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National Dementia Dialogue 2015
NationalDementiaDialogue2015ConsultationPaper@gov.scot

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To whom it may concern

The Royal College of Nursing (RCN) is the UK's largest professional association and union for nurses with around 420,000 members, of which around 40,000 are in Scotland. Nurses and health care support workers make up the majority of those working in health services and their contribution is vital to delivery of the Scottish Government's health policy objectives.

The RCN welcomes the opportunity to respond to this consultation. We have focused this response on some of the themes raised within the consultation paper which are relevant to our members.

Integrated support at home

Developing care and support which is appropriate to meet the needs of people with dementia is a challenge with which health and social care services must grapple.

RCN supports the work by Alzheimer Scotland to further develop their model for dementia support within an integrated health and social care system. We agree that 'The integration of adult health and social care provides an opportunity to coordinate the interventions required to support people with dementia and their carers in the community.'¹

Dementia-specific home based care is a positive step to ensure person-centred and appropriate care is available for people with dementia in the community. We support in principle the 8 Pillars model, and would be interested in information on the impact and learning from the five pilot sites in order to fully understand and make comment on its benefits.

¹ Alzheimer's Scotland. 2015. 8 Pillars of Community Support
[http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.p
df](http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf)

The Principles for Planning and Delivering Integrated Health and Social Care² are intended to be the driving force behind the changes in culture and services required to deliver integration reforms successfully and improve outcomes. It is important that the implementation of the 8 Pillars model reflect these principles to ensure quality and safety of care, and align with national policy and the strategic aims of local Integration Authorities (IAs).

The consultation paper proposes that the post-diagnostic dementia link workers currently located in integrated community mental health teams should move into primary care, as part of primary care based memory clinics. As these are to be tested through the Primary Care Transformation Fund, we assume that the proposal is for the clinics and link workers to be located in general practice. We agree that the location of these clinics should be in primary care services (defined more broadly to include other community based care), but not necessarily within general practice. Because IAs will be the organising body for the majority of community based health and social care in the future, it is our view that the decision on location of the memory clinics should be the responsibility of the IAs in order to maximise connections across the rest of health and social care within their local area.

Palliative care

Palliative care is an approach that is used not only at the end of life, and should be provided alongside active treatment where appropriate. Further, much of the palliative care received by people with dementia is delivered not by specialist staff but as part of general care. Within the new Framework for Action on Palliative and End of Life Care³, the government has committed to the development of an Educational Framework by NES and SSSC; this provides an important opportunity to shape the future of palliative care training and ensuring all staff have access to the skills and resources they need to deliver palliative care to people with dementia.

When RCN surveyed our members about end of life care in 2014, we found that nursing staff want more education and information in this area of practice. In response we developed an online learning resource on the fundamentals of caring for people at the end of life, with an additional resource on nutrition and hydration, which was one of the areas where our members felt they needed more specific guidance⁴. We recommend use of these resources to support nurses and health care support workers in delivering end of life care.

Anticipatory care planning is an increasingly important part of care, and for people with life limiting illness is critical to ensure the care and support they receive reflects what matters to them. When working with people with dementia, it is particularly important that staff have the tools and training to identify the person's preferences and understand capacity in order to support ongoing care planning.

Workforce development

It is vital that all those who support people with dementia, including nurses, have an understanding of dementia and the impact the condition has on the individual and their families. The challenge in developing and upskilling workforces in line with *Promoting Excellence*⁵ will be in ensuring all the right staff have been targeted and training delivered.

² Scottish Government. 2014. Principles for Planning and Delivering Integrated Health and Social Care <http://www.gov.scot/Resource/0046/00466005.pdf>

³ Scottish Government. 2015. Strategic Framework for Action on Palliative and End of Life Care <http://www.gov.scot/Publications/2015/12/4053>

⁴ RCN. 2015. Online learning resource: Getting it right every time <http://rcnendoflife.org.uk/>

⁵ Promoting Excellence Framework - <http://www.gov.scot/resource/doc/350174/0117211.pdf>

The *Triangle of Care – carers included: A guide to best practice for dementia care in Scotland*⁶ is one practical tool which was co-designed by carers, people with dementia and practitioners to help professionals and commissioning organisations put overarching dementia policies into context in order to provide better and more person-centred care for people with dementia. It describes a therapeutic relationship between the person with dementia, staff member and carer that promotes safety, supports communication and sustains wellbeing. As the 3rd Dementia Strategy continues the previous Strategy's work of improving staff knowledge and skills, this tool can help to embed dementia-appropriate approaches.

While the paper notes the significant role of allied health professionals in supporting implementation of the 3rd Dementia Strategy, nurses and health care support workers are the biggest health workforce and play an enormously important role in the care of people with dementia. To ensure people with dementia receive the best possible care, the new dementia strategy should consider the broad requirements of the nursing workforce with regard to training and dementia friendly environments and working processes in which to practice.

In particular, as better approaches to dementia care and support enable more people to live at home, more people with dementia will access district nursing services. As such, the 3rd Dementia Strategy should take into account the report and recommendations of the Chief Nursing Officer's Review of District Nursing, due to report in April.

Acute general hospital care

Access to dementia specialist nurses in an acute setting can deliver substantial benefits for people with dementia and their families⁷ where the specialist role is well designed, the post holder appropriately trained and strong leadership provided by health and social care organisations.

However it is also important that all staff working in acute settings understand and can respond to the needs of people with dementia. In recognition of the importance of getting acute care right for people with dementia, RCN has developed the *SPACE Principles* which are designed to ensure all people with dementia in hospital settings receive appropriate care⁸. The principles identify the essential factors for good dementia care: staff who are skilled and have time to care; partnership working with carers; assessment and early identification of dementia; care plans which are person centred and individualised; and environments that are dementia friendly. We recommend the principles and associated resources as effective and well evaluated tools which can help implement better dementia care in general hospital settings.

Care homes

The care home sector will also need to adapt in order to better care for an ageing population with more complex conditions including dementia. The RCN, along with other key

⁶ Royal College of Nursing. 2015. Triangle of Care – carers included: A guide to best practice for dementia care in Scotland. Developed in partnership with Carers Trust Scotland, NHS Greater Glasgow & Clyde, University of Stirling Dementia Services Research and Dementia Carers Voices

⁷ Royal College of Nursing and University of Southampton. 2013. Dementia development programme – Evaluation summary report
http://www.rcn.org.uk/_data/assets/pdf_file/0006/577176/RCN_Dementia_Development_programme_Evaluation_summary_report.pdf

⁸ Royal College of Nursing. 2011. SPACE Principles <https://www.rcn.org.uk/clinical-topics/dementia/professional-resources>

stakeholders, joined with the Scottish Government and COSLA to form the Taskforce for the Future of Residential Care in Scotland⁹. Its 2014 report made a series of recommendations including person-centred services and development of new accommodation that is more tailored to care needs, better partnership working, and ensuring that the workforce is adequately trained to respond to higher levels of dementia.

The report provides recommendations on how to design high quality care home services and workforce in the future. These recommendations should be taken into account as the 3rd Dementia Strategy is developed, and in the implementation of the 8 Pillars model.

As noted in the consultation paper, overuse of psychoactive medication for people with dementia continues to be a problem and more training for staff on how to manage stress and distress without antipsychotics would help reduce inappropriate prescribing.

Implementation of the 8 Pillars and Dementia Strategy

The 8 Pillars model and 3rd Dementia Strategy will be launched in the context of serious resource pressure. While the delivery of better care and support for people with dementia and other long term conditions must be a priority for health and social care, it must also be deliverable. It would be helpful to include comment in the final strategy on how the proposed reforms will be implemented within the context of current service delivery.

We welcome the opportunity to respond to this consultation and support the approach described by the consultation paper. We would be happy to support the government and Alzheimer Scotland as you further develop your approach to improving care for people living with advanced dementia.

For further information or to discuss any of the points raised please contact Alice Gentle on 0131 662 6177 or at alice.gentle@rcn.org.uk.

Yours sincerely,



Theresa Fyffe
Director

⁹ Scottish Government. 2014. Residential Care Taskforce Report
<http://www.gov.scot/Resource/0044/00444581.pdf>