia receiving training that satisfies the learning outcomes in the Skills for Care knowledge and skills set on dementia.
  - 7 - Co-operating with other providers (regulation 24) including sharing information in relation to the admission, discharge and transfer of people who use services

- Developing and implementing observational methodologies including SOFI 2 (Short Observational Framework for Inspection) to ensure that we capture the experiences of people who have cognitive or communication difficulties which affect their capacity to voice their opinions.
- Completion of our special review of healthcare in care homes which we anticipate will highlight issues in relation to older people and people living with dementia and follow up on the findings
- Developing policy briefings and focused additional guidance for operational staff to ensure awareness of relevant issues for older people and people living with dementia.
- Establishing a new older people's advisory board and smaller dementia reference group to actively engage with stakeholders and people who use services so that they can inform and influence our work.
- We would encourage people to access the full text of our position statement and action plan for further details of these and our other proposals.

### **First Quarterly Progress report**

- CQC has started to register services under the new Health & Social Care Act (2008). NHS Trusts came into scope of the new registration regime first in April 2010, followed by adult social care and independent healthcare providers in October 2010. Other providers will start to come into scope of the new registration regime this year, including primary dental care and independent ambulance services from April 2011, followed by primary medical services, such as GPs and out of hour's services, from April 2012. All of these services have the potential to provide care or treatment for people living with dementia.
- For those providers who are now registered under the Health & Social Care Act (2008), CQC will be undertaking ongoing monitoring of compliance with the essential standards of quality and safety, to ensure that the services continue to meet the expected standards of care and treatment they have been registered to provide. Where a provider is found to be non-compliant, CQC has a range of enforcement activities at its disposal to take swift action against poor performance.
- It is too early to comment in a meaningful way on the impact the new regulatory model is having on the quality of dementia care and the experiences of people living with dementia using registered services at this stage. However, it is worth noting that a number of providers, including Trusts and care home providers, have already been dealt with using enforcement actions e.g. instructed to submit urgent action plans on how they will improve to comply with certain regulations where they have been found to be underperforming or, in some cases,

services have already been de-registered and closed because they have put people using that service at unacceptable risk.

- CQC is working to develop Quality and Risk Profiles (QRP) for every registered provider, which will gather together all of the intelligence and evidence we hold about that provider so we can determine the intensity of our regulatory activity with them e.g. how often we need to inspect that service in person, what regulations we need to specifically focus on with them, etc. These QRPs will be shared with providers so that our process with them is transparent. We are also designing something similar we will be able to share publicly, to help the wider public, including people living with dementia and their carers, to make informed decisions about the services they wish to use. This is still work in progress.
- We have provided links on our website to enable local groups or people who use services to tell us about their experiences in using health or adult social care services regulated by CQC :

For individuals giving feedback on their experience of care:

<http://www.cqc.org.uk/yourviews/feedbackaboutyourcare.cfm>

For feedback from local groups:

<http://www.cqc.org.uk/yourviews/feedbackfromlocalgroups.cfm>

SOFI 2 reflects the change in the regulatory framework and the wider range of services that CQC regulates. It can be used in care homes, hospitals and independent healthcare settings where people with dementia, learning disabilities, autism and language/cognitive impairments are being cared for or treated. It can be used over shorter and longer time periods depending on the needs of the visit.

SOFI 2 links to the essential standards of quality and safety and to the outcomes that people who use health and social care should expect. In particular:

- Outcome 1: Respecting and involving people who use services
- Outcome 4: Care and welfare of people who use services
- Outcome 5: Meeting nutritional needs
- Outcome 7: Safeguarding people who use services from abuse
- Outcome 9: Management of medicines
- Outcomes 12, 13 and 14: Suitability of staffing

Train the trainer courses are being held in February and March 2011 in readiness for training to be rolled out in the regions later in the year. SOFI 2 training will be compulsory for all compliance inspectors to attend.

- At the moment, CQC is still on track to complete the review into health care in care homes by July 2011. The fieldwork inspections are currently taking place in nine regions across the country. Nine care homes are involved within each region, comprising of 3 care homes for adults with learning disabilities, 3 residential care homes for older people, and 3 nursing homes for older people. There will be a focus on issues around continence and medication. Although this is not a dementia specific review, given the nature of the site visits and the focus of the inspections, it is likely that the findings will be highly relevant for people living with dementia and the quality of dementia care.
- CQC is developing an information guide on dementia for its frontline staff. This will complement, not replace, the essential standards of quality and safety and will serve to assist compliance inspectors on their visits to services or in their preparation for site visits. The draft document has been produced in consultation with various external stakeholders, including people living with dementia and carers. This information guide is still going through its governance procedures and is not yet ready for publication. The aim is to have it available for staff in time for the roll out of the SOFI 2 training so that compliance inspectors can see how the tools sit alongside each other and complement one another.
- The proposal of establishing an older people's advisory board is currently on hold. A review is taking place of the existing advisory boards to determine if they are fit for purpose, both for CQC but also so that external stakeholders feel they are engaged in the right way and have adequate opportunities to influence the work of CQC in a meaningful way. CQC will be able to make a decision about establishing an older people's advisory board once this review has been completed. The idea of establishing a smaller dementia reference group, consisting of people living with dementia and their carers, if they wish, has been taken forward to some extent. Individuals living with dementia who had initially voiced their interest in such a group were involved in shaping the draft information guide on dementia. CQC also used existing networks, groups and individual contacts of people living with dementia and carers to comment on this piece of work (including Experts by Experience, Innovations in Dementia, and local third sector groups through the CQC Speak out Network). We aim to build on this 'virtual reference group' over coming months to improve the way in which CQC involves people living with dementia in its work.

## **Second Quarterly Progress report**

- CQC has started to register services under the new Health & Social Care Act (2008). NHS Trusts came into scope of the new registration regime first in April 2010, followed by adult social care and independent healthcare providers in October 2010, primary dental care and independent ambulance services from April 2011, followed by primary medical services, such as GPs and out of hours services, from April 2012. All of these services have the potential to provide care or treatment for people living with dementia.
- For those providers who are now registered under the Health & Social Care Act (2008), CQC will be undertaking ongoing monitoring of compliance with the essential standards of quality and safety, to ensure that the services continue to meet the expected standards of care and treatment they have been registered to provide. Where a provider is found to be non-compliant, CQC has a range of enforcement activities at its disposal to take swift action against poor performance.
- A number of providers, including Trusts and care home providers, have already been dealt with using enforcement actions where they have been found to be non compliant against certain standards e.g. instructed to submit urgent action plans on how they will improve to comply with certain regulations where they have been found to be underperforming or, in some cases, services have been de-registered and closed because they have put people using that service at unacceptable risk.
- CQC is continuing to fully develop Quality and Risk Profiles (QRP) for every registered provider, which will gather together all of the intelligence and evidence we hold about that provider so we can determine the intensity of our regulatory activity with them e.g. how often we need to inspect that service in person, what regulations we need to specifically focus on with them, etc.. These QRPs will be shared with providers so that our process with them is transparent. We are also designing something similar we will be able to share publicly, to help the wider public, including people living with dementia and their carers, to make informed decisions about the services they wish to use. This is still work in progress.
- We are also in the process of improving and updating our public website to make it easier for people to find relevant and appropriate services and to make informed decisions about which services to use. The new website is due to be launched towards the end of the summer.
- We have provided links on our website to enable local groups or people who use services to tell us about their experiences in using health or adult social care services regulated by CQC :

For individuals giving feedback on their experience of care :

<http://www.cqc.org.uk/yourviews/feedbackaboutyourcare.cfm>

For feedback from local groups :

<http://www.cqc.org.uk/yourviews/feedbackfromlocalgroups.cfm>

SOFI 2 reflects the change in the regulatory framework and the wider range of services that CQC regulates. It can be used in care homes, hospitals, independent healthcare settings and mental health services, where people who experience difficulties in communicating, for example some people with dementia, learning disabilities, autism and language/cognitive impairments, are being cared for or treated. It can be used over shorter and longer time periods depending on the needs of the visit. (At this stage, SOFI 2 cannot be used for domiciliary care services or in hospices).

SOFI 2 links to the essential standards of quality and safety and to the outcomes that people who use health and social care should expect. In particular:

- Outcome 1: Respecting and involving people who use services
- Outcome 4: Care and welfare of people who use services
- Outcome 5: Meeting nutritional needs
- Outcome 7: Safeguarding people who use services from abuse
- Outcome 9: Management of medicines
- Outcomes 12, 13 and 14: Suitability of staffing

Trainers have now been trained in each of our regions and the roll out of the training for our compliance inspectors will commence from June 2011 onwards on a regional basis. SOFI 2 training will be compulsory for all compliance inspectors to attend.

- CQC is still on track to complete the review into health care in care homes by July 2011. Although this is not a dementia specific review, given the nature of the site visits and the focus of the inspections, and the fact that approximately two thirds of people living in care homes are living with some form of dementia, it is likely that the findings will be highly relevant for people living with dementia and the quality of joined up dementia care.
- CQC has developed an information guide on dementia for its frontline staff. This will complement, not replace, the essential standards of quality and safety and will serve to assist compliance inspectors on their visits to services or in their preparation for site visits. The document has been produced in consultation with various external stakeholders, including people living with dementia and carers. This Information Guide is still going through its final governance stage but



we aim to have it signed off and available for staff in time for the roll out of the SOFI 2 training, so that compliance inspectors can see how the tools sit alongside each other and complement one another.

- The proposal of establishing an older people's advisory board is still on hold. A review is taking place of the existing advisory boards to determine if they are fit for purpose, both for CQC but also so that external stakeholders feel they are engaged in the right way and have adequate opportunities to influence the work of CQC in a meaningful way. CQC will make a final decision about establishing an older people's advisory board once this review has been completed. The idea of establishing a smaller dementia reference group, consisting of people living with dementia and their carers, if they wish, has been discussed. Individuals living with dementia who had initially voiced their interest in such a group were involved in shaping the draft Information Guide on dementia. CQC also used existing networks, groups and individual contacts of people living with dementia and carers to comment on this piece of work (including Experts by Experience, Innovations in Dementia, local third sector groups through the CQC Speak Out Network). CQC is currently deciding how best to engage with the wide range of stakeholders we have contact with, including people with experience of using services and carers, in all of the work that we do so that we can make most effective and efficient use of peoples' voices and views.

## Care UK

### What are your plans as an organisation to respond to these challenges between now and 2014?

To provide solutions to some of these challenges we are steadily moving away from sending staff on training courses outside of their home services:

- Within our Residential and Community Care services we are already utilising the provision of e-learning for dementia training with this being supplemented by more traditional training sessions held within the individual services.
- Within our Residential Care Services we are also delivering experiential training to capture not only the 'what is dementia' but also 'what it may feel like to have dementia' as well as strategies that focus on non-medical approaches and the impact of the environment on the resident.

Our service development teams work with members of the operational teams and outside experts to ensure that the designs of all new builds take into account the needs of residents with a dementia when designing internal and external environments as well as ensuring that the internal designs (colour, signposting, size of units, lighting etc) are providing a positive impact and are fit for purpose.

Our proposed approach to the development and operation of dementia care services within our Residential care sector can be categorised as coming within four key themes:

- Leadership
- Expertise
- Training
- Philosophy

The key elements of the themes can be summarised as follows:

- Dementia leads to be in each care service to promote best practice and continuous improvement. The Dementia Leads within the services will receive training to ensure that they can act as mentors and coaching within their individual services.
- Dementia trainers to deliver experiential training
- Further focus, training and development of activities (including Activity Based Care) in our operations to promote physical, social, spiritual, psychological well-being.

- Environmental improvements to our existing facilities where these would lead to quality of life benefits for customers.
- New builds to be fit for purpose in the delivery of specialist dementia care
- To work in partnership with external consultants in the engagement of customers with end stage dementia to ensure that all are able to have a say.
- To continue with our customer involvement programmes
- Development of integrated care solutions, where we have multiple service offers.

## **First Quarterly Progress report**

### Training

- Dementia awareness training is being delivered to all care staff within our services where their service provision caters for people with a form of dementia using an e-learning system. This training is delivered as part of their induction as well as forming an integral part of their on-going rolling training programmes.
- This type of learning/training provides increased flexibility. Staff are able to complete the training “on-site” and in an environment where they feel more comfortable. I.e. within a group setting or on an individual basis and at their own pace.
- The e-learning programme only confirms completion, when all modules, within the dementia awareness package, have been successfully completed with every member of staff achieving a 100% pass rate at the assessment stage of each of the modules. This dementia awareness training is also supplemented by more traditional training sessions at the individual services. Over the past 7 months we have been piloting a more interactive training programme. This pilot is being conducted within our Residential Care services division. This unique training provides an insight into “what it may feel like” to live with dementia and includes participants wearing aids to simulate some of the common problems that dementia sufferers experience including sensory disruptions, cognitive impairments, memory loss, mobility issues and dexterity impairments. This training experience covers areas ranging from perplexing behaviour to effective communication and nutritional support.
- The pilot is due to complete March 2011 and to date all staff within the pilot region, regardless of designation have received the experiential training and a dementia journey. The results from this training have

been very positive with managers, senior staff, residents and relatives reporting positive changes in practice. For example: Reductions in the incidents of aggression towards staff and other service users, increased involvement within meaningful occupation and activities, increased mobility around the homes and better sleeping patterns.

Within the pilot region we have also recruited and trained dementia leads and activity staff. The dementia leads have all received training via PSS over an intensive 5 day course covering areas such as:

- What is dementia
- Communication
- Person centred Care
- Medication – antipsychotic drugs
- Activities and meaningful occupation
- Nutrition – eating and drinking
- Dignity and choice
- Dementia Journey

With the activities staff receiving training from NAPPA areas such as:

- Understand what activity is
- Understand the stages of dementia and how to provide appropriate activities
- Understand how to evaluate activities for individuals with dementia

The dementia leads within the home act as a role model, providing advice and support to both staff and relatives/carers.

### Environments

- Services within our Residential care division have had input from our Service Design team and specialist dementia therapist.
- Within our new builds the design team have worked with the architect to ensure that the design of the building is fit for purpose, looking at areas such as general design, lighting, layout, size of units, size and number of lounges, reduction of dead ends and corridors that lead to meaningful places.
- Following commencement of build or in the case of refurbishment, they then work closely with the project managers to ensure that fixtures and fittings are appropriate for those living in the home with a dementia, looking at areas such as; contrasting colours, floor/wall coverings, cues/clues/signposting, and types of furniture, signage, and meaningful areas of occupation.
- Within the pilot region the service design team have utilised the 'Design for people with Dementia' audit tool designed by Stirling University to

review and develop the environments. To date the services within the pilot area have made some significant developments e.g. memory boxes for all rooms, improved signage, use of signposting and clues, improved use of contrasting colours, rummage boxes, increased sensory items and homely furniture usage i.e. fireplaces

- A New project is due to commence in March 2011 with Innovations in dementia and Methodist Homes Association. This two year project is to look at how to increase service user involvement and engagement with customers with complex care needs or within end stage dementia.

## **Second Quarterly Progress report**

- We are continuing to work to our three year Dementia Care strategy.
- To date 550 staff have received our experiential dementia training, this training enables the staff to perceive care from the perception of the residents, which allows staff to see and feel the impact of their care delivery as well as encouraging them to see their responsibility within it.
- We continue to develop approaches for improving the quality of life of all our residents through the use of dementia friendly environments. All new builds and existing homes going through a refurbishment programme are fitted with memory boxes, appropriate signage and are being designed to ensure that the environment is dementia friendly.
- Our "dementia-friendly" environments are based upon physical and social elements:
  - Homely and stimulating
  - Encourage residents to bring in personal items in order to decorate their bedrooms to their own taste
  - Provide meaningful occupation and plenty of activity
  - Assist our residents to be as independent as possible with the use of appropriate signage, memory boxes, signposting and reinforcing the function of a room
  - Reduce features that could cause confusion e.g. mirrors, lack of contrast in the use of colours , use of confusing patterns
  - Encourage our residents to find their way around the building, and discourage entry into inappropriate areas
  - Encourage access to safe outside spaces
  - Improves a sense of security, especially for people who are not mobile, by increasing their familiarity with different areas of the home.
- Our marketing teams work closely with our Dementia team to ensure that all materiel is in line with our dementia strategy.

- Our clinical governance team has agreed the use of a new audit tool that captures the outcomes of the experiences of those we care for, with this audit tool being sent to all our homes for completion in June.
- Third annual review of anti-psychotic drug use has identified further improvements. We continue to work closely with local GP's and other health team members regarding reductions in the use of anti-psychotic drugs.
- We have commenced a service user engagement project with Innovations in Dementia and Methodist Homes Association. This two year project looks at ways to increase involvement and engagement with service user who have a form of dementia, complex care needs or within end stage dementia.

## Chartered Society of Physiotherapy

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- In collaboration with the College of Occupational Therapists, the Chartered Society of Physiotherapy intends to produce a resource for carers of people with dementia, to support them to identify strategies to manage seating, postural support and the physical management of their family member or client safely and effectively.

*Progress: We are liaising with the Colleague of Occupational Therapist (COT), namely Karin Tancock and will be arranging meetings, with the aim to produce a resource by December 2011*

- In partnership with CPMH the Society intends to develop an information resource for referrers and commissioners that will identify why the provision of specialist services for people with dementia is essential particularly with regard to pain management which is frequently misdiagnosed as challenging behaviour.

*Progress: Have arranged to meet with the Chartered Physiotherapists in Mental Health (CPMH) to discuss taking this work forward*

- The Society through its many networks will promote to physiotherapists, carers and other professionals the wide range of good practice in the field of physiotherapy and dementia care.
- Resources will be developed to educate carers and health and social care workers in the areas of: Falls prevention, pain relief, nutrition and promotion of mobility post discharge.
- Resources will be developed to educate physiotherapists who work in generic services about the specialist needs and approaches to the management of dementia.

## **Counsel and Care**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

Counsel and Care is currently working to a strategy of influencing the new government to take forward the care funding and reform agenda, and is a founding member of the Campaign to End Loneliness. We incorporate dementia into these pieces of work by:

- ensuring that a funding solution takes into account the burgeoning numbers of people who will be living with dementia by 2014 and beyond
- Researching and promoting the use of befriending and other solutions to loneliness, which includes people with dementia and their carers.

### **First Quarterly Progress report**

- Launch of the Campaign to End Loneliness: This Campaign, launched on 1 February has produced a report, part of which outlines the affects of loneliness on dementia and how prevention of loneliness can help support people with the early stages of dementia. This can be accessed at:

[http://www.campaigntoendloneliness.org/pdfs/safeguarding-the-convey\\_-\\_a-call-to-action-from-the-campaign-to-end-loneliness.pdf](http://www.campaigntoendloneliness.org/pdfs/safeguarding-the-convey_-_a-call-to-action-from-the-campaign-to-end-loneliness.pdf)

- Our new Care Home Handbook provides advice and information about what to do when moving in to a care home. It also includes detailed information about the special needs an older person with dementia may have when looking for a new residential setting.
- Counsel and Care have responded to and is a member of the External Reference Group for the Dilnot Commission which will publish on the future funding of care and support in July 2011. We have submitted to this Commission our position on the funding of care and support in light of the increasing population of people with dementia and the importance of addressing their needs in future.

### **Second Quarterly Progress report**

- Counsel and Care has nothing to report for the past quarter.



## **Craegmoor**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Craegmoor has a three year Dementia Care strategy detailing actions and expectations for dementia care within the Company.
- There is a dedicated lead for the Dementia Care Strategy, who also provides advice and support for individual services.
- There is a team of Quality Development Support Managers who visit each home regularly to support care delivery and audit key areas of care.
- Craegmoor is investing in a range of staff training to support best practice in the delivery of dementia care, establishing a leader in dementia care in every specialised service.
- Craegmoor works closely with people living in our services, their families and friends to develop and support the way in which care is delivered. People are encouraged to become involved in decisions that affect them at a service and company level. The initiative Your Voice enables people's opinions to be heard throughout Craegmoor, through individual interactions, comment cards, meetings at home, regional and national levels and annual questionnaires.
- Craegmoor is developing a network of Dignity Champions to promote dignity and respect in every aspect of care delivery. The network will be supported by regional workshops to share best practice and key challenges.
- As a company we aim to increase our work with friends and families, supporting people to understand the rights of people living with dementia, our philosophy of care and the effects of dementia.
- Craegmoor works in collaboration with learning bodies, in particular participating in research and developing training.

### **First Quarterly Progress report**

- We are continuing to work to our three year Dementia Care strategy.
- The Quality Development Advisor for Dementia works to develop strategic initiatives and directly supports individual services to ensure a consistent informed approach to dementia care within our Craegmoor services. Strategic initiatives include the introduction of resources, for example Best Practice Guides, Weekly Sparkle (reminiscence

newspaper), easy access to National Documents and reports, and the development of a portfolio of environments that are as supportive and enabling as possible.

- The Quality Development Team continues to work with services, providing support during visits and through a system of audit.
- The first round of Leading in Dementia Care courses led by the Association of Dementia Studies at the University of Worcester has now been completed. A number of Home Managers, Deputy Managers and Quality Development Support Managers completed the course. Deputies, nurses and senior carers are currently applying to join the Dementia Practitioners course, also led by the Association of Dementia Studies.  
The second round of Leading in Dementia care course will start later this year.
- The Your Voice Forum continues to operate in the Older Peoples' Division. People living in services are able to influence service and company level decisions if they choose to do so. Craegmoor has recently held the National Forum for Your Voice; this was an opportunity for people using our services to meet directly with the Chief Executive Officer, Chief Operating Officers and a number of Directors. The Older People Division was represented by a service user at the biannual event.
- Craegmoor is also investigating other ways in which we can gain people's opinions, particularly people who live with communication impairment.
- The Dignity Champion project will be starting shortly. The proposal for the project has been finalised and a budget for the project has been put in place.
- Included in each of our internal audits is an outcome that relates to the inclusion of families and friends, both in relation to care planning (where appropriate) and in the service delivered in the home. We plan to offer information sessions for relatives and friends, which will be led by the Quality Development Team.
- We continue to work with organisations to promote and support excellent dementia care. Recently we have shared our practice with the Department of Health and the Salvation Army. We continue to work with the Association of Dementia Studies.
- Craegmoor has just completed the second survey of the use of antipsychotic medication in its Older People Homes. The first survey was conducted in December 09 and the information gathered was used to establish a baseline measurement and understanding of the use of this particular type of medication. The second survey will be used to

measure progress in reducing the use of antipsychotic medication and provide further information about use and prescribing patterns.

## **Second Quarterly Progress report**

- We are continuing to work to our three year strategy.
- The Quality Development Advisor for Dementia works to develop strategic initiatives and directly supports individual services to ensure a consistent informed approach to dementia care within Craegmoor. We are currently focussing on the dining experience within our homes.
- Craegmoor has completed the second survey of the use of antipsychotic medication in its Older People Homes. The first survey was conducted in December 09 and the information gathered was used to establish a baseline measurement and understanding of the use of this particular type of medication. The second survey demonstrated the level of antipsychotic medication use for people living with dementia in Craegmoor Older People services is 14.33%, a reduction of 3.33% from last year.
- Living Spaces has been launched to Craegmoor homes. The project was developed to ensure that we provide high quality environments that meet the needs of the people living in them. The aim is to define a number of environments that support and enable people whilst providing choice to the services involved.
- This was a joint project between different departments in Craegmoor and a number of outside organisations namely PPG Paints, Renray Healthcare, Eco Lab, Panaz and Danfloor.
- The Quality Development Team continues to work with services, providing support during visits and through a system of audit.
- The first Dementia Practitioners course has started for nurses and seniors carers. The course is led by the Association of Dementia Studies based at the University of Worcester.
- The Your Voice Forum continues to operate in the Older Peoples' Division. People living in services are able to influence service and company level decisions if they choose to do so. Craegmoor is also investigating other ways in which we can gain people's opinions, particularly people who live with communication impairments.
- Included in each of our internal audits is an outcome that relates to the inclusion of families and friends, both in relation to care planning (where appropriate) and in the service delivered in the home.

- We continue to work with external organisations to promote and support excellent dementia care.

## Department of Health

### What are your plans as an organisation to respond to these challenges between now and 2014?

- Work in consultation with partner organisations to identify key outcomes which people with dementia and their carers expect. This work will feed into the consultation on Transparency in outcomes - a framework for the NHS and the Department's "zero-based review" of social care data collection.
- The appointment of Professor Alistair Burns as the first National Clinical Director for Dementia to promote clinical and professional engagement in the design and management of services.
- The NHS National Quality Board is looking at the dementia care pathway and ways to support improved commissioning, workforce capability and better quality data.
- The NICE Quality Standards in Dementia Care were launched in June 2010. The Department is working with NICE and the National Quality Board to ensure harmonisation of the Standards with the National Dementia Strategy
- The appointment of three National Dementia Champions for the NHS, the independent sector and social care, who will: provide leadership at local level; encourage and embed delivery at all levels; and support local accountability.
- Reducing the use of antipsychotic medication - the National Clinical Director for Dementia is leading the work to implement the recommendations in the report into the over-prescribing of anti-psychotic medication, with the support of an Advisory Group.
- The revised NHS Operating Framework for 2010/11 highlights that the NHS and its partners must give a greater priority to dementia. Local organisations will be expected to publish how they are delivering on quality outcomes so that they can be held to account by local people.
- Developing a comprehensive commissioning pack to support local commissioners to deliver improved services for people with dementia.
- The establishment of a Workforce Advisory Group chaired by the National Clinical Director, to deliver objective 13 of the Strategy - an informed and effective workforce for people with dementia.
- The Department provides substantial funding for health research, through the National Institute for Health Research (NIHR) and the

Policy Research Programme (PRP), which is available to support high quality research in all areas of health science, including dementia.

- A time-limited Ministerial Advisory Group on Dementia Research (MAGDR) has been established, bringing together the main bodies with an interest in dementia research. The aim of the Group is to suggest ways to increase the volume, quality and impact of dementia research.
- Support for a Demonstrator Site Programme to test models of delivery for the role of dementia adviser and for peer support networks.
- A National Audit of Dementia Services commissioned from the NHS Information Centre. The initial audit findings are expected to be available in autumn 2010 and will help local areas to prioritise areas for action.
- Development of a Good Practice Compendium, which is accessible online via the Dementia Information Portal, aimed at bringing together examples in improving dementia care from across the regions.
- A resource guide on end of life care for people with dementia has been produced for health and social care professionals which provides links to information sources, resources and good practice.

### **First Quarterly Progress report**

Since the publication of the National Dementia Declaration on 26 October 2010, the Department of Health has made progress in a large number of the areas set out in its Action Plan:

- The Operating Framework for the NHS in England 2011/12, published on 15 December 2010, reinforces the priority attached to dementia. It states that people with dementia and their carers need information to help them understand the range and quality of local services and that NHS organisations are expected to make progress on implementing the National Dementia Strategy, working with their social care partners.
- The NHS National Quality Board (NQB) System Alignment in Dementia Care Subgroup published its full report on the NQB web pages in December 2010.
- DH has provided funding of £1.9m to enable the NHS in the South West, under the leadership of Sir Ian Carruthers as the National Dementia Champion for the NHS and working jointly with the Alzheimer's Society, to take forward work with all Strategic Health Authorities to accelerate improvements in the prescribing of anti-psychotic medication.
- DH is developing, with the Alzheimer's Society, a multi-disciplinary care pathway for the management of agitation in people with dementia and

for the review of medication on people already receiving anti-psychotics. It is anticipated that this will be ready by the end of March 2011.

- Work on the commissioning pack for dementia for the NHS and social care is now well underway. There are two domains – early diagnosis and interventions and general hospital care. The pack is due to be published in April 2011.
- DH has commissioned Skills for Care, working with Skills for Health, to develop common core principles for dementia care. The common core principles are due to be published in April 2011.
- DH is working with the Oxford Deanery to trial a new approach to dementia education and training for GPs and practice staff. An initial workshop with Leadership Fellows took place in December 2010.
- A major National Institute for Health Research (NIHR) Dementia Research Workshop was held on 14 January 2011. At the workshop Paul Burstow MP, Minister of State for Care Services, announced an intention to launch a themed call on dementia research across seven of the NIHR programmes in March 2011.
- The National Audit of Dementia Services is being taken forward by the NHS Information Centre and will provide local NHS and social care organisations with a measure of their progress in areas such as the provision of memory services, number of clinical leads in acute hospitals, expenditure on services for people with dementia and use of anti-psychotic medication. Initial results are expected in Spring 2011.
- With respect to the care of older people with dementia in general hospitals, the National Clinical Directors for Dementia and Older People wrote to Medical Directors and Chief Nursing Officers on 5 January 2011 to bring to their attention the interim findings from the Royal College of Psychiatrists' Audit in General Hospitals. The National Clinical Director for Dementia has agreed to meet with all SHA Medical Directors in their regional meetings to highlight the issue for individual medical and nursing directors of trusts and to gain a sense of progress and local activity.
- 'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia was published on 10 November 2010 and provides guidance on best practice in assessing, managing and enabling risk for people living with dementia.
- Good Practice Compendium – an assets approach, which brings together examples in improving dementia care from across the regions, was published on 10 January 2011.

- DH, jointly with the Alzheimer's Society and the University of Bradford, hosted a Dementia and Big Society Think Tank on 16 February 2011.

## **Second quarterly report**

During the period March-May 2011, the Department of Health has made further progress in a number of the areas set out in its Action Plan.

- The Department is working with the Dementia Action Alliance and the NHS Institute on the development of a national "call to action" to reduce the use of antipsychotic medication. The call will be launched in June.
- DH is developing, with the Alzheimer's Society, a multi-disciplinary care pathway for the management of agitation in people with dementia and for the review of medication on people already receiving antipsychotics. It is anticipated that this will be available in June.
- Work on two sections of the Dementia Commissioning Pack, early diagnosis and intervention and hospital based services, was completed by the end of April. Further work is being carried out on community based services and antipsychotic medication and the pack is due to be published in the summer.
- DH is continuing to work with Skills for Care and Skills for Health on the development of the Common Core Principles for Supporting People with Dementia. The draft principles have been widely discussed, including by the National Dementia Strategy Workforce Advisory Group, and are due to be published in June.
- DH has carried out further work with the Oxford Deanery to trial a new approach to dementia education and training for GPs and practice staff. The National Clinical Director for Dementia attended a training day for GP registrars in the Deanery on 1 April 2011.
- The National Institute for Health Research (NIHR) issued a themed call for research on dementia on 9 March 2011. The call covers the fields of cause, cure and care, including prevention. Applicants were asked to submit proposals by 20 May 2011.
- The Ministerial Advisory Group on Dementia Research (MAGDR) held its final meeting on 30 March 2011 before publication of its findings and recommendations. A Route Map and Headline Report on further work resulting from the recommendations of the Group will be published before the summer Parliamentary recess. These will cover a number of different actions. A follow up meeting of MADGR will be held 12 months after publication of the Route Map to check on progress.
- The National Audit of Dementia Services continues to be taken forward by the NHS Information Centre and will provide data about the provision of



memory services, number of clinical leads in acute hospitals, expenditure on services for people with dementia and use of antipsychotic medication. The initial findings from the audit are expected this summer.

- During March 2011 the Department piloted an awareness campaign in two regions, Yorkshire & Humber and the North West, focusing on early diagnosis. The Department will be evaluating the effectiveness of the campaign before deciding whether to roll it out on a national basis.
- In the context of a changed architecture for the delivery of health and social care and the greater emphasis on Big Society and social enterprise, the Department is beginning work with the Design Council on an innovation programme to engage leaders in the design industry and the private and third sectors to develop innovative solutions for the future for dementia care.

## **English Community Care Association**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

In order to address these issues ECCA will between 2010 and 2014 do the following:

- Have a focused awareness campaign with ECCA members and other care providers on the objectives of the Dementia Strategy
- Develop an innovation exchange with SCIE to identify and cascade examples of good practice in dementia care
- Work with the British Geriatric Society to develop a model of good practice for Primary Care Services to Care Homes
- Develop links to the regulator (CQC) to inform their regulatory role in ensuring this model is delivered

### **First Quarterly Progress report**

#### **Introduction**

Since the launch of the Declaration, ECCA has been working with its members and other external stakeholders to publicise the Declaration, identify the objective of improving support for people with dementia and their carers right across society, and following through on some of the specific actions that we have committed ourselves to as a signatory to the Declaration.

#### **Challenges**

As we said in the Declaration, there are a number of enormous challenges to delivering improved care for people with dementia and supporting their carers. These challenges have been exacerbated by the economic situation and the levels of cuts that are being levied on care providers by local authority commissioners.

Faced with this reality, ECCA has been stressing the benefits to everybody of getting services to people with dementia right and challenging providers to see high quality care as one of the foundations of improving efficiency.

#### **Progress on specific actions**

##### Innovation Exchange

ECCA is working with SCIE to develop the Innovation Exchange. We have agreed that this will be part of the Dementia Gateway and we are currently collecting examples of good practice for inclusion in the Exchange.

## BGS Primary Care in Care Homes

ECCA is working with the BGS on this project which is well advanced and will be launched towards the end of the year. This project is looking at the support available to care providers from primary care and should help in the reduction of the use of anti-psychotic medication.

## Gold Standards Framework

I have spoken at a conference on end of life issues and particularly challenged GSF to further develop pathways for people with dementia who are coming to the end of life. The response of GSF has been fantastic and their services are being rolled out to more care providers. This will undoubtedly have an impact on the experiences of people with dementia at the end of their lives and will hopefully improve the experiences of their carers at this difficult time.

## British Care Awards

We are discussing with the British Care Awards an award for dementia excellence which will be badged as an ECCA award.

## Publicity and profile raising

Since the launch of the Declaration, I have included it in 11 speeches and several columns. We launched ECCA's commitment to the Declaration in our November newsletter.

## **Conclusion**

Given what is happening in the external environment and the severe pressures on funding that all stakeholders are facing, we are content with progress to date. We would have liked to have gone further, but realistically this would not have been possible.

The Declaration is, however, gaining a great deal of profile and many other initiatives are seeking to replicate it as a response to the change to a localism and Big Society agenda which is being advanced by the coalition government.

It is good to see that the Dementia Declaration has led the way and given a template for others to follow. We thank and commend the Alzheimer's Society for its foresight in launching this initiative which will undoubtedly in the fullness of time and as more people engage with it have an impact on the lives of people with dementia and their carers.

## **Second Quarterly Report**

### **Introduction**

Since our last progress report ECCA has continued to work with its members and other external stakeholders to publicise the Declaration, identify the objective of improving support for people with dementia and their carers right across society, and following through on some of the specific actions that we have committed ourselves to as a signatory to the Declaration.

In regard to external stakeholder engagement we have been targeting some of the larger private firms that supply the sector and are hoping to get some of these bodies to produce their own declarations

## **Challenges**

The major challenges to delivery of the declaration remain the funding position, the lack of engagement by primary care and local authority eligibility criteria, which means entry into the care system is at high level dependency and this mitigates against the development of lower level support services

Faced with this reality, ECCA has been stressing the benefits to everybody of getting services to people with dementia right and challenging providers to see high quality care as one of the foundations of improving efficiency.

## **Progress on specific actions**

### Innovation Exchange

The joint project with SCIE to develop the Innovation Exchange has progressed very slowly and there is little progress to report.

### BGS Primary Care in Care Homes

ECCA is working with the BGS on this project which is well advanced and will be launched towards the end of the July. The project is looking at the support available to care providers from primary care and should help in the reduction of the use of anti-psychotic medication.

### Technology and innovation

ECCA has formed a link with the MyAmego monitoring service and has seen some very impressive examples of how it supports people with dementia to have more autonomy choice and control and reduce anti-psychotic prescribing

### British Care Awards

The Great British Care Awards judging has taken place and some excellent examples of dementia care have been highlighted

### Publicity and profile raising

Since the last report I have included issues around Dementia Care in 16 speeches and several columns.

## **Conclusion**

This is an extremely challenging time for the Care Sector and this has had an impact upon our progress in delivering the declaration. However, we remain committed to delivering on our objectives and maintaining the momentum of the declaration.

## **Four Seasons Health Care**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- All Dementia Care Units/Homes to be validated as PEARL homes by 2014
- Continue to use DCM (Dementia Care Mapping - a specialised observational assessment tool) to establish the views of the person living with dementia and to help train our staff in person centred approaches
- To continue to provide 2 day Person Centred Care training to all our dementia care units/homes
- To review the PEARL criteria each year to ensure that it is aligned to latest government recommendations i.e. National Dementia Strategy,
- NICE Guidelines and Outcomes and also that it contains recommendations in relation to very latest evidence/research based practice.
- To continue to review our Dementia Care Manual annually in line with the PEARL criteria review (as policies/guidance are aligned to the PEARL programme)
- To continue to listen to our residents, our relatives and our staff and to act on suggestions for improvements
- To continue to update the knowledge of the Dementia Care Team to enable our staff within the Company to share our knowledge
- To continue to work towards our Dementia Care Vision and help all our staff working within our homes to recognise that each person living with dementia is unique.

### **First Quarterly Progress report**

- There are now 35 homes accredited
- DCM is being utilised within the PEARL homes particularly every 3 months to help develop care plans and improve levels of well-being
- We have now developed an e-learning package to cover most of the theoretical underpinning knowledge to care for a person living with dementia and continue to provide classroom based sessions for homes across the UK

- PEARL criteria has been reviewed and has increased from 143 criteria to 152. We have also aligned it to NDS and CQC outcomes. We have also produced a detailed 12 month action plan to help homes to achieve PEARL status
- Dementia Care Manual is currently being reviewed by all team members. New policies have had to be introduced to support additional PEARL criteria
- We work with individual homes across the UK and interview staff and relatives listening to their comments and suggestions. As a Company, we also conduct an annual Customer Survey
- One of the Dementia Care Team is currently undertaking a post graduate course with Bradford Dementia Group. The remainder of the team will access varying dementia care conferences throughout the year
- 3 hours every 6 weeks at our Dementia Services Team Meeting is also dedicated to new learning to help us to develop and enhance our knowledge in the field of Dementia Care
- We are carrying out 6 dementia care conferences across the UK this year to work with our staff to achieve our Dementia Care Vision

## **Housing and Dementia Research Consortium**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

The four founder members have contributed to a fund to employ someone part-time until the end of this financial year (end March 2010) to move the agenda forward. It is hoped that a successful research bid would include funding this role in the longer term. The core group will review the position at the beginning of 2011. The role of the research co-ordinator is to:

- develop the research agenda
- make links with research partners
- find funding
- prepare research proposals with research partners - one bid has recently been submitted
- develop a website
- use opportunities to raise awareness and understanding of housing with care and the need for research, in the context of people with dementia
- link with the membership, providing updates and any other information likely to be of use to them
- continue to link with the Housing Learning and Improvement network.

In any successful research bid, the HDRC will:

- identify suitable research sites
- be an active partner in shaping the research methodology
- ensure that researchers have a proper understanding of the housing with care setting
- ensure that people with dementia and their carers are properly and ethically involved
- use its networks to disseminate research findings and encourage implementation in practice.

### **First Quarterly Progress report**

- We have developed a list of key research questions that are priorities for the consortium and have approached a number of potential research partners.
- We submitted one bid for funding together with an academic partner which unfortunately was not successful.
- We are holding a meeting of key researchers in the areas of the built environment and assistive technology to come up with three proposals upon which to seek funding. We have a number of ideas for seeking funding – but welcome others' ideas.



- We are hoping to be able to pull together a programme of relevant research for submission to NIHR.
- Without resources to fund its development, the website has proved a challenge; now one of our core members is developing it on a voluntary basis in her spare time.
- We have published some good practice guidance called “Living Beyond Dementia” based on our literature review of housing with care for people with dementia, circulated it to our membership, uploaded it on the Housing LIN website and included information about it in the Housing LIN newsletter.
- We have notified our membership of other relevant research, e.g. EVOLVE and PSSRU research into specialist vs generalist domiciliary care.
- Both the Housing LIN network and our membership network can be used to spread messages such as the next stage of the awareness raising campaign.
- The housing sector is at present not part of the Alliance. I will ensure the Alliance Secretariat get the names of housing with care providers who have schemes catering for people with dementia so that they can be invited to join the Alliance. They will be having considerable contact with people with dementia and can make a positive contribution if they are included.

## **Jewish Care**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

#### Funding

- Jewish Care will continue to lobby for appropriate funding to provide relevant and high standard services to people with dementia and their carers. Whenever possible we will endeavour to lobby politicians, at local and national levels, and commissioners that good dementia care requires and is given a realistic budget. In accordance with the personalisation agenda, we will endeavour to educate people on the true cost of high quality dementia services. Jewish Care's campaign and fundraising department will continue to highlight services for people with dementia as a high priority with potential funders and benefactors.

#### Advocating on behalf of people with dementia; Jewish Care commits to:

- Ensuring people with dementia and their carers have access to a skilled workforce, in a wide range of services that are knowledgeable about dementia and can offer flexible approaches to individual challenges.
- Continuing and developing a team of Dementia Care Champions in residential and nursing homes supported by senior leads for dementia who take on the role of Champion's mentors. Champions will use the VIPS framework to promote and measure high quality services (from now to 2014 and beyond)
- The establishment of Dementia Care Champions for day and home care services (establish by June 2011)
- Continuing Dementia Care Mapping (DCM) in dementia services.

#### Educating the work force:

- All paid and unpaid staff will continue to access induction and ongoing training provided by Jewish Care's specialist Disabilities and Dementia Service. With the availability of the QCF dementia pathways from October 2011 Jewish Care undertakes to support staff working with people with dementia to achieve these qualifications. (2010 - Develop routes of access to QCF dementia units for all Jewish Care staff working with people with dementia & from 2011 to 2014 to support and monitor the achievement of these qualifications)

#### Respite care:

- Jewish Care will continue to offer respite care to people with dementia. We will develop a clear policy on respite care by the end of 2011.

#### End of Life care for people with dementia:

- All of Jewish Care's residential and nursing homes will be registered with the Gold Standards Framework (GSF) by the end of 2011. Jewish Care is currently working with University College London and The King's Fund on research into end of life care for people with dementia. The findings of this research will be published in 2011.

#### Upgrading and building residential and nursing accommodation:

- In September 2010 Jewish Care opened a new dementia care nursing and residential home. The home's built environment follows the latest dementia specifications. A programme of refurbishment and building is currently under review for existing and planned new buildings.

#### Assistive technologies (At):

- In October 2010 Jewish Care will establish an Assistive Technologies' Committee to monitor development in this area for people with dementia and to advocate for clients have access to them.

#### Younger people with dementia in the Jewish Community:

- Throughout 2011 Jewish Care's Community Support Service and Advice and Support Service will gather data about younger people with Dementia in the Jewish Community. This information will be used to develop a plan of action for future years.

#### **First Quarterly Progress report**

- Jewish Care has found that there is pressure on rates of pay from local authorities (LAs) for day and residential service placements.
- LAs are funding fewer days per funded client and grant funding to cover the time before individual funding is agreed is being cut .
- In the last 3 months Jewish Care has found that clients with dementia are finding it is increasingly difficult to get funding for residential placements. The experience is that there is an unwillingness to consider residential placements.
- The Government's request that LAs should not pass on their cuts to 3rd sector organisations is not being heeded. At best rates are being kept unchanged whilst we deal with inflation at 4% and over. So in real terms funding is reducing on all fronts, and as a charity we face the dilemma of either subsidising people by an even greater amount or saying to LAs that we can no longer continue providing the service.

Some initiatives that have been undertaken with staff have included:

- Work on memory boxes and life history at Otto Schiff Home. This has helped staff and relatives work together to provide some visible reminders that celebrate the lives and achievements of the residents.
- Dementia training refresher courses for all staff at Vi & Jon Rubens House using the Alzheimer's Society programme Tomorrow is Another Day.
- A Music for Life Project at Otto Schiff House with joint participation from people with dementia, staff and volunteers.
- A placement for mentoring staff at Lady Sarah Cohen House helpful for developing staff members' person centred approaches and this has been evidenced through a Dementia Care Map
- 25 Dementia Care Champions met on December 16th 2010 for a full day's workshop on implementing the VIPS framework. For this quarter of the year they are working with their teams to develop greater understanding of the perspectives of individuals with dementia and how to respond empathically.
- Padraic Garrett has been appointed to take the lead on developing Dementia Champions for Day and Home Care Services. An initial meeting to plan the way forward has been set for April 8th 2011.
- Dementia Care Maps have taken place at Lady Sarah Cohen House and Ella and Ridley Jacobs Home. The maps have been followed up with feedback to staff teams and action plans have been set. A schedule for maps has been set for 2011 with every home having a DCM of at least 5 hours as part of Jewish Care's annual Quality Assurance (QA) process.
- Jewish Care's has developed a QCF strategy. 27 care staff will undertake the dementia pathway for the level 2 QCF diploma and 16 will take level 3. This will commence in April 2011. In addition team leaders with existing NVQ 3 will undertake the dementia QCF certificate. Nurses with team leaders' responsibilities will also be given this opportunity.
- A full day induction on person centred approaches to working with people with dementia has been revised to reflect current standards and developments. Additional centralised one day training days on dementia are also available throughout the year.
- Jewish Care has set up a working group to investigate how we can provide more creative provision for respite that can enhance the wellbeing of the person with dementia and their carer. The group is looking at how a new respite unit with 6 beds at the Otto Schiff home in Golders Green can develop to provide more creative approaches with the possibility of also offering occasional guest accommodation for family carers in an adjoining building. It is envisaged that respite

guests and their carers can have access to Community Centre facilities during their stay.

- Rosetrees Residential Home has been accredited by the Gold Standards Framework (GSF). 6 other homes are in the process of gaining accreditation. Train the trainer GSF programmes have been particularly appreciated by senior staff. Research on End of Life for People with Advanced Dementia (ELCAD) at Lady Sarah Cohen Home is in its final stages with analysis of post intervention results underway. Anecdotal evidence suggests that, following the implementation of a comprehensive programme of training for staff, there has been a reduction in unnecessary admissions to hospitals to hospital towards end of life and palliative care in the home is improving. In addition, a higher number of advanced wishes are being recorded in care plans. More compliments have been recorded from the relatives of people who have died in the home. A volunteer coordinator has been appointed and she has begun setting up a group of volunteers to provide befriending for people at end of life and for their carers. She is developing a training programme in conjunction with this.
- The Princess Alexandra Home has had significant remodelling to allow more rooms to offer en suite facilities. Strategy groups have been set up to look at the restructuring and upgrading of facilities at two other sites. A community based approach is envisaged for these sites and the challenge will be to have buildings that respond to the changing needs of the community. A wider and more creative and more flexible range of services for people with dementia and their carers are envisaged for these sites.
- An Assistive Technologies Committee has been set up. Information will be collated and made available through Jewish Care's web site and through Jewish Care Direct. Some initiatives being investigated include: Keeping in Touch (KIT) which aims to encourage and assist care home residents to keep in touch with family and friends and with events in the outside world via simplified email and easy-to-use computers and software and CIRCA which is a standalone reminiscence facility, using photographs, video clips and music on touch screen. The committee has also run a trial with BUDDI a simple tracking device, using satellite technology to enabling, encouraging and maintain independence without the fear of getting lost.
- A strategy has yet to be developed on how to reach and support younger people with dementia in the Jewish Community. This will be discussed at the February Dementia Consultative Group.

## **Local Government Group**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Organise a presentation to the Community Wellbeing Board and provide regular updates
- Develop briefings for lead members and provide opportunities for discussions at our regional lead member networks
- Consider opportunities for workshops at the National Children and Adults Conference each year
- Consider developing a conference in the LGA programme at an appropriate moment
- Assist in promoting material for councils through website and newsletters

### **First Quarterly Progress report**

- The LGG has nothing to add to the Action Plan. The template above still reflects the LGG position.

### **Second Quarterly Progress report**

- The LGG is working in partnership with the All-Party Parliamentary Group on Dementia to launch the APPG's latest report on saving money in dementia care and delivering better outcomes for people with dementia. The launch will take place in July at Local Government House and Cllr David Rogers OBE, Chairman of the LGG's Health and Wellbeing Board, will speak at the event.

## **MHA**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We will be continuing to seek opportunities for the development of new specialist care homes, particularly in urban and deprived areas
- We are developing, through conversion of our existing sheltered housing schemes, and new-build, new housing with care services to include specialist dementia care
- We are developing more community services for people with dementia including personal care, dementia day care, carers' support groups, befriending, signposting and regular contact, especially where we can link this with existing or new care homes and schemes nearby to enable sharing of resources and staffing, and maximise the use of volunteers.
- Our dementia training strategy will include local dementia champions, new e-learning and other induction training in dementia awareness for all staff, training resource packs and targeted training for care staff, both in specialist and general care settings
- We are committed to research into care and support for people with dementia, including into pioneering work with music and reflexology therapies, and will initiate and participate in research with academic, funding and provider partners, including through the Housing and Dementia Research Consortium (HDRC).
- We will be developing more opportunities to raise awareness locally to our services with resource libraries in homes and schemes, holding public events and sending out "signposting" newsletters
- We will work closely with local healthcare colleagues to give people as much information and support as possible, using single assessment processes where available, easier access, shared resources and a joint approach to high quality end of life care.

### **First Quarterly Progress report**

- We are progressing a number of development opportunities for new specialist homes, both by new-build and acquisition in a variety of locations. These include dementia specific services. Three such developments are very close to completion.

- Our programme of conversion of sheltered schemes to provide personal care is progressing at a pace, with several incorporating specialist dementia services.
- We have embarked upon a programme of expansion of our community services, both new volunteer-led initiatives and linked with our existing care homes and housing schemes. We are also developing our domiciliary care services to older people living within or near our Housing with Care schemes, including people with dementia.
- We have completed our new e-learning training for dementia awareness, are trialling new dementia training packs, and are identifying the resources for targeted training. Many services have identified local champions with others to come.
- We have commissioned research into our reflexology service, which will complete in 2011, and are seeking academic partners for a major piece of research into music therapy for people with dementia. Our involvement in the HDRC continues, and this has included the recent publication of a literature review on Dementia and Housing with Care (“Living beyond Dementia”).
- We have established a standard for resource libraries in each of our services and are encouraging local awareness events to inform local communities about dementia.
- We are working hard in our individual services throughout the UK to develop partnerships with local healthcare services where links are weaker, to integrate care and support and make information, resources and transitions easier. We are specifically working more closely with other agencies to ensure a joint approach to end of life care including use of pathways and frameworks.

## **Second Quarterly Progress report**

- Two homes providing specialist dementia services have been opened in Derby and Bristol.
- MHA has opened a new purpose built facility in Newport Pagnell which offers apartments with care services which includes people living with dementia.
- This work continues with the expansion of our community services.
- MHA’s dementia staff training strategy continues to be rolled out to all care support services. A project to assess the support which can be



provided to MHA's staff dementia training programme by universities specialising in this work has commenced.

- Other activity listed in our Action Plan is on-going

## **Mental Health Foundation**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Completion of the Dementia Choices project in 2011. This will produce a range of information and guidance aimed at people with dementia, their families and staff working in social care to support and promote the use of self directed support (e.g. personal budgets) for people with dementia. These will be available in April 2011 and we plan to disseminate them through our media and communications networks and through a national event and regional events.
- Completion of the Home Improvements grant making scheme in 2011-12. This scheme has funded 4 innovative, service improvement projects aimed at benefitting people with dementia in care homes. All the projects will be producing project reports and we plan to produce a report for the whole scheme which we would disseminate through our media and communications networks and possibly a national event.
- Updating our information booklets on dementia for people with dementia, family carers, and children and young people.
- Ensuring that issues affecting people with dementia are included in our on-going project work on mental capacity issues.
- Ensuring that people with dementia are included, as appropriate, in our on-going project work on promoting positive mental health and well-being for the general population, as well as projects tackling more specific mental health issues (e.g. depression)
- Starting with information and advice, consider practical ways in which our services can be adapted to ensure that they meet the needs of people living with dementia and carers.

### **First Quarterly Progress report**

- The Dementia Choices project continues on time for completion by the end of March 2011 when the information and guidance will become available. It will also include a resource for trainers involved in training social care staff who work with people living with dementia about self directed support. The Dementia Choices project will produce a range of information and guidance aimed at people with dementia, their families and staff working in social care to support and promote the use of self directed support (e.g. personal budgets) for people with dementia.

- Progress of the Home Improvements grant making scheme. This scheme has funded 4 innovative, service improvement projects aimed at benefitting people with dementia in care homes.
- Three of the four projects have now completed (although two have yet to submit their final reports) with the fourth one due to complete in April 2011. The final report will be produced in summer 2011.
- We have yet to secure the resources to do this work on mental capacity issues
- People with dementia are included in the Best Interests Decisions Study (BIDS) that we are doing with Bristol and Bradford Universities. They are also explicitly included in several other mental capacity project proposals we are developing.
- Starting with information and advice, consider practical ways in which our services can be adapted to ensure that they meet the needs of people living with dementia and carers: No specific activity to report.

## **Second Quarterly Progress report**

- The Dementia Choices project officially finished at the end of March 2011. It produced a range of information materials to raise awareness and understanding about self directed support for people with dementia and their families. These included:
  - An awareness raising postcard
  - An information leaflet for people with dementia, their families and friends
  - A guide for practitioners and other social care staff
  - A resource for trainers involved in training social care staff.

All of these materials are available for free at:  
[www.mentalhealth.org.uk/dementiachopices](http://www.mentalhealth.org.uk/dementiachopices)

- A short film is currently being produced to complement the materials and a policy briefing about the project and personalisation and dementia more generally is also being planned.
- All four projects have now completed and final reports have been received from three of them. The final overall report will be produced in summer/autumn 2011.
- We have now secured the resources to do this work and the revised booklets are in the final stages of redrafting. These will be available in the summer.

- People with dementia are included in the Best Interests Decisions Study (BIDS) that we are doing with Bristol and Bradford Universities. They are also explicitly included in several other mental capacity project proposals we are developing.
- The DEEP project has begun and the mapping exercise is planned to begin in July 2011.

## **National Care Forum**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

The NCF has developed 'best practice guidance on dementia care' for our members. We have also led a study tour to Denmark and Sweden in 2010 to look at best practice models and learning from other countries.

We will continue to work in partnership 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
- Supporting dementia champions
- Building on our relationship with SCIE and resource initiatives such as the Dementia Gateway
- Utilising our international networks to ensure learning on best practice from around the world is shared
- Working with the National Skills Academy for Social Care to inform the leadership programme to support dementia care services
- Leading work with the Department of Health to improve medication management in care homes
- Completing joint work with NCPC on supporting people with dementia at the end of life
- Ensuring that best practice from our members is disseminated and shared

### **First Quarterly Progress report**

- The NCF issues a weekly News letter to all members. This has included the latest news in relation to the NDS Strategy and developments across the sector. It also captures best practice examples re innovation which members share. On a monthly basis a DH newsletter specifically on dementia and care homes has been appended to the NCF newsletter. NCF members and staff have contributed to this.
- NCF has been represented on the NDS IRG by Sharon Blackburn (Policy and Communications Director). Outcomes from these meetings have been communicated to members.
- Sharon Blackburn also works on behalf of NCF with the NCPC as National Advisor on Older People. NCPC continue to produce learning materials and have organised conferences regarding dementia.

- NCF organise an Annual Home Managers/Service Managers Conference. It is attended by c 200 Managers and senior staff across the NCF membership. Dementia services are always an integral part of the event.
- NCF AGM was an opportunity for members to meet at an NCF member site to see firsthand dementia services and explore care models and the lived environment.
- NCF staff and members recently participated in an International Event held in Birmingham to explore and hear from experts regarding design innovation for people who have dementia.
- Dementia Services remains a key topic for the NCF Practice Forum.
- The Order of St John Charitable Trust (an NCF member) now has an Admiral Nurse. NCF supports and promotes the Admiral Nurse approach.
- NCF as members of the European Association of Homes and Services for the Ageing (EAHSA) (Sharon Blackburn is a Board Member) are engaged in tour and conference participation/planning- Dementia continues to be a key topic. Likewise NCF are the English chapter of IAHSA, Andrew Larpent NCF Chairmen is Vice Chair of the IAHSA Board. An International Conference will take place in Washington DC in October 2011. NCF are presenting at the conference.
- NCF have been successful securing funding from the DH to improve medication management in care homes.
- NCF has reviewed the Skills for Care Dementia modules for the new QCF.

## **Second quarterly progress report**

As well as the continuation of some of the work above, including representation on IRG, significant work this quarter includes

- NCF held its 8th Annual Conference on the 10/11 May 2011. Vicki Combe from Alzheimer's Society led a workshop on the work the Dementia Action Alliance
- NCF have been successful securing funding from the DH to improve medication management in care homes. The project was launched in March 2011. It will be completed in September 2011.
- NCF have been members of the Reference Group on the Dementia Commissioning Pack.

- Des Kelly addressed the ‘Thinking Differently about Dementia in Essex’ conference.

Some of NCF Members Activity (this is just a sample) in relation to Dementia Care:

- **Accord Care and Support** are now offering Dementia specific Cafes.
- **Avante Partnership** are working with Canterbury Christchurch university regarding Dementia Care
- **Central and Cecil** – Lead Dementia Care Champion across the Group; Dementia champions at each care home. Supported by quarterly meetings. They are joining this work up with the work of the Dignity Champions. They are piloting MyAmego an Assistive Technology system that allows people with dementia to be more independent. They have a local dementia action strategy and action plan. They are using the PEACH philosophy which supports the NDS. People using services and their carers/staff can give feedback through the ‘Star Experience’.
- **CLS/ Belong** – are implementing new models of care in their Belong villages. They use design and the environment to enable people with dementia to have more personalised services. Kerry Fisher was recipient of the Lifetime Achievement Award in Dementia Care at the UK Dementia Congress.
- **HICA Group** – have created new care and housing solutions for people with dementia that are innovative and personalised.

## **National Council for Palliative Care**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Working with our expert group on dementia, we will continue to lobby for greater integration of palliative and end of life care with dementia. We will continue to produce publications and training resources.
- We will hold a national conference on dementia and end of life care, 'Achieving A Good Death with Dementia' national conference on 8th December 2010
- Develop accredited training with the Alzheimer's Society based on NCPC's Care to Learn Resource Pack and Dementia Module
- Continue to work in Hertfordshire to support integrated pathways for palliative and dementia care locally, as part of our role to turn policy into practice
- Seek to develop communications guide to help professionals talk about end of life care issues with people with dementia and their families. This work would be led by the experiences of people with dementia and their carers, and build on our successful communication guide for COPD and end of life care.
- Continue to work with care homes and housing organisations to support them in their delivery of end of life care for their clients, including people with dementia.
- Build on our work to date on personalisation and end of life care to consider practical approaches to personalising services for people with dementia approaching the end of life
- With the Dying Matters coalition, develop further information and resources to support people to be confident in discussing their end of life care preferences. This will include work to support all staff to improve their own confidence so they are better able to discuss these sensitive issues with those they care for, and families and carers.

### **First Quarterly Progress report**

- We held a national conference achieving a Good Death with Dementia: Best Practice and Innovations in the Current Climate in December 2010. The conference was held in partnership with the Alzheimer's Society, Dementia UK and Dying Matters. The keynote speech was given by Prof Alistair Burns, National Clinical Director for Dementia,



who was challenged by delegates to ensure end of life care for people with dementia remains a key priority going forward.

- We wrote to the Minister, Paul Burstow, to stress the need for dementia and end of life care agendas to be joined together and ask for an update on how he is approaching this issue.
- We submitted a response to the APPG for Dementia's inquiry on cost savings and delivering better outcomes for people with dementia. Our key recommendation was for greater integration of dementia and end of life care planning and delivery.
- Began work on communications guide, carrying out in depth interviews with people with personal experience of dementia.

## **Second Quarterly Progress report**

- We received an encouraging reply in relation to the letter we had submitted to the Minister Paul Burstow on the urgent need to join up the 2008 national end of life care strategy with the 2009 dementia strategy. Further talks were held with the National Clinical Director for dementia Prof Alistair Burns on how we can move forward this agenda through partnership working.
- We are organising a joint meeting of the APPG on Hospice and Palliative Care (which NCPC administrates) and the APPG on Dementia (which Alzheimer's Society administrates) to raise awareness of this issue. Confirmed speakers include Alistair Burns and Prof Sir Mike Richards (National Clinical Director for end of life care), and campaigner and former carer Barbara Pointon.
- We began a review of 16 sites originally identified by NCPC's Dementia Working Group as examples of good practice in 2007, to track and review their progress, achievements and current challenges in improving palliative care for people with dementia
- We are finalising Difficult Conversations a booklet for professionals on how to approach discussions about end of life with people with dementia and their carers, based on in-depth interviews with 50 people with experience. This will be launched at the joint APPG meeting in July.

## **NHS Confederation**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Arrange seminars on dementia and associated topics (eg Ambulance Service Network event in December 2010)
- Consider including a session on dementia at our annual conference and exhibition in 2011
- Update our website to provide signposting and supportive material for our members relating to the dementia declaration
- Promote appropriate material to our members via electronic newsletters.

### **First Quarterly Progress report**

Seminar held on 10 February, hosted by the Ambulance Services Network, examining partnership working between health and social care organisations to improve the quality of care for people with dementia. Speakers included:

- Professor Alistair Burns, National clinical director for dementia, Department of Health
- Anna Selby, operational director mental health, Milton Keynes Community Health Services
- Vicky O'Leary, clinical development manager, Great Western Ambulance Service NHS Trust
- Andrew Chidgey, head of policy and public affairs, Alzheimer's Society

Conference planning is underway, and will be finalised by mid-April.

Our website provides links to the latest publications and policy documentation on dementia issues.

Key publications are summarised and included in our fortnightly 'Health Policy Digest' which is circulated to all our members. This also includes links to the full publication

### **Second Quarterly Progress report**

- We intend to establish a member commission on improving patient experience. The commission will focus on how the NHS can ensure care, compassion and dignity for all patients. Its function will be to undertake research and policy analysis, including hearing expert evidence from a range of individuals and organisations. We will publish a report setting out the commission's findings and deliver a programme of influencing activities to encourage implementation of the commission's recommendations.
- We have now confirmed the following session at our annual conference and exhibition, 6-8 July 2011.

- **Delivering quality care for older people**

Older people are the most extensive users of healthcare services and often have complex and multiple needs. Amid reports of sub-standard quality care for some older people, this session will consider the challenges of providing better services for older people across a range of settings and how providers can achieve real improvement in the quality of care provided for older people, including those with dementia. Speakers are: Sir Keith Pearson, Professor Alistair Burns, Cynthia Bower and Professor

- Our website provides links to the latest publications and policy documentation on dementia issues.
- Key publications are summarised and included in our fortnightly 'Health Policy Digest' which is circulated to all our members. This also includes links to the full publication.

## Orders of St John Care Trust

### What are your plans as an organisation to respond to these challenges between now and 2014?

- OSJCT recognises the need for a strategic focus on delivery of dementia services. Over the coming 12 months we will review our existing services and identify the key components for our model of care, learning from our experiences to date and the knowledge and research from colleagues at Stirling University amongst other acknowledged clinical and academic experts.
- We will implement an audit process that captures the outcomes of the experiences of those we care for and a system by which this will underpin our ongoing learning and improvement.
- We will continue to listen to the views and opinions of those we care for, their families and friends, and enable them to influence our actions.
- In conjunction with colleagues at The Alzheimer's Society, we will build on our existing training programme and introduce in 2011 the new accredited Champions of Dementia Care Leadership Programme.
- During 2011 we will review all our care environments and include recognised principles of good practice in all refurbishments and new builds, particularly through the use of colour, lighting, acoustics and way finding.
- We will identify ways to both creatively and innovatively improve our existing Homes' environment to support activities of daily living and we will undertake to provide unrestricted access to external space for all residents by 2012.
  1. Longer term goals will be to develop further the range of activities involving arts and music and increase our volunteer network to enhance friendships and lifestyles.
  2. identify ways to raise awareness locally, support carers groups and provide access to resource centres in our homes
- We will continue to work towards our vision of Dementia Care, acting on the information we receive from residents and their families. We will support our staff to achieve best practice through a process that is inclusive of reflection and review.

## First Quarterly Progress report

- OSJCT is currently reviewing key senior roles in line with our strategic objectives which include the development of our dementia care services.
- The executive board has agreed the need for an audit tool that captures the outcomes of the experiences of those we care for and a system by which this will underpin our ongoing learning and improvement. Work is now underway to achieve this by the summer
- In January 2011 OSJCT launched, with the Alzheimer's Society, the next level in our staff development programme. The first 3 groups consisting of Home Managers and County Dementia Leads will be completing the accredited Champions In Dementia Care Leadership Programme over the coming months
- A Trust Director has been tasked to work with all the Home Managers providing specialist dementia care to review the physical environment and identify improvement measures to enable the environment to better support people with dementia and their families.
- OSJCT were successful in a joint bid with the Southwest Strategic Health Authority in gaining a place on the Design Council Programme this year. This will specifically look at how the environmental improvements being made in an OSJCT care home environment have a direct impact on resident well being, reduce falls, promote independence and reduce the inappropriate use of anti-psychotic medication. Also how such improvements to the environment support families and staff. In addition the Strategic Health Authority will be looking to see what learning can be transferred to the acute and community settings.
- In conjunction with Dementia UK, OSJCT is pleased to have welcomed an Admiral Nurse to the team. This role strengthens the support and leadership to our care homes

## Priory Group

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- All our care homes will be purpose built with the person living with dementia in mind. Every home will have a minimum of 2 trained Dignity Dementia Champions and every member of the care team will be trained to deliver true person centred care

*Progress: Our Dignity Dementia Champion (DDC) development course commenced in January 2011 and to date 2 modules have been completed by home managers and one other from each home.*

- Our model of enriched care will continue to be at the core of all we do and the 7 Strands of Care That Lead to True Person Centred Care in a Priory House will be our mantra and instilled in every person that provides care and support to people living with dementia and those embarking on that journey. Moving forward,

*Progress: This is implemented and being developed via the above DDC*

*This is also under review via auditing and dementia mapping to ensure implementation, and understanding*

- The Priory Group will develop relationships with every member of the disciplinary team, forging community links with them and offering colleagues training and development in dementia care. Always A Last Resort is policy in the care homes and will continue to be utilised in order to prevent over use and reliance on antipsychotic medicines.

*Progress: This is being developed at each home. Always a Last Resort is monitored monthly and actioned as appropriate*

- The Priory care homes division will continue to be led by a proactive Director of Dementia Services who will lead on best practise initiatives. Full inclusion of people living with dementia and those supporting them through the journey will be another way of ensuring all the homes become centres of excellence.

*Progress: I am currently recruiting to the Head of Dementia Services, and in the absence of this person various personnel are progressing our Dementia Strategy*

- In terms of regulation inconsistencies, we respond to this through developing a consistent approach to dementia care in all our homes

*Progress: Ongoing*

## Royal College of GP's

### What are your plans as an organisation to respond to these challenges between now and 2014?

The revised Dementia Strategy Implementation Plan (Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, DoH 2010) prioritises 4 areas for quality improvements in dementia care. Primary care, and GPs, has key involvement in 3 of these:

- Good quality diagnosis and intervention
- Living well in care homes
- Reduction of antipsychotic drugs in dementia.

The RCGP's role will be focused on these 3 areas, initially at a national level, through the work of the RCGP champion for Ageing/Older People (Professor Louise Robinson) via:

i) Ministerial Advisory Group for Dementia led by Professor Alistair Burns the national dementia lead. This group has selected primary care as a key area for intervention and early diagnosis by gps as a priority area through dissemination of educational initiatives and promotion of gp-friendly cognitive assessment tools.

ii) BGS Care Homes project: Professor Robinson is RCGP representative on this (completion 2011). Outcomes include: guidance for gps for improved health care in care homes and advice to GP commissioners on models for better quality health care.

*Progress: BGS Care Homes project: Professor Robinson is RCGP representative on this (completion 2011). This project due for completion in spring 2011. Guidance is developed.*

iii) A national advisory group on anti-psychotic prescribing (Professor Robinson; primary care lead for RCGP). This group will be facilitating a national primary care audit; identifying local models of good practice and developing national guidance.

Specific outcomes thus identified will be achieved by 2012 and will include:

- A range of educational resources focused on dementia that are available to both RCGP members through the college, but also to all NHS GPs via sources such as the DoH Dementia Information Portal.
- Cognitive assessment tools that are acceptable and user friendly to GPs
- Guidance for GPs on the provision of better health care in care homes



- Identifying models of good practice on the reduction of anti-psychotic drug prescribing in primary care
- National guidance developed in collaboration with other relevant colleges ie Royal College of Psychiatry, on the prescribing of anti-psychotic drugs in dementia.

### **First Quarterly Progress report**

- National Dementia Conference organised for GPs (Sept 2011).
- Three areas to be covered in detail: Good quality diagnosis and intervention; living well in care homes; reduction of antipsychotic drugs in dementia.
- All talks to be available on website to ensure all RCGP members have access.
- In addition Professor Robinson is working with the Department of Health to develop GP commissioning kits on:
  1. Good quality diagnosis and early intervention.
  2. Better care in hospitals for people with dementia.
- Plan to develop educational advice/teaching tool for GPs in collaboration with RCGP/RC Psych.

### **Second Quarterly Progress report**

- **RCGP National Dementia Conference** organised for GPs 22<sup>nd</sup> September 2011.

All areas of dementia care relevant to primary care will be covered but with a special emphasis on three areas to be covered in detail: Good quality diagnosis and intervention; living well in care homes; management of behavioural problems and reduction of antipsychotic drugs in dementia. All talks to be available on website to ensure all RCGP members have access.

- **Department of Health GP commissioning kits for dementia care:**  
For information see [www.doh.org.uk/en/publicationsandstatistics/](http://www.doh.org.uk/en/publicationsandstatistics/)

Professor Robinson is one of a group of clinical experts working with the Department of Health to develop commissioning guidance for GPs on dementia care. Two have already been completed and a third is planned on community care services including care in care homes. The packs are planned for an official launch in summer 2011. The two completed packs include:

1. Good quality diagnosis and early intervention.
  2. Better care in hospitals for people with dementia.
- **British Geriatrics Care Homes Project.** Guidance for primary care staff on how to provide better health care in care homes is being finalised this month. This project will be officially launched by Baroness Greengross of Notting Hill on 30<sup>th</sup> June 2011 at House of Lords.
  - **Anti-psychotic drug prescribing.** Professor Robinson on behalf of the RCGP has been part of the National Advisory Group on reducing anti-psychotic drug use in people with dementia. A multi-disciplinary care pathway has been developed by the group; this will be disseminated by the Alzheimer's Society with a national launch anticipated for in summer 2011. This will be hopefully accompanied by a national call to reduce the prescribing of these drugs.

The care pathway will be relevant to primary care teams, mental health teams and care home staff and will give practical and evidence based guidance on:

- i) Non-drug approaches to managing behavioural problems in dementia.
  - ii) Alternative drugs to use instead of anti-psychotic drugs and
  - iii) Reduction of anti-psychotics in people with long term use.
- **Educational resources for GPs – Summary of progress to date**  
In addition, a range of educational resources for GPs have been developed by the RCGP e-learning unit and Professor Robinson. These are available to RCGP members via the following website  
<http://elearning.rcgp.org.uk/mod/course/search.php?search=dementia>

This link should bring up the relevant content, including the new Mental Health in Older People course launched on the OLE a few weeks ago and some recent Essential Knowledge Update items. Several of these are focused specifically on dementia diagnosis and care, whilst others also have relevance to caring for people with dementia. Specific modules include:

- 1) GPS\_09\_003 The Role of the GP in Caring for Older People- Chantal Simon
- 2) GPS\_09\_006 Prescribing for older people- Chantal Simon
- 3) GPS\_09\_007 Falls Assessment- Vinay Karanam, Nataraj Kasaravalli
- 4) GPS\_09\_008 Acute Confusion and Off Legs- Shane O'Hanlon
- 5) GPS\_09\_009 Memory Problems in Older People- Emma Vardy, Louise Robinson

- 6) GPS\_09\_010 Care of People with Dementia - Emma Vardy, Louise Robinson
- 7) GPS\_09\_012 Assessing mental capacity in older people- Chantal Simon, Emma Vardy
- 8) GPS\_09\_013 Elder Abuse- Shane O'Hanlon, Desmond O'Neill
- 9) GPS\_09\_014 Support for Older People and Their Carers - Chantal Simon

## Royal College of Nursing

### What are your plans as an organisation to respond to these challenges between now and 2014?

- Support and delivery on a national project/campaign on the care of people with dementia in acute care settings
- Working collaboratively with other organisations to ensure that good dementia care practice is disseminated and shared
- Supporting increased understanding of and development of skills in dementia care through sharing of resources to members via Forums and online learning.
- Campaigning for specialist nurse roles, including dementia care nurses
- Supporting the development of nurse leaders, including for dementia care to support and deliver improvements in care
- Campaigning and raising awareness of the need to protect frontline services, which directly affect people with dementia and their carers.
- Promoting the delivery of dignity in care via an ongoing campaign and sharing of resources.

### First Quarterly Progress report

#### Support and delivery on a national project/campaign

The following work has been achieved:

- A national survey to collect examples of best practice has been widely publicised and disseminated. This has involved gathering information on the nature of improvements in delivery of care for people with dementia and their families in general hospital settings, how these were achieved and what were the drivers and barriers. Over 500 responses have been received so far and the closing date is 25th February 2011. Findings will be analysed during March 2011.
- This has raised awareness and prompted organisations to consider how they are delivering and supporting care for people with dementia in hospital.

Next steps:

- A survey of people with dementia and family carers will be undertaken to validate the findings from the survey.

- An external reference group including experts from the field will support and advise on the development of guidance and resources.
- Findings from the survey will be used to develop resources and guidance to support improvements in the delivery of care.

#### Working collaboratively with other organisations

- Key stakeholders from the Royal Colleges, Allied Professions and voluntary sector organisations have met to discuss and develop shared support and dissemination of the RCN dementia project for acute care.

#### Supporting increased understanding

- Findings from the project and examples of best practice will be shared at the RCN Congress on 11th April 2011
- An on line learning resource guide on dementia is being developed for RCN members and will be promoted and disseminated.

#### Campaigning for specialist nurse roles

- The contribution of dementia specialist nurses such as Admiral Nurses was actively promoted as part of the Nursing Counts campaign.  
[http://www.rcn.org.uk/data/assets/pdf\\_file/0008/302489/003581.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0008/302489/003581.pdf)
- A research study is currently being developed by the RCN Learning and Development Institute to investigate the contribution and impact of specialist nursing across long-term conditions and public and family health patient pathways.

#### Supporting the development of nurse leaders

Discussions are underway about the development and support of nurse leaders in dementia care.

#### Campaigning and raising awareness of the need to protect frontline services

Frontline First is an ongoing campaign which identifies current cuts taking place in nursing posts across the country and the negative impact of this on frontline care. It also seeks to identify waste in the NHS and highlights innovations to improve care. This campaign is being supported by wide range of organisations and has been widely publicised in the media.

<http://frontlinefirst.rcn.org.uk/>

#### Promoting the delivery of dignity in care

- The dignity campaign continues to be supported by the RCN.  
<http://www.rcn.org.uk/development/practice/dignity>
- The Principles of Nursing Practice were also launched in November 2010 to help promote dignity in care.

These principles articulate what quality nursing care looks like and provide a framework for supporting the evaluation of care through the development of useful measures.

<http://www.rcn.org.uk/development/practice/principles>

## **Second Quarterly Progress report**

### **Support and delivery on a national project/campaign: Dignity in Dementia; Transforming general hospital care**

- A survey of health care professionals was carried out in January and February 2011 to identify examples of best practice that help improve the delivery of care for people with dementia in general hospital settings. Information was gathered on the impact of developments as well as factors that both supported and hindered improvements.

More than 700 responses were received from professionals, Findings indicated that a number of approaches are required to support improvements in care. However, most important was felt to be the involvement of family carers, and the training and development of staff.

- A survey has now been launched to gather perspectives and views of family carers and people living with dementia about the most important ways of improving their experience of care in hospital. The closing date for this survey is **16<sup>th</sup> June 2011**. For further details please see [www.rcn.org.uk/dementia](http://www.rcn.org.uk/dementia)
- Findings from this, combined with the survey of professionals, will be used to inform the development of guidance and resources to influence care.
- The outcomes of the project will be launched at a national conference on: 21st September 2011 at Aintree Racecourse, Liverpool and will include a celebration of innovations in practice delivered by a range of professionals working in acute care settings.

### **Supporting increased understanding of dementia for nurses**

- Findings from the project and examples of best practice were shared at the RCN Congress on 11th April 2011
- Work is underway to develop learning resources and guidance on dementia for the RCN website

### **Other**

- The RCN is continuing to make Dementia a key priority for 2011/12 and wishes to extend the programme of work into a second year once the first phase is complete in September 2011.

- Funding is currently being sought to ensure that outcomes from Year 1 might be supported and disseminated further to influence the delivery of care.

# Royal College of Physicians

## Second Quarterly Progress report

- We have launched a project on medication in care homes , with RCGP, RCPsych and BGS.
- We have met with National Clinical Director for dementia.
- We have commissioned article for our College Journal (Clinical Medicine) on dementia.
- We have asked the examination department to look at including more questions on dementia in the MRCP examination.
- We are partners with RCN on Improving quality of care for people with dementia who are in a general hospital.
- We are working on Quality Mark for care in wards who deal with older people.



## Royal College of Psychiatrists

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Identify and promote examples of good service delivery across the UK.

*Progress: Members are encouraged to highlight and promote good service delivery and this discussed in the Executive committee and consumer forum Working Group set up of Old Age Faculty Executive Members Poster organised for residential meeting in March to encourage reporting of examples of good service delivery.*

- Continue to work on the reduction of age discrimination which is particularly marked in the field of mental health.

*Progress: Contribution to policy making through meetings of the Executive Council of the Royal College of Psychiatrists.*

- Contribute to the development of a national research agenda incorporating longitudinal studies of ageing, improved recruitment of research participants, and evaluation of secondary prevention strategies for people with current dementia, improved recognition and management of behavioural and psychological symptoms, improved research in care homes and promoting a research culture amongst non-specialist workforce.

*Progress: Contact made with Directors of DeNDRoN, Scottish Dementia Clinical Research Network and equivalent networks in Wales and Northern Ireland.*

- Support and evaluate progress on the English and Scottish Dementia Strategies and help refine future service developments as a consequence.
- Support our members in delivering the National Dementia Strategy, the NICE Guideline on Dementia and the NICE Quality Standards to improve standards of care

*Progress: Linked to Bullet 1 we are attempting to identify areas of new practice. This is achieved by the Faculty and by the College Divisions throughout England (ongoing)*

- Set up formal personal links with other professional organisations to ensure coherence of service planning and the planning of educational and training programmes.
- Work to promote the recommendations of our College report on Psychiatric Services for Black and Minority Ethnic Older People.

*Progress: Meeting with Chief Executive of Alzheimer Society and Alzheimer Scotland. Meeting with Alistair Burns, National Clinical Director*

- Expand the role of our well established Consumer Forum to ensure more widespread input of the views of people with dementia and carers particularly into training programmes.

*Progress: Nil to report.*

- To improve quality standards of Memory clinics through national accreditation service and dementia wards through AIMS accreditation service.

*Progress: Meeting on the 16 July to discuss UK wide remit of this group. A training curriculum in Old age psychiatry was approved by PMETB and Consumer forum has agreed to participate and offer help in the training of Psychiatric trainees*

*MSNAP Report received on the 16 February. A National Dementia audit is planned in General Hospitals by RCPsych to identify deficiencies in current service and promote good practice. Pilot is completed and full report is expected in Summer 2011*

## Skills for Care

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

Skills for Care and Skills for Health have developed a range of units and qualifications (linked to existing National Occupational Standards) which are available on the Qualification and Credit Framework from September 2010, these units and qualifications are:

- 8 units at level 2
- 8 units at level 3
- Level 2 Award Awareness of Dementia
- Level 2 Certificate in Dementia Care
- Level 3 Award Awareness of Dementia
- Level 3 Certificate in Dementia Care
- In addition, there are level 2 and 3 dementia specific learning pathways as part of the level 2 and 3 diploma in health and social care (available from January 2011)

*Progress: All units have been completed and are part of the qualifications and credit framework*

Skills for Care has developed, jointly with Skills for Health, and is implementing a Workforce Training and Education Development Action Plan for Dementia:

- The Action Plan has been formally submitted under a joint report to the Department of Health. The Plan is being implemented through the range of ongoing Sector Skills Council Commitments for example developing the Qualifications and Credit Framework. (QCF).

*Progress: Completed*

- Skills for Care, jointly with Skills for Health, have developed a range of units on the Qualifications and Credit Framework that support workforce development on dementia specifically.

*Progress: Completed*

- Skills for Care is committed to review its range of projects and products to identify opportunities to build dementia specific relevance, as appropriate, into the work streams

*Progress: Ongoing*

- Skills for Care, jointly with Skills for Health, is developing a range of resources that will support the workforce to support carers better. Version 1 of the framework and supporting resources will be available from Autumn 2010, with Version 2 and impact evaluation findings available from Summer 2011.  
([www.skillsforcare.org.uk/developing\\_skills/workingwithcarers/working\\_with\\_carers.aspx](http://www.skillsforcare.org.uk/developing_skills/workingwithcarers/working_with_carers.aspx))

*Progress: Skills for Care and Skills for Health are also developing common core principles to support the dementia workforce across social care and health.*

- Skills for Care jointly with Skills for Health has developed a suite of principles and competences for End of Life Care. The competences and principles are available on the website ([www.skillsforcare.org.uk/developing\\_skills/endoflifecare/endoflifecare.aspx](http://www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx)). Further work to raise awareness, support implementation and to refine and develop these is ongoing and additional guidance and findings will be available from April 2011.

*Progress: Completed*

- Skills for Care is committed to ensuring dignity is at the heart of all we do through both our existing products and services and integral to our ongoing work programmes.

*Progress: Ongoing*

- Skills for Care has a range of products and resources that support Strategic Workforce Planning, supported through the Integrated Local Area Workforce Strategies (InLAWS) process.

*Progress: Ongoing work*

## Skills for Health

**What are your plans as an organisation to respond to these challenges between now and 2014?**

### Skills for Health Strategic Aims:

- Engage with health sector employers to ensure we can be the authoritative sector voice on skills and workforce development for the whole sector.
- Inform the development and application of workforce policy through research and the provision of robust labour market intelligence.
- Implement solutions which deliver a skilled, flexible and modernised workforce capable of improving productivity, performance and reducing health inequalities.
- Champion an approach to workforce planning and development that is based on the common currency of National Occupational Standards

### Resources specific or relevant to Dementia; available or in development:

- Skills for Health has developed National Occupational Standards (NOS) or competences to describe what individuals need to do, what they need to know and which skills they need to carry out to effectively perform an activity.
- They can be used by all health professions, and all levels of staff, whether in the independent or voluntary sectors or in the NHS.
- Skills for Health has developed and is implementing , jointly with Skills for Care, a Workforce Training and Education Development Action Plan for Dementia
- The Action Plan has been formally submitted under a joint report to the Department of Health. The Plan is being implemented through the range of ongoing Sector Skills Council commitments for example developing the Qualifications and Credit Framework. (QCF).

Skills for Health, jointly with Skills for Care, has developed a range of units and qualifications (linked to existing National Occupational Standards) that specifically support workforce development for dementia services. These will be available on the Qualification and Credit Framework from September 2010, these units and qualifications are:

- 8 units at level 2
- 8 units at level 3
- Level 2 Award Awareness of Dementia

- Level 2 Certificate in Dementia Care
- Level 3 Award Awareness of Dementia
- Level 3 Certificate in Dementia Care
- In addition, there are level 2 and 3 dementia specific learning pathways as part of the level 2 and 3 diploma in health and social care (available from January 2011).
- Skills for Health is supporting a range of local dementia workforce development initiatives. These will benefit not only the workforce but also people that use services. In some cases, this work, may lead to resources that can be made available at a national level for sharing more widely. For example, in Oxford a new role of Dementia Advisor has been developed working across GP Practices, which is now being taken forward to become a National Transferable Role.

Skills for Health is committed to review its range of projects and products, as appropriate, ensure that the needs of dementia services are reflected.

- Skills for Health, jointly with Skills for Care, is developing a range of resources that will enable the workforce to support carers better. Version 1 of the framework and supporting resources will be available from Autumn 2010, with Version 2 and impact evaluation findings available from Summer 2011.
- Skills for Health, jointly with Skills for Care, has developed a suite of principles and competences for End of Life Care.
- The competences and principles are available on the website. Further work to raise awareness, support implementation and to refine and develop these is ongoing and additional guidance and findings will be available from April 2011.
- Skills for Health is committed to ensuring dignity is at the heart of all we do, through both our existing products and services, and integral to our ongoing work programmes.
- Skills for Health has a range of products and resources that support Strategic Workforce Planning, including the Six Steps Methodology and a suite of National Occupational Standards. The National Occupational Standards (competences) include a specific suite, which defines the knowledge, understanding and performance criteria for service commissioners and these could support GP consortia as a common building block, for role development, and subsequent education and training initiatives to support these roles. Use of the Six Steps, across any organisation will help ensure that decisions made on workforce design and the recruitment of new staff and teams are sustainable and

realistic; and that they fully support the delivery of high quality patient care, productivity and efficiency.

### Internal awareness raising

- Ongoing activity to embed consideration of dementia in all skills and workforce development work streams.

### **First Quarterly Progress report**

#### Dementia Common Core Principles

- The first draft of the dementia common core principles, being developed jointly by Skills for Health and Skills for Care, is now out to consultation and testing across the health and social care sectors.
- The aim of this set of common core principles is to ensure that every setting delivering care becomes 'dementia friendly' with staff who can recognise the signs of dementia, make appropriate adjustments to their work and the environment and refer on to specialist services when required. They will provide the underpinning principles for training and development, both for local implementation or more formal learning that leads to qualifications.
- The introduction of Common Core Principles will enable health and social care services to respond in a timely and appropriate way to the needs of people with emerging signs of dementia as well as those with a confirmed diagnosis of the condition. They have been developed using current policy and guidance and are mapped to functions, National Occupational Standards and Qualification & Credit Framework units to promote workforce development. Practitioners will use a range of competences in their role, including a range of shared (or foundation) competences, such as communicating effectively, and promoting a culture that values and respects the diversity of individuals.

#### Dementia Advisor Role

- The dementia advisor role has been developed, in Oxfordshire, as a shared role across health and social care. SFH has worked in collaboration with a wide range of stakeholders. Based in GP surgeries the dementia advisor is available to work with people who are at the beginning of their journey with dementia but also with those people who are further along that road. The role provides a point of contact for people requiring information on issues and services relating to dementia. Dementia advisors provide personalised information to people with dementia and their carers. This includes appropriate signposting to alternative organisations, giving advice on

finance matters, incontinence, services for carers. The majority of the referrals to the service are made by GP's or clinicians from the memory clinics. The service is delivered over the phone or face to face to meet individual needs.

- Early indications show that where dementia advisors are deployed visits to the GP are reduced and that service users are very satisfied with the service. They report a better quality of life as a result of having access to more information and being able to access support networks and services more easily. It is therefore possible that people are able to stay longer in their own homes though this evidence is not yet available.
- Initially working out of 4 GP surgeries, the role is now in 10 surgeries and more are signalling their interest. The impact of the dementia advisor is being studied and the report is due in early spring.
- In May 2010 work Skills for Health began work to develop the role into a Nationally Transferable Role (NTR). This approach will facilitate other areas to understand the level and scope of the role, the specific competences required, and the learning and development which underpins the role. By referring to the NTR template for the role employers will be able to identify how they can implement the role within their own locality and ensure service users are able to access the benefits demonstrated in Oxfordshire. The role will be published through the Skills for Health website before March 2011.

#### QCF Units

- The dementia specific units are now on the Qualifications and Credit Framework as planned.

#### Related programmes of work

- Carers Matter; everybody's business – developed in partnership with Skills for Care and due to be launched in March 2011, provides guidance and resources for employers and organisations to support the learning and development of the workforce to improve and enhance support for carers.
- Through our regional director we are working with the Norfolk and Waveney Health Innovation and Education Cluster (HIEC) to ensure synergy between their work on dementia and our work on development of the common core principles.



## Social Care Institute for Excellence

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- Develop and promote the Dementia Gateway to new and existing audiences, including the health care workforce - on-going

*Progress: New content added to Gateway includes features on Being withdrawn and Activity in the later stages of dementia; case studies on Food choices, Fronto-temporal dementia, Team work and leadership, and Responding to feelings unlocks solutions. Comms plan for further dissemination in development; business case developed to highlight expansion possibilities.*

- Produce and promote three new Social Care TV films on dementia and disseminate to key audiences by March 2011

*Progress: 3 SCTV films made and rough cuts viewed; final versions due in March; content covers end of life care, young onset dementia and participation in service development.*

- To maximise choice and control for people with dementia and their carers, SCIE continues to develop products on personalisation.
- A new At a Glance briefing on personalisation and mental capacity will examine how people with dementia can be fully involved in decision making. To be launched by November 2010

*Progress: At a Glance briefing on personalisation and mental capacity completed and launched; available on SCIE's website at <http://www.scie.org.uk/publications/ataglance/ataglance33.asp>*

- Identify good practice in what Local Authorities are doing or plan to do to prevent abuse among all groups including people with dementia and disseminate this on the SCIE website by March 2011

*Progress: A survey of what Local Authorities are doing to prevent abuse has been completed and the messages from this work will be published at the end of March.*

- Develop national commissioning guidance to help local authorities to commission care homes which provide safe abuse-free services for people with dementia by March 2011

*Progress: The first draft of this guidance is currently being peer reviewed and should be ready for publication in March.*

- Produce a research briefing on dementia in BME older people in the UK by December 2010

*Progress: Research briefing on BME older people and dementia completed; awaiting launch date*

- Work with the Department of Health to develop a range of resources on dementia, the first of which is an interactive Early Intervention Toolkit for frontline NHS and social care commissioners to prevent or delay the need for more specialist and life-changing interventions for people with dementia by February 2011

*Progress: Early intervention toolkit – Windows of Opportunity – completed and work undertaken to create interactive content. Currently being built by web team; ready for launch mid-March.*

- A new section of the Dignity In Care Guide will be added on 'dignity for care workers', improving the role and status of care workers to underpin service quality by March 2011

*Progress: This will be one of our priorities for 2011-12*

- Support the quality of the Independent Mental Capacity Advocate (IMCA) service. The largest group of people who access IMCAs are people with dementia who, for example, need support in getting care which meet their needs and wishes. Resources to be produced include guides on Access to the Court of Protection and the IMCA role in the Deprivation of Liberty Safeguards and six training films by January 2011

*Progress: Guides on Access to the Court of Protection and The IMCA role in the Deprivation of Liberty Safeguards completed and due for launch in March. 4 training films also complete; to be launched end of March.*

- A project to understand how best to involve older people with high support needs and their carers in SCIE's work will be complete by summer 2011.

*Progress: Planning stages of project started; scoping work beginning early March; project aims to address the participation of older people with high support needs in SCIE and more broadly in health and social care.*

## **Second Quarterly Progress report**

- Develop and promote the Dementia Gateway to new and existing audiences, including the health care workforce

*Progress:*

- a) New content added to the Gateway includes features on **Working with families** and **Reminiscence**, and a case study **Knowing me, Knowing my family**
  - b) Priorities for 2011/12 set – content to be added to support the reduction in inappropriate use of anti-psychotic medication; to address the needs of the homecare audience; to support care staff to work effectively alongside family carers; to add links to recent news and research; to develop a good practice exchange in conjunction with ECCA; to further disseminate and publicise the resource
  - c) Workshop to be delivered at the European Social Services Conference in Poland
- Produce and promote three new Social Care TV films on dementia and disseminate to key audiences by March 2011

Progress: films launched May 2011 on **Young Onset Dementia**, **End of life care**, and **Participation in Dementia Care Planning**  
<http://www.scie.org.uk/socialcaretv/default.asp>

- To maximise choice and control for people with dementia and their carers, SCIE continues to develop products on personalisation.

*Progress: publication of **SCIE report 40: Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers** and publication of associated *At a glance: Personal budgets briefing: learning from the experiences of older people and their carers**  
<http://www.scie.org.uk/publications/ata glance/ata glance40.asp>

- Safeguarding projects, including identifying good practice to prevent abuse among all groups including people with dementia, and capturing service user views

*Progress: **Safeguarding Adults – prevention strategies** and **Safeguarding Adults – service user views** due for launch 24/5/11; also **Safeguarding Adults – SCTV films**.*

- Develop national commissioning guidance to help local authorities to commission care homes which provide safe abuse-free services for people with dementia by March 2011

*Progress: The second draft of this guidance is in development, and is likely to be published early autumn.*

- Produce a research briefing on dementia in BME older people in the UK by December 2010

*Progress: **SCIE research briefing 35: Black and minority ethnic people with dementia and their access to support and services** published March 2011 (<http://www.scie.org.uk/publications/briefings/briefing35/index.asp>)*

- Work with the Department of Health to develop a range of resources on dementia, the first of which is an interactive Early Intervention Toolkit for frontline NHS and social care commissioners to prevent or delay the need for more specialist and life-changing interventions for people with dementia by February 2011

*Progress: **Windows of opportunity: prevention and early intervention in dementia: a tool for commissioners and providers** launched March 2011 (<http://www.scie.org.uk/publications/windowsofopportunity/index.asp>)*

- Support the quality of the Independent Mental Capacity Advocate (IMCA) service. The largest group of people who access IMCAs are people with dementia who, for example, need support in getting care which meet their needs and wishes. Resources to be produced include guides on Access to the Court of Protection and the IMCA role in the Deprivation of Liberty Safeguards and six training films by January 2011

*Progress: **4 Social Care TV films** launched March 2011 (<http://www.scie.org.uk/socialcaretv/topic.asp?guid=377dbe1b-de0c-4d66-bb87-22a243542db2>). IMCA ADASS/SCIE guides on **Accessing Court of Protection and Deprivation of Liberty Standards** due for launch 18/5/11. **9 modules of e-learning** have also been developed and will be launched in June.*

## Southern Cross

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

#### National Dementia Declaration Action Plan

- The planned review of Dementia service provision at Southern Cross Healthcare will undertake to identify the most appropriate, innovative and timely models of care to ensure the highest standards of care for residents with dementia care needs. Current initiatives include the introduction of: Training - Tomorrow Is Another Day Part 1, Southern Cross Diploma Workbook Understanding Person Centred Dementia Care, externally sourced and accredited courses at Stirling and Bradford.

#### *Progress*

- *A Dementia Lead has been appointed from April 2011, to develop and co-ordinate the Dementia Strategy for Southern Cross Healthcare*
- *All homes have been allocated a budget for training including Dementia specific training.*
- *Training stats are checked on a regular basis by the Area manager to ensure agreed monthly targets are achieved.*
- *Internal Service Quality Inspectors will continue to observe staff practice and review training stats at internal inspection, to ensure compliance with agreed standards.*
- *Internal company trainers are now focussed on delivering training to meet the needs of each individual home for their specific clients*

#### Environment

- Core standards for signage and decoration are being developed by the estates department. Some homes have used the Stirling Environmental Audit to accredit their physical environments. Many homes have developed their dementia care environments to reflect local interest

and involve residents, families and communities in this process. Person Centred Care Introduction of the 'Choices' and the development of outcome audits.

### *Progress*

*Further work remains to be completed by the Estates Department to roll out the Company standard for signage.*

*Further work remains to be completed with regard to having a company standard for the appropriate dementia environment that meets the needs of client within individual homes*

*The Choices tool has been delivered to all homes in the UK and is being used by staff in many settings*

The following are currently less developed and will be developed as part of the longer term strategy:

- Training - Induction awareness training and handbook for all staff. Inclusion of dementia care topics and particularly leadership in dementia care in the Home Manger Training programme. Formalised links with the major training organisations for facilitating placements and providing learning opportunities.

*Progress: Work is in the early stages of development and progress will be made once the Lead for Dementia is in post*

- Environment - There is only limited use of assistive technologies. These generally take the form of alerts to risk of falls but a more sophisticated approach to technology could ease transitions, protect dignity, provide useful data to assist person centred care and risk assessment and aid communication.

*Progress: Little progress has been made with the Environment, but this will be progressed over the coming year with the appointment of the Dementia Lead*

- Person Centred Care - Improved care planning documentation, outcome audits that measure well being and staff engagement (DCM, SOFI), a 24hour, 7day a week approach to activity, involvement of residents and family in selection and recruitment and day to day decision making and local policy making.

*Progress: This approach is being developed in local areas across the Company, but there is no central lead to co-ordinate and share Best Practice across the group. Progress should be seen in summer 11*

- Overarching initiatives such as the development of an internal standards framework or benchmarking tool and campaigns to support

learning and person centred care such as an Arts in Care programme have not got past the idea stage. Inclusion of this type of idea in a declaration could prove to be a useful impetus. Research has been supported by the Ethics Committee.

*Progress: No progress has been made in these initiatives over the past 3 months.*

## **Stroke Association**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We will seek to increase awareness and understanding of dementia and stroke amongst stroke professionals, stroke survivors and their families so that the signs are recognised earlier and people referred to a dementia specialist.
- We will provide relevant information, advice and support to stroke survivors with dementia.
- We will seek to ensure that the review process is able to identify those stroke survivors with dementia and make referrals.

### **First Quarterly Progress report**

#### Awareness amongst stroke professionals:

- The topic for the 2010 Royal Lecture in November focussed on vascular dementia, delivered by Prof Hugh Markus. The lecture was attended by stroke professionals.

#### Awareness amongst stroke survivors and families:

- A feature on vascular dementia is planned for the organisation's quarterly magazine Stroke News.

#### Relevant information, advice and support to stroke survivors:

- A factsheet is available – Dementia after stroke

#### Review process able to identify stroke survivors with dementia and make referrals:

- No further progress

#### Other:

- A policy position on vascular dementia is being developed.



## **Thomas Pocklington Trust**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- We will work with dementia and sight loss organisations with the aim of increasing mutual awareness and understanding and encouraging collaboration that can result in better outcomes for people with concurrent dementia and sight loss and those who care for them: this is ongoing work and includes an active role in the dementia and sight loss interest group of VISION2020UK
- Year on year we will seek to secure funds to support and / or commission research and development projects that address the needs and aspirations of people with concurrent dementia and sight loss and those who care for them; this is ongoing
- We will work with other organisations that are seeking to undertake research and development projects around dementia and sight loss so that our research findings and experiences in practice may inform their work and that findings from other research informs our research and practice; this is ongoing
- We will seek to ensure that staff in our operational services understand dementia and its effects and, as appropriate and possible, we will draw on specialist resources to ensure that; this is ongoing.

### **First Quarterly Progress report**

- The Dementia and Sight Loss Group of VISION 2020 UK ran the first national conference on concurrent dementia and sight loss. Despite the snow over 80 people participated and feedback was very positive. The value of further work in this area was highlighted by participants at the event, both in discussion there and in follow up discussion. We have continued to raise awareness of findings from our research into issues around concurrence of dementia and sight loss, including presentations to DETN and articles in sight loss vision journals.
- A likely priority for research funding in this area in 2011-12 is to address issues in design that can support people with concurrent dementia and sight loss.
- We are supporting the plans of another organisation for research into the experiences of eye examinations among people with dementia. This work could inform the development of effective optometric practices. We have opened discussions with the Eye Health Alliance

about the potential for its work to address issues of domiciliary eye care for people with dementia.

- Support for staff to develop knowledge and skills about support for people with dementia will be considered in our operational training review.

### **Second Quarterly Progress report**

- Thomas Pocklington Trust has nothing to report for the past quarter.

## University of Stirling: Dementia Services Development Centre

### What are your plans as an organisation to respond to these challenges between now and 2014?

- We will expand our team and our range of services to match the need of providers
- We will increase our research input to the courses and books that we provide
- We will increasingly provide our services free at the point of delivery by finding new funding models.
- We will rely increasingly on electronic communication, for example building on our free on line library

### First Quarterly Progress report

- We renew and update our list of associates to ensure we are working with the highest quality of training and consultancy practitioners.
- We ensure that all our events and courses are evaluated and update subsequent services.
- In response to expressed need by dementia service providers, we have increased the range of courses we deliver in England, Wales & Northern Ireland as well as in Scotland
- All our publications are reviewed and updated on a rolling programme, for example, we are currently updating the Design for Dementia Audit Tool, to reflect recent research into the design of balconies and outside space, the acoustic environment for people with dementia, and revised guidance on lighting.
- An extensive programme of training is being provided free at the point of delivery within Northern Ireland in 2011/12. We continue to seek funding opportunities to support this to happen within all areas of the UK where possible.
- Recent innovations have included the revision of our websites. An example of this is the promotion of our library and information services through a user-friendly service, called 'Eileen's Answers'.  
<http://dementia.stir.ac.uk/eileensanswers> All of our training, education and consultancy services are promoted and supported through our regular e-bulletins and mail shots

## Second Quarterly Progress report

- We have recruited associates and seconded staff for the delivery of training, education, consultancy and information services. These experts are grounded in real practice and offer flexibility. Our associate team now includes architects (including landscape), a lighting engineer, social science and anthropology graduates, as well as clinical and social work colleagues – a network of whom some are based outside of the UK. We have expanded the numbers of participants in our Best Practice culture change course, about 200 in the last few months who between them are taking up to 1600 health and social care workers from statutory and independent sectors through the programme. 10-20% of these are in acute hospital settings.
- Our researchers are “translating” course materials into accessible publications. The most recent is a short “end of life” textbook which is based on the research based “end of life” distance learning module. The popular “Ten Tips for Carers” book which was based on a literature review is being evaluated for its clinical effectiveness in partnership with the University of Leeds. We continue to distribute it and have just passed the 13,000 mark. Current research strands include the effect of trauma on dementia, use of technology, remote and rural communities, music at the end of life, the role of animals and pets, communication and a range of practical issues including diagnostic and post diagnostic support.
- The DSDC has secured funding to provide free training and education across a range of our services. For example we got funding from the Big Lottery to design and deliver a distance learning module called “Transitions”, which teaches health and social care staff about how to support carers of people with dementia at three transition points; diagnosis, going to a care home or hospital and when their loved one is at the end of life. Around 40 students from health, social care and voluntary sector backgrounds are doing this from charitable funding. Other courses provided free at the point of delivery include a train the trainer programme called Best Practice, which is designed to change the culture in the unqualified health and social care workforce working on the front line in acute hospitals, care homes and day care. We have free places in design schools, degree courses, leadership courses and other services through generous donations received via the Dementia Services Development Trust. We are funded through Comic Relief to provide free training and information events for carers of people with dementia and the consultation on this is complete and the first programmes have been delivered free of charge and with carer support, travel, information publications and DVDs and refreshments on offer at no cost.
- We have started to use Skype and videoconferencing to have overseas colleagues deliver lectures and take part in seminars as part of our

educational and information programmes. The DSDC library is available on line as part of the NHS eLibrary and DSDC staff have contributed extensively to e-learning materials on other websites such as the SCIE portal and the dementia Managed Knowledge Network. Our dementia shop provides free downloads of a range of books on telehealth and telecare (including one last month on telecare and falls), and a free downloadable dementia design checklist. We send regular email communications to a network of over 10,000 contacts, and our website now has short video clips and a news stream. We use Facebook and Twitter, and we have made a new DVD for distribution to help people to understand our services. Our lecture theatre now has videoconferencing facilities.

## **WRVS**

### **What are your plans as an organisation to respond to these challenges between now and 2014?**

- WRVS plan to reach out to existing and new partners to share the proven impact of the services that WRVS provide, we intend to stimulate both potential referrals of older people including those living with dementia's and identify funding to enable WRVS to help and support more people. Our growth strategy is ambitious and when in operation it will enable WRVS to share best practise from one community to another.
- WRVS are actively attracting and recruiting new types of volunteers that will enable us to deliver our vision for WRVS services, we are developing new opportunities, streamlining our processes and increasing our visibility both nationally and locally.
- WRVS are also focusing on being very clear about the social impact of what we do and how this can support those living with Dementia's, we are joining up our services and providing an integrated offer to those living at home or in clinical environments. Older people will be in the driving seat in the development of individual care packages which will be outcomes focused and relevant to the individual.

### **Second Quarterly Progress report**

- WRVS in the first Quarter published a 2 page spread on raising awareness of those living with Dementia in the WRVS Action magazine which is sent to approx 45,000 WRVS volunteers, the magazine is also placed in WRVS services including our 350 hospital sites. The article highlighted the WRVS commitment to supporting the dementia action alliance and the WRVS vision for the future and how our work can support older people living with dementia and their carers.
- WRVS have been successful in recruiting new volunteers and a number of volunteers are already trained as outcome co-ordinators to enable service users to be at the heart of the decisions about the services they wish to receive, a number of volunteers have already received training on basic dementia awareness and it is intended that basic dementia awareness training will be afforded to all volunteers and staff within WRVS.
- WRVS has commenced the roll out of its integrated service offering and 4 service hubs are currently in operation, the service hub provides community/hospital access to WRVS services and it is hoped that

those living with dementias or their carers will be able to access services at the earliest opportunity before crisis intervention is required.

- WRVS has commenced work with partners in Leicestershire, Sheffield, Northamptonshire and Scotland and continues to actively seek new partners to deliver integrated services across all WRVS services nationally.
- WRVS has produced a Dementia awareness leaflet with support from the Alzheimer's society, it is our intention to launch the leaflet during Dementia awareness week in July 2011. The leaflets will be placed in WRVS retail outlets in England and with some 10 million transactions taking place annually it is hoped the leaflets will raise awareness as well as signposting both service users and carers to the help and support they need.