

Changing Minds, Improving Lives in Scotland

Focus on Dementia

July 2018

Photo courtesy of Lewis Houghton



Improvement Hub
Enabling health and social care improvement

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Introduction

Focus on Dementia is the national improvement programme for dementia in Scotland, based within Healthcare Improvement Scotland's Improvement Hub (ihub).

This report sets out a summary of our key achievements in the last year to support the implementation of key commitments within Scotland's third dementia strategy.¹

This work would not have been possible without the dedication and commitment of staff and leaders at all levels to support our work. Meaningful engagement and involvement of people living with dementia and carers is and continues to be critical to our success. Strong partnership working with Scottish Government, Alzheimer Scotland, NHS boards, Health and Social Care Partnerships and national organisations, including NHS Education for Scotland, Scottish Care and Care Inspectorate, has been invaluable in informing our work.

We look forward to continuing to work together to improve the experience and outcomes for people living with dementia and carers through supporting the implementation of Scotland's third dementia strategy.¹

Why are we focusing on dementia?

There are 90,000 people living with dementia in Scotland and, by 2020, it is estimated that there will be around 20,000 new cases diagnosed each year.² Scottish Government launched the third dementia strategy in May 2017 setting out a vision for change and Focus on Dementia has a key role in supporting the implementation of key commitments within the strategy.¹



"I have been a member of the National Dementia Carers Action Network (NDCAN) for about 3 years, and have met many dedicated people along the way who are committed to improving the lives of people with dementia and their carers. My optimism was boosted when I found out about the Government's dementia strategies, but I soon realised the hard work was putting these strategies into practice. Focus on Dementia is doing this hard work to implement the vision of the strategies, and I applaud them for involving people with dementia and carers in their work. Sharing our experiences helps people to understand how services impact on our lives in both good and bad ways, and our insight helps to make these services more effective."

- Maureen Huggins,
National Dementia Carers
Action Network



About Focus on Dementia

We work in partnership with national organisations, health and social care practitioners, people living with dementia and carers to improve quality of care across a range of settings from diagnosis through to end of life care.

Our work supports improvements in:

- diagnosis and post-diagnostic support
- integrated care co-ordination in the community
- acute care
- Specialist Dementia Units
- palliative and end of life care, and
- testing the value-based global standard set for dementia.

All of this work is supporting the implementation of Scotland's third dementia strategy and informing future policy and practice.





“Being a member of the Focus on Dementia team as a professional advisor (psychiatry) is a constant joy due to the appreciation and value given to my expertise but also the opportunity to work on areas of interest for me such as ethics and legal aspects of quality improvement. It also gives me the opportunity to reach out to my colleagues in Psychiatry of Old Age in Scotland and beyond and share with them the excellent work carried out by the team.”

– Cesar Rodriguez,
Consultant Old Age Psychiatrist

Clinical engagement

The role of our national clinical leads is invaluable to informing our work and wider clinical engagement. They are practising clinicians who are up to date with clinical practice and provide a direct connection between the world of working clinicians and our improvement work. Health and social care staff in the units supported by the Focus on Dementia team can relate to the fact that there are people in the team who have current experience of the pressures and successes of clinical roles and are able to identify with their concerns and priorities.

This is a vital link which helps to inform the quality improvement work and ensures that the improvement approaches are appropriate and relevant to real life clinical situations. Through the clinicians’ professional bodies and work structures, it also provides a route from the ihub into wider clinical networks, helping to engage with teams on the ground as well as contributing at a strategic level. This works in both directions, keeping the ihub informed of clinical developments and good practice as well as feeding information outwards about the ihub’s methodology and projects.

June Wylie (Healthcare Improvement Scotland)
with Maggie Muir (National Dementia Carers
Action Network) co-chairing the May 2017 event



Engaging with people with dementia and carers

Throughout our work, we have been privileged that people living with dementia and carers have given up their time to share their experiences and support our developments. We could not have achieved all that we have without the support of the Scottish Dementia Working Group, National Dementia Carers Action Network and Dementia Carer Voices and we thank them for their continued support going forward.

Myra Lamont from National Dementia Carers Action Network asking the panel a question from the audience



“As an NDCAN member, I was privileged to represent dementia carers on the Focus on Dementia quality improvement work streams. I was respected as an equal partner with lived experience, able to contribute to discussions, challenge and be involved in specific pieces of work, to improve outcomes for people living with a diagnosis of dementia and their carers. Knowing my contribution would help others gave me great satisfaction, as well as being a valued member of the Focus on Dementia team. Improvement in the quality of care, especially post-diagnostic support is crucial, not only does it standardise care making it equitable, it focuses on the individual which is so relevant in the management of a person living with a diagnosis of dementia and in supporting the carer. My lived experience of providing long term dementia care gave me an understanding, knowledge and expertise, which enabled me to fully contribute along with my professional colleagues to understand important aspects of dementia care that were relevant to the development of the Quality Improvement Framework for Post-Diagnostic Support.”

- Myra Lamont, National Dementia Carers Action Network

Our areas of support

Diagnosis and post-diagnostic support

Scotland remains the only country in the world to guarantee (local delivery plan target) that anyone being newly diagnosed as having dementia has a minimum of one year's post-diagnostic support with an identified named worker. Every NHS board area in Scotland reports on their performance to inform a national dataset. This data tells us that since 2014, over 6,000 people in Scotland with dementia each year have received post-diagnostic support with an identified post-diagnostic support practitioner. Of those people referred for dementia post-diagnostic support, over 60% of people receive this within 3 months of their diagnosis.²

Whilst there are examples of good practice in this area, we know that variation exists throughout the country in the delivery and uptake of post-diagnostic support. We are, therefore, working in collaboration with post-diagnostic support leads, practitioners and partner organisations to support continuous improvements, in line with Commitment 1 of Scotland's third dementia strategy.¹

Commitment 1

We will revise the national post-diagnostic dementia service offer to enhance its focus on personalisation and personal outcomes in the delivery of post-diagnostic services.

Commitment 2

We will test and independently evaluate the relocation of post-diagnostic dementia services in primary care hubs as part of the modernisation of primary care.

Our key work streams include:

- understanding and improving the quality of post-diagnostic support, and
- testing the relocation of post-diagnostic support within primary care.

Understanding and improving the quality of post-diagnostic support

We have been working with post-diagnostic support practitioners to develop and test a framework that identifies what a good post-diagnostic support service looks like and supports services to make improvements to how they deliver post-diagnostic support. Called the Quality Improvement Framework for Post-Diagnostic Support, the framework has been informed by listening to people living with dementia, carers and staff views and experiences. It will be available for publication in summer 2018, following a period of testing and further consultation with post-diagnostic support leads. Feedback from this work has been very positive.

We are now working with partners to support the identification and development of quality measures for post-diagnostic support. A document for people living with dementia and carers on what they should expect from a good quality post-diagnostic support service is also being developed to complement the framework and this will be co-produced with the Scottish Dementia Working Group, National Dementia Carers Action Network and through local group consultation.



"We would be happy to roll out the framework and agree that it is a useful self-assessment framework for post-diagnostic support services to review the quality of post-diagnostic support and is also useful to identify areas of change/improvement."

"It highlights much of what we have been striving to do for a number of years now. I believe that a framework such as this will offer clarity of the expectation of post-diagnostic support work."

"The framework is looking really good and we don't have any improvements to suggest. We like the way the information has been presented with key information in the body of the framework and the supporting information as appendices."

- Post-diagnostic support practitioners

Testing the relocation of post-diagnostic support within primary care

In April 2017, we were delighted to announce the three GP clusters chosen to be innovation sites to test the delivery of dementia post-diagnostic support from GP practices in Dumfries and Galloway, North East Edinburgh and Shetland. This 2-year programme, commissioned by the Scottish Government's Dementia Innovations Unit following consultation with the Primary Care Engagement and Innovation team, invited Integration Joint Boards to support clusters to apply. The initiative is being led by the Focus on Dementia team in partnership with NHS Education for Scotland, Alzheimer Scotland and Scottish Government.

It is anticipated that by relocating post-diagnostic support within primary care, people will feel more comfortable accessing support from a familiar environment and with the support of a team who are known to them.

Outcomes for this work

By September 2019:

- people living with dementia will have access to post-diagnostic support from a primary care setting
- people living with dementia and carers will experience high quality post-diagnostic support from a primary care setting, and
- staff within these sites will have improved knowledge, understanding and confidence in supporting people living with dementia and carers.

We are supporting the test sites to use quality improvement tools to ensure there is a clear structure for capturing the learning and value of delivering post-diagnostic support from a primary care setting. NHS Education for Scotland are supporting the sites' educational needs. Each site is taking a different approach to delivering post-diagnostic support in their setting.

About the test sites

Nithsdale (Dumfries and Galloway) cluster includes GP practices working across 14 surgeries. The population in the Nithsdale cluster is 59,217 people; of these, 593 people currently have a diagnosis of dementia in this GP cluster.³ Nithsdale is changing its system to ensure GPs can have direct access to post-diagnostic support services for their patients and are supporting GPs to diagnose dementia rather than referring all cases to Community Mental Health. Initially, the focus is on one practice, Gillbrae, before rolling out to other practices. An occupational therapy assistant is now based in Gillbrae to support post-diagnostic support delivery.

North East Edinburgh cluster includes eight GP practices from Leith Walk to The Inch. The population in the North East Edinburgh cluster is 57,724 people; of these, 740 people currently have a diagnosis of dementia.⁴ North East Edinburgh cluster has employed a dementia service facilitator to support people who are worried about their memory following a diagnosis of dementia and plan to run post-diagnostic support group work sessions for people and their carers. They are currently testing post-diagnostic support group work sessions for people and their carers from the GP surgeries and are also keen to make their GP practices dementia friendly.

Shetland cluster involves all 10 GP practices in NHS Shetland. The population is 23,000; of these, 170 people currently have a diagnosis of dementia.⁵ NHS Shetland has seconded an occupational therapist into Scalloway Health Centre to:

- co-ordinate delivery of post-diagnostic support from primary care
- raise awareness of post-diagnostic support with staff and public
- improve access, uptake and quality of post-diagnostic support generally, and
- incorporate home-based memory rehabilitation as part of the post-diagnostic support offer.

Face-to-face workshop with all three test sites in Edinburgh, September 2017



Dementia friendly GP practices

We have linked up with the charity, Alzheimer's Society and their Dementia Friendly GP Initiative. Alzheimer's Society generously shared this work with the sites testing the relocation of post-diagnostic support in primary care and other interested parties through a WebEx on 29 November 2017.

Alzheimer Society has now shared their guide with Alzheimer Scotland and we are working together to adapt this for Scotland and plan to test this within our North East Edinburgh and Shetland cluster sites.



"I'm currently working with primary care to develop Dementia Friendly GP practices across the locality - the WebEx reminded me of the importance of having a person with dementia/carer to 'walk through' the practices to support this work."

"Documents provide evidence and support to assist practices to become dementia friendly."



"Learning about the multidisciplinary approach. Assessment and delivering news of diagnosis being done in the home. The role of the dementia guides."

"Well organised and run to time. I work in a very remote area where travel is prohibitively expensive. Access to examples of good practice and new ideas in short WebEx like these is essential to prevent professional isolation. Information excellent and well supported with evidence and demonstration of outcomes. As indicated particularly like the idea of Dementia Guides and the whole systems approach."

"Learning more about the model and feeling inspired by best practice."

"Hearing positive focused work in these current times and seeing how GPs are willing to be more flexible about the consultations they provide and recognising that people with communication support needs require longer appointments."

"I think we don't sell ourselves well enough in Scotland! This service was effectively developed by commissioners. We don't have that model here - and it is more difficult for those actually delivering the services to take time out to reflect on and share their good practice."

The Golden Ticket Webinar: a primary care dementia model

On 19 March 2018, over 50 people joined the WebEx: The Golden Ticket: a primary care dementia model hosted by the Focus on Dementia team. Dr Emma Costello and Kim Grosvenor of High Weald, Lewes Havens, Clinical Commissioning Group in East Sussex, delivered a presentation about their award winning initiative to support people living with dementia which originated from a GP-led pilot in Buxted Medical Practice. The Golden Ticket delivers a holistic mix of services to address health and wellbeing, supporting people living with dementia and their carers in every aspect of their lives.

Everyone who joined the WebEx said they had improved their knowledge and understanding of making improvements to dementia care and support in primary care; 83% of delegates said the learning and sharing from the WebEx will support them in their practice.

To listen to the WebEx, please visit:
[www.knowledge.scot.nhs.uk/
supportingpeopledementia/resources.aspx](http://www.knowledge.scot.nhs.uk/supportingpeopledementia/resources.aspx)

Acute care

People living with dementia are more likely to be admitted to hospital than people without dementia due to coexisting conditions and/or secondary complications of dementia such as falls, fractures and infections. People living with dementia over the age of 65 occupy an estimated 25% of acute beds. When admitted to acute care they tend to have a longer length of stay, have adverse outcomes such as falls, pressure ulcers and infections, and are more likely to be discharged to a care home.⁶ Commitment 7 of Scotland's third dementia strategy focuses on supporting improvements in acute care across Scotland.¹

Commitment 7

We will continue to implement national action plans to improve services for people with dementia in acute care and specialist NHS care, strengthening links with activity on delayed discharge, avoidable admissions and inappropriately long stays in hospital.

We have been working in collaboration with NHS Grampian to understand the critical success factors for improvement dementia care within an acute general hospital. The findings from our report, Identifying Critical Success Factors for Improved Outcomes for People with Dementia and their Carers in Acute Care: a Focus on NHS Grampian, have been published and are available on the ihub website; the report has been downloaded over 200 times since its publication: <https://ihub.scot/media/2298/20170523-fod-grampian-report-1-0-web.pdf>

The work has received much interest locally in NHS Grampian and has featured in the local media and was nominated for an Aberdeen City Health & Social Care Partnership award. It has also featured on a number of blogs, including the Let's Talk about Dementia Blog (<https://britishgeriatricsociety.wordpress.com/?ref=spelling>), which was viewed by 112 people and the British Geriatric Society Blog (<https://letstalkaboutdementia.wordpress.com/>).

The work has also been shared at numerous events, including:

- poster presentation at Dementia Champions Graduation Event (14 March 2017)
- workshop at Focus on Dementia Conference (10 May 2017)
- oral presentation at Alzheimer Europe Conference (2-4 October 2017)
- keynote presentation at Newcastle Trust Dementia Conference (6 February 2018)
- poster presentation at National Conference and Dementia Champion Graduation (14 March 2018)
- oral presentation at Nordic Countries Dementia Seminar (10 April 2018)
- poster presentation at Scottish Caring and Dementia Congress (18 April 2018), and
- poster presentation at NHSScotland 2018 Event (18-19 June 2018).

The report is also available in print format and has been distributed widely across Scotland to partners and at events. The report has received positive feedback about how it has increased knowledge and may contribute to positive experience and outcomes for people living with dementia.



"This report gave me a greater insight into their world and what works when supporting people with dementia."

"I have had positive feedback from others saying it has improved their knowledge."

"The report was very helpful for me in gaining insight into how work against the 10 care actions is being supported within the acute."

"It is a nicely presented book that can be shared with senior charge nurses and dementia champions to aid their understanding of the 10 care actions."

Specialist Dementia Units

Across the NHS in Scotland, patients are admitted to Specialist Dementia Units for further assessment or treatment of their symptoms associated with a dementia diagnosis. In 2015, Scottish Government identified 92 units across Scotland with approximately 1,800 beds.

Commitment 7 of Scotland's third dementia strategy focuses on improving specialist NHS care for people living with dementia.¹

Commitment 7

We will continue to implement national action plans to improve services for people with dementia in acute care and specialist NHS care, strengthening links with activity on delayed discharge, avoidable admissions and inappropriately long stays in hospital.

We are working with Specialist Dementia Units across Scotland to improve the experience and quality of care for people within Specialist Dementia Units by adopting a demonstrator model approach with four Specialist Dementia Units to:

- understand improvement priorities relevant to local context and support improvements, and
- establish a learning and improvement network for all Specialist Dementia Units in Scotland to share good practice across all Specialist Dementia Units and to enable staff to connect with each other.

Through experience based co-design approaches, using observation, interviews and other participatory approaches, including co-design events, each of our four demonstrator sites have identified their improvement priorities. These include:

- activity
- building a resilient team
- stress and distress
- handover/staff communication
- mealtimes
- environment, and
- information for carers.



The next phase of this work will be to support these improvements in practice and to share learning. We will continue to build on the momentum of our learning and improvement network to connect practitioners across Scotland to share good practice and spread the learning.

Outcomes for this work

- Specialist Dementia Unit demonstrators have now identified their improvement priorities based on staff, patient and carer experience and observation (using experience based co-design approach). The priorities include stress and distress; activity; mealtimes; environment; team development, and information for carers and families.
- By March 2019, Specialist Dementia Unit demonstrator sites will be continually improving to support improved outcomes for people living with dementia and carers.
- By March 2019, staff within Specialist Dementia Unit demonstrator sites will have improved knowledge, understanding and confidence in supporting people living with dementia and carers.

Palliative and end of life care

As the numbers of people living with dementia increase, the proportion of people dying with dementia will also grow. Advanced dementia presents the most complex phase of the illness and needs a co-ordinated and planned approach to care.⁷ Inequality in the provision of palliative and end of life care for people with dementia is well evidenced.

- Two in every five people with dementia die in hospital.⁸
- Three quarters of people with dementia have been shown to have at least one emergency department attendance in their last year of life and 44.5% in the last month.⁹
- There is a growing evidence base which suggests that people with dementia are not being appropriately identified for end of life care, and that they have less access to, and receive poorer quality, care than people with other terminal illnesses.¹⁰

Scotland's third dementia strategy features palliative and end of life care for the first time and sets out the following commitments:¹

Commitment 5	We will test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model.
Commitment 6	We will work with stakeholders to identify ways to make improvements in palliative and end of life care for people with dementia.

We are working with Healthcare Improvement Scotland's Living Well in Communities team to support these commitments. Work to test and evaluate Alzheimer Scotland's Advanced Care Dementia Palliative and End of Life Care Model is under way within one care home setting in Dundee.

This work will also support Commitment 1 of Scotland's Strategic Framework for Action on Palliative and End of Life Care 2016-2021.¹¹



Testing the value-based global standard set for dementia

We are working with colleagues in Dumfries and Galloway and occupational therapists from Home Based Memory Rehabilitation Services in Scotland to test the first global standard set for dementia. The development of the standard set was led by Scottish Government and the International Consortium for Health Outcome Measurement.

Through this work, we aim to learn about the experience of practitioners using the standard set to support improvement in dementia care. In collaboration with the International Consortium for Health Outcome Measurement, we held an event on 26 April 2018 to share our learning from this work. Guest speakers who have had experience of testing the standard set within NHS England in Doncaster and University of Manchester joined us to share their progress and learning.

Outcome for this work

- By March 2019, our aim is that teams will have tested elements of the standard set to provide insights into the impact of post-diagnostic support on the quality of life of carers and cognition of people living with dementia.

Panel discussion chaired by Dr Brian Robson (Healthcare Improvement Scotland) at the Focus on Dementia event in May 2017



Sharing practice, knowledge and resources

Our networks

Networks are increasingly being used in health and social care to connect staff working in a specific area of practice. We are working with NHS Education for Scotland and Alzheimer Scotland to develop and support two networks. Our aim is to build communities of staff, with a common purpose and expert knowledge, who can connect with each other, through networking, information exchange, learning and improvement. We use a range of methods to support our network activity, including online forums for discussion and information, newsletters and face-to-face opportunities through regional and national events.

Specialist Dementia Units Learning and Improvement Network

This network is for staff who work in the 92 Specialist Dementia Units in Scotland. Our network activity to date includes:

- an online forum (60 members)
- an email distribution list (257 members)
- three regional events, and
- a national event focusing on topics identified as priorities by network members.

Post-Diagnostic Support Network

This network is for dementia link workers and other staff who provide post-diagnostic support. Network activity to date includes:

- a newsletter, currently received by 130 post-diagnostic support practitioners
- face-to-face events - 47 practitioners attended our recent technology workshops, and
- regular online meetings each year open to anyone interested in post-diagnostic support
 - 50 professionals attended our most recent online meeting.

Celebrating Practice and Network Event

On 5 October 2017, we ran an event in partnership with NHS Education for Scotland and Scottish Government, where 150 Specialist Dementia Unit staff attended the Specialist Dementia Units - Celebrating Practice and Network Event in Stirling. Maureen Watt MSP, Minister for Mental Health, made a keynote speech and was able to view some of the 32 Specialist Dementia Unit posters. Specialist Dementia Unit staff also presented seminars on their work with seven concurrent sessions:

- person-centred interventions
- stress and distress
- improving practice and care
- systematic change and improvement
- Specialist Dementia Unit demonstrator sites
- complex physical care needs, and
- working in partnership.

The programme concluded with a panel discussion chaired by Michelle Miller (Healthcare Improvement Scotland) involving Hugh Masters (Scottish Government), Maureen Taggart (Alzheimer Scotland), Susanne Forrest (NHS Education for Scotland) and Stephen Lithgow (Healthcare Improvement Scotland).

From 31 conference attendees who responded to our evaluation survey, the event was rated 4.5/5 in terms of overall conference rating and 4.3/5 in terms of networking opportunities (with 1 being the lowest and 5 the highest).



“Found the event useful and informative.”

“Excellent, my knowledge has been noticeably enhanced.”

“I found the Erskine concurrent session really interesting.”



Poster presentation



Panel discussion

Confident Conversations about Technology Workshop

We worked with partner organisations, including Alzheimer Scotland, Scottish Fire and Rescue, and industry colleagues to offer a workshop aimed at post-diagnostic support link workers, post-diagnostic practitioners and others who support people living with dementia and their carers following a diagnosis of dementia.

Through a mix of practical and theoretical sessions, the workshop enabled practitioners to have confident conversations to support people to make future plans to include the use of technology.

Highlights

- Thirty-three practitioners attended the workshop from all over Scotland, including link workers, community psychiatric nurses and allied health professionals.
- Presentations from people with lived experience, Alzheimer Scotland, Scottish Fire and Rescue and industry.



“I feel more informed and optimistic about people having options for safety at home, allowing people to feel empowered.”

“Can’t believe the fantastic technology available.”

“Seeing videos today has made me realise people with dementia can learn new skills.”

“I feel much more able to advise my patients/families on options to minimise risk of increased dependence.”

“Feel better equipped to advise people having seen the examples.”

“This has super boosted my current knowledge of dementia.”

“I pledge to share my learning with my colleagues and use this to promote the use of technology as an intervention/way of improving quality of life.”

“I pledge to talk to people about technology within the context of their person plan.”



Staff working within Specialist Dementia Units receiving their 'Playlist for Life Establishment' awards



Playlist for Life

In supporting improvements in post-diagnostic support and Specialist Dementia Units, Focus on Dementia has been working with Playlist for Life to support personalised music as part of a range of therapeutic interventions to improve the experience of people living with dementia. As a result of this learning:

- a bespoke Playlist for Life training session has been developed for post-diagnostic support practitioners, and
- 10 Specialist Dementia Units across Scotland have become official 'Playlist for Life Establishments'.

Positive feedback has been received from staff involved in this work who are now continuing to identify appropriate opportunities to include Playlist for Life as part of a range of therapeutic interventions to improve the wellbeing of people living with dementia.



“Playlist for Life were delighted to have the opportunity to work in partnership with Healthcare Improvement Scotland. With their support, we delivered three cohorts of certified training during 2017 across many of the NHS boards in Scotland. A joint award ceremony followed, with 10 sites being registered as Playlist for Life Establishments. The partnership with Healthcare Improvement Scotland was vital in making this a success. Thanks to Michelle Miller and her team for all their help and support. The Specialist Dementia Units who took part in this project are now integrating playlists into care, helping to improve the wellbeing of people living with dementia.”

– Playlist for Life

National events



“It was an absolute pleasure to be involved with this very important event, and also meet members of the Focus on Dementia team. The staff I have met show a genuine commitment and excellent value base in their interactions which I observed repeatedly throughout the day. You all deserve a ‘well done’ as the planning and organisation of such a positive day takes a great deal of organising and real team work.” – Maggie Muir, NDCAN

“The event was fantastic and extremely motivating.”

“Excellent speakers. Excellent posters and a great chance to network.”

“Thanks to everyone involved in today’s event. Great mix of presenters and presentation styles! Brilliant day.”

Over the last year, we held a series of national events to support sharing of good practice. These received wide geographical representation from across Scotland, across different professional groups, from other partner organisations, and people living with dementia and carers.

Focus on Dementia: Making Strategy a Reality – May 2017

Alongside our partner organisations, including Alzheimer Scotland, NHS Education for Scotland, Scottish Government, The Alliance, Scottish Social Services Council, Care Inspectorate, Scottish Care, housing colleagues and Health and Social Care Partnerships across Scotland, we hosted a national event on 10 May 2017 at the Crowne Plaza Hotel, Glasgow. The event, co-chaired by Maggie Muir, National Dementia Carers Action Network (NDCAN) and June Wylie, Healthcare Improvement Scotland, showcased the work of Focus on Dementia, our partner organisations and other dementia initiatives. Over 240 delegates gathered together from Health and Social Care Partnerships to share experiences and best practice along with people living with dementia and carers.



Dementia Parliamentary Reception – November 2017

On 23 November 2017, we hosted, in partnership with Alzheimer Scotland, a reception at the Scottish Parliament. Attendees had the opportunity to hear, through a panel discussion, how we are working in partnership to support the implementation of Scotland's third dementia strategy. The reception opening address was given by Maureen Watt MSP, Minister for Mental Health, and the panel, chaired by Dr Dame Denise Coia, Healthcare Improvement Scotland, included representation from the Scottish Dementia Working Group and the National Dementia Carers Action Network. The evening was rounded off by a performance by the Musical Memories Choir from Hamilton who had the audience clapping and singing along!



Musical Memories Choir, Hamilton,
performing at the Parliamentary Reception

Improving Co-ordination . . . Improving Care Event - February 2018

On 22 February 2018, 200 delegates, including Health and Social Care Partnership staff, housing colleagues, partner organisations and people with lived experience came together to learn and share best practice in integrated care co-ordination models to support people to live well in the community. Through a range of presentations, workshops and panel discussions, attendees:

- heard about people's experience of care co-ordination in the community
- shared good practice examples of care co-ordination in the community
- learned practical approaches to improving care co-ordination, and
- networked with delegates to learn from their experiences of care co-ordination.

Key messages from the day

- Improving co-ordination does improve lives, including clinical outcomes.
- Importance of relationships, trust, values and the person at the centre.
- Listening to and valuing the experiences of people, their families and carers.
- Importance of home and local community assets.

Of those who responded to our event's evaluation survey, 97% said they had improved their knowledge and understanding of care co-ordination and that this would help inform their practice.



- “Networking.”
- “Good networking time.”
- “Hearing of other projects.”
- “Workshops were inspiring.”
- “Some very informative workshops.”
- “Great speakers and lots of variety.”
- “Variety of presentations.”
- “Listening... to those with lived experience.”
- “Discussions were informative.”



Pat Barrett (Scottish Dementia Working Group), Thea Laurie (National Dementia Carer Action Network),
Sue Lavery (The Alliance), Barbara Sharp (Alzheimer Scotland) and June Wylie (Healthcare Improvement Scotland)

Stephen Lithgow (Healthcare Improvement Scotland)
visiting Tokyo Metropolitan Institute of Gerontology



Global reach

Sharing of good practice goes beyond our colleagues in Scotland and, in the last year, we had the opportunity to share our work with colleagues in other countries through international webinars, presentations, meetings and events.

Collaboration with Japan - February 2017

In February 2017, as part of a Scottish Government delegation, Stephen Lithgow presented on Scotland's dementia strategy, Focus on Dementia and post-diagnostic support at an event at the British Embassy in Tokyo with 90 regional dementia stakeholders from across Japan. Together with Dr Shuichi Awata (Tokyo Metropolitan Institute of Gerontology) and Dr Louise Ritchie (Stirling University Dementia Centre), Stephen also undertook two seminars with 80 inpatient and community dementia staff and researchers at the Tokyo Metropolitan Institute of Gerontology. This focused on Scotland's post-diagnostic support and City Dementia Strategies (Glasgow City Dementia Strategy).

Subsequently, Stephen helped support Professor Akiko Tajima, Occupational Therapist, Tokyo and Japanese colleagues to visit dementia initiatives in Scotland, including a visit to the 415 Housing and Technology Project. In April 2017, staff from the institute also visited Julie Miller and Michelle Miller of Focus on Dementia to discuss the Quality Improvement Framework for Post-Diagnostic Support.

In May 2017, Michelle Miller presented at the Alzheimer Disease International Event in Tokyo, sharing learning from testing the Alzheimer Scotland 8 Pillars model and contributing to an international pre-event session to discuss models of care co-ordination.

Cesar Rodriguez (Healthcare Improvement Scotland) at the Alzheimer Europe Conference

Lynn Flannigan (Healthcare Improvement Scotland) at the Alzheimer Europe Conference

Alzheimer Europe Conference, Berlin: 'Care today, cure tomorrow' - October 2017

The Focus on Dementia team presented our work at the Alzheimer Europe Conference in 2017. This annual conference brings together all types of people who are affected by dementia - living with the disease, caring for someone with the disease or working in the field of dementia - and gives delegates the opportunity to share and exchange their experience and knowledge. Speakers from different EU Member States and further afield, share varying approaches and developments from their countries. Julie Miller presented a poster on "A Quality Improvement Framework for Post-Diagnostic Support", Lynn Flannigan presented an oral presentation on "Identifying Critical Success Factors which Lead to Improved Outcomes for People with Dementia, Carers and Staff in Acute Care", and Cesar Rodriguez presented an oral presentation on "Adults with Incapacity (Scotland) Act 2000. Improving Knowledge and Compliance in Acute Hospitals in Tayside".



Webinar: International Perspectives on Supporting People with Dementia and Caregivers – January 2018

Michelle Miller, Portfolio Lead for Focus on Dementia, presented to 966 people from across USA, Canada, New Zealand, India, Australia, Singapore, Romania, Argentina, the UK and Ireland. The webinar, International Perspectives on Supporting People with Dementia and Caregivers, was held on 30 January 2018. This invitation to present was following publication of an article that Michelle had written in the Generations Journal for the American Society on Aging.¹³

In the webinar, Michelle talked about the dementia context in Scotland and how Focus on Dementia is supporting the implementation of the dementia strategy into practice. This was part of the National Alzheimer's and Dementia Resource Center USA webinar series in collaboration with the Administration for Community Living in USA and American Society on Aging. To listen to the webinar, please visit: <https://lnkd.in/dieUFBD>

Collaboration with Nordic Dementia Network – Stockholm, April 2018

Focus on Dementia was asked to present the Scottish Dementia Policy content and our contribution to its delivery at the Nordic Dementia Network in Stockholm on 10 April 2018 on behalf of the Nordic Welfare Centre.

The Nordic Welfare Centre is a Stockholm and Helsinki-based institution under the Nordic Council of Ministers. Their mission is to enhance social policy work in the Nordic countries through communication, research and development, networking and international co-operation. As part of this work on behalf of the official Nordic government co-operation, Nordic Welfare Centre co-ordinates a Nordic network of senior officials and national experts on dementia.

The 17 network members represent the health and social authorities and national expert institutions in all five Nordic countries and three self-governing areas. The network was interested in learning more about the Scottish dementia strategy and especially how the Scottish authorities are working with strategy implementation and improvement through the ihub's Focus on Dementia portfolio.



Lynn Flannigan attended on behalf of the Focus on Dementia team and was able to share policy and practice with colleagues from the five Nordic countries and was also able to attend a site visit to Silviahemmet, which is a non-profit foundation devoted to improving the quality of life for people living with dementia and their families. Silviahemmet provides day care opportunities for people living with dementia and also provides non-academic education programmes.

Raising awareness of dementia at Healthcare Improvement Scotland

We held a variety of sessions to raise awareness of dementia for Healthcare Improvement Scotland staff during Dementia Awareness Week in June 2017 and World Alzheimer's Disease month in September 2017. These included:

- NHS Education for Scotland's Promoting Excellence Informed Level training sessions delivered by Julie Miller and Irene Robertson from Healthcare Improvement Scotland
- Dementia Friends sessions delivered by Anne McWhinnie and Fiona Kane from Alzheimer Scotland, and
- presentations by Tommy Whitelaw from Dementia Carer Voices (The Alliance).

Sessions were held across both our Glasgow and Edinburgh offices. More informally we held 'tea and blether' sessions where we raised dementia funds and turned the staff room in Delta House purple! The Minister for Mental Health, Maureen Watt MSP, attended the tea and blether in the Edinburgh office where they were treated to a performance by Healthcare Improvement Scotland's Big Sing choir.



"Thanks very much to you and the team for organising this session, it makes such a difference when you hear how our work touches so many people. You guys should feel proud."

"I enjoyed the dementia friends session enormously. Tommy Whitelaw was very emotional and I was wrung out by the end."

"I really enjoyed the session and found it interesting and practical for both my professional and personal life. Thanks."

"I think one of the most 'sticky' points from this was the analogy of the bookcase and losing shelf after shelf so that only your oldest memories were left."

Tommy Whitelaw asked staff to make a pledge to make a difference for people living with dementia; here is what some people said:

- I pledge to get involved in local organisations to use some of my spare time to visit people who feel alone or isolated. I want to make a difference.
- I pledge to take my mum to Millport to re-ignite those memories and share together.
- I will remember that the work I do affects people's lives.
- I pledge to find local organisations and get my mum more involved in the community.
- I pledge to do everything I can to make a difference.
- I pledge to ensure that equity is at the heart of all the work I am involved with.

Read more about our pledges at:

<https://dementiacarervoices.wordpress.com/2017/09/12/healthcare-improvement-scotland-launch-pledge-trees/>



Staff at Healthcare Improvement Scotland following completion of their dementia friends training with Anne McWhinnie (Alzheimer Scotland)



Michelle Miller (Healthcare Improvement Scotland) with Dame Dr Densie Coia, Chair of Healthcare Improvement Scotland Board, with Maureen Watt MSP, Minister for Health and Robbie Pearson, Chief Executive of Healthcare Improvement Scotland during Ms Watt's visit to during Dementia Awareness week of 2017



Next steps

In the year ahead, we will continue to work in partnership with other national organisations and with people living with dementia and carers to continue to achieve the following.

- By March 2019, Specialist Dementia Unit demonstrator sites will be continually improving to support improved outcomes for people living with dementia and carers.
- By March 2019, staff will be using the Quality Improvement Framework for Post-Diagnostic Support as a self-assessment tool to support improved quality of post-diagnostic support.
- By March 2019, teams will have tested and evaluated the International Consortium for Health Outcomes Measurement dataset in order to understand the impact of post-diagnostic support on the quality of life of carers and cognition of people living with dementia.

Outcomes for this work

- By March 2019, staff will have increased access to information on good practice in dementia care.
- By September 2019, staff will have improved knowledge, understanding and confidence in supporting people living with dementia and carers.
- By September 2019, people living with dementia will have access to post-diagnostic support from a primary care setting.
- By September 2019, people living with dementia and carers will report experiencing high quality post-diagnostic support from a primary care setting.

You can follow our progress and activities by visiting the ihub website: www.ihub.scot

Twitter: [@FocusOnDementia](https://twitter.com/FocusOnDementia)

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