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# Leadership and innovation in hospital care: Alzheimer Scotland Dementia Nurse Consultants report 2015–2020

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Priorities and actions 2019–2020

Joint Scottish Government and  
Alzheimer Scotland publication



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**Henry Simmons**  
Chief Executive, Alzheimer Scotland

It is quite remarkable to see how much progress has been made within the acute care environments of our NHS. Much of this is because of the dedication and leadership of the Alzheimer Scotland Dementia Nurse Consultants and the sustained partnership and joint investment in this work between the Scottish Government, NHS Boards and Alzheimer Scotland. Of course, the work of the Nurse Consultants is one part of a substantial improvement programme that includes our Allied Health Professional Consultants, the ever-growing and critical role of the Dementia Champions who are part of the highly successful overall Promoting Excellence Programme and indeed the senior leaders who support the Consultants locally and who ensure that we maintain momentum towards delivering on the 10 Dementia Care Actions. There are many other partners and professionals who support this work without whom we would not be achieving such good progress, however the work of the Scottish Dementia Working Group and the National Dementia Carers Action Network must be acknowledged as one of the most important contributions. Their commitment, experience and support has been central to the development and evolution of this work from the outset.

It is inevitable that, when you seek to improve the experience for people with dementia in acute hospital wards, many other factors will come into play and need to be considered. As the report highlights, issues such as delayed discharge, unplanned admissions and indeed the ongoing pressures on all aspects of the NHS will have an important impact. However, the essence of this work and the reason for the joint investment has always been about ensuring the highest quality of hospital experience for the person with dementia and their families as is possible. In this regard there is no doubt that we have made significant progress however, given the size and scale of the challenge, much remains to be done and this report helpfully sets out a vision for moving forward.

On behalf of Alzheimer Scotland, our members, supporters and donors we are delighted to see the outcomes of this work and we would wish to thank all the Nurse Consultants and the local and national teams that have made this possible. We are also extremely grateful to our NHS colleagues and the Scottish Government for their ongoing commitment to jointly fund this work in partnership with us. It has been a highly effective collaboration which, as the report highlights, is delivering tremendous outcomes and enormous value and one we hope will continue long into the future.



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**Clare Haughey MSP**

Minister for Mental Health, Scottish Government

Improving dementia care in acute NHS settings has been an important part of all of the Scottish Government's three National Dementia Strategies and associated work.

We know that at any one time around a quarter of acute hospital beds are occupied by people over 65 who have dementia. Getting the service response right every time for people with dementia who require a hospital admission remains a central part of our shared national work – not only to ensure that the person feels better supported but also so that people are cared for in a timely, effective and person-centred way when they need care and treatment in acute hospital care.

The result of a partnership between the Scottish Government, Alzheimer Scotland and NHS Boards, the Alzheimer Scotland Dementia Nurse Consultants (ASDNCs) has been important in driving strategic local change and improvement in this key area of dementia care. This report sets out achievements by the ASDNCs between 2015-2018 in areas such as helping to embed and lead expertise in dementia care and develop staff capability.

This work has been taken forward in tandem with the roll-out of the Dementia Champions programme which has now trained 950 staff, drawn from acute care and associated health and social services settings. Part of this is of course ensuring that health and social services staff are enabled to work together seamlessly so that when people with dementia are in hospital, they are discharged timeously and effectively with the right support in place.

This work supports other major priorities for the Scottish Government, such as continuing to tackle delayed discharge. The Older People Acute Hospital inspections also continue to play an important role in driving forward improvements in the care of people with dementia in hospitals. Starting in February 2012, 81 inspections have now been carried out, focussing on the quality of care provided for older people while they are in an acute hospital. Inspections include wide-ranging issues that matter most to patients – such as: privacy, dignity, compassion and respect while they are in hospital, as well as ensuring the right assessments and screening are carried out, including those on dementia and cognitive impairment.

All of this activity is complemented by our national investment in supporting delivery of the two national dementia workforce programmes; Promoting Excellence and Connecting People, Connecting Support, along with the national dementia services improvement programme; Focus on Dementia.

And, as with all of our national work on dementia, I cannot emphasise strongly enough the benefit we derive from the direct involvement of people with dementia and their carers and I thank them for their commitment, dedication and time.



**Henry Rankin**

Member, Scottish Dementia Working Group

As a national campaigning group of people with dementia, the Scottish Dementia Working Group (SDWG) feel strongly that people with dementia should have a positive experience when accessing hospital care. Central to this process should be good communication at all points.

Regardless of whether an admission is planned or is an emergency, it is essential that the person with dementia be kept up to date and made aware of what to expect at each stage. I have personally experienced how unsettling it can be when hospital staff do not take the time to engage with those they care for or introduce themselves, as it is often the smallest interactions that make the biggest difference. Fortunately, the Alzheimer Scotland Dementia Nurse Consultants (ASDNC) and the Dementia Champion programmes demonstrate the difference that can be made when staff are empowered to work in partnership with people with dementia. I have had the advantage of observing the difference first hand and feel passionately that both programmes can and do make a real difference to the lives of those with dementia.

It is important that all professionals in the field of dementia feel able to provide personalised and rights-based care. SDWG look forward to continuing to support ASDNC, Dementia Champions and the ongoing implementation of the National Dementia Strategy.



**Maureen Huggins**

National Dementia Carers Action Network

When I cared for my dad, who had dementia, my focus was on enabling my parents to continue to enjoy life together at home. Admission to hospital has the real potential to exacerbate a person's dementia. This happened in my family and led to a move to a long-term specialist unit in a nursing home and a premature death.

Since joining National Dementia Carers Action Network (NDCAN) in 2015, I personally have witnessed a vast improvement in the understanding of dementia by healthcare professionals through the Alzheimer Scotland Dementia Nurse Consultant role and the training of the Dementia Champions. It is heartening to see the inclusion of Allied Health Professionals in this programme so that rehabilitation can be accessed by someone with dementia. Another NDCAN member fed this back about acute care in 2017.

The care my dad received was outstanding. All the staff cared for him with kindness; one-to-one when necessary and prioritised settling him over intervention, whilst still treating, if possible. It was testament to all the good work that has been going on for years. The difference in our experience since the last admission over 18 months ago is breathtaking.

However, we hear also there are still problems and inconsistency with the hospital environment and wider system as well as a lack of one-to-one support and effective involvement of patients and family carers. This means that the patients' holistic needs are not always met. Good quality home and community support must be more readily available to help prevent health problem necessitating hospital treatment and to enable timely hospital discharge. I don't believe we are there yet in all areas but the presence of high-quality staff who are trained and experienced in dementia care and support has started us along the right road. We warmly welcome this report and the refocus on the 10 Acute Care Commitments going forward to continue that work.

# Summary of the Alzheimer Scotland Nurse Consultant group actions for 2019–2020

## Expert Practice

### Practice actions

- Getting to know me review – demonstrate personalised and rights-based care in practice
- Focus on preventing inappropriate admission and facilitating timely discharge
- Improving observation and engagement in hospital.

## Supporting delivery of Commitment 7 of the National Dementia Strategy 2017–2020

- Demonstrate leadership to support the development of an action plan for Commitment 7 of the third National Dementia Strategy
- Monitor progress – explore the value of a short, focused national audit of dementia care in hospitals
- Work with Scottish Government to refine the dementia benchmarking data
- Increase engagement with dementia improvement specialist leads, Allied Health Professionals and acute components of Commitment 7.

## Professional leadership & consultancy

## Education, training and development

### Education, training and development: the right workforce

- Review and assessment of progress with Promoting Excellence training to date including joint working with the Dementia Champions programme
- Identify priority areas for further Promoting Excellence training roll out in NHS boards.

## Practice & service development: research & evaluation

- Examine current best practice across mainland and island boards, to detail transferrable lessons learned to other boards
- Explore the possibility of a collaborative realistic evaluation project
- Explore the interface between acute general hospital care and specialist dementia care transformation work.

## Practice & service development

The purpose of this report is to set out a strategic plan and vision which outlines the main priorities, actions and Key Performance Indicators (KPIs) for the Alzheimer Scotland Dementia Nurse Consultant (ASDNC) group for the years 2019–2020. This is drawing on key achievements and impact areas from 2015–2018 and in line with both Commitment 7 of the third National Dementia Strategy (2017–2020) and the 10 Dementia Care Actions in hospital care. The report does not focus on local priorities for individual ASDNCs – these will be set as local needs dictate. The priorities identified here reflect the central funding (approx 33%) from Alzheimer Scotland and Scottish Government and what the ASDNCs will realistically aspire to deliver in 2019–2020.

This report sets out a direction of travel for the ASDNCs in 2019–20 in line with the timescales of the third National Dementia Strategy 2017–2020. It presents a summary of the work of ASDNCs in the period 2015–2018 and follows on from the previous report 'Shifting the paradigm together: Alzheimer Scotland Dementia Nurse Consultants and Allied Health Professional Consultants' report 2015<sup>1</sup>.

The report is set out in three parts:

- **Part 1** provides an evidence-based picture of hospital care for people with dementia and their families in Scotland
- **Part 2** highlights the impact of the ASDNCs since the last report in 2015
- **Part 3** sets out key national priorities and actions for ASDNCs in the next two years.

The ASDNCs will continue to work within their individual boards to deliver the 10 Dementia Care Actions in hospital, based on local needs and priorities. The actions in this report are actions for the ASDNCs to deliver, as an expert group that reflects the national funding support from Alzheimer Scotland and Scottish Government.

Dates and responsibilities are not included (but all are proposed to be completed by the end of 2020). A detailed action plan, with dates, will be developed alongside the report by the ASDNCs and regularly reviewed.

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<sup>1</sup>Alzheimer Scotland, 2015. Shifting the paradigm together: Alzheimer Scotland Dementia Nurse Consultants and Allied Health Professional Consultants  
[https://www.alzscot.org/assets/0002/1161/FINAL\\_AS DNC\\_and\\_AHP\\_Review\\_2014-15\\_\\_2\\_.pdf](https://www.alzscot.org/assets/0002/1161/FINAL_AS DNC_and_AHP_Review_2014-15__2_.pdf)

## Part 1:

# Where are we now? The national picture of hospital care for people with dementia



## The policy response

In 2009 the Mental Welfare Commission report<sup>2</sup> 'Starved of Care' looked into the death of Mrs V. highlighted key system and care failures in hospital care. A series of responses primarily aimed at general hospital care followed, one of which was the adoption of joint funding by Scottish Government of a network of ASDNCs to expand the provision into every NHS board.

The first Scottish Government National Dementia Strategy in 2010<sup>3</sup> noted that **'Too often admission to a general hospital led to unsatisfactory experiences for many people with a diagnosis of dementia and their family carers'** and included two key change areas to improve care:

1. Following diagnosis - by providing excellent support and information to people with dementia and their carers
2. In general hospital settings - by improving the response to dementia, including alternatives to admission and better planning for discharge.

The first National Dementia Strategy reflected the evidence that people with dementia and their families would only get the care they need in hospitals when there was a recognition that system changes would be required to the way that hospital care was delivered. Similarly, professionals and other paid carers would require the skills, knowledge and attitudes to allow them to deliver high quality dementia care. Previously professionals working in general hospitals did not anticipate that many, if not most, of the patients they would be caring for would be over 65 and have multiple pathologies, including dementia, and training and education reflected that perception.

This situation and the consequences were nobody's fault. It arose because of changes in demographics and service delivery systems that had perhaps not fully been reflected in professional education and workforce planning. The situation, nevertheless, needed to be repaired. This was, and remains, a key aspect and goal of the ASDNC programme in Scotland.

<sup>2</sup>MWC Summary investigation report, into the care and treatment of Mrs V.

<https://www.mwscot.org.uk/media/52055/Starved%20of%20care%20summary.pdf>

<sup>3</sup>Scotland's National Dementia Strategy <https://www2.gov.scot/Publications/2010/09/10151751/0>

Alongside the development of the ASDNCs, a further significant product of the first National Dementia Strategy was the publication of the 'Dementia Care Actions in Hospital' in 2013. These were developed collaboratively with a wide range of stakeholders and reflected the need to articulate the known aspects of care that would improve the experience of people with dementia and families. The 10 actions continue to be the focal point for all the work of the ASDNCs and other associated education, improvement and service delivery to the present day.

The second National Dementia Strategy, in 2014<sup>4</sup> set out for the first time to understand more fully the current provision of specialist dementia units and improve the care in those settings. The strategy also highlighted the key interface between general hospital care and specialist dementia units and the impact on transfers, readmissions and length of stay.

The third National Dementia Strategy, in 2017<sup>5</sup> continued this focus on improving the care of people with dementia in general hospitals and specialist NHS dementia hospital settings.

For the first time these two areas were brought together into one commitment:

**Commitment 7 of the National Dementia Strategy 2017-2020 states:**

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.

In relation to the 'acute care' focus of the dementia strategy and the role of the ASDNCs, it is important to be clear about the definition and parameters of 'acute care'. Acute care is evolving and increasingly happens outside of general hospitals. Wider system structures also impact on the work of general hospitals including the care and support available in the community. So, although the focus on acute general hospitals is at the centre of the ASDNCs work, other areas where care is given also form part of the role. The rationale for this is:

1. The key policy drivers from Scottish Government all point towards the need for expansion of community-based services and for people to be cared for as close to home as possible. Care arrangements in the community have a direct bearing on preventing unnecessary admissions to hospital and facilitating timely discharge. The work of the ASDNCs therefore, necessarily, also involves working with community-based resources that impact on the work of hospitals including the work of NHS24
2. The type and scale of acute care provision varies across boards in Scotland, particularly when considering larger boards and smaller boards, including the island boards. The changing nature of acute hospital provision means that ASDNCs do spend more time working outside the hospital environment
3. Community hospitals have an increasingly important role in the provision of acute healthcare in Scotland and the work of ASDNCs reflects this.

Therefore, community hospitals are included alongside acute general hospitals when the term 'general hospital' care is used in this report and the work of the ASDNCs in community settings is also important. This is also in line with the proposed roll out of the Older People in Acute Hospitals (OPAH) scrutiny programme to community hospitals, the Specialist Dementia Care planned for 2019-2020<sup>6</sup> and the Mental Welfare Commission themed visit to people with dementia in community hospitals 2018<sup>7</sup>.

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<sup>4</sup>Scotland dementia strategy 2013

<sup>5</sup>Scotland's National Dementia Strategy 2017-2020 June 2017.

<https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/>

<sup>6</sup>[http://www.healthcareimprovementscotland.org/our\\_work/inspecting\\_and\\_regulating\\_care/adhoc\\_reports/opah\\_opac\\_review\\_report.aspx](http://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/adhoc_reports/opah_opac_review_report.aspx)

<sup>7</sup> MWC Themed visit to people with dementia in community hospitals (May 2018)

[https://www.mwscot.org.uk/media/409326/dementia\\_in\\_community\\_may2018.pdf](https://www.mwscot.org.uk/media/409326/dementia_in_community_may2018.pdf)

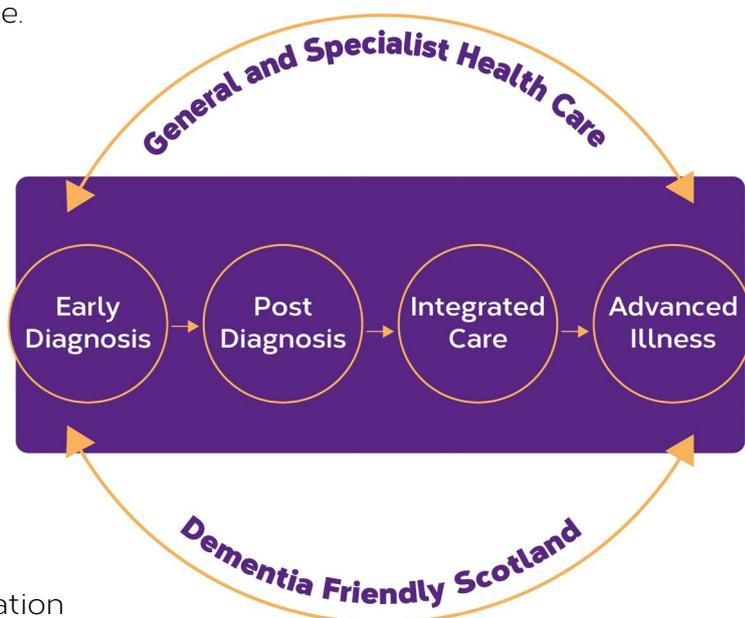
## Specialist dementia care: an important interface

The interface between specialist dementia care and general hospitals is a key factor in providing high-quality, seamless care. A finding of the Mental Welfare Commission report into the death of Mrs V was the adverse impact of numerous transfers between the two settings. Recent work in this area has led to the far-reaching conclusions and recommendations of the Transforming Specialist Dementia Hospital Care report, led by an ASDNC. Given that ASDNCs spend on average 15% of their time in mental health settings, predominantly in specialist dementia care settings, it is important to further develop links and learn from best practice and expert practitioners in SDC including the Dementia Specialist Improvement Leads (DSIL) network. There are now 66 DSILs in place across Scotland.

Hospital care is delivered by a wide range of healthcare professionals, and linking with other professional groups is essential. ASDNCs and nursing alone will not maximise the potential for change. An important aim will be to develop further collaboration with 'Connecting People, Connecting Support: Transforming the Allied Health Professionals' contribution to supporting people living with dementia in Scotland, 2017-2020, and the Allied Health Professional (AHP) Consultants. This reflects the critical role that AHPs play in ensuring improved hospital and discharge outcomes as well as enabling people to remain safely and confidently in their own homes and communities for as long as possible.

## Hospital care and whole system transformation

All the evidence reviewed for this report highlights that hospital care is interdependent on the quality and availability of other services and support to people with dementia in the community and a range of other settings. For example, early diagnosis; access to post diagnostic support and link workers; primary care; third sector and voluntary services; family carer support; advanced dementia and end of life care; generic mental health services; and availability of person-focused community support and care, all have a significant impact on the need for people to be admitted to hospitals and on timely discharge.



Alzheimer Scotland  
- Vision for Transformation

Numerous other policy areas, aligned with Health and Social Care Integration, also impact on hospital care. The work of the ASDNCs in 2015-2018 reflects the need to engage with this further to develop a whole systems view of hospital care. The ASDNCs have been active locally and nationally in developing post diagnostic support strategies, Alzheimer Scotland locality and Dementia Link Workers collaborations, specialist dementia care policy development and practice, self directed support and a range of other community initiatives, aimed at keeping people well in their own homes for as long as possible.

Steps are also being taken to further develop ASDNC engagement with key national policy and practice developments. For example The Excellence in Care<sup>8</sup> programme will provide access to nursing and midwifery sensitive assurance and improvement data at ward, NHS Board, Health & Social Care partnership and national level. The Excellence in Care programme will use specialist dementia unit indicators to focus on some of the challenges in this report, such as anti-psychotic use, the assessment for stress and distress and the provision of therapeutic activity. Two ASDNCs sit on the national steering group and are offering expert advice to the programme<sup>9</sup>. Enabling, Connecting and Empowering is an important development area highlighted for the ASDNCs in 2019-2020<sup>10</sup>.

## Summary

Scotland has recognised the importance of high-quality care for people with dementia and their families in all three dementia strategies and is at the forefront internationally of challenging the often dominant negative paradigm around caring for older people in hospital settings. The ASDNCs not only rightly focus on directly improving the care experience for people with dementia and families but they also have far-reaching aspirations to improve care across a range of settings. The commitment of the Scottish Government and Alzheimer Scotland to fund a Nurse Consultant for dementia in every health board reflects those aspirations. One of these is to promote caring for people with dementia not as a "second-best" career option for professional carers, but to demonstrate 'in vivo' that specialising in the dementia care field is a positive career aspiration with a tangible pathway leading to consultant/specialist level in every board in Scotland. There is, currently, no other area of clinical nursing practice in Scotland that demonstrates this commitment to high level nursing roles; dementia is unique in this regard, with the consultants and specialists working individually in NHS boards and together nationally to promote system change.

In 2019-2020 the group are ambitious to capitalise on this as a key expert reference group for people with dementia, hospital care practice and policy-makers, including testing of new approaches and initiatives.

### Key points

- Improving the experience of hospital care for people with dementia and their families remains a high priority in Scottish Government and all dementia strategies
- Commitment 7 of the third National Dementia Strategy highlights the importance and connectedness of general hospital and specialist dementia care
- Delayed discharge, avoidable admissions and inappropriately long stays in hospital are key policy action areas
- Progress has been made in raising awareness and the skills, knowledge and attitudes of staff, thereby 'shifting the paradigm'
- Whole system approaches are essential to 'strengthen the links' with activity and improvements in hospital care.

### Recommendations

- Closer links need to be forged between the work of specialist dementia care and general/ community hospital care, as called for in Commitment 7.

<sup>8</sup>Scottish Government/ISD (2018) Excellence in Care Available online <http://www.isdscotland.org/Products-and-Services/Excellence-in-Care/>

<sup>9</sup>Scottish Government/ISD (2018) Excellence in Care Available online <http://www.isdscotland.org/Products-and-Services/Excellence-in-Care/>

<sup>10</sup>Scotland's Digital Health and Care Strategy - Enabling, Connecting and Empowering April 2018

## Dementia and hospital care in Scotland: where are we now?

### Prevalence: the scale of the issue in general hospitals

This section considers the current information on the number of admissions to general hospital care for people with dementia, alongside action areas highlighted within Commitment 7 of the third National Dementia Strategy, namely delayed discharge, avoidable admissions and inappropriately long stays in hospital.

The primary source of data relating to people with dementia over the age of 65 in general hospitals in Scotland is via Information Services Division Dementia Benchmarking data<sup>11</sup>. Collected since 2011, the data is collated in four categories – number of admissions, readmissions within a year, length of stay and discharge to a care home for people admitted from their own home. As the Information Services Division Dementia Benchmarking data notes, caution should be used in interpreting this data as there continues to be a significant under-recording of dementia diagnoses in general healthcare services and that variation in some of this data can partially be attributed to variations in diagnosis-recording practices across Scotland. Consequently, any trends observed over time may be due, in part, to improvements in these recording practices. Under-diagnosis or delayed diagnosis of dementia is also thought to impact on the known numbers of people with dementia in hospitals.

An analysis in England of inpatient statistics for people previously recorded as having a dementia diagnosis showed that only 51% of 263,000 admissions to hospital in 2014-2015 had a recorded diagnosis of dementia. This means that 49% of these admissions did not have a recorded diagnosis of dementia in hospital<sup>12</sup>.

Caution needs to be exercised in reaching any conclusions as to whether rates of admission, readmissions, discharge to a care home and length of stay are problematic for people with dementia. Hospital admissions are often necessary for people with dementia and further data collection and research would need to be carried out to be able to reach any conclusions.

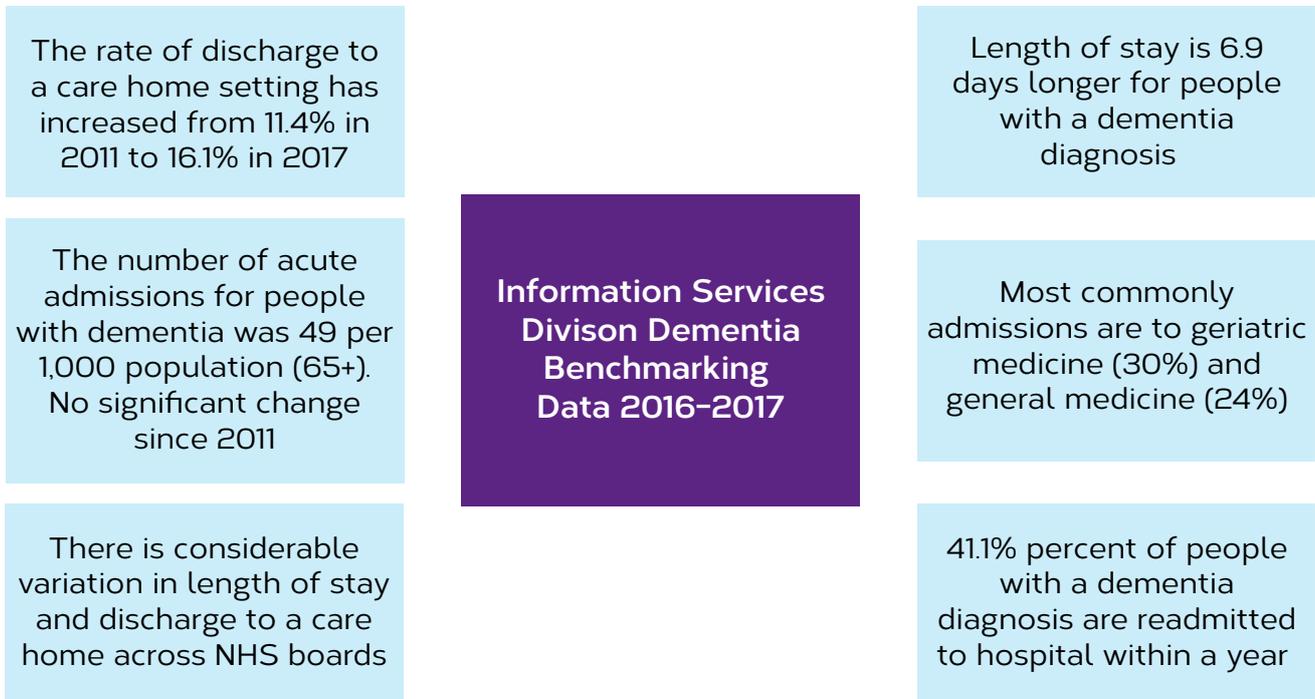
The most recent Information Services Division dementia benchmarking data (2016-2017) indicates:

- In 2016-2017, the number of acute admissions for people with dementia was 49 per 1000 population (65+) which is a slight increase from 46 per 1000 population (65+) in 2011-2012. The most common high-volume specialities were 24% to general medicine and 30% geriatric (sic) medicine
- In 2016, the average length of stay for in a hospital environment for people with dementia (65+) showed a decrease to 17.3 days from the 18.7 days listed in 2011-2012. The average length of stay for people over the age of 65 without dementia decreased from 10.8 days in 2011-2012 to 10.4 days in 2016-2017. The statistics show that people with dementia spent an average of 6.9 days longer in hospital than people without
- In Scotland, acute readmissions within 365 days for dementia discharges showed a small increase from 40.8% in 2010-2011 to 41.1% in 2015-2016. Discharges with no dementia readmitted within 365 days showed a small decrease from 36% in 2010-2011 to 35.7% in 2015-2016. This equates to an additional 1504 admissions for people with hospital compared to if the rate was 36% i.e. the same rate as for people with no dementia diagnosis
- The proportion of dementia spells admitted from private residence in Scotland that followed the 'Home > Hospital > Home care' path shows a decrease from 67% in 2011-2012 to 61.3% in 2016-2017. The 'Home > Hospital > Care Home' path shows an increase from 11.4% in 2011-2012 to 16.1% in 2016-2017. There was wide variation for people with dementia discharged to a care home across mainland boards (9.2% to 21.6%).

<sup>11</sup>ISD Dementia Benchmarking data <https://www.isdscotland.org/Health-Topics/Quality-Indicators/Publications/data-tables2017.asp?id=2011#2011>

NB 2016-17 due to be published 15/1/2019 – 2017-18 due to be published March 2019

<sup>12</sup><https://files.digital.nhs.uk/publicationimport/pub19xxx/pub19812/focus-on-dementia-jan-2016-v1-r1.pdf>



According to Information Services Division Dementia Benchmarking data, the number of admissions to acute general healthcare facilities for people with a diagnosis of dementia across Scotland in 2015-2016 was 49,183 or 7.8% of all admissions (which equates to 850,865 bed days), an increase from 7.4% (45,772 episodes: 823,896 bed days) in 2015-2016. In England the figure from official sources is 6% of all admissions.

Multiple authors argue that this is a gross underestimation due to under-recording of dementia on admission. Boaden (2016)<sup>13</sup> highlights that some hospitals report a 50% bed occupancy and estimates that bed occupancy rates for people with dementia in the UK are likely to be around 25%. A systematic review carried out in 2011 has identified that, internationally, the prevalence estimations for people living with dementia within general hospitals range from between 12.9%-63% across studies<sup>14</sup>.

We know that time in hospital can often have a negative effect on the health and wellbeing of people with dementia<sup>15 16</sup>. Poor care can cause further deterioration and the economic costs can also be considerable. Costings for this have not been carried out in Scotland. In England there have been attempts to capture the costs<sup>17</sup> and in 2010, £265 million was estimated as wasted on poor dementia care in hospitals. This estimate included increased length of stay costs (£117 million), readmissions and emergency readmissions (£122 million) and falls (£25 million). Suitable data to estimate costs in Scotland is not currently available.

<sup>13</sup>Boaden (2016). *Fix Dementia Care Hospitals*. Alzheimer's Society. Available online [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix\\_dementia\\_care\\_-\\_hospitals.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_-_hospitals.pdf)

<sup>14</sup>Mukadam, N. and Sampson, E.L., 2011. A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International Psychogeriatrics*, 23(3), pp.344-355

<sup>15</sup>SAMPSON, E., LEURENT, B., BLANCHARD, M., JONES, L. and KING, M., 2013. Survival of people with dementia after unplanned acute hospital admission: a prospective cohort study. *International Journal of Geriatric Psychiatry*, 28, pp. 1015-1022.

<sup>16</sup>Harrison, K et al (2016) *New institutionalisation following acute hospital admission: a retrospective cohort study*. *Age and Ageing Advance*; 0, -17

<sup>17</sup>Insight report *An economic analysis of the excess costs for acute care for patients with dementia*. December 2013. [www.chks.co.uk](http://www.chks.co.uk)

## Delayed discharges

The annual summary of occupied bed days and census figures up to March 2018<sup>18</sup> show that during 2017-2018, approximately 1 in 13 (7.8%) occupied beds in NHS Scotland were due to delayed discharges. The main reasons were:

- Awaiting completion of care arrangements
- Awaiting place availability
- Complex delay reasons
- Awaiting community care assessment
- Other including funding, transport, patient and family related reasons.

In 2016-2017 the estimated cost of delayed discharges in NHS Scotland was £125 million, with an estimated average daily bed day cost of £234. We lack a definite figure for the bed occupancy rates for people with dementia in general hospitals; precise costs cannot be estimated. However when looking at the main reasons for delay and factoring that 69% of these beds were occupied by people aged 75 years and over, it is likely that many of these will impact on the discharge of people with dementia.

There is clear UK and international evidence of the additional economic costs of caring for people with dementia in general hospitals; predominantly through the current length of stay and delayed discharge rates. What is less clear is whether these additional costs could be reduced or whether this is the additional care that people with dementia require, particularly in relation to length of stay (less so for preventable admissions and delayed discharges). Further detailed exploration of the data is required to inform decision making and planning.

## Quality of Care: evidence of improvement in the care of people with dementia and family carers in general hospitals

Evidence and data on changes to the quality of care 2015-2018 can also be seen to be limited. The key sources of evidence are the Older People in Acute Hospital scrutiny programme, the Mental Welfare Commission Community Hospital report and local visits<sup>19</sup>.

### OPAH Inspections: dementia care findings

The last Health Improvement Scotland (HIS) and OPAH review report of inspections across hospitals in 2014 highlighted training as the key improvement in dementia care. A number of staff had completed training courses in dementia such as the Dementia Champions training programme. Staff trained in line with the Promoting Excellence framework and some nursing assistants have also completed a 'best practice in dementia' course.

A rapid review of the 30 acute hospitals and 3 community hospital inspections was carried out for dementia care specific findings, in line with the OPAH methodology which considers 5 key themes including 'dementia and cognitive impairment'.

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<sup>18</sup>Delayed Discharges in NHSScotland Annual summary of occupied bed days and census figures up to March 2018  
<https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/>

<sup>19</sup> <https://www.mwscot.org.uk/publications/local-visit-reports/>

## Key findings in relation to dementia – commonly reported in most inspections

### Strengths

- Environmental improvements evident
- 'Getting to know me' evident in the majority
- ASDNCs and Dementia Champions in place
- 4AT (rapid clinical instrument for delirium detection) and cognitive assessment evident
- Liaison teams
- Carer involvement and flexible visiting times
- Staff training and education
- Adults with Incapacity (Scotland) Act 2000 Section 47 completion improved
- Linking with Health and Social Care Partnerships

### Areas for improvement

- Person centred planning for people with dementia based on the 'Getting To know me' document – limited evidence of impact on individual care plans at ward level
- Dementia Champions presence noted but lack of role definition and structure to improve noted
- ASDNCs noted in some reports but no detail on impact of role
- Observation and human rights issues noted in some hospitals

The improvements driven by national and local initiatives to improve the identification and care of people with cognitive decline and delirium were also noted in many of the inspection reports.

ASDNCs are closely linked into the HIS-OPAH inspection process at a local level. At pre-inspection, this engagement can include: leading the self-assessment for the cognitive impairment element of the assessment tool, collating supporting evidence and identifying areas for improvement. After the inspection: formulating actions required in relation to dementia; leading specific dementia care working groups, and liaising with clinical colleagues to provide updates to HIS and Executive teams.

ASDNCs will continue to work at a national level with HIS as clinical experts to further develop cognitive impairment and dementia as key features of future inspections.

## Community hospitals

The primary source of evidence in 2015-2018 is the Mental Welfare Commission themed visits to people with dementia in community hospitals (May 2018). The themes from general hospitals were largely similar in Scotland's community hospitals. The report found that care and treatment was generally good, but there was a lack of focus on patients' dementia-related needs. It also highlighted issues with the dementia-friendliness of the environment, care planning, activities provision and staff training.

## Summary of findings for community hospitals: where are we now?

Almost three quarters of the wards had access to an ASDNC. Three quarters of the wards had Dementia Champions on the ward team and a further 15% had access to a Dementia Champion based elsewhere. Wards commented positively about their impact with clear benefits noted in the report. The levels of specialist training within the nursing team varied considerably and there was a lack of clarity about the different levels of knowledge and skills required by staff at the different Promoting Excellence dementia skills and knowledge framework levels. The Mental Welfare Commission report recommends that all wards in community hospitals are able to access support from staff at the Enhanced level, including Dementia Champions, and from staff operating at the Expertise level of Promoting Excellence.

Care plans recorded physical health care interventions well, but there was a lack of care planning for care and support focusing on the patient's dementia with care planning for stressed and distressed behaviour in only a few cases. The recommendation was that staff use care planning systems which include a focus on supporting patients' needs in relation to their dementia. These should be based on personal life story information.

The Mental Welfare Commission also focused on prescribed psychotropic medication. A quarter of the people were prescribed medication 'if required' for agitation and more than half did not have a care plan for the use of this medication. In terms of adults with incapacity (AWI), they note that three quarters of patients had a certificate of incapacity in place, in most cases with a treatment plan which has improved since the commission's 2010 visit to people with dementia in general hospitals.

The two OPAH inspections to community hospitals are not enough to reach any conclusions, but of note is the widely reported difference between the two inspection reports in terms of person-centred care, cognitive assessment and AWI, physical environment and personalised care planning.

### Key points

- Dementia is under-recorded for hospital admissions in national data sets. Consequently, data on the prevalence of dementia in hospital settings is potentially inadequate, and substantive data on the overall impact of successive dementia strategies on hospital care is limited
- Current national data shows that 7.8% of all admissions to hospitals are for people over 65 with a dementia diagnosis. The best estimate of the true figure, based on current published evidence available on the prevalence of dementia among all older people hospital care is that at least 20% of all hospital beds are occupied by people with dementia
- Commitment 7 focuses on delayed discharge, length of stay and avoidable admissions for people with dementia. The best assumptions that can be reached from national data are that:
  - » People with a dementia diagnosis spend on average 6.9 days (40%) longer in hospital than people with no dementia diagnosis
  - » Delayed discharge data is not available for people with a dementia diagnosis. Analysis of the delayed discharge data shows that the average age and the reasons for delayed discharge mean that people with dementia are likely to be significantly over-represented
  - » Data on avoidable admissions for people with dementia is not available
- There is evidence that the quality of care has improved. Dementia friendly environments, staff training and education, additional roles including the ASDNCs and Dementia Champions, human rights and family and carer joint working are consistently seen to be in place and making a difference
- Whilst the 'Getting to know me' document is now in widespread use, person-centred planning for people with dementia needs to be improved
- Enhanced engagement (previously called 'observation') and working with stress and distress (including the prescribing of anti-psychotic medications) are important quality of care and economic issues which require focus.

### Recommendations

- Better recording of dementia prevalence across hospital settings is required to determine a more enhanced understanding of demand and allocation of resources and subsequently provide better care and support
- Close attention and monitoring of progress in meeting Commitment 7 of the third National Dementia Strategy is essential
- Person-centred planning, stress and distress and enhanced observations are critical areas of care requiring attention and best practice initiatives.

## Where we are now: summary and conclusions

The focus on hospital care in all of the National Dementia Strategies has led to a raised awareness of the needs of people with dementia in hospitals, alongside structural improvements such as the ASDNCs, Dementia Champions, Focus on Dementia and a suite of training resources from Promoting Excellence such as the Acute Care Resource and Stress and Distress training. This progress is highlighted and detailed in the third National Dementia Strategy and many of the improvements are seen in scrutiny reports of acute and community hospitals. The progress that has been made and the positive direction of travel was highlighted at the 2018 Alzheimer Scotland Annual Conference.



- An Alzheimer Scotland Dementia Nurse Consultant in every Scottish Health Board and NHS 24
- An Alzheimer Scotland AHP expert group and one AHP Dementia Consultant Greater Glasgow and Clyde
- 950 Dementia Champions graduated since 2011 - 120 currently on programme
- Significant focus and progress in Specialist Dementia Care - DSIL Programme



Slide showcased during Alzheimer Scotland annual conference, 2018.

International commentators have described Scotland's approach to acute hospital care and recent developments as "world class" and many of the improvements have been replicated across the UK and internationally. But challenges remain around the consistent application of person-centred care planning. Adults with Incapacity legislation and human rights, and education and training of staff across NHS boards and hospitals in Scotland.

Information Services Division Dementia Benchmarking data shows that prevalence, readmission rates and length of stay remain largely unchanged since 2011 but there are significant differences across boards. Discharge to care homes has increased. Economic costs are important to consider in terms of delayed discharge and additional length of stay days in hospital allied to other costs including the increasing costs of one-to-one observation across boards. Further quantitative and qualitative data is required to fully understand the current picture and to track change over time.

The current evidence base, and associated data, on prevalence and quality of care could be greatly improved to clearly identify the impact that these achievements have had on the quality of hospital care for people with dementia and the gaps that need to be prioritised. Similarly, the recently published *Delivering Fair Dementia for People with Advanced Dementia* report (2019) calls for urgent action to improve the recording of dementia prevalence across all health and social care settings<sup>20</sup>. ASDNCs will be actively involved in liaising with Information Services Division and the Scottish Government on developing and reviewing the usefulness of the benchmarking data and will explore carrying out small scale snapshots of bed occupancy of people with dementia to inform intelligence for planning.

<sup>20</sup>*Delivering Fair Dementia Care For People With Advanced Dementia The Fair Dementia Care Commission Alzheimer Scotland* [https://www.alzscot.org/assets/0003/2670/McLeish\\_Report\\_WEB.pdf](https://www.alzscot.org/assets/0003/2670/McLeish_Report_WEB.pdf)

## Part 2:

# The Alzheimer Scotland Dementia Nurse Consultants



Alzheimer Scotland Dementia Nurse Consultants

## The role of the ASDNCs 2015–2018: aspirations and expectations

Alzheimer Scotland launched the Specialist Dementia Nurse Programme in 2006, with posts created over a four-year period in four territorial Health Boards. In 2010, Alzheimer Scotland launched a Dementia Nurse appeal, which also attracted funding from the Scottish Government. By the end of 2012, funding for a Dementia Nurse Consultant was available to each territorial health board in Scotland. Since 2015 every NHS board has had an Alzheimer Scotland Dementia Nurse in post and funding is now shared between Alzheimer Scotland, Scottish Government and NHS boards. In addition, there is a national ASDNC post focused on specialist dementia care jointly funded by Alzheimer Scotland and Scottish Government.

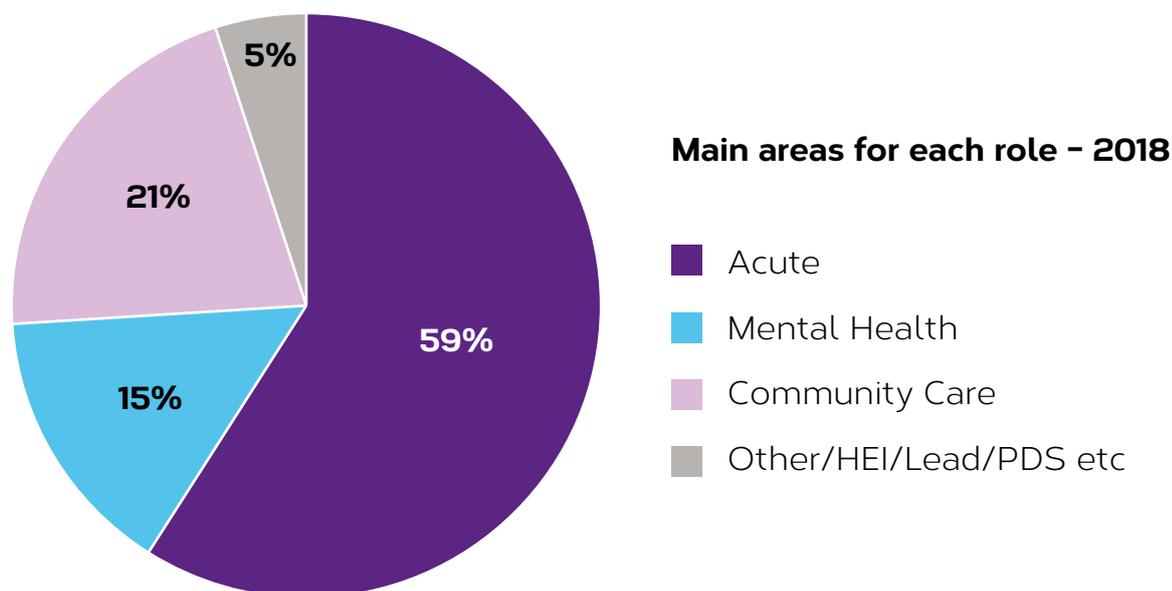
The original measures of impact in the Memorandum of Agreement between Alzheimer Scotland and NHS boards were:

- To reduce the number of people with dementia who have been prescribed anti-psychotic medication
- To increase the satisfaction with care reported by people with dementia or their carers
- To reduce the number of people with dementia referred to residential care
- To increase the number of people discharged home with flexible community support services put in place.

The ASDNCs were formally evaluated in 2014 and two previous ASDNC reports were published in 2013 and 2015. This report picks up on some of those key themes ensuring clarity of the role of the ASDNCs and the best practice ways of working.

## The current roles of the ASDNC group

The majority of ASDNCs currently spend most of their time in acute hospital care work but this is not consistent across all boards. A survey of the ASDNCs in four broad areas in December 2018 shows the following aggregated division of the role in the diagram below:



The title of all the nurses includes “Alzheimer Scotland” and the role includes expectations of alignment with the Alzheimer Scotland vision and strategy work and other national policies and platforms. The ASDNCs are currently taking steps to increase the internal Alzheimer Scotland visibility and, through increased engagement with Alzheimer Scotland, have based consultation events with a focus to hospital care. Separate bespoke engagement events focused on hospital care to inform the evidence base of progress in meeting Commitment 7 will be convened by ASDNCs.

## The work of the ASDNCs 2015–2018: What has been achieved?

This section details the range of work, mapped against the four domains of the Nurse Consultant role, that the ASDNCs have either led or played a major part in the period 2015–2018. The list is not exhaustive but represents the most common areas of work across all boards. More detailed information can be accessed via the references in Appendix A. The majority of the ASDNCs have completed Quality Improvement (QI) methodology training and three recently completed the Scottish Improvement Leader (ScIL) programme. A range of improvement methodologies have been employed in driving forward and evidencing the change, in particular those focused on visiting hours, transfers, and preventing unnecessary admissions.

### Expert practice

- Stress & Distress: non-pharmacological strategies have been developed and implemented including developing one-to-one interventions, anti-psychotic medication use, snapshots and practice
- Audits
- Leadership in strategies to promote frailty/delirium/cognitive impairment assessment including appropriate use of 4AT tool
- Observation and engagement policies: enhanced observation strategies developed and the reduction in the use of anti-psychotics was audited
- Adults with incapacity: leadership in developing local and national principles, documentation and staff awareness. Working with Mental Welfare Commission and Health Improvement Scotland to offer expert advice at national level
- Patient flow initiatives: admissions, transfers and moves policies – changes audited and published.

- 'Getting to know me' training and awareness with advanced dementia practice & end of life care incorporated into the care process
- 'Wander walking' policies and staff training developed
- Specific pathways developed, for example Ophthalmology and NHS24 in relation to cognitive impairment, dementia and delirium
- Expert clinical opinion, guidance given on complex care situations, patient review and management
- Support of carers e.g. carer café's, carer support and education in ward settings and university settings e.g. carers academy
- Dementia care mapping initiatives.

### **Professional leadership and consultancy**

- Leadership in developing Welcome Wards: a person-centred visiting initiative
- Working to improve the care and interface between community hospitals, specialist dementia care units and acute hospitals
- Leadership and input at local level to OPAH inspection processes. National input to inspection methodology process review and development
- Presenting and attending Cross Party Group on dementia at the Scottish Government
- Developing specific community-based services, for example Community Behavioural Support Service
- Chairing a range of board level groups, e.g. Quality of Care and Standards Council
- Input at Alzheimer Scotland Dementia Resource Centres, Alzheimer Scotland local engagement events and involvement in awareness raising during Dementia Awareness Week
- SIGN Guidelines development input.

### **Education, training and development**

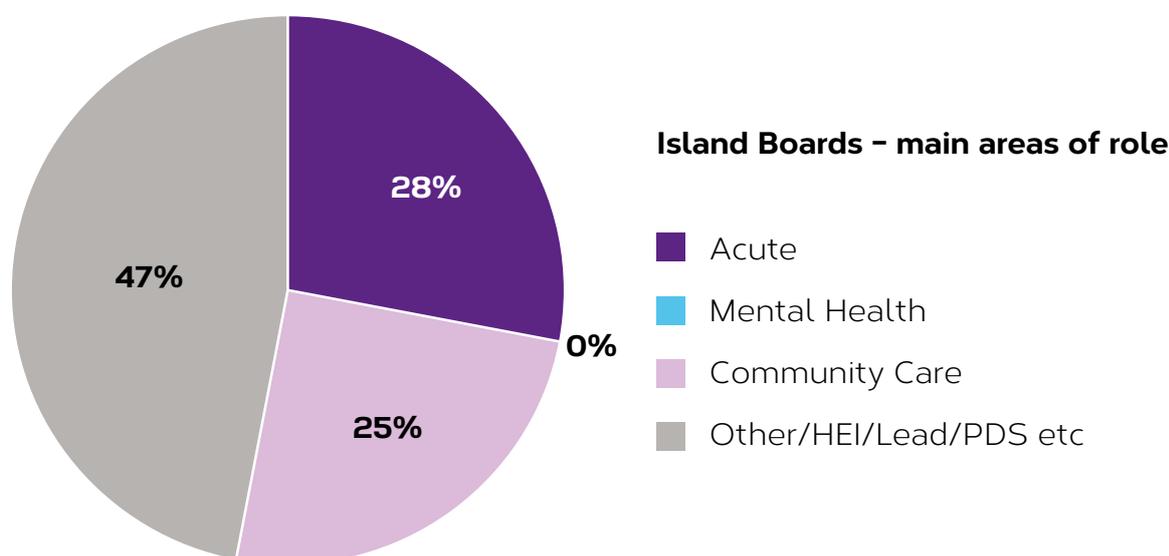
- Promoting Excellence training: developed and delivered across a wide range of health and social care staff in all boards – all boards at Promoting Excellence levels
- Supporting Dementia Champions: input to national training programme, local support through networks and ongoing training and support
- Stress and Distress training at expert level: local training programmes developed and delivered
- Input in to wide range of pre and post registration training courses in Universities and awareness sessions, education and training to a range of health and social care professions
- Development of an eLearning module on dementia for NHS24 staff
- Strategic perspective on education e.g. development training strategy, planning education and provision
- Involvement in the development of Learnpro modules: Delirium, Capacity and Consent.

### **Practice and service development: research and evaluation**

- Conference presentations: local, national and international
- Discharge planning with carers and partners in care
- Dementia friendly wards
- NHS24 Care Home communication tool jointly developed with Erskine Care Homes
- Collaborating with University departments on curriculum development and peer reviewed publications
- Leading and collaborating with other organisations to produce best practice reports, for example Focus on Dementias 'Critical factors' report and collaborative presentations at national and international events
- Churchill fellowship awarded
- Won national awards, e.g. Scotland's Dementia Awards
- Local and national press in relation to improvement projects
- Practice audits
- Formal research studies.

## The role of ASDNCs in NHS island board

This section highlights (and celebrates) the different role that island nurses perform. As can be seen in the diagram below, island board nurses work differently with around a quarter of their time spent in acute settings. This is driven by scale and an agreed whole system approach, the local role and title that Alzheimer Scotland nurses have and local acute care and specialist dementia care provision.



The major proportion of work tends to be in a community setting with support for a range of dementia care related initiatives, such as providing Dementia Assessment and Treatment services, post diagnostic support, promoting excellence education and training, along with a range of PE education/training and a range of other community resources and initiatives (some of which are detailed below). The primary aim for all island boards remains to improve care in community settings and ensure that potential crisis situations that might result in admission to hospital are avoided. At the time of the report two of the island boards were discussing a change in the role to focus more on direct acute care working.

### Acute hospital care specific

#### NHS Orkney

- Implementation of personalised care plans for cognitive difficulty
- Volunteers for stimulation
- Multi-faceted approach to AWI improvement.

#### NHS Shetland

- Focus on reducing unnecessary admissions to the acute hospital and or psychiatric care in Aberdeen due to the person's dementia. During the past 13 months there have been no admissions to either, due to dementia related behavioural issues.

#### NHS Western Isles

- Supportive function in decommissioning of long-term ward for people with dementia
- Quality Improvement work on recognition and management of delirium in acute care
- Development of care management aspect of 8 pillar model and the advanced practice team.

## Training

- All island boards have committed to education and support to health and social care staff in community settings who are supporting people with a dementia diagnosis.

### **NHS Orkney**

- Experiential learning for all student nurses, social care, voluntary sector and community groups and stress and distress training at expert level
- Palliative and end of life training in dementia (feedback available) training delivered at skilled and enhanced level.

### **NHS Shetland**

- Delivered promoting excellence skilled level training to social care workers, community nurses, hospital nurses, dental staff and GPs. Dementia Friends training to a range of people across Shetland such as secondary school pupils, community groups and businesses.

### **NHS Western Isles**

- Participation in educational framework for all health and social care staff with direct training delivery to Stress and Distress Functional Analysis level.

## Community

### **NHS Orkney**

- Collaborative working to provide clinical advice to support a project funded by Life Changes Trust and implemented by Age Scotland Orkney. This has resulted in provision of a Dementia Hub; a one stop shop for advice, information, support and access to other services
- Promotion of dementia friendly environments to help people to live well in their own communities.

### **NHS Shetland**

- Developed a local Prescribing and Review Pathway for Behaviour Modifying Medications
- Partners in a three year project funded through the Northern and Arctic Partnership with partners in Norway, Sweden and the Western Isles looking at the use of technology to support people with a diagnosis of dementia to remain more independent at home. Findings have been presented at conferences in Norway, Sweden, Western Isles and Inverness
- NHS dementia services awarded an Excellence in Care Award for innovation by the Chief Nursing Officer
- One of three national pilot sites for trialling Post Diagnostic Support within Primary Care.

### **NHS Western Isles**

- Successful primary care project for nurse-led dementia assessment in GP surgeries with no referral process which has improved diagnosis at earlier stage and uptake of post diagnostic support (98%)
- Leading, developing and agreeing on local Dementia Strategy including public consultation (significantly adopting a 5 and 8 pillar model with advanced practitioners)
- Lead on development of Integrated care pathway
- Lead on review of post diagnostic service.

Whilst the role of the island Alzheimer Scotland nurses is different from mainland Alzheimer Scotland nurses, they are an important part of the ASDNC group and the actions detailed in this report are designed to be appropriate to all Alzheimer Scotland nurses whether island or mainland based.

### **Key points – the role of ASDNCs**

- ASDNCs continue to be appointed to every health NHS board in Scotland and spend most of their time in direct work improving general and community hospital care
- A wide range of local improvement activities, using a range of methodologies, have been carried out with demonstrable results
- The island boards perform a more whole-systems orientated approach to improving dementia care with significant results
- The ASDNC group has engaged with a number of national practice and policy arenas in an expert consultative capacity.

### **Recommendations**

- The mainland ASDNCs should maintain the hub of their work as general and hospital care and Memorandum of Agreements should continue to state this
- National actions for the ASDNC as a group should be pursued to maximise the value of the expertise within the group. These national priorities should be set according to the evidence presented in this report
- Further focus on generating evidence of achievement, including through KPIs, should be a priority.

## Part 3:

# Key policy and practice priorities for the ASDNC national group

This section sets out the key practice priorities, actions and key performance indicators for the period 2019–2020. These priorities follow on from the evidence presented in the previous sections in relation to current, and emerging, policy and practice drivers; the evidence base on the quality of care and the current activity areas of the ASDNCs as individuals and as a group. Emerging areas, gaps and areas for renewed focus have been identified and prioritised.

## The national role of ASDNCs in supporting the delivery of Commitment 7 of the National Dementia Strategy 2017–2020

### Actions

- Demonstrate leadership to support the development of an action plan for Commitment 7 of the third National Dementia Strategy by convening stakeholder workshops to explore current state of progress on delivering Commitment 7 and develop a consensus led future priorities/workplan across stakeholder groups
- Monitoring progress, by:
  - » Explore the value of a short, focused national audit of dementia care in hospitals, led by ASDNCs and utilising the Dementia Champions network, mapped against the 10 Dementia Care Actions in hospitals to inform further development and priority setting for Commitment 7
  - » Work with Scottish Government to refine the dementia benchmarking data set including the feasibility of small-scale snapshots of bed occupancy.
    - » Increase engagement between specialist dementia care, DSILs, AHP and acute components of Commitment 7.

### KPIs

- Evidence of engagement with key stakeholders to explore input to current governance and monitoring of Commitment 7
- Develop and facilitate workshops and produce workplan, priorities and implementation plan with stakeholders
- Evidence of adding to the evidence base of prevalence of people with dementia in hospital care.

## Policy interfaces and expert voice: internally and externally

### Actions

- Using the expertise of the ASDNC group to:
  - » Work with Alzheimer Scotland to develop evidence-based position statements on key topical issues
  - » Where appropriate, work with Alzheimer Scotland and others to test new approaches in practice environments
- Refocus on acute care as the key area of focus for the ASDNCs with continued engagement of Executive Nurse Directors
- Plan increased engagement with Alzheimer Scotland localities and teams
- Increased the engagement with national practice and policy, e.g. Excellence in Care.

### KPIs

- Focus on acute care for ASDNCs revisited and agreed with boards and **Scottish Executive Nurse Directors**
- Key expert input to Alzheimer Scotland position statement on the use of 'identifiers' for people with dementia in acute hospitals
- Audit proposal developed: each ASDNC leads on auditing in depth one of the 10 Dementia Care Actions in own board followed by input and cross reference to other boards
- Evidence of increased Alzheimer Scotland visibility and engagement with Alzheimer Scotland locality teams.

## Practice priorities

### The right workforce – leadership in training and education

NHS Education for Scotland are currently updating the original Promoting Excellence knowledge and skills framework to ensure that it is fit for purpose. In line with this ASDNCs will explore the current training in place across boards, assess the impact this training has had and identify strategic priorities for future rollout.

There is clear evidence that the interface between ASDNCs and Dementia Champions, and thereby the support arrangements for Dementia Champions, is critical to ensure that the Dementia Champions operate effectively as agents of change<sup>21</sup> (also see 2014 ASDNC/Dementia Champion evaluation). With nearly 1000 Dementia Champions in practice at the time of the report, ensuring that support arrangements are based on best evidence and consistently applied is essential. Several of the scrutiny reports drew attention to a perceived lack of clarity on the role and expectations of Dementia Champions in practice.

### Actions

- Focus on leadership, influencing, planning of training programmes for all staff groups, with less on delivery particularly at an Informed level
- Carry out impact assessment of promoting excellence training to date as part of the broader audit of acute care and dementia, including the range of approaches to working with Dementia Champions
- Lead and re-develop plans for the strategic implementation of promoting excellence levels across boards.

<sup>21</sup>Jack-Waugh, Ritchie and McCrae (2018). *Assessing the educational impact of the dementia champions programme in Scotland: Implications for evaluating professional dementia education*. Available online

## KPIs

- Audit and impact assessment of current promoting excellence training in boards.
- Strategic plans for sustainable delivery of promoting excellence developed.
- National best practice framework and guidelines to maximise the working relationship between ASDNCs and Dementia Champions developed and implemented, including role definition, dedicated time and other support arrangements, and identification and expectations of Dementia Champions in clinical practice settings.

## Personalised and rights-based care

'Getting to know me' was developed by the ASDNC group in 2015 as a national document. There is clear evidence that it is now used in all boards (except NHS Dumfries and Galloway which uses 'This Is Me'), but less evidence of direct impact on individualised care and care planning.

## Actions

- Audit usage of 'Getting to know me' and carry out impact assessment of 'Getting to know me' across boards on personalised care and care planning
- Explore the fit of 'Getting to know me' with other recent initiatives promoting person centred care. For example 'What Matters To Me'
- Develop recommendations for the further development of 'Getting to know me' and ensure maximum impact at practice level.
- In collaboration with people with dementia and family carers, develop '5 key points for your hospital admission'
- Launch and monitor uptake and impact using Dementia Champions network, and review as necessary.

## KPIs

- Audit and impact assessment of 'Getting to know me' completed and reported
- Proposed redevelopment and relaunch of 'Getting to know me' (v2.0) with best practice guidelines for impact developed as necessary.
- Information developed and launched.

## Preventing inappropriate admission and facilitating timely discharge

As discussed earlier a key feature of Commitment 7 of the National Dementia Strategy is 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. Improvement to these will be driven primarily by whole-system change so the ability of the ASDNCs to directly impact on these is therefore limited. However, even small changes will yield in significant improvements in the experience of people with dementia and cost savings. Improvements to transfers and moves within hospitals will also be considered here.

## Actions

- Examine current best practice across the boards, in particular in the island boards, to detail the lessons learned that could be transferrable to other boards. Explore the possibility of a collaborative realistic evaluation project
- Build on current local best practice on transfers and moves, informed by national NHS Scotland audit and data
- Explore the interface between acute general hospital care and specialist dementia care transformation work through the DSIL network, including preventing admission and timely discharge to and from specialist dementia care settings.

## KPIs

- Key learning and best practice within scope of ASDNC role set out to impact on unnecessary admissions, transfers and timely discharge rates
- Key actions identified with specialist dementia care leads and DSILs to improve interface between specialist dementia care and other hospital care.

## Improving observation and engagement in hospital

A critical emerging practice issue is the response to people with dementia in general hospitals who, for a number of reasons, may need an enhanced level of staff support, commonly known as 'observation'. The recently published Improving Observation Practice framework<sup>22</sup> for mental health settings argues that 'current observation practices are inconsistent and often infringe people's human rights, show a tendency to view this support as a 'task' often carried out by junior/bank/agency staff without the requisite skills and knowledge and a lack of person-centred proactive risk assessment and care planning'. Anecdotal evidence suggests that many of these issues are the same for people in acute general hospitals. This is a costly intervention when person-centred preventative strategies would be preferable and potentially more effective.

The ASDNCs have been in discussion with Focus on Dementia and involved in the development of the proposal and priority setting exercises led by Focus on Dementia. Maximising the infrastructure in place across Scotland's boards, including the ASDNCs and Dementia Champions is seen as critical to success and will be a guiding principle.

## Actions

- Explore and set out how the Improving Observation Practice framework can cross over into general hospital settings in collaboration with Focus on Dementia and the Scottish Patient Safety Programme for Mental Health (SPSPMH)
- Develop guidelines with principles, approaches and best practice model
- Initiate small tests of change to test new enhanced engagement approaches
- Work in partnership with Focus on Dementia to deliver the proposed national hospital collaborative.

## KPIs

- New guidelines developed in collaboration with SPSPMH and HIS
- Small tests of change conducted and reported
- Evidence of joint working and successful impacts of the hospital collaborative.

<sup>22</sup>Scottish Patient Safety Programme Healthcare Improvement Scotland From Observation to Intervention A proactive, responsive and personalised care and treatment framework for acutely unwell people in mental health care. December 2018 <https://ihub.scot/project-toolkits/improving-observation-practice/from-observation-to-intervention/>

## Part 4:

# Conclusion and next steps

The previous ASDNC report was titled 'Shifting the paradigm together', and, so, has it shifted? The evidence shows that the work of the ASDNCs and Dementia Champions; Promoting Excellence based education and training; improved environments; human rights including AWI and carer involvement have shifted the paradigm towards a greater awareness and understanding of the needs of people with dementia in hospital. So, is the work of Commitment 7 and the ASDNCs done? Could it be argued, as some authors have, that the continuation of a focus on improving the care for a single disease in hospital care is not needed and focusing on improving care for all older people is the best way forward? The evidence clearly points to no.

The prevalence of dementia in the current population alongside the ageing population and thereby the number of people with dementia in acute hospitals indicates the continued extreme importance of getting this care right, against the costs at a human and resource level of getting this care wrong. The evidence indicates that whilst the infrastructure has developed, the quality of care is improving, and awareness is increasing, there is still much to be done to embed and sustain this improvement as there is wide variation across boards. Life story work through 'Getting to know me' is now widespread but there is consistent evidence that the focus of care planning often remains on physical care and that personalised care and care planning based on 'Getting to know me' for dementia is not widespread. Recent evidence also continues to show there is much work to do to change attitudes to dementia care and ways of working to ensure personalised care<sup>23</sup>. Further drive, resolve and leadership is essential to provide clear evidence of improved quality of care for people with dementia in hospitals. The cost of poor care to large numbers of people with dementia in hospital dwarfs the funding for ASDNCs and indeed all other structural and resource approaches.

The evaluation of the ASDNC and the Dementia Champion role in 2014 concluded that there was evidence of a significant amount of change and improvement work initiated by the two roles, which would likely not have happened without them<sup>24</sup>. Whilst the ASDNCs do not operate alone, many others contribute to the changes we have seen. It seems likely that the same conclusion would apply for the period 2015-2018, were many of the changes would not have happened without them.

The improvements to dementia care in hospitals have been noted elsewhere as has the importance of inter-agency collaboration and multi-disciplinary working. Sustainable change will require a whole-system approach across all health and social care settings and professions. The Mental Welfare Commission report into the care of Mrs V in 2011, demonstrated the need for specialist dementia care and acute hospital care to work together, and the consequences if they don't. These are therefore the priorities that the ASDNC group will focus on in 2019-2020; providing leadership, demonstrating change and enacting personalised care planning for people with dementia across all hospitals in Scotland.

This report and actions will be used to prepare a detailed action plan with key deliverables, dates and responsibilities. An annual monitoring report based on the action plan will be prepared and made available at the end of years 2019 and 2020.

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<sup>23</sup>Featherstone K et al (2019) Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards and its consequences. *International Journal of Nursing Studies* January 2019  
<https://www.sciencedirect.com/science/article/pii/S0020748918302682?via%3Dihub>

<sup>24</sup>Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/Specialists & Dementia Champions in bringing about improvements to dementia care in acute general hospitals NHS Education for Scotland Final Report  
Sophie Ellison Glenys Watt Ian Christie April 2014  
[https://www.nes.scot.nhs.uk/media/2711493/impact\\_evaluation\\_-\\_final\\_report.pdf](https://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf)

## Glossary

|        |   |
|--------|---|
| AHP    | Allied Health Professionals                         |
| ASDNC  | Alzheimer Scotland Dementia Nurse Consultant        |
| DSIL   | Dementia Specialist Improvement Leader              |
| HIS    | Health Improvement Scotland                         |
| KPIs   | Key Performance Indicators                          |
| OPAH   | Older People Acute Hospital                         |
| ScIL   | Scottish Improvement Leader                         |
| SEND   | Scottish Executive Nurse Directors                  |
| SPSPMH | Scottish Patient Safety Programme for Mental Health |
| QI     | Quality Improvement                                 |

## Appendix A

# Key evidence of impact and esteem: the four domains of the nurse consultant role

### Professional leadership and consultancy

Skinner, H (2017) iHub: Celebrating Practice and Networking Event Specialist Dementia Units. A pilot study to explore the effects of individualised music on agitation in patients with moderate to severe dementia NHS Fife

Skinner, H et al (2015) Think Delirium (Joy Reid, Karen Goudie, Mahri Edgar, Aylene Kelman) June 2015 NHS Conference – poster presentation

Skinner, H et al (2015) Partners in Care. June 2015 NHS Conference – poster presentation

Skinner, H (2017) A pilot study to explore the effect of individualised music on agitation in patients with moderate to severe dementia in a specialist mental health setting: a single case experimental reversal design study May 2017 Abertay University Research Conference – Poster presentation.

Mantle, R (2016) Scholar of the Florence Nightingale Foundation- 'Exploring the impact of using a personal profile tool on the attitudes of nurses providing care for people with dementia in a general hospital setting'. <https://florence-nightingale-foundation.org.uk/abstracts/research-scholarship-ruth-mantle/>

Irvine L – Finalist in the 'Improving the Patient or Carer Experience' – Individual category in NHS Grampian's Recognition Awards for Teams and Staff – the GRAFTAS in 2014 and 2015

Stephen Mulla. 2019 Queens Nurse Development programme cohort. QNIS Scotland

### Expert Practice: Practice and Service Development

Scotland's Dementia Awards 2018 winner: Bridging the gap between acute and community care, NHS Ayrshire and Arran

Scotland's Dementia Awards 2017 winner: Best Acute Care Initiative: NHS Forth Valley – 'Improving the journey for people with dementia in the acute hospital setting – a collaborative approach'

Taggart, M and Kinnaird, L (2018) Transforming specialist dementia hospital care: independent report. SG and AS

Mantle, R (2015) Plenary session on- '10 Dementia Care Actions- Transforming Dementia Care in General Hospitals in Scotland'. 30th International Conference of Alzheimer Disease International- Perth, Australia

Irvine L – Finalist in the Sue Pembrey Award Exemplary Nurse Leader 2017. NHS Grampian

Coghill, G – Evaluation of Individualised Care Planning for People with Cognitive Difficulty: Admission and Rehabilitation Ward (2018). NHS Orkney

Coghill, G - Evaluation of the Impact of Volunteer Visits for People with Cognitive Difficulty (2018). NHS Orkney

Coghill, G - Audit of AWI - Capacity to Consent to Medical Treatment performance (2018). NHS Orkney

Shewan, A et al (2017) 'We have a new hospital: future proofing the dementia workforce 2017 and beyond'. Alzheimer Europe conference 2017. Poster & oral presentation.

## **Education and Training**

Lyn Irvine - Role of the Alzheimer Scotland Dementia Nurse Consultant Vimeo, NHS Education for Scotland (2015)

Garton, J and UWS (2018) Evaluating the impact of the dementia champions in NHS D&G.

Andy Shewan (2018) Developing Observation Guidelines for Patients with Mental Health Conditions in Acute Hospital Care. Poster presentation. Dementia Champions Graduation, Edinburgh

Helen Skinner & University of Dundee (2018) Scenario based learning for registered and unregistered staff on older people's care and people with dementia.

Helen Skinner - A digital information postcard for people living with dementia in Fife. <https://clicktime.symantec.com/3EVfsPi7kvypi5mvF1Lg9dt6H2?u=www.livingwithdementiainfife.scot.nhs.uk>

## **Research and Evaluation**

Holland, S. & Kydd A. (2015). Ethical issues when involving people newly diagnosed with dementia in research. *Nurse Researcher*, Vol 22 (4), pp. 25-29

Skinner, H. (2016) Partners in care - Involving and supporting carers in the hospital setting, NHS Fife. 26th Alzheimer Europe Conference November 2016 "Excellence dementia research and care" Copenhagen. Oral presentation

Wood N, Cairns Y and Sharp B (2017) How collaboration is improving acute hospital admission for people with dementia. *Nursing Older People*. 29, 9,21-25. doi: 10.7748/nop.2017.e990

FoD (2017) Identifying critical success factors for improved outcomes for people with dementia and their carers in acute care A focus on NHS Grampian.

Collaborating with the Shetland Remoage Project <http://remoage.eu/project/results>

Shields, S & Burns, P (2018) Signifiers - Supportive or Stigmatising; "Asked for Help" A person Centred Approach to Symbols. 28th Alzheimer Europe Conference 2018 "Making dementia a European priority" - Barcelona

Mantle, R (2015) Winston Churchill Memorial Trust Fellowship- 'Make every moment count: cultivating connections with people with dementia'

Mantle, R (PhD in progress 2018) PhD Scholarship - 'Bringing the Virtual into Reality: Immersive Virtual Environment Technology and Wellbeing for people living with dementia in rural settings: An action research project

Clarke, C., Mantle, R. (2016) Using risk management to promote person-centred dementia care. *Nursing Standard*. 30, 28: 41- 46

## Appendix B

# Ten Dementia Care Actions in Hospital (Scottish Government 2013)

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## Dementia Care Actions in Hospital



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.



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