

# Promoting Excellence in Dementia Care

Issue 3 • December 2012



## The Right Support

Post-diagnostic support for people with dementia

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# Welcome

NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) are working in partnership to support the delivery of the educational actions outlined in Scotland's National Dementia Strategy.

The intention of this work is to improve staff skills and knowledge in both health and social services settings to enable them to provide more effective and appropriate care and support services for people with dementia, their families and carers.

Welcome to our third newsletter, keeping you up to date with developments which, with your help, are having a positive impact on;

- **the lives and experiences of people with dementia, their families and carers; and**
- **the staff providing care and support**

This issue highlights the work taking place to improve post diagnostic support and palliative care for people living with dementia and their families and carers.





## Winners of Scotland's Dementia Awards 2012!

A ceremony to celebrate the winners of the first ever Scotland's Dementia Awards was held at Hampden Park on 20 September.

The awards (a partnership between Alzheimer Scotland, NHS Education for Scotland, NHS Health Scotland and Scottish Social Services Council) showcased the creativity, innovation and dedication that can make a real difference to people living with dementia and their families and carers across Scotland. From over 120 applications for the inaugural event, three outstanding initiatives were shortlisted for each category,

### Best acute care initiative

**Winner:** Ward 44, Victoria Hospital, NHS Fife

**Shortlisted finalists:**

**Older Adult Mental Health Liaison**, NHS Grampian

**Getting to Know Me**, NHS Lanarkshire

### Best innovation in continuing care

**Winner:** Dundonald House, Ayrshire

**Shortlisted finalists:**

**Talking Mats**, Talking Mats Ltd, Stirling

**Craft Café**, Viewpoint Care Homes and Impact Arts, Edinburgh

### Best community support initiative

**Winner:** Facing Dementia Together project, Alzheimer Scotland & East Renfrewshire CHCP

**Shortlisted finalists:**

**Befrienders Highland**, Inverness

**Rovers Group**, Alzheimer Scotland in South Aberdeenshire

## Best dementia friendly community initiative

**Winner:** Motherwell Dementia Café, Motherwell Community Mental Health Team for Older Adults, NHS Lanarkshire

**Shortlisted finalists:**

**Dundee FC Supporters' Society**, Dundee FC, Dundee  
**Alzheimer Scotland Golf Day**, Alzheimer Scotland Lothian Early Onset Support Service and Uphall Golf Club

## Best educational initiative

**Winner:** Bridge to Vision – Royal National Institute for Blind People

**Shortlisted finalists:**

**Memory Joggers**, Alzheimer Scotland, East Dunbartonshire Training for Dementia Champions, University of the West of Scotland

## Most innovative partnership

**Winner:** Argyll & Bute Dementia Teams – Argyll & Bute Council, NHS Highland and Alzheimer Scotland

**Shortlisted finalists:**

Morison's Solicitors, VOCAL and West Lothian Carers  
Royal National Institute for Blind People and Alzheimer Scotland

## Lifetime Achievement Award

The Lifetime Achievement Award was given to **Professor Mary Marshall**, in recognition of her outstanding contribution to the improvement of care and support given to people with dementia in Scotland.



Professor Mary Marshall receives the Lifetime Achievement Award

To find out more about Scotland's Dementia Awards, visit:

[www.ScotlandsDementiaAwards.org.uk](http://www.ScotlandsDementiaAwards.org.uk)

or email:

[ScotlandsDementiaAwards@alzscot.org](mailto:ScotlandsDementiaAwards@alzscot.org).





## Post-diagnostic support for people with dementia

For people with dementia, their families and carers, getting the right support following a diagnosis can greatly improve their quality of life throughout their dementia journey.

It can enable and empower them to understand and come to terms with dementia as well as plan for the future and take control of the supports and service they may need. While there are local examples of the positive impact of this kind of support, it is not consistent across Scotland. For this reason a key area for service improvement set out in Scotland's National Dementia Strategy is to improve the support and information that people with dementia and their carers receive following a diagnosis.

Approaches to improving post diagnostic support vary but following the success of a pilot in East Renfrewshire and Renfrewshire, Alzheimer Scotland developed the '5 Pillar' model which they identified as essential in supporting people after diagnosis. The model is outlined in the diagram on the next page.

These are key areas of activity and although different approaches can be used to deliver a given pillar it essential that the full range is offered to each person.

They provide a framework to ensure information and support is provided over an extended period of time. This includes emotional, social and practical support, to come to terms with dementia, maintain connections, access resources, develop plans and prepare for the future.

Further details of the model are available on the Alzheimer Scotland website:

**<http://dementiascotland.org>**

## Five Pillars of Post Diagnostic Support



The five pillars are:

- 1 **Understanding the illness and managing symptoms**
- 2 **Supporting community connections**
- 3 **Peer support**
- 4 **Planning for future decision-making**
- 5 **Planning for future care**

To support staff in health and social care in taking forward this model, NES and SSSC in partnership with Alzheimer Scotland supported a pilot of a Post Diagnostic Support programme based around the five pillars.

The pilot programme was offered in early 2012 to 36 participants and is currently being repeated with a further 60 staff. The first pilot was offered to those already taking forward post diagnostic support in Dementia Demonstrator sites in North Lanarkshire, Midlothian and Perth and Kinross. It was also offered to those engaged in relevant, dementia-focused work funded through the Change Fund programme. The current pilot was extended to frontline staff in health and social care across Scotland working with people with dementia in the period following a diagnosis of dementia. Practitioners found the programme gave them an opportunity to reflect on their practice and the importance of considering the perspective of the person with dementia.

### Here's what they had to say.

“ ‘Took a step back and made me really think about what I could do to improve my practice’.

‘Presentations have made me more aware of how important it is to get things right so I have broken some of the ties of my old, everyday practice’.

‘Importance of ‘staying connected’ with hobbies, friends, environment, sharing that you have dementia’.

### What next?

This direction of travel was fully endorsed in March by Nicola Sturgeon as Cabinet Secretary for Health, Wellbeing and Cities who gave a personal guarantee that all people receiving a diagnosis of dementia would be entitled to a minimum of a year's post diagnostic support from 2013. Test sites in Argyll and Bute, East Renfrewshire, Glasgow City and South Ayrshire are investigating the workforce and resource implications of this guarantee and we can anticipate more learning opportunities in the year ahead for health and social services staff providing this much needed support.





## Focus on Palliative and End of Life Care in Dementia

Supporting and caring for people with dementia as they go through their journey and reach the end of their life is both a privilege and a responsibility for health and social services staff. Helping people to maintain dignity and influence through this process is crucial to the quality of their lives and to the lives of their families, carers and friends.

Until recently there was a tendency to believe that palliative care was only relevant at the end of life and mainly concerned with a diagnosis of cancer. However the benefits of a palliative care approach are now well recognised as much wider. For people with dementia this has been in areas such as post diagnostic support and making plans for the future treatment, care and understanding the person's priorities; supporting and including the family and carers through the experience and proactively managing symptoms such as pain and distress. We therefore need to ensure that the health and social services workforce supporting people with dementia are capable, confident and caring in their practice.

In 2009 NES funded Alzheimer Scotland to develop and deliver a Palliative Care programme for frontline staff working in health care. This was based on the award winning palliative care 'Beyond Barriers' project (Alzheimer Scotland 2006-2008). Family and friends of people with dementia were involved in delivery of the programme. Communication was at the heart of the training, which acknowledged the importance of person-centred care and demonstrated how a palliative care approach enhances quality of life for people with dementia.

During 2010/11 NES/SSSC worked in partnership with Alzheimer Scotland in reviewing the learning materials for further roll out of their programme and ensuring it had a clear 'fit' with **Promoting Excellence**. To build capacity and capability across the workforce and ensure greater reach and much wider impact the established training for trainers programme was continued but focused on offering places to;

- **Care homes.**
- **Care at home services.**
- **NHS mental health specialist dementia services, in particular inpatient services.**
- **And a small number of places offered to educational organisations who prepare health and social care staff to work in the above settings.**

The programme consists of three days of training and learning. After which facilitators are then expected to deliver the programme to staff groups.

The first cohort of 75 staff completed the palliative care in dementia training for trainers programme and a further cohort has been recruited and is being trained at present. The highest percentage of applicants has been from the care home sector and evaluation of the completed course has been positive.

### Participants commented:



*'Challenging – excited and it is our time in dementia'.*

*'Inspired to get started'.*



It was evident to facilitators that there was much more awareness of the later stages of dementia in the workforce than there had previously been, and much still to do to make sure each person with dementia is supported through the whole of their journey.





# Other Developments

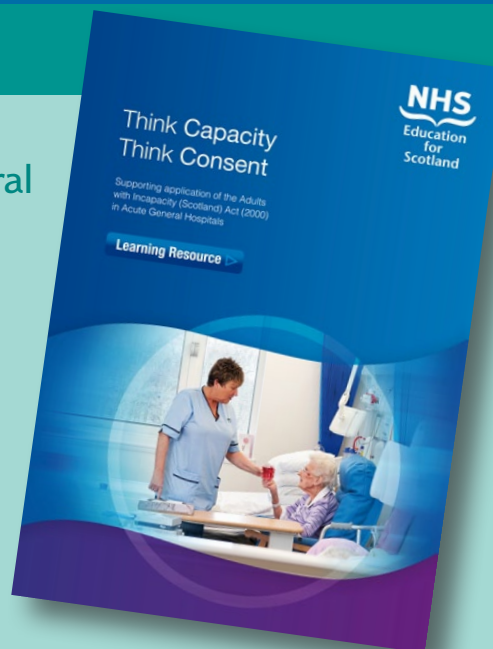
## Think Capacity Think Consent

### Supporting application of the Adults with Incapacity (Scotland) Act (2000) in Acute General Hospitals

Assessment of capacity to consent to treatment is an important legal and ethical issue for staff working in acute general hospitals. It is estimated that between 30% and 52% of people admitted to hospital will lack capacity to consent to treatment.

A new learning resource has been developed which provides essential information about the application of Part 5 of the Adults with Incapacity (Scotland) Act 2000 to ensure staff in acute general hospital settings safeguard the rights of people who lack capacity to consent to treatment.

<http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/think-capacity-think-consent.aspx>



## Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource



This new learning resource is designed to help staff develop an understanding of dementia from a psychological perspective. It is aimed at staff who are working with people with dementia, their families and carers at the Enhanced Dementia Practice Level as identified within **Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers**

You can download this new resource here  
[http://www.nes.scot.nhs.uk/media/1559931/enhanced\\_resource\\_fullv2.pdf](http://www.nes.scot.nhs.uk/media/1559931/enhanced_resource_fullv2.pdf)

## Call for Dementia Ambassadors



Do you work in the social services sector, especially in care homes, care at home and adult day care settings? Are you passionate about providing better care and support for people with dementia, their families and carers? Do you want to contribute to improving the dementia knowledge and skills in the workforce? If so then please join a growing group of Dementia Ambassadors across Scotland by contacting Anne Tavendale **Anne.Tavendale@sssc.uk.com** for more information.

## Why not visit the Dementia Managed Knowledge Network (MKN)

The Dementia MKN provides an opportunity for health and social services staff to share knowledge and experience and support each other in the shared goal to promote excellence in dementia support and care. It can be accessed at: **[www.knowledge.scot.nhs.uk/dementia.aspx](http://www.knowledge.scot.nhs.uk/dementia.aspx)** and you can go straight to Promoting Excellence's resources at: **<http://www.knowledge.scot.nhs.uk/home/portals-and-topics/dementia-promoting-excellence.aspx>**



## In focus in our next issue:

### Dementia leaders across Scotland

Thirteen Health Boards now have a dedicated Alzheimer Scotland Dementia Nurse Consultant or Specialist along with the National Allied Health Professional Dementia Consultants. These leaders provide expert strategic and operational leadership, consultancy, direction and guidance to all partners involved in the design, development and delivery of services and support for people with dementia.







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