Focus on Dementia
Supporting improvements for people with dementia in acute care
Acknowledgements

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- NHS Ayrshire & Arran
- NHS Borders
- NHS Fife
- NHS Forth Valley
- NHS Grampian
- NHS Greater Glasgow and Clyde
- NHS Lothian, and
- NHS Shetland.
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There are 90,000 people with dementia in Scotland. People with dementia are more likely to be admitted to hospital and generally have a longer length of hospital stay. Admission is not always related to their dementia and can result in increasing complexities of assessment, treatment of care and discharge. The hospital environment can be a disorientating place for the person with dementia.

Since both National Dementia Strategies were introduced in Scotland, the first published in 2010 and the second in 2013, there has been a significant amount of time, investment and commitment within NHS boards and other partner organisations, to ensure that, when admission to hospital is unavoidable for people with dementia, the care experience is safe, co-ordinated, dignified and person-centred. This report recognises and celebrates the success of a number of innovations and good practice.

It clearly demonstrates that enabling Alzheimer Scotland Dementia Nurse and Allied Health Professional Consultants to take a strategic lead within their NHS boards, assisting Dementia Champions and teams to deliver frontline change and the commitment at Board level to the 10 Dementia Care Actions are having a positive impact on improving the quality of care and experiences of people with dementia, their families and carers within acute hospitals.

This report only provides a snapshot of the wide range of work that is being undertaken across Scotland. However, building on the progress that has been made and working collaboratively to further embed and sustain improvements will continue to demonstrate sustainable, measurable outcomes for people with dementia, their families and staff.

We are therefore delighted that the Scottish Government’s proposal for the next National Dementia Strategy (2016–2019) includes a continued focus on improving quality of care and experience in hospital settings, with a key priority to involve families as key partners in care. Continuing the national focus will help to drive a culture of continuous improvement and good practice sharing in order to deliver high quality dementia care within our acute hospital settings.

Henry Simmons  
Chief Executive  
Alzheimer Scotland

Hugh Masters  
Associate Chief Nursing Officer  
Scottish Government
Introduction

There are an estimated 90,000 people with dementia in Scotland and numbers are expected to double in the next 25 years. It is estimated that people with dementia over 65 currently occupy 25% of acute hospital beds at any time. People with dementia generally stay in hospital longer, are more likely to experience falls, pressure ulcers or infections and have higher associated costs of care. Over a third of people with dementia who go into hospital from their own homes are discharged to a care home setting.\textsuperscript{1} When admission to hospital is unavoidable, we want to ensure care is safe, co-ordinated and person-centred.

The 10 Dementia Care Actions (Figure 1) were created to support the implementation of commitment 10 of the National Dementia Strategy (2013-2016).\textsuperscript{2} All NHS boards are fully committed to continuous improvement across the 10 care actions.

\textbf{Figure 1: The 10 Dementia Care Actions}

1. Identify a leadership structure within NHS Boards to drive and monitor improvements
2. Develop the workforce in line with Promoting Excellence
3. Plan and prepare for admission and discharge
4. Develop and embed person-centred assessment and care planning
5. Promote a rights-based and anti-discriminatory culture
6. Develop a safe and therapeutic environment
7. Use evidence-based screening and assessment tools for diagnosis
8. Work as equal partners with families, friends and carers
9. Minimise and respond appropriately to stress and distress
10. Evidence the impact of changes against patient experience and outcomes
To further support implementation of the strategy, Focus on Dementia is a partnership improvement programme which brings together and maximises the skills, expertise and knowledge of improvement professionals, policy practitioners and the third sector in order to support the continuing transformation and modernisation of dementia services in Scotland.

The programme focuses on delivery of the key commitments: 1, 2, 3, 10 and 11 of the second National Dementia Strategy\(^3\) namely diagnosis, post-diagnostic support, home-based care co-ordination in the community and hospital care.

Over a number of years, the Alzheimer Scotland Dementia Nurse and Allied Health Professional (AHP) Consultants, Dementia Champions and frontline teams within NHS boards have developed and implemented a range of innovative approaches to improve the care and experience of people with dementia, their families and carers within acute hospitals. Whilst we recognise that there is variation in quality, pace and scale of improvement in some areas, this report sets out a range of case studies provided by NHS boards of some of these approaches so far, which offers key learning to inform further developments and optimise spread and sustainability.
Case studies

The case studies contained within this report are supporting NHS board’s activity against the 10 care actions, with a particular emphasis on 4 of the 10:

- **Care Action 1:** Identify a leadership structure within NHS boards to drive and monitor improvements
- **Care Action 2:** Develop the workforce in line with Promoting Excellence
- **Care Action 8:** Working as equal partners with families, friends and carers
- **Care Action 9:** Minimise and respond appropriately to stress and distress

This work builds on examples of good practice which are highlighted within the Alzheimer Scotland Dementia Nurse Consultant annual review (2014-2015).⁴
Care Action 1: Identify a leadership structure within NHS boards to drive and monitor improvements

All NHS boards have identified Executive and Operational Leads for Commitment who are responsible for identifying, reporting and monitoring progress of local improvement plans and priorities, including relationships with Dementia Champions and other associated programmes of work.

Alzheimer Scotland Dementia Nurse Consultants are currently in post within 13 NHS boards, working alongside three AHP Dementia Consultants providing expertise and strategic leadership to drive forward improvements in dementia care, with a strong focus on acute care.

Over 600 frontline acute care staff are also currently trained as Dementia Champions. These staff have enhanced knowledge and skills at an operational level and, by working collaboratively, have a shared commitment to provide the best care and support for people with dementia, their families, carers and staff within this setting.

An evaluation report looking at the impact of Alzheimer Scotland Dementia Nurse Consultants and the Dementia Champions states that: “Improving experiences and outcomes for people with dementia care in acute general hospitals is recognised in Scotland’s Dementia Strategies as requiring significant cultural change and service development. Despite the enormity of the task and the relative small scale and immaturity of the initiatives, a significant amount of change and improvement work has been initiated by the two roles, and would likely not have happened without them.”

The following case study outlines an innovative approach to leadership which has been implemented within NHS Forth Valley.
Tripartite model of leadership: Commitments 10 and 11

What was the problem?
In the temporary absence of the Alzheimer Scotland Dementia Nurse Consultant, staff identified the challenge of sharing information and limited opportunity to consider spread and therefore develop a joined-up approach across NHS Forth Valley. As a result, an opportunity to test a new model of working as an interim measure was identified.

What is the situation now?
A tripartite model of leadership has been in place since October 2015 to cover the Alzheimer Scotland Dementia Nurse Consultant post in the interim period. This team consists of a Team Lead from Liaison Psychiatry, a Senior Charge Nurse from a Specialist Dementia Unit and a Dementia Champion. There is now visible leadership in relation to Commitments 10 and 11 in NHS Forth Valley with clearly outlined roles and responsibilities, including clear, concise action planning around the 10 care actions. The blended acute and mental health clinical and system expertise allows excellent collaborative working across settings, with increasing opportunities for ongoing learning and sharing. The Dementia Champion network has also been re-established.

What’s next?
• Scoping exercise of workforce development and education in relation to Promoting Excellence.
• Development of role descriptor for Dementia Champions.
• Ongoing progress and review of Commitments 10 and 11 action plans.
• Provide regular updates about the team and the work in the form of a bulletin on the staff intranet.
• Future projects planned which will enhance the involvement of carers as partners in care.
What are the benefits for the patients and families
People with dementia and their families and carers report feeling more involved in their care through increased use of Getting to Know Me document and Playlist for Life in both acute and community settings. The development of processes and documentation allow for a more dementia-friendly culture and improved patient experience.

What are the benefits for staff?
- Dementia Champions feel re-energised and confident to contribute to development and delivery of improvements.
  
  “My motivation had dipped as it felt my role had been forgotten about, I feel more enthused now to progress and make a difference with support.”  
  
  (Dementia Champion)
- Increased awareness and support across all staff groups in caring for people with dementia and their families and carers.
- Over 600 staff have received ward-based training and staff have reported increased confidence in working with patients with dementia and their families as a result of this.

  “I now have the confidence to discuss the Butterfly Scheme and the Getting to Know Me with patients and relatives.”  
  
  (Staff nurse)
- A small audit following the education sessions showed 100% compliance with the use of the Getting to Know Me document allowing for more person-centred care.

What are the benefits for the organisation?
- NHS Forth Valley now has a designated and distributed leadership team who are driving improvements in inpatient dementia care with strategic and operational visibility across the clinical areas.

Challenges
- Work ongoing to ascertain where the new team sits within the NHS Forth Valley structure and to strengthen the team’s position within existing groups.
- Two of the leads continue to have responsibility for their substantive posts.
- Continuation and sustainability of Commitments 10 and 11 progress and future development and how this will link to the new National Dementia Strategy.

Nicola Wood, Team Lead Liaison Psychiatry for Older People; Barry Sneddon, Senior Charge Nurse; Yvonne Cairns, Dementia Champion, NHS Forth Valley
Care Action 2: Develop the workforce in line with Promoting Excellence

Promoting Excellence: A framework for health and social services working with people with dementia, their families and carers was developed by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support the educational actions arising from Scotland’s National Dementia Strategies. The framework details the knowledge and skills that all health and social care staff should aspire to achieve in relation to their role, in order to meet the needs of people with dementia, their families and carers.

NHS board reporting indicates that there have been significant achievements within some areas in implementing education and training against the Promoting Excellence framework, as well as a change in staff attitudes and practice towards people with dementia, their families and carers. As well as traditional methods of education, some of the case studies below provide further innovative examples of how to continue to support the paradigm shift within acute care.
Introduction of a nurse led teaching ward round

“On starting in post as Alzheimer Scotland Dementia Nurse Consultant, I spent time joining the medical ward rounds on the Medicine of the Elderly wards. This was useful to identify concerns and issues around caring for people with dementia in an acute ward setting. As the complex discharge ward did not have a specific medical ward round, I decided to introduce a nurse led teaching ward round.

I introduced a weekly ward round where I spent focused time with registered nurses, healthcare support workers (nursing and AHP) and nursing auxiliaries. The focus was education and was centred on a person with dementia, undertaking a holistic assessment of their care needs, making the connections between theory of dementia care to the practicalities of delivering person-centred care in an acute ward. New knowledge is imparted along with role-modelling behaviour.

The nurse led teaching ward round has now been spread to a further three wards. Staff are asked to complete a dementia confidence rating scale and a dementia knowledge rating scale before starting each session. This allows me to measure changes in knowledge and confidence before and after input. The nurse led teaching ward round is tailored to meet the individual learning needs of the nurse/AHP with whom I am spending dedicated time. As the learning is centred on a ‘real life’ patient, the learning is very powerful and meaningful. It is true learning in action. Each learner is also given a dedicated pack with useful resources to support their learning.

Not only do the healthcare professionals that I have spent time with now have an increased knowledge and understanding of caring for people with dementia but it ensures that the person with dementia is receiving the best care possible.

The complex discharge ward also noted a weekly audit looking at dementia and cognitive impairment care has improved following the introduction of the nurse led teaching ward round.”

Helen Skinner, Alzheimer Scotland Dementia Nurse Consultant, NHS Fife
Informed about dementia

A number of educational approaches within Glenrothes Hospital in NHS Fife have improved staff knowledge, skills and confidence at an 'Informed' level. Scoping identified that domestics, receptionists, porters and kitchen staff within the community hospital were not offered any dementia education. Dementia training sessions, Learnpro modules and development of a dementia education board has resulted in 80–100% of ancillary staff now trained to Informed level. Staff have reported an increased confidence when interacting with people with dementia and also report feeling valued within the team due to time invested by management with protected learning time.

Amanda Simpson and Mahri Edgar, Dementia Champions, NHS Fife

The Dementia Box

When admission to hospital is unavoidable for people with dementia, NHS Fife recognised that its task-orientated care approach within a busy and noisy A&E environment was impacting on levels of stress and distress for people with dementia. The 'Dementia Box' is a teaching resource developed and implemented by a Dementia Champion to help healthcare professionals empathise and understand the experience of stress in a busy environment, whilst encouraging staff to undertake the NES elearning Dementia Care in the Emergency Department module. Staff are asked to rebuild an origami box whilst at the same time being asked lots of complex questions. This helped staff understand what stress and distress feels like. This increased understanding has helped staff to understand the needs of people with dementia. This unusual approach to learning has increased uptake and completion of the elearning module for A&E staff and paramedics and has led to a more person-centred approach to care with fewer staff members providing direct care to the person with dementia.

Lucinda Gorrie, Dementia Champion, NHS Fife
Collaborative approach to dementia and carer awareness

NHS Grampian has taken a collaborative approach to improve dementia awareness for pharmacy undergraduates at the Informed level of Promoting Excellence. Partnership working between Robert Gordon University, NHS Grampian, Alzheimer Scotland and Dementia Friends Scotland has raised awareness of the national dementia drivers and provided context to the knowledge base being used by future pharmacists where the person is at the centre and where the use of supporting technology can be understood within the pharmacy environment.

Four 3-hour sessions for over 100 2nd year undergraduate pharmacy students have taken place at Robert Gordon University in order for them to become Dementia Friends. Students now feel much better informed about dementia and how to support people with dementia and their families when out on placements and in communities.

“I thought dementia was just memory loss but this session has opened my eyes that it is much more.” (Student)

“...I now understand how I react has a big impact on their day or even life.” (Student)

“...be more patient and listen to what the person has to say.” (Healthcare professional)

“...lets other people know about Dementia Friends.” (Pharmacy educator)

Lyn Irvine-Brinklow, Heather Tennant, Sarah Geoghegan, Rosie Leavett, Bex Wright, Iain Rowe and Alison Strath, NHS Grampian, Dementia Friends Scotland and Robert Gordon University School of Pharmacy & Life Sciences
**Adults with Incapacity for podiatry patients**

Lack of knowledge, understanding and awareness of the Adults with Incapacity (AWI) Act amongst community and podiatry staff led to specific training being developed and delivered to podiatry staff in NHS Fife. Training was provided to all podiatry staff and now 100% of podiatry staff are aware of their role and responsibilities and in response have developed and implemented a Podiatry Adults with Incapacity Standard Operating Procedure to ensure compliance with the AWI Act. This supports that no treatment should be delivered to a person unable to consent without appropriate consent from their Welfare Guardian and/or an AWI certificate in place.

Karen Mellon, Dementia Champion, NHS Fife

**Raising awareness of Dementia Champions and best practice staff**

Feedback from families and carers within NHS Grampian identified that it was not always easy to identify the 54 Dementia Champions and growing number of staff trained in the Best Practice in Dementia Care Programme within the clinical areas. Recognising an area for improvement, staff have now developed a poster that helps colleagues, carers and visitors identify staff members who have enhanced knowledge and skills in dementia care and are supporting clinical areas in NHS Grampian to become dementia friendly/enabling environments.

“Seeing this poster makes me think this ward might have more information so I guess it might encourage me to ask.” *(Carer)*

“It was good to see the posters in the wards. I think this also supports staff to identify carers.” *(Carer support worker)*

Heather Tennant, Carer Information Strategy and Lyn Irvine-Brinklow, Alzheimer Scotland Dementia Nurse Consultant, NHS Grampian
Evidence-based training for healthcare support workers

In order to identify change ideas for improving the quality of care and experience for people with dementia within occupational therapy and physiotherapy acute services in Gartnavel Hospital, Glasgow, a service evaluation was undertaken. This highlighted that healthcare support workers within the service were the staff group who often were able to spend extra time with people with dementia and therefore had the opportunity to improve their care experience.

The Best Practice in Dementia Care for Healthcare Support Workers programme developed by the University of Stirling was identified as an effective approach to upskill and support this staff group. To date, 23 occupational, physiotherapy and generic healthcare support workers have completed the training.

The programme continues to be of great value for this staff group, proving to increase awareness and confidence when working with patients with dementia, their families and carers. Support workers have reported significant impact on patient experience and their ability to influence others, including nursing staff, families and carers.

• People with dementia are now prioritised for a rehab session in one clinical area.
• People with dementia are now included in open gym sessions
• Significant impact noted on patient mood, behaviour and interaction following one to one person-centred sessions
• One support worker described the difference made when she spent time in the session doing the patient’s hair.

Funding has been successfully secured from NES Career Fellowships and has allowed purchase of training packs and planned delivery and support for a further two cohorts. The aim will be to continue to train all occupational therapy and physiotherapy support workers, with a view to offering the training to all AHP support workers in the future.

Jennifer Marler, Dementia Champion and Shona Ballentyne, Practice Development Occupational Therapist, NHS Greater Glasgow and Clyde
Care Action 8: Working as equal partners with families, friends and carers

The importance of carers as equal partners has long been recognised as crucial in the planning and delivery of care and support within health and social care.\textsuperscript{6,7} Research has shown that enhanced communication methods and sharing of personal information around who and what matters to individuals are essential to improving patient and carer experiences for people with dementia in acute hospitals. It is acknowledged that the person with dementia, their family and carers play an important role and that their knowledge ensures that the person with dementia gets the right care and support which reflects their needs and wishes, as well as remaining involved in decisions that affect them.
John’s Campaign

Traditionally, within acute hospital settings, carers have been restricted to hospital visiting hours. Over 35 NHS hospitals and wards in Scotland now have signed up to John’s Campaign (www.johnscampaign.org.uk) pledging their commitment to allow family and carers of people with dementia to have the right to stay as they wish with their loved ones whilst in hospital.

This enables carers to be there when they are needed most, contributing key information and support to ensure the person with dementia’s needs and preferences are met.

“We would never separate a child from their parent for that period of time, so why should it be any different for a person with dementia, who takes comfort from seeing the familiar faces of relatives and carers?”
(Staff member, NHS Lanarkshire)

“I think John’s Campaign is a fantastic idea as it gives great comfort to patients and their families and carers that they can be close to each other as much as possible during a hospital stay.”
(Carer, NHS Lanarkshire)
Older people in acute hospital inspections

The aim of the older people in acute hospital (OPAH) inspections is to provide assurance that the care of older people and people with dementia in acute hospitals is of a high standard whilst providing a methodology to also drive improvement.

A summary of OPAH inspection findings from November 2014–February 2016 relating to Outcome 5 (The patient, with dementia (or cognitive impairment), experiences care that is tailored to meet their individual needs and promotes their mental wellbeing) highlighted consistent areas for improvement across the majority of those NHS boards inspected. These included:

• NHS boards must ensure current legislation to protect the rights of patients who lack capacity is fully and appropriately implemented. In order to do so, all staff who have a professional role in the implementation of the legislation must receive training appropriate to their role.

• NHS boards must ensure systems are in place to record key personal information, such as power of attorney about people with dementia or other cognitive impairments. This information should be used and shared with staff involved in the care of the patient.

These areas of improvement support the continued focus around working together as equal partners with families, friends and carers within hospital settings as outlined in Care Action 8.

The following case studies outline some of the approaches that are working well within a number of NHS boards.
Improving use of Getting to Know Me in acute hospitals

Within NHS Lothian, a survey identified that although the Getting to Know Me form (Alzheimer Scotland) is valued by AHP staff, the forms were not always accessible or fully completed. The Getting to Know Me (Figure 2) form was identified as a beneficial tool to support people living with dementia who are inpatients in an acute hospital, however use and implementation of the form varied across wards.

The Model for Improvement and PDSA (Plan, Do, Study, Act) cycle approach (Figure 3) was used to plan tests of change in four acute ward areas by a team of AHPs. By the end of the project, several changes had been implemented which impacted on the use of Getting to Know Me forms. These included:

- having named staff responsible for ensuring forms had been issued, collected and filed, and
- heightened awareness of the forms by using posters and informal discussions with staff, and including the forms in admission packs.

Figure 2: Getting to Know Me form

![Getting to Know Me form](image-url)
Benefits to patients and carers:
- An easy to use tool that allows the wishes and values of the person with dementia to be recorded for use by those who are caring for them in hospital.
- Prevention of repetitive questioning from hospital staff about a patient’s preferences, routines and habits.

Benefits to staff:
- Easy to access information which could be used to support care provision and build therapeutic relationships.
- Access to information which could be used to reduce stress and distress in people living with dementia who require inpatient care.

The full report can be accessed at: www.qihub.scot.nhs.uk/quality-and-efficiency/focus-on-dementia/resources.aspx
Developing and implementing personalised plans using the Essential 5 bundle

The ‘Essential 5 Quality Criteria Bundle’ and guidance document was co-designed with a number of partners and then tested within four health and social care services to support improvements in post diagnostic support services in Scotland. The Essential 5 bundle clarifies the minimum level of personalised outcome planning for the care of people with dementia, supported by staff and involving families, carers and others close to the person. The bundle approach provides a structured way of improving the process (Figure 4) to improve quality and reduce variation, tying the changes together into a package that people should follow for every person, every time.

The bundle is now available for implementation across all agencies and although developed initially to support post-diagnostic support, it is potentially transferable across health and social care settings.

Within one of the community hospitals in NHS Ayrshire & Arran, it was acknowledged that care planning was not always person-centred. Work had been carried out to implement the Getting to Know Me document within the clinical area. However, there was significant variation in ensuring the meaningful information gathered within this document was informing care plans and then subsequently applied in practice.

Figure 4: Essential 5
John’s story
John is 75 years old with a diagnosis of Lewy Body Dementia and delirium. After several weeks in a general hospital, John was admitted to a continuing care ward for further assessment, with increasingly frequent episodes of stress and distress. Although John had a Getting to Know Me document completed by his daughter, a review of documentation showed that none of the information around who and what matters to John was outlined in his plan of care.

Due to his increasing stress and distress, the number of 1:1 nursing observations increased and antipsychotic medications were prescribed. A personalised care plan was developed with John and his daughter Kirsty with one of the staff from the project group.

Using the Model for Improvement and PDSA methodology, a project team within Kirklandside Hospital is currently testing and implementing a range of change ideas to improve the care and experience for patients, families and staff. They are improving compliance with Getting to Know Me and What Matters to Me information and having discussions with relatives and carers around developing a plan of care, focusing on individual strengths and capabilities. They have adapted the Essential 5 bundle to fit the hospital context and are currently reviewing the care plans against the bundle.

“I felt really listened to and then the information acted upon; I also feel that I have a good rapport with staff now and am able to voice any concerns without any problem.” (Family member)

“By reviewing the plan against the Essential 5 bundle and going through each element, we were able to evidence aspects of good personal planning but also where there were gaps for improvement.” (Staff)

Kirsty Park, Staff Nurse, NHS Ayrshire & Arran
Dementia and delirium carers café

Staff from Alzheimer Scotland and the dementia team in NHS Fife identified a challenge in supporting carers when a person with dementia is admitted to hospital. In response, a dementia and delirium carers café has been set up by staff, on a monthly basis, in the hour before visiting time. This provides an open space for carers to get information and support, exchange views and news in an informal relaxed atmosphere. Discussing this with someone away from the ward area allows an openness and a degree of critical feedback without fear of repercussion. It also provides the opportunity to signpost carers to other services and sources of support in Fife which carers have found tremendously useful.

A PDSA model was adopted. Initially, dates were planned for three consecutive months to hold the cafés on a test basis. Posters were produced to promote the cafés and displayed on the Medicine of the Elderly wards. The three dates were held with one or two carers attending each café. As the initial feedback from those attending was positive, three more dates were set with further consideration given on how the café could be better promoted. A5 flyers were produced to be given to relatives. Links were made with Fife Carers Centre who promoted the café on their Facebook page and also on NHS Fife’s Facebook page. Further promotion within the Medicine of the Elderly wards prompted medical staff to ask for the café to include support for carers of patients with delirium, as many of the patients experience this and carers find it very distressing. New posters were developed to include delirium as a focus.

Although attendance numbers have been small, those attending have given very positive feedback, as the quote below demonstrates.

“Thank you - not just for information and advice but also for your very pleasant and calm approach to such a distressing subject.”

We intend to continue with the cafés because if one person benefits from attending, it makes it worthwhile.

Helen Skinner, Alzheimer Scotland Dementia Nurse Consultant, NHS Fife
Reminiscence group

A similar approach within Golden Jubilee National Hospital has also proved successful. Over the past 4 years, Alzheimer Scotland in West Dunbartonshire has worked in close partnership with the Clinical Education Team and the Lead Nurse for Dementia within the Golden Jubilee. In September 2015, a partnership project to host a dementia cafe within the hospital was agreed. The Alzheimer Scotland Dementia Advisor and Community Activity Organiser facilitated the reminiscence group with support from a Golden Jubilee volunteer.

Within the group we had local photographic images of Clydebank, football reminiscence materials and a quiz which proved to be very popular. Although the attendance numbers for the group are small and the ratio of staff/volunteers is high, we felt that this was necessary to give the group the best possible start.

Feedback from a couple of family members who attended with their relatives has been very positive. Two family members commented on how much better their relative’s mood had been for the remainder of the day after attending the group.

Sandra’s story

Sandra, our dementia link worker, was working with an elderly lady who was reluctant to leave the house. This was causing both her and her sister (her main carer) to become very isolated. Sandra encouraged them to attend the group. They both enjoyed the experience and attended three out of the six sessions. In addition to this, they also attended our musical memories group and more importantly the woman agreed to a support worker.

The support worker encouraged the lady to go out with her and she really enjoyed a visit to a garden centre. The link worker was delighted with this outcome as it made a difference to the quality of life for both the person with dementia and her sister who was able to enjoy attending the group with her and meeting other people. This also demonstrates that by attending small informal groups, people who may be initially reluctant to engage with formal social care support can become more accepting of this and more importantly can continue to live a good quality of life where they are less socially isolated.

We will continue to run the group fortnightly for six sessions which will then be reviewed. In the longer term, we hope that the group can also be a fortnightly information and advice service which can be used by visitors or staff within the hospital. The Dementia Advisor will provide the information and advice, and the Community Activity Organiser together with Golden Jubilee dementia trained volunteers will run the activities.

Fiona Kane, Dementia Advisor, Alzheimer Scotland

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Carer information facility

NHS Grampian has been exploring opportunities to influence carers to engage with their own health needs. The carers service has been established at the Aberdeen Royal Infirmary site since 2009. In 2013, following a service review and introduction of carers legislation, the existing healthpoint and a carer information point were amalgamated to form a unique healthpoint/carerspoint service. Questionnaires were made available to carers who visited the service over a 4-week period and the findings underline the importance of person-centred carer support. Carers visit the carer information facility for various reasons and therefore the service provides an opportunity for carers to consider their own health and wellbeing needs whilst accessing relevant information to support their caring role.

“It is helpful and needed for carers to understand what is available to support them in their caring role. The amount of stress on a fulltime carer looking after family members is greatly underestimated.”

(Carer, Grampian)

Following feedback from Healthcare Improvement Scotland during an older people in acute hospital inspection, the hospital now has a dedicated information wall for the older age group. Information includes:

- wellbeing advice in relation to topics such as nutrition and falls
- legal information in relation to power of attorney
- Getting to Know Me document and information leaflet, and
- Age UK resources, and local information to support patients, carers and staff.

Heather Tennant, Carer Information Strategy, NHS Grampian and Gil Barton, Robert Gordon University
Examples of Dementia Champions supporting excellent person-centred care

The caring compassionate relationship between staff and the person with dementia, their families and carers could be considered the essence of person-centred care. The following two case studies highlight the important contribution of the staff who have taken the time to focus and understand who and what matters to the person with dementia, their families and carers to improve safety, care co-ordination and humanity within hospital settings.

“Mrs A was an elderly patient with dementia on our ward who was diagnosed with oral cancer. On our ward, Mrs A could get very upset but responded well to patience and affection, I had a good relationship with both her and Mr A; she referred to me as her “pal”. She became very fond of a toy dog which was acquired for the ward to provide comfort for our patients; she named him “Mac”. He could be found with her most of the time. I introduced myself to Mr A as the Dementia Champion and what my role involved; he said he felt reassured as he didn’t feel most nurses understood about dementia. He was happy to complete the “This is Me” document. Following surgical review Mrs A required to be transferred to a mainland hospital for further treatment. As they had no immediate family to assist them with this, I accompanied Mrs A to the mainland and stayed with her throughout her treatment.

I stayed with Mrs A throughout her stay on the ward, tending to her personal care, preparing her for theatre and escorting her and Mac to the anaesthetic room. My presence was also there in recovery once she came round. Leaving her only at night when she was settled, I advised the staff that if I was needed during the night to contact me on my mobile phone. This was seen as invaluable as on the fourth night of her admission as Mrs A became very distressed and my presence back to the ward was needed. On arriving back to the ward, I was met by a very distressed Mrs A and that night was spent in the Day Room as she felt more relaxed there. I was there on medication rounds and administering fragmin injections as prescribed as she was reluctant to take drugs from staff who were strangers to her. I assessed pain levels and obtained analgesia for her when she needed it. I purchased appropriate food stuffs from the hospital shop such as ice cream as this provided comfort to Mrs A and was not available routinely on the ward.”

Maxeen Peterson, Dementia Champion, NHS Shetland
“Jenny lives well with dementia in a local residential care home but following a fall was admitted to hospital with a fractured neck of femur and subsequent delirium. She had a hemi-arthroplasty, a surgical repair of her hip, and following surgery recovered slowly but steadily, including resolution of her delirium.

Prior to admission Jenny was independently mobile therefore the orthopaedic ward supported her recovery in a way which was person-focused, recognising her strengths and abilities. Within one week of her surgery, Jenny could mobilise with a wheeled zimmer and one nurse for short distances, safely transfer with the support of one member of staff and was ready to transfer downstream to the local community hospital.

The Dementia Champion within the unit discussed the possible transfer with Jenny’s daughter and among the concerns raised was the issue that Jenny, now a widow, had previously looked after her husband and he had died in that community hospital. While there was no evidence that Jenny could remember the hospital, her daughter was anxious that she might and that if so she would find it distressing. The Dementia Champion contacted the care home, explained the circumstances and asked if they were able accommodate Jenny’s current level of mobility and could continue to support her further recovery. They agreed; they could and they would.

Armed with this information, the nurse declined to send Jenny to the community hospital and arranged discharge direct to the care home. The Dementia Champion in this case reduced risk of exacerbating any disorientation and the possible recurrence of delirium by resisting the easy option to move her patient from one ward to another before the next move on to the care home. The Dementia Champion also showed great compassion in recognising the lady might be distressed by being nursed in the unit where her husband had died.

This combination of compassion and skilled clinical intervention are what the Dementia Champions were created for.”

Peter Lerpeniere, Alzheimer Scotland Nurse Consultant, NHS Borders
Care Action 9: Minimise and respond appropriately to stress and distress

We know that if the person has dementia, this impacts on individual care needs in terms of complexity and intensity of need. The very nature of being admitted to an acute hospital can trigger a stress and distress response and this can be further complicated by interaction within this environment. Psychological and behavioural symptoms are often treated with sedatives or antipsychotic medications; however, these are often ineffective and used inappropriately. In light of this, there is an increasing emphasis on the use of non-pharmacological interventions to improve the wellbeing of people with dementia. Being aware and recognising the needs of the person with dementia during a hospital stay is crucial in order to be able to provide safe, effective, person-centred care and treatment.

A number of NHS boards have shared case studies to outline preventative and proactive approaches to respond to those people with dementia who may experience stress and distress.
Feedback using Playlist for Life

NHS Grampian and NHS Forth Valley have both embraced the use of personalised music as an invaluable non-pharmacological intervention for people with dementia (visit [www.playlistforlife.org.uk](http://www.playlistforlife.org.uk)).

“I would recommend this to anybody and everybody. If you’re sick and tired or disillusioned; sit down, put the headphones on and sit back and just listen.” *(Person with dementia)*

“When I’m here with him he often drifts off, if I put on his playlist of music he’ll often open his eyes and it brightens him up. I’ve seen a good change in him since we came here. No-one should have to be without music.” *(Family member)*

“He is sensitive to loud noises which would often seem to trigger the agitation - some of his memories must be quite horrific of times during the war. But we haven’t had as many outbursts since he started listening to the music – the music blocks out the noises, which helps a lot.” *(Staff member)*

**Julie Warrender, Nurse Manager, NHS Grampian**

The Playlist for Life project report by NHS Forth Valley is based on a study undertaken of one patient and one carer. The outcome measures for the patient included rate, duration, attention and attitude and for family members was to assess if playing music during their visits had an impact on the level of engagement.

- One family member who used Playlist for Life stated he witnessed his wife ‘getting comfort from her new routine’ and he felt the process had ‘definitely been worthwhile.’
- The patient had been witnessed making comments such as ‘that’s nice’ and ‘oh god.’
- Staff members not only noticed a reduction in distressed behaviours from the patient, but also noted that her husband was looking physically better.
- The results from the study indicate that the use of personalised music as an emotional stimulus holds the potential to evoke memories and reconnect patients with families again.

**Yvonne Cairns, Dementia Champion; Clare Calder, Quality Improvement Facilitator; Oonagh Cameron, Quality Improvement Manager; Tracey Gow, Psychiatric Liaison Nurse, NHS Forth Valley**
Bringing people together through music and dance

A multidisciplinary activities group has been established in Woodend Hospital, Aberdeen, with the objective to bring patients and relatives together at a regular event to reduce social isolation, boredom, stress and distress. A PDSA cycle was used to identify the problem and to plan the improvement work. It was started on a small scale with activities being carried out in one ward and was then tested on a larger scale which proved successful. Large events are now being planned every 3 months.

“There was a real buzz in the room, patients were meeting and chatting with other patients, one in particular met an old friend and didn’t realise she was in hospital.”

“On return to the ward, patients seemed relaxed and content – reducing levels of stress and distress.”

“I get a real sense of pleasure and satisfaction to see loved ones enjoying themselves in a very relaxed atmosphere.”
Reducing stress and distress using activity boxes

As well as introducing social events in Woodend Hospital, staff were keen that patients are able to access different activities. Using the Model for Improvement, activity boxes were introduced and tested in one ward area and then implemented across the service.

Evaluation showed that introducing activity boxes encouraged the patients to come together in the day room and socialise, encouraging conversation and interaction. If a patient does not want to go to the day room, the staff now feel increasingly confident and happy to support some of the activities on a 1:1 basis.

Families reported that they also felt happy to go home and leave their loved ones knowing that anxieties, stress and boredom could be reduced as they would be encouraged to participate in the activities to reduce isolation.

Meaningful open visiting

All wards in Woodend Hospital have now also adopted open visiting. This is not extended visiting times, but open in the sense that families and carers are welcome on the wards at any time throughout the day and evening to sit with their loved ones. Families and carers are also encouraged to come in during mealtimes and assist their loved one with their meals which has also helped alleviate some anxieties voiced by relatives when they weren’t present.

This has not only reduced levels of stress and distress for patients but families report that they have much more interaction with the multidisciplinary team and medical staff. They report that they have less anxiety about their loved one as they can visit at any time rather than having to wait for visiting time.

Julie Warrender, Nurse Manager, NHS Grampian
Pocket ideas – a moment in time

Within NHS Ayrshire & Arran, an activity team was established to focus on the importance of meaningful activity for older people in hospital.

The initial prototype incorporated a selection of quick activities, conversation starters, pictures, inspirational quotes and games. Using improvement methodology during January 2014, the prototype was tested, and the results were documented with the use of a simple evaluation tool. The outcome was incredibly positive and highlighted that no additional time was required to use ‘Pocket ideas’. It enhanced positive interactions with staff and patients, reinforced the importance of person-centred care, encouraged meaningful experiences and enhanced the quality of life journey for an older person during a period in hospital.

“Great way to help get to know patients better and find out their individual interests.”

“Very useful and helpful as a student to help build my confidence to engage with patients.”

“I had a lady unwilling to wash and dress. I started going through some questions out the book, she soon engaged with me and agreed to personal care.”

“The ‘a moment in time’ book was great, especially talking about all the Scottish places and people, brought back good memories for my dad.”
(carer)

The final tool has been completed and is being rolled out across Ayrshire for older people’s services. It is hoped that Pocket ideas will be available and shared with other NHS boards, local authorities, third sector and carers. The final PDF will also be available soon and accessed on the activity website www.nhsaaa.net/activelyengaged

Andrea Boyd, Occupational Therapist and Project Lead, NHS Ayrshire & Arran
Activity blanket

Within NHS Fife, a Dementia Link Nurse has designed an activity blanket for people with dementia in order to prevent stress and distress during their stay in hospital. The blanket is designed with various materials, fabrics, textures and colours to provide comfort, stimulation and a distraction for the patient.

The blanket stays with the patient until they are discharged and then laundered and returned to the ward. The blanket eases stress and anxiety levels when being faced with unfamiliar surroundings as well as multidisciplinary staff attending to the patient’s daily needs. It keeps them busy and helps to keep them calm and relaxed. Family members and friends have commented how relaxed their loved ones appear and how this has helped to put their minds at ease whilst they are in hospital.

Lisa Brown, Nursing Auxiliary/Dementia Link Nurse, NHS Fife
Summary

The scope and breadth of activity across all NHS boards around the 10 care actions is evident. However, interestingly the case studies within this report highlight that the main focus within the NHS boards represented are across the following four care actions:

- **Care Action 1:** Identify a leadership structure within NHS boards to drive and monitor improvements
- **Care Action 2:** Develop the workforce in line with Promoting Excellence
- **Care Action 8:** Working as equal partners with families, friends and carers
- **Care Action 9:** Minimise and respond appropriately to stress and distress

The case studies identify excellent pockets of improvement activity which clearly demonstrate the enthusiasm, innovation and dedication of the staff within hospital settings to continue to improve the quality of care and experience for people with dementia, their families and carers. However, there is a recognised need for consistency and a continued focus on measurement and evidence to improve outcomes for people with dementia, their families and carers.
Next steps

Focus on Dementia is committed to:

- working in partnership with Alzheimer Scotland Dementia Nurse and AHP consultants and partners within NES to continue to build capacity and capability of Quality Improvement and subject matter expertise within NHS boards
- continuing an improvement focus to involve families as key partners in care
- optimising spread and sustainability
- exploring further opportunities to gather experience of people with dementia, families/carers and staff across Scotland, and
- supporting a whole systems approach to demonstrate improvements in safe, person-centred and co-ordinated care across the pathway for people with dementia.
References


