Transforming Specialist Dementia Hospital Care

Alzheimer Scotland
Action on Dementia

Scottish Government
Riaghaltas na h-Alba
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This report is part of the consensus-based stakeholder response to the Mental Welfare Commission's report into specialist NHS dementia care in 2014. It is an independent review of the sector commissioned by The Scottish Government, and makes recommendations on the modernisation of specialist NHS dementia care. This work was led by Alzheimer Scotland's National Dementia Nurse Consultant, a post that was jointly funded by Alzheimer Scotland and the Scottish Government.

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Executive summary

Introduction:

- This report sets out a model of specialist hospital care for people with dementia who have intensive and complex clinical care needs that require high level expert care.
- Specialist dementia hospital care is required for people with dementia who have an acute psychological presentation as a result of dementia or co-morbid mental health illness. The clinical needs of this group can only be met in a hospital environment.
- Whilst a psychological presentation may necessitate being admitted to hospital, the person will also have additional physical, emotional and social care needs. This requires a highly skilled multi-disciplinary workforce that can deliver therapeutic interventions, care and treatment.
- It also provides an approach to the safe transition of people who do not have a clinical need to remain in hospital and can be cared for in more homely settings in the community, with the appropriate level of multi-disciplinary professional input to support those providing day-to-day care.
- The findings and recommendations of this report were made possible by the overwhelming enthusiasm of staff working in this area to welcome the Alzheimer Scotland National Dementia Nurse Consultant to visit their unit and share their practice. This included staff within the specialist dementia units, mental health leads for quality excellence in specialist dementia care, executive directors of nursing and allied health professionals, consultant psychiatrists and psychologists, pharmacology and social work.
- This collaborative approach also included people with dementia and their families, Chief Nursing Officer's Directorate, Commitment 11 Excellence in Specialist Dementia Care Group of the National Dementia Strategy and the Mental Welfare Commission.

Background:

- The Mental Welfare Commission's (MWC 2014) review of dementia continuing care units identified serious concerns with quality of care, environments, access to multi-disciplinary professionals and adherence to legal requirements for providing care.
- A roundtable discussion[a] was hosted by Alzheimer Scotland in 2014 following on from the above report to develop a better understanding of the issues and challenges and identify what could be done to remedy these.
- The key outcome of this roundtable was the appointment of an Alzheimer Scotland National Dementia Nurse Consultant to undertake a review of NHS specialist dementia care environments. This post was jointly funded by Alzheimer Scotland and the Scottish Government.
- Ten NHS Boards were included in this review, with 63 individual specialist care environments visited from a total of 92 with the purpose of 1) evaluating the quality

a Chaired by Professor Graham Jackson and attended by representatives from Scottish Government, NHS Health Boards and Royal College of Psychiatrists

and appropriateness of specialist hospital care in dementia and 2) developing an understanding of the issues around transition and discharge from hospital.

- During these visits staff demonstrated how they were delivering person-centred care within challenging circumstances and environments. These challenges included unsuitable buildings, design and layout that hindered the delivery of person-centred care, lack of access to multi-disciplinary professionals and the needs of patients ranging from acute psychological symptoms to end-of-life care.
- The Alzheimer Scotland National Dementia Nurse Consultant also brought her own in-depth understanding of the context of these environments and the needs of people who require specialist dementia hospital care. This specialist knowledge and understanding, combined with the extensive consultation enabled the Nurse Consultant to provide the recommendations within this report.

Issues with current provision:

- The Alzheimer Scotland National Dementia Nurse Consultant found:
  - Specialist dementia wards are frequently located in environments that do not support person-centred care and can increase the distress of the person with dementia and their family.
  - There is a lack of access to the multi-disciplinary professionals required to support the complex care required in dementia.
  - There is difficulty with transition, resulting in the largest proportion of patients in the specialist dementia wards being those who do not have a clinical need to be in hospital.
  - This makes it difficult to provide appropriate care for the current wide range of differing needs. It also means that resources are not being targeted effectively.
  - Staff within specialist care are committed to providing good quality care, but are hindered by the current obstacles.
- There is a lack of integration between these specialist hospital environments and the wider health and social care systems.
- This results in specialist dementia hospital units sitting in isolation, without the same focus on discharge to more appropriate care environments that is the case with acute hospitals.
- This often results in the window of opportunity being missed for safe transition to a more appropriate community setting to enhance quality of life.
- Most people with dementia can be cared for in the community throughout the illness. This requires a multi-disciplinary coordinated and planned approach to support those providing day-to-day care.
- There will be a small number of people with dementia who have acute clinical care needs that require specialist hospital care for a period of time.

- It is estimated that up to one percent of people with dementia will require management in a specialist dementia hospital environment at any one time[b]. This will result from severe psychological symptoms of dementia or the combined influence of a co-morbid mental health condition.

Moving forward:

- This report sets out a model of modern specialist hospital units based on quality of care for people with dementia who have intensive and complex clinical care needs and require high level expert care.
- It also provides an approach to build community capacity to support the safe transition of those who do not have a clinical need to remain in specialist hospitals and can be cared for in more homely settings in the community.
- Going forward, the Advanced Dementia Practice Model (Alzheimer Scotland 2015) provides the integrated and comprehensive evidence-based approach to support people in the community and ensure that people with dementia do not remain in hospital unnecessarily.
- Based on the evidence presented in this report, there is an urgent need for widespread redesign of specialist dementia hospital provision across Scotland. This will enable current resources to be used more effectively.
- The decommissioning and re-design process can be delivered as a one-time transformational change.

Recommendations:

- That specialist NHS dementia care is modernised, providing high quality, human rights-based care, specifically for individuals who cannot be cared for in the community.
- Integration Joint Boards develop a transition plan and a local engagement strategy with their partners, including NHS Boards and people living with dementia, for any necessary de-commissioning process and re-investment in specialist dementia units and to develop further community capacity in health and social care services.
- That the Scottish Dementia Working Group and National Dementia Carers Action Network provide the representative groups for this local engagement.
- Integration Joint Boards and NHS Boards assess the proportion of people with dementia that can be safely transitioned to more appropriate community settings.
- The Alzheimer Scotland National Dementia Nurse Consultant provides expert guidance at both a national and local level.
- Integration Joint Boards and NHS Boards build strong and strategic local engagement on:
    - Any necessary de-commissioning and re-directing of resources to the development of specialist dementia hospital units and
    - building further community health and social care services.

b Brodaty et al (2003) "Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery" Medical Journal of Australia https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service

- NHS National Procurement to commission the design of a blueprint for a specialist dementia unit that can be implemented by each NHS Board.
- There should be no financial detriment for families as part of the decommissioning process, with the financial cost of the care and treatment of the person with dementia being transitioned to the community continuing to be met by the NHS Board.
- The legal status of patients being transitioned to the community is reviewed and the appropriate legal documentation put in place.
- The creation of modern specialist dementia units that will provide centres of excellence to treat the small number of people with dementia who have a clinical need to be in hospital.

  The estimated 45[c] specialist dementia units required across Scotland will provide a highly skilled practice area and make it an attractive specialism for ambitious and talented practitioners to deliver highly skilled therapeutic interventions.

  Promoting Excellence Framework the foundation for evidence based care for all practitioners. Leaders and senior practitioners ensuring that everyone working within the unit are trained at the appropriate level to ensure a high quality therapeutic approach.

  They will be underpinned and supported by the Charter of Rights for People with Dementia and their Carers in Scotland, the Promoting Excellence Framework, the AHP Framework Connecting People, Connecting Support and the Standards of Care for Dementia in Scotland.
- The timeframe for this process will extend beyond the end-point of Scotland's 2017-2020 National Dementia Strategy

c This is based on an estimated 560 people with dementia who require care and treatment in a specialist dementia unit.

1. Introduction

1.1 Introduction

This report is part of the consensus-based stakeholder response to the Mental Welfare Commission's report into specialist NHS dementia care in 2014. The independent review of the sector was commissioned by the Scottish Government, and makes recommendations on the modernisation of specialist NHS dementia care. This work was led by Alzheimer Scotland's National Dementia Nurse Consultant, a post that was jointly funded by Alzheimer Scotland and the Scottish Government.

Most people with dementia can be cared for in the community[d] throughout the illness. This requires a multi-disciplinary, professional, coordinated and planned approach to support those providing day-to-day care[e]. There will be a relatively small number of people with dementia at any one time who have acute clinical care needs that require specialist hospital care for a period of time. This will result from severe psychological symptoms of dementia or the combined influence of a co-morbid mental health condition.

However, an estimated 60 percent of current patients with dementia do not have this clinical need and could be more appropriately cared for in the community. This means the specialist dementia hospital population has a wide range of needs that cannot be appropriately accommodated alongside each other. It also results in resources being used inefficiently and does not facilitate skilled practitioners to deliver highly specialised interventions for people with an acute clinical need.

This report sets out a model of a modern specialist hospital unit based on quality of care for people with dementia who have intensive and complex clinical care needs and require high level expert care. It also provides an approach to building community capacity to support the safe transition for those who do not have a clinical need to remain in hospital and can be cared for in more homely settings in the community.

Going forward, the Advanced Dementia Practice Model (Alzheimer Scotland 2015)[f] provides the integrated and comprehensive evidence-based approach to support people in the community and ensure that people with dementia do not remain in hospital unnecessarily.

d Continuing to live at home or in a care home

e This includes family carers, care homes, care at home service and day care

f Alzheimer Scotland (2015) "Advanced dementia practice model: understanding and transforming advanced dementia and end-of-life care" https://www.alzscot.org/campaigning/advanced_dementia_model

1.2 Background to report

The Mental Welfare Commission's (MWC 2014)[g] review of dementia continuing care units identified serious concerns with quality of care, environments, access to multi-disciplinary professionals and adherence to legal requirements for providing care. A roundtable discussion[h] was hosted by Alzheimer Scotland in 2014 following on from this report to develop a better understanding of the issues and challenges and identify what could be done to remedy these.

The key outcome of this roundtable was the appointment of an Alzheimer Scotland National Dementia Nurse Consultant to undertake a review of NHS specialist dementia care environments. Ten NHS Boards[i] were included in this review, with 63 specialist care environments visited from a total of 92 with the purpose of:
1) evaluating the quality and appropriateness of specialist hospital care in dementia; and
2) developing an understanding of the issues around transition and discharge from hospital.
The Nurse Consultant also carried out extensive consultation with key stakeholders, including people with dementia and families, as part of this process. The findings from this review are presented in full in Appendix 1 of this report.

The recommendations of this report are based on the findings of the review by the Alzheimer Scotland National Dementia Nurse Consultant. Improvements since the review have been explored in a smaller number of NHS Boards and are incorporated into the recommendations within this report.

The recommendations are also informed by the improvement programme of work from the Commitment 11 Quality and Excellence Specialist Dementia Care Group. This work has been ongoing since September 2014, with NHS Boards submitting their self-assessment and improvement plans to the Commitment 11 Group. This work has been continued through a programme led by Focus on Dementia[j] that is working with four individual specialist dementia hospital units across Scotland. Additional improvement has been delivered through the Promoting Excellence Framework (2011), with the Dementia Specialist Improvement Leads Programme being introduced to cascade enhanced and expert education and training to support change and improvement.

g Mental Welfare Commission (2014) "Dignity and respect: dementia continuing care visits" http://www.mwcscot.org.uk/media/191892/dignity_and_respect_-_final_approved.pdf
h Chaired by Professor Graham Jackson and attended by representatives from Scottish Government, NHS Health Boards and Royal College of Psychiatrists
i Review took place between April 2015 and March 2016 and included Ayrshire and Arran, Dumfries and Galloway, Fife, Forth Valley, Grampian, Greater Glasgow and Clyde, Lanarkshire, Lothian, Scottish Borders and Tayside.
j Health Improvement Scotland

1.3 Context and legal framework for specialist dementia hospital care

The National Dementia Strategy for Scotland[k] is underpinned by the "Charter of Rights for People with Dementia and their Carers in Scotland" (2009)[l]. This includes ensuring that the human rights of people with dementia are respected, protected and fulfilled. The Charter also stipulates that people with dementia have the right to health and social care services provided by people with an appropriate level of training on dementia and human rights.

The Promoting Excellence Framework (2011)[m] takes this forward into practice through outlining the knowledge and skills required by health and social care practitioners. This is set out in four different levels of skill and knowledge determined by a practitioner's role and level of responsibility. There has also been focused attention and improvements in specialist dementia hospital provision through the Commitment 11 Group of the National Dementia Strategy (2013 to 2016)[n].

Specialist hospital care in dementia sits within the principles and provisions of the Adults with Incapacity (Scotland) Act 2000 and Mental Health (Care and Treatment) (Scotland) Act[o]. The review by the Alzheimer Scotland National Dementia Nurse Consultant found that only a small number of patients are subject to a compulsory treatment order under the Mental Health (Care and Treatment) (Scotland) Act.

Whilst legislation and guidelines provide the framework for staff to work within, there is also a need for ongoing training and support in ethical decision making. There is unlikely to be a single right answer in any given situation and staff within specialist dementia hospital care require support in the complex ethical dilemmas that can arise (Nuffield Council on Bioethics 2009)[p].

k The first National Dementia Strategy was published in 2010, with subsequent updates published in 2013 and 2017

l "Charter of Rights for People with Dementia and their Carers in Scotland" (2009) https://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf

m NHS Education for Scotland and Scottish Social Services Council (2011) "Promoting Excellence Framework" http://www.gov.scot/Resource/Doc/350174/0117211.pdf

n Commitment 11: "We will set out plans for extending the work on quality of care in general hospitals to other hospitals and NHS settings."

o Mental Health (Care and Treatment) (Scotland) Act 2003 and updated provisions in Mental Health (Scotland) Act 2015.

p Nuffield Council on Bioethics (2009) "Dementia ethical issues" http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf

1.4 Outline of report

Section 2: People with dementia who need specialist hospital care

This section provides an understanding of when people with dementia may require specialist hospital care. It also presents current data on the number of people with dementia in specialist hospital environments and an outline of the Advanced Dementia Practice Model (Alzheimer Scotland 2015).

Section 3: Current approaches to specialist dementia hospital care

This section provides an understanding of current approaches to specialist hospital care in dementia. It provides a summary of the key findings of the review by the Alzheimer Scotland National Dementia Nurse Consultant. It also provides a synopsis from recent findings from the Mental Welfare Commission's visits to specialist dementia hospital environments.

Section 4: Transforming specialist dementia care

This section takes forward the issues and challenges outlined in the report and presents a blueprint for a specialist dementia unit through outlining the core specialisms and approach required. It also puts forward a case for a one-off transformational change through decommissioning and re-design of specialist dementia care across Scotland.

Section 5: Conclusion and recommendations

This section provides the concluding remarks and sets out a series of recommendations to guide the decommissioning and transformation process.

2. People with dementia who need specialist hospital care

2.1 Introduction

This section will demonstrate that most people with dementia can continue to be cared for in the community throughout the illness. It will show that only a small proportion of people with dementia require specialist hospital care. As the number of people with dementia increases, recognising and responding to these factors will be of key importance in reshaping dementia hospital provision with the essential component of specialist community support to ensure resources are used efficiently.

2.2 People with dementia who will require specialist hospital care

The experience of dementia is unique to each individual and dependent on factors relating to underlying health, personality, biography and social context. As dementia progresses, the physical nature of the illness becomes more to the fore – the influence of social and psychological aspects will also continue to be prominent.

People will often have co-morbid physical or mental health conditions that will combine with dementia in a complex way. The possible range of physical, psychological and social issues in dementia requires a bio-psychosocial holistic approach in providing appropriate care and treatment for the individual.

Health care practitioners will have a key role in responding to the increasing physical nature of advancing dementia, the impact of co-morbid conditions and supporting psychological wellbeing. This specialist support can be provided in the person's current place of residence[q] for most people with advanced dementia. Section 2.4 outlines how people can continue to be supported in the community to avoid unnecessary hospital admissions.

There will be a small proportion of people who will require specialist dementia hospital care and treatment. This group will experience very severe and persistent psychological distress and behaviours that would be too challenging to be managed in mainstream settings, irrespective of how much specialist support is provided.

The types of issues include aggression and physical violence, self-harm, high risk to self and/or others and ongoing extreme disinhibited behaviours, with lack of recognition of inappropriateness. They will often be physically mobile and possibly younger. It also includes people with dementia who have acute mental health conditions such as psychosis, schizophrenia and severe depression with suicidality.

This group will also have complex physical health care needs, along with the requirement for meaningful occupation and social stimulation. This requires a multi-disciplinary professional approach in addition to the nursing and specialist clinical care support who will provide day-to-day caring.

Brodaty et al (2003)[r] provide a "seven-tiered model of management of behavioural and psychological symptoms of dementia". They estimate that up to one percent of people

q Continuing to live at home or in a care home

r Brodaty et al (2003) "Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery" Medical Journal of Australia https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service

will be within the highest tiers and require management in a psychogeriatric or neuro-behavioural unit. This will include people with acute psychiatric illness and severe behavioural problems complicating their dementia.

The intensity of experience is likely to continue for a relatively short period of time until the presentation changes. This may be ongoing for a period of around 18 months and will diminish as the illness progresses and physical robustness reduces. The person can then be safely transitioned to being cared for in a community setting, once this clinical need to remain in hospital no longer exists.

2.3 Specialist dementia hospital population

There were 1,886 NHS Old Age Psychiatry specialist beds for people with dementia in Scotland in June 2014[s]. The work carried out by the Alzheimer Scotland National Dementia Nurse Consultant suggests that this number is likely to have reduced to some extent since the audit was carried out.

Official statistics provide approximately 1,850 as the number of NHS Old Age Psychiatry beds in 2016 (ISD 2017)[t]. Official statistics also show that there are 4,400 Geriatric Medicine beds in 2017. These official statistics includes people with an organic illness (dementia) and those with a functional illness (mental ill health conditions such as depression, bi-polar and schizophrenia). It is therefore difficult to provide a precise number of patients with dementia, given the frequency of co-morbid conditions and under-diagnosis of dementia.

2.4 Advanced Dementia Practice Model and Advanced Dementia Specialist Team

Those providing day-to-day support require specialist support in responding to the complex physical, psychological and social issues that occur in advanced dementia. The Advanced Dementia Practice Model (Alzheimer Scotland 2015) provides an integrated and comprehensive approach to respond to this most complex phase of the illness and support people to remain in the community.

The Advanced Dementia Specialist Team provides the specialist input required to support those already providing care. They will provide expert assessment, medical interventions and guidance on skilled, person-centred approaches to care. These specialist practitioners are located within this team on a full, part-time or consultancy basis. It includes specialist consultants, psychologists, allied health professionals and mental health and general nursing practitioners.

The care plan provides a planned and coordinated approach to support the person through advanced dementia and end-of-life. It will identify the practitioners required to support the person's care, bringing in specialist support where this is not already being provided. This approach will enable most people to remain within the community. It will also provide the multi-disciplinary professional team necessary to enable people to safely transition from hospital to the community when they no longer have a clinical need to remain.

s Scottish Government audit of NHS Boards for National Dementia Strategy Commitment 11 Working Group

t 1,160 long stay beds and 3,235 in units other than long stay https://www.isdscotland.org/Health-Topics/Hospital-Care/Beds/

2.5 Current practice

Current practice is not consistent with this optimum approach to specialist care in dementia. The following section will demonstrate that people are currently being admitted to hospital who can be cared for in community settings and are then unable to be safely transitioned out because of lack of appropriate care in the community.

3. Current approach to specialist dementia hospital care

3.1 Introduction

This section provides an understanding of current approaches to specialist hospital care in dementia. Evidence presented comes from the extensive and in-depth review by the Alzheimer Scotland National Dementia Nurse Consultant[u]. This review included consultation with a wide range of key stakeholders such as practitioners and people living with dementia. It outlines the key problems in the quality and appropriateness of provision. It also highlights that many people do not have a clinical need to be in hospital, but that challenges with transitioning from these environments means that the number of people remaining in hospital is much higher than necessary.

A synopsis of the findings of the Mental Welfare Commission's reports[v] in specialist dementia care environments is provided. The good practice examples from the review by the Alzheimer Scotland National Dementia Nurse Consultant are then presented along with an understanding of some of the improvements since that time.

3.2 Findings of review by the Alzheimer Scotland National Dementia Nurse Consultant

3.2.1 Hospital population

Admission to assessment units was often not because of clinical need to be in hospital. It could broadly be defined as relating to a lack of appropriate care and support in the community. This included the lack of an appropriate care plan for the person to remain in their current place of residence, and distress in dementia not being adequately supported by specialists in the community. The range of needs within specialist units and transition units varied widely from psychological symptoms of dementia and co-morbid mental health illness to end-of-life. Occupancy levels varied across the NHS Boards. Low occupancy was noted in three Boards with occupancy levels around 70 percent.

3.2.2 Workforce skills and knowledge and access to multi-disciplinary professionals

The skill mix and ratio of professional staff in these environments was lower than that of all other mental health areas. In most areas there was a lower ratio of registered mental health nurses to clinical support staff. A small number of NHS Boards had higher ratios of professional staff, with 55 to 60 percent registered mental health nurses.
Access to multi-disciplinary professionals in assessment units was at a higher level compared with specialist dementia units. However, the level varied between NHS Boards. Only two wards had dedicated social worker time, with all others having a referral system. Most of the specialist and transition units for people with complex needs associated with

u A full report on the review is provided in Appendix 1
v Inspections that took place during 2016 and 2017

advanced dementia had no access to the multi-disciplinary professional team including psychology, pharmacy and allied health professionals.

Half of the assessment units had access to allied health professionals and there was very limited access to pharmacy and psychology. The specialist and transition units had virtually no access to these professionals – access to pharmacy was minimal and they were not participating in medication management or multi-disciplinary reviews. Access to other professionals could be available through a referral approach, but length of waiting time was an issue. Due to increased referrals from community teams, very few people with dementia in the specialist and transition units were supported by the psychological service.

The cost of beds varied widely. Higher costs did not equate to quality of care and access to a greater number of specialists compared with the less costly beds. Whilst many of the specialist beds are in mental health services, some are managed within community hospitals and others within primary care, where there is limited access to specialist dementia professionals. Two Boards had transferred the care and treatment of patients with dementia to a specialist unit in England because of the lack of a hospital environment that could provide specialist care within Scotland.

3.2.3 Environments

Older facilities were in use in many areas which required significant investment for upgrade and maintenance. Specialist dementia units continue to be located on upper floors with no easy access to outdoor areas. These can be old, institutional environments in locations that are difficult for families to visit using public transport.

In many cases the built environment presented challenges for staff in providing person-centred quality care and added to the distress of patients and families. There was a lack of privacy, with bed and toilet areas being shared by up to six people with no personal shower or wash areas.

Purpose-built dementia units had been developed in some areas, with others to be completed by 2019. At the time of the review, four NHS Boards were implementing a bed remodelling plan, driven by low occupancy and units being housed in outdated buildings.

3.2.4 Transitions

The length of stay within assessment units was an average of eight to 12 weeks. However, it could be up to two years in some instances and increased significantly when there were legal issues such as lack of specific relevant powers through power of attorney or guardianship. Discharge from these environments was often to a care home or NHS specialist bed either in hospital or in a contracted-out location. Delays in discharge were attributed to lack of funding for a care package and the availability of appropriate care settings within the community.

The length of stay within specialist and transition units ranged from one year to 15 years, with an average of four and a half years. The specialist dementia units exist in isolation and are disconnected from wider health and social care services commissioned by Integration

Joint Boards. Challenges to discharge included social work considering it to be a low priority as the person was in a place of safety. Families were apprehensive about care being provided outwith the specialist hospital environment and there was a lack of knowledge about alternative appropriate accommodation and support. Failed previous discharge to a care home was a common reason why people remained in NHS care.

3.3 Good practice examples and changes implemented since the time of review

There was evidence of good practice at the time of the initial review and follow-up visits by the Alzheimer Scotland National Dementia Nurse Consultant. It was evident throughout the review that staff were committed to providing a high standard of care. However, they were often frustrated and hindered by the issues outlined in the previous section.
The Promoting Excellence Framework (2011) had been implemented in every NHS Board visited. Most assessment units held reviews once or twice weekly, with families invited as appropriate.

Good practice in pre-discharge was noted in two Boards. In one, hospital staff and family would visit the care home to offer support to care home staff. The other had consultant-led clinics within care homes which successfully reduced admissions to the ward with outreach working. Two Boards reported a significant reduction in admission where psychiatric liaison teams had been established to support the care homes in their areas.

At the time of the review, there had been a number of recent improvements, including an activity room and areas for family to use or stay overnight. Some units had activity coordinators, with volunteers and community groups providing support for activity and connection. Many of the units visited had activity programmes planned.
Although some units had excellent facilities and activity rooms, staff shortages and lack of time meant the majority were locked, with no therapeutic activity going on within the unit at the time of the visit. When activity was carried out it was provided by nurses, with few units having access to specialist allied health professionals.

3.4 Mental Welfare Commission reports

Around 30 Mental Welfare Commission reports on specialist dementia care environments were reviewed. The visits took place throughout 2016 and 2017 across NHS Board areas in Scotland. The issues identified by the Commission were consistent with the extensive review conducted by the Alzheimer Scotland National Dementia Nurse Consultant.
Reports noted recommendations from previous visits – this highlighted that improvements are being made in areas of concern previously raised by the Commission. However, significant issues remained across many of the environments recently visited.

Most frequently occurring was a failure to evidence person-centred care planning and lack of access to multi-disciplinary specialists. A need for meaningful activity and tailored or person centred activity for patients was also recognised in many areas. There were

some instances of a failure to record documentation in relation to the relevant Acts[w] in the patient's file and to consult proxy decision makers and involve family members. Environmental concerns included overly clinical settings, unsuitable buildings and dignity and privacy being compromised.

3.5 Moving forward

This section has demonstrated that specialist dementia units are frequently located in environments that do not support person-centred care and can increase the distress of the person with dementia and their family. It has also shown a lack of access to the multi-disciplinary professionals required to support the complex care required in dementia. There is a disconnection between these specialist services and the wider health and social care commissioned by Integration Joint Boards. This creates difficulties with transition and results in a significant proportion of patients in the specialist dementia wards having no clinical need to be in hospital. This makes it difficult to provide appropriate care for the current wide range of differing needs. It also means that resources are not being targeted effectively. Staff within specialist care are committed to providing good quality care, but are hindered by the current obstacles.

The following section provides a model of specialist dementia care for those who have a clinical need to be in hospital. It also outlines an approach to the safe transitioning of the current group of people with dementia in specialist hospital environments who would be more suitably cared for in community settings.

w Mental Health (Care and Treatment) (Scotland) Act 2003 and Adults with Incapacity (Scotland) Act 2000

4. Transforming specialist dementia care

4.1 Introduction

Based on the evidence presented in this report, there is an urgent need for widespread redesign of specialist dementia hospital provision across Scotland. This includes the transition of most patients to the community, so they can be cared for in more appropriate settings to enhance their quality of life.

The decommissioning and re-design process can be delivered as a one-time, transformational change. This will require NHS Boards and Integration Joint Boards to review their community provision and capacity; making investments as required to provide the specialist support for those providing care in the community[x]. Moving forward, the Alzheimer Scotland Advanced Dementia Practice Model (2015) provides an approach to ensure that people with dementia are supported within the community.

Our vision is that the modern specialist dementia unit provides a centre of excellence to deliver quality treat and care for the small number of people with dementia who will have a clinical need to be in hospital. This will provide a highly skilled practice area and make it an attractive specialism for ambitious and talented practitioners to deliver therapeutic interventions.

4.2 Collaborative approach of the review

This vision was made possible by the overwhelming enthusiasm of staff working in this area in welcoming the Alzheimer Scotland National Dementia Nurse Consultant to visit their unit and sharing their practice. It included staff within the specialist dementia units, mental health leads for quality excellence in specialist dementia care, executive directors of nursing and allied health professionals, consultant psychiatrists and psychologists, pharmacology and social work.

This collaborative approach also included people with dementia and their families, the Chief Nursing Officer's Directorate, Commitment 11 Excellence in Specialist Dementia Care Group of the National Dementia Strategy, and the Mental Welfare Commission.

x To provide specialist support to care homes and people with dementia who continue to live at home.

4.3 Transformational change: decommissioning and re-investment

The review carried out by the Alzheimer Scotland Dementia Nurse Consultant identified that most patients did not have a clinical need to be in hospital and could be cared for in a community setting. The modest estimation of the proportion of people with dementia who do not have a clinical need to remain in hospital is 60 percent[y].

This estimate is based on extensive consultation by the Alzheimer Scotland National Dementia Nurse Consultant with the multi-disciplinary professional teams and managers across the 63 units included in the review. The Alzheimer Scotland Dementia Nurse Consultant is also aware of work done by some NHS Boards in this area to assess the needs of patients to remain within these units. Whilst this work is not within the public domain, it is the understanding of the Alzheimer Scotland Dementia Nurse Consultant that this work is consistent with the evidence collected throughout the review.

There is also an urgent need for a widespread redesign of specialist dementia hospital provision across Scotland for the estimated 40 percent of people who have a clinical need to be cared for in these environments. This is essential to ensure access to multi-disciplinary professional specialists, provide an environment that supports person-centred care and deliver the required highly skilled therapeutic care and treatment.
It is not possible to provide a precise number of people with dementia in specialist dementia hospital units[z]. The most recent figure available is that of 1,886 NHS Old Age Psychiatry beds for people with dementia in 2014[aa]. This number will have reduced in light of the redesign that has taken place since that time. For the purposes of this report, we estimate a current figure of 1,400 beds.

Based on this figure, 840 people with dementia could be safely transitioned to the community with appropriate support, with 560 specialist dementia hospital beds required across Scotland. The estimated 560 people who need to be cared for in a specialist care unit is less than one percent of the estimated number of people with dementia[bb]. This is consistent with the estimate provided by Brodaty et al (2003)[cc] in the "seven-tiered model of management of behavioural and psychological symptoms of dementia". This would require 45 12-bedded specialist dementia units across Scotland for the estimated 560 people.

The average cost of providing a specialist dementia hospital bed is £2,520 per inpatient week[dd]. This equates to an annual cost of £183 million per year – £110 million of which is on the 60 percent of patients who do not have a clinical need to be in hospital. This £110 million per year could be re-invested in providing highly specialised dementia hospital care and supporting community provision, so that people with dementia are not admitted to hospital unnecessarily.

y There was general consensus throughout the review that between 60% to 80% of these beds are not required and that the care of this client group could be met within alternative care environments (Appendix 1).

z Outlined in Section 2.3

aa Scottish Government audit of NHS Boards for National Dementia Strategy Commitment 11 Working Group

bb There is an estimated 90,000 people with dementia in Scotland in 2017 – 560 is 0.6 percent of this total.

cc Brodaty et al (2003) "Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery" Medical Journal of Australia https://www.mja.com.au/journal/2003/178/5/behavioural-and-psychological-symptoms-dementia-seven-tiered-model-service

dd Based on average cost of inpatient bed per week for geriatric psychiatry ISD (2016) "Speciality group costs: inpatients in long-stay specialities National Statistics release"

The potential savings can be demonstrated by using a current 30-bedded unit as an example. The current average cost for 30 patients is £3.9 million, based on the £2,520 average weekly cost. Implementing a 12-bedded unit with additional multi-disciplinary input will result in the weekly cost per patient rising – we have estimated this would rise to £3,500 per patient for this example, which would cost £2.2 million per year for 12 patients. If £1,000 cost per week followed each person being transitioned to the community, this would be an annual cost of approximately £936,000 per year. This indicative example shows a potential overall saving of £800,000 per year for the decommissioning and transformation of a 30-bedded unit

An average of 60 people with dementia per NHS Board can be safely transitioned to the community with the appropriate level of multi-disciplinary support for those providing day-to-day care. This varies across areas, from an estimated 22 in NHS Borders to 164 in NHS Greater Glasgow and Clyde[ee]. Similarly, the number of specialist hospital beds required across Scotland will vary according to population size and need. Again, this will vary from 15 in NHS Borders to 109 in NHS Greater Glasgow and Clyde[ff].

The review by the Alzheimer Scotland Dementia Nurse Consultant took place between April 2015 and March 2016. We therefore recommend that NHS Boards re-assess the proportion of people with dementia that can be safely transitioned to more appropriate community settings as an initial task in the de-commissioning and transition process.

4.3.1 Transition to community and health board planning

An integrated and comprehensive approach is required to support people living with dementia in the community. A coordinated and planned approach is necessary to tackle the acute issues that can arise and enable the delivery of optimum care. Those providing day-to-day care[gg] require specialist support in responding to the complex issues that can arise in dementia. They have a need for advice and guidance on caring to support the reduction of unnecessary hospital admissions.

The decommissioning process will require NHS Boards and Integration Joint Boards to evaluate the level and capacity of community resources to facilitate safe transition. There will be a need to invest where the required multi-disciplinary specialist support is not sufficient to support care homes and people living at home. A proportion of the resources released from reducing the hospital population can be re-invested in building community capacity. The example under section 4.3 shows that there can be savings on current resources, even with £1,000 per week following each person being transitioned to the community.

The review by the Alzheimer Scotland Dementia Nurse Consultant found the financial implications to be part of the reluctance from families in transitioning the person to the community. There should be no financial penalty for families as part of the decommissioning process. The care and treatment of the person with dementia being transitioned as part of the decommissioning process should continue to be met by the NHS Board.

ee This is based on the overall estimated number of people with dementia in Scotland and the proportional breakdown across each NHS Board according to population age and size.

ff A breakdown by NHS Board is provided in Appendix 2

gg This includes family carers, care homes, care at home service and day care

The appropriate legal documentation would be required to transition a person who does not have capacity to consent to the move to a community setting. Welfare power of attorney or guardianship may be held by a family member giving them specific relevant powers.

Where guardianship or power of attorney does not exist, the legal protection required to move a person who lacks capacity should be adhered to, which may delay transition on occasions. Moving forward, the process of seeking guardianship would be commenced when a person is admitted to the specialist dementia unit.

4.3.2 Supporting and involving families

The review by the Alzheimer Scotland National Dementia Nurse Consultant identified that the family may be anxious about the person being transitioned to a community setting. The circumstances that led to the person with dementia being admitted to hospital may have been a crisis; once the situation had stabilised, the family may continue to consider hospital to be the most appropriate environment. They may be unaware that there are more appropriate community environments that could provide a better quality of life for the person. It is important to engage closely with the family to work through any apprehension in a supportive manner to reach a resolution.

The family should be fully involved in the transition planning process, with their views listened to and concerns addressed. They should be assured that the ongoing bio-psychosocial needs of the person with dementia will be reviewed and met within the community setting. They should also be certain that there will be no financial penalty as a result of the transition to a community setting.

Where the person is moving to a care home, the family should have the opportunity to visit and meet with staff who will be providing care. There should be a room prepared and opportunity for the family to personalise it. It is likely that most people would be moving to a care home, but there may be occasions when the person is returning home. In these instances, close family members will have had a significant input into this decision.

Moving forward, the family would be part of the ongoing assessment process within the specialist dementia unit. They would be aware that the person's presentation and care needs had evolved over time and there would be an incremental approach to safe transition planning within the multi-disciplinary team. Furthermore, there would have been no expectation that the person would have remained in the unit beyond the intensive clinical need; a well-planned safe transition to the community would be the aim.

4.4 Specialist dementia care unit

The specialist dementia unit is designed to provide care and treatment to 12 people with dementia who have a clinical need to be in hospital and who are unable to be supported in a community setting, no matter the level of specialist support provided. The unit will deliver highly skilled care and treatment focused on the therapeutic relationship, delivered by a multi-disciplinary team responding to acute and intensive psychological conditions. The multi-disciplinary team within the unit will have additional support from specialist practitioners, as well as voluntary and community organisations in providing holistic care and treatment in response to the physical, psychological and social needs of each patient.

4.4.1 Patient profiles

Guidance on the appropriateness of hospital care in this area is based on a single eligibility question "Can the individual's care needs be met in any setting other than hospital" (Scottish Government 2015)[hh]. The care, treatment and support of most people with dementia can be provided in settings other than a hospital - this includes continuing to live at home or in a care home. Whilst there will be fluctuations in a person's health and the pattern of declining cognitive and physical function is neither fixed nor predictable, care and treatment for most people can be provided in community settings.

There will be a small proportion of people with dementia at any one time who will require specialised hospital care because of acute psychological symptoms resulting from their dementia and the complex interplay of co-morbid mental health conditions, necessitating substantial health care input. This requirement for specialist hospital care is not condition specific. It requires a holistic assessment of the individual, based on the person's overall needs and presentation.

People requiring specialised hospital care are likely to be in the advanced phase of dementia, as determined by the complexity and severity of symptoms. In addition to this, underlying health is a key factor and the influence of co-morbid mental health illness may result in a person with moderate dementia being admitted to the unit.

This group will experience severe behavioural and psychiatric symptoms. This will relate to people with enduring mental health conditions such as chronic schizophrenia, psychosis and severe depression with suicidality. It will also include people who demonstrate extreme behaviours that are harmful to themselves and others, including physical violence. The level of risk involved can require three people to provide care and support at any one time.

The specialised and multi-disciplinary professional approach within the unit will provide the care and treatment required to improve or stabilise the medical condition over a period of time, which may be around 18 months for many patients. The person will then be safely transitioned, once their condition has stabilised for a sufficient period of time and presentation has changed so that it is possible for care to be provided in a community setting.

hh Scottish Government (2015) "Hospital based complex clinical care http://www.sehd.scot.nhs.uk/dl/DL(2015)11.pdf

4.4.2 Multi-disciplinary assessment

Many people being admitted to the specialist care unit will have an existing care plan, as they may be transferred from an assessment unit or have been receiving intensive support in a community setting. This may include a detailed formulation plan given the presence of psychological symptoms.

The initial step will be for the multi-disciplinary team to review any existing plan and identify where changes or additions should be made. This may include bringing in additional specialist practitioner/s to review a particular aspect of a patient's presentation.

Each specialist practitioner will conduct their individual assessment of the patient's presentation and needs. They will then take part in the multi-disciplinary review for each patient.

Ongoing regular review will then be required on a weekly basis with the multi-disciplinary team in evaluating care, managing medication and making appropriate changes to the care plan of each patient.

Whilst the person with dementia will be admitted to the specialist care unit as a result of severe psychological symptoms, they will also be experiencing a range of physical health care problems. In addition to this, there will be a need for social stimulation and meaningful occupation. The range of physical, psychological and social issues will require a bio-psychosocial approach to assessment and care planning in understanding and responding to individual experience.

The range of assessment tools utilised by the multi-disciplinary team in their evaluation of the individual's needs should be based on providing a holistic, person-centred approach. This would also include formulation such as the Newcastle Model (James 2011)[ii] in using a bio-psychosocial approach to understand the potential causes of psychological distress. Additional tools would be utilised in the assessment and responses to depression, anxiety and medication review.

Dementia Care Mapping (Bradford University)[jj] provides a structured action cycle approach to assessing and reviewing the ongoing needs of the unit and individual patients. This includes person-centred planning, staff training needs and monitoring and implementing improvements to care.

4.4.3 Multi-professional care and treatment

The table below outlines the core group of health and social care specialists who will be located within the unit on a full-time or part-time basis.

ii James (2011) "Understanding behaviour in dementia that challenges" Jessica Kingsley Publisher London

jj University of Bradford "Dementia care mapping" https://www.bradford.ac.uk/health/dementia/dementia-care-mapping/

Table 1: Specialist dementia care unit multi-disciplinary team

Practitioner	Description
Registered Mental Health Nurses	Directly involved in all care and treatment of each patient. Direct advanced statements and anticipatory care planning.
Registered General Nurses	To respond to and treat physical health care needs.
Clinical Support Workers	Deliver person-centred care under the direction of the nurse professionals.
Nurse Consultant	Provide expert advice in dementia care and treatment. Provide supervision of nursing within unit.
Advanced Nurse Practitioner	Support the mental health nursing and provide medication input
Consultant Psychologist	Assessment and prescribing of individualised interventions, formulation plans and neuropsychiatric assessment and treatment.
Consultant Psychiatrist	Formal diagnosis of dementia and other mental health illness. Involvement in the management and ongoing review of care and treatment.
Specialist Registrar Old Age Psychiatry	Substantive time on the ward and oversee care and treatment in deputising for Consultant Psychiatrist
Junior Doctor	Assigned to unit as part of training to develop understanding of specialism – provide support for physical health.
Occupational Therapist	Work with the person to develop and maintain a routine of everyday activities that creates a sense of purpose and supports a good quality of life. They can advise on changes to the everyday environment and equipment and adaptions.
Physiotherapist	Help restore movement and function through exercise, manual therapy, education and advice. Physiotherapy uses physical approaches to promote, maintain and restore physical, psychological and social well-being.
Speech and Language Therapist	Assess, diagnose and manage a range of communication and swallowing needs. The role also encompasses environmental adaptations to support communication, eating and drinking.
Dietitian	Assess, diagnose and treat diet and nutrition problems using the most up-to-date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate food choices.
Activities Coordinator	Develop person-centred care planning for activities of interest delivered individually and as part of group work.
Mental Health Social Worker	Carry out needs assessment, pre-discharge and discharge planning and community care assessment.
Pharmacist	Assist in the review and management of medication.

Additional specialist health care support

There will also be a need to access a wider range of specialist practitioners in response to the specific requirements and wellbeing of each patient. This will be determined by the assessed bio-psychosocial needs of each individual patient. It will include specialist consultants, such as a geriatrician for complex physical conditions and a cardiologist for heart and vascular health.

Additional allied health professional support will be important, including podiatry to help people stay mobile and independent, and arts therapies delivering highly specialist psychological therapies for difficulty in communication and expressing emotions verbally. Patients may reach end-of-life in the specialist dementia care unit because of a co-morbid condition such as cancer. Access to palliative care specialists will be key to managing pain and other distressing symptoms experienced at end-of-life.

Social and community connections

It will be important to provide social stimulation and meaningful occupation, so that people remain connected and engaged. This includes supporting continued involvement in the person's existing hobbies, interests and spiritual practices. This will involve utilising connections with external agencies, voluntary organisations and community networks. It will include patients being supported to take part in activities outwith the hospital and community resources coming into the unit to provide social engagement.

The activities coordinator will work with the person and those closest to them to identify opportunities to link with supports within the community. The activities coordinator will also develop person-centred care planning for activities of interest delivered individually and as part of group work.

4.4.4 Staff quota

The table below outlines the staffing level within the specialist dementia care unit. This will be the basic level of cover provided by the multi-disciplinary team. This will be under continual review according to the needs of patients and may be increased for particular needs, such as those requiring continuous observation of a patient for their wellbeing and the safety of others.

The multi-disciplinary team is split into the different staff groups and disciplines. Total nursing and clinical care workers equates to 29.8 whole time equivalent staff. An additional 5.4 whole time equivalents will include consultant psychologist, consultant psychiatrist, junior doctor, allied health professionals and additional practitioners including nurse consultant, advanced nurse practitioner, pharmacy and social worker with Mental Health Officer status. The unit should also take students of each profession in order to make this an attractive career choice for the future workforce.

Table 2: Specialist dementia unit staffing for seven-day week

Practitioner	Level of staffing full time equivalent	Grade
Nursing and clinical care workers		
Senior Charge Nurse	1.0	Band 7
Charge Nurses	3.0	Band 6
Registered Mental Health and General Nurses	15.4	Band 5
Clinical Support Workers	10.4	Band 3
Additional nursing staff		
Nurse Consultant	0.1	Band 8B
Advanced Nurse Practitioner	0.4	Band 7
Consultants		
Psychologist	1.0	Band 8
Psychiatrist	0.5	
Additional doctors		
Specialist Registrar Old Age Psychiatry	0.5	
Junior Doctor	0.5	
Allied health professionals		
Occupational Therapist	0.5	Band 7
Physiotherapist	0.3	Band 6
Speech and Language Therapist	0.3	Band 6
Dietitian Additional practitioner	0.3	Band 6
Pharmacist	0.5	Band 7
Social Worker with Mental Health Officer status	0.5	

4.4.5 Knowledge and understanding of dementia

A sound understanding of dementia is essential for all those providing care and treatment within the specialist dementia unit. The Promoting Excellence Framework (2011) provides a structured approach to understanding the level of knowledge and skill required by staff in health and social care services to provide human rights based care and support in accordance with the Charter of Rights (2009)[kk].

kk "Charter of Rights for People with Dementia and their Carers in Scotland" (2009) https://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf

The level of knowledge and skill required by each practitioner will be determined by their role and level of responsibility within the multi-disciplinary team. The Promoting Excellence Framework provides four levels[ll] of knowledge and skills that staff require to support people with dementia and their family at different phases of the illness[mm]. It also provides "key quality of life indicators" that staff should be supporting people to achieve.

As a minimum, all **ancillary and non-clinical staff** supporting the units should have the knowledge and skills set out in the "Informed" level of Promoting Excellence.
As a minimum, all **clinical staff** should have the knowledge and skills set out in the "Skilled" level of Promoting Excellence, inclusive of clinical support workers and wider team members including roles such as volunteers.

All **professionally registered staff** including medical, clinical psychology, nursing and allied health professionals, will as a minimum have the knowledge and skills set out at the "Enhanced" level of Promoting Excellence.

Specialist dementia units should also receive multi-disciplinary support from practitioners operating at the **"Expertise"** level of Promoting Excellence – noting that this level of practice becomes role and discipline specific. These practitioners should include clinical psychologist, nurse consultant, advanced nurse practitioner, psychiatrist, activity coordinator and a range of allied health professionals.

In addition, there will be a minimum of one practitioner who has completed the NHS Education for Scotland intensive capacity and capability building Dementia Specialist Improvement Leads programme (DSILS). There should be strategic and organisational support and leadership to maximise the role of staff who have completed the training to enable DSILS', to cascade enhanced and expertise education and training to support change and improvement.

4.4.6 Working with families

Close family members are partners in care and it is essential that these key relationships are recognised and respected. Staff within the unit should be aware of the powers held by the family member/s, such as power of attorney or guardianship. The family carers have their own rights in addition to those assumed when acting for the person with dementia to "full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making" (Charter of Rights 2009).

The family member/s should be encouraged to be active participants in the care of the person with dementia, including treatment discussions and being invited to multi-disciplinary team reviews. This should be ongoing throughout the person with dementia's stay in the unit and during discharge planning. Whilst attending the multi-disciplinary team review will be appropriate for some, others will be more comfortable in having more informal discussions with those providing care and for their views to be listened to and taken into account in this way. As the family will have been integral to care planning throughout the stay in the unit, the discussion around possible transition will occur gradually and not be presented suddenly.

ll Informed, skilled, enhanced and expertise levels.
mm Staff are most likely to be working with people at the "Living well with increasing help and support" and "End-of-life and dying well" phase of illness.

Visiting times should be flexible, with the family member/s encouraged to remain as long as they wish. They should be encouraged and supported to continue to make the contribution to care that is important to them and of which they are capable. Family members should be made aware of the possible financial support to enable them to visit the unit, depending on their personal circumstances.

4.4.7 Environment and physical space

It is essential that the specialist dementia unit is a purpose built physical environment. It is not appropriate or acceptable for this highly specialised care and treatment to be provided in an adapted building. The specialist built environment provides the opportunity to maximise the therapeutic potential of the space and supports the comfort, safety and activity of patients. It can also act to reduce the occurrence of distress.

Design features that respond to the experience of the illness as well as age-related impairments, can support person-centred care. It provides an enhanced working environment for staff to deliver person-centred care and a welcoming and supportive environment for people visiting the unit, who may spend a large part of their time with their family member, supporting their care. Some important features in dementia design are outlined in Table 3 below.

Table 3: Some examples of key design features

Built environment	Purpose built environment that maximises therapeutic potential through layout, design and key features.
Sound	Absorbance from ceilings, floors, window covering and soft furnishing to support audible communication. Quiet ambience with noise minimised.
Corridors	All corridors lead to meaningful places, with endings avoided or made into an interesting feature for engagement and activity.
Signage	Clear signage to help wayfinding for everybody, with pictures and graphics in addition to words.
Bedrooms	Individual en-suite facilities, room recognisable with easy visibility of bed and personal items on display.
Meaningful occupation	Facilities that support engagement in occupation, activity and social stimulation.
Outside space	Access to outside space during the day from communal areas.
Safety	Environment to minimise risk of self-harm and injury.

The specialist dementia unit requires an innovative approach to design that delivers maximum therapeutic potential. NHS National Procurement is well positioned to commission the design of a blueprint for the optimal environment to support specialised dementia hospital care. Through this competitive process, an innovative and creative design team can be appointed to create a blueprint that can be used by all NHS Boards to build the specialist dementia unit that provides a living and working environment and supports maximum therapeutic potential and enhances the full potential of each individual patient.

5. Conclusion and recommendations

There is an urgent need for extensive improvement of specialist dementia hospital provision in Scotland. This specialist area of practice has been overlooked for too long. There is a lack of the multi-disciplinary specialist care and treatment required and there are environments that are not conducive to person-centred care. Most people in specialist dementia hospital environments can be more appropriately cared for in community settings.

A decommissioning and re-design process would enable the development and roll-out of centres of excellence that would provide the small proportion of people with highly complex psychological needs the care and treatment they need. It would also allow resources to be transferred to the community so that care homes and those providing day-to-day care can receive specialist support and people with dementia are not admitted to hospital, unless it is essential to their clinical care needs. This would provide an efficient re-commissioning of current resources and tackle inappropriate admissions and unnecessarily lengthy stays in hospital.

Recommendations:

- That specialist NHS dementia care is modernised, providing high quality, human rights-based care, specifically for individuals who cannot be cared for in the community.
- Integration Joint Boards develop a transition plan and a local engagement strategy with their partners, including NHS Boards and people living with dementia, for any necessary de-commissioning process and re-investment in specialist dementia units and to develop further community capacity in health and social care services.
- That the Scottish Dementia Working Group and National Dementia Carers Action Network provide the representative groups for this local engagement.
- Integration Joint Boards and NHS Boards assess the proportion of people with dementia that can be safely transitioned to more appropriate community settings.
- The Alzheimer Scotland National Dementia Nurse Consultant provides expert guidance at both a national and local level.
- Integration Joint Boards and NHS Boards build strong and strategic local engagement on:
    - Any necessary de-commissioning and re-directing of resources to the development of specialist dementia hospital units and
    - building further community health and social care services.
- NHS National Procurement to commission the design of a blueprint for a specialist dementia unit that can be implemented by each NHS Board.
- There should be no financial detriment for families as part of the decommissioning process, with the financial cost of the care and treatment of the person with dementia being transitioned to the community continuing to be met by the NHS Board.
- The legal status of patients being transitioned to the community is reviewed and the appropriate legal documentation put in place.

- The creation of modern specialist dementia units that will provide centres of excellence to treat the small number of people with dementia who have a clinical need to be in hospital.

  The estimated 45[nn] specialist dementia units required across Scotland will provide a highly skilled practice area and make it an attractive specialism for ambitious and talented practitioners to deliver highly skilled therapeutic interventions.
  Promoting Excellence Framework the foundation for evidence based care for all practitioners. Leaders and senior practitioners ensuring that everyone working within the unit are trained at the appropriate level to ensure a high quality therapeutic approach.
  They will be underpinned and supported by the Charter of Rights for People with Dementia and their Carers in Scotland, the Promoting Excellence Framework and the Standards of Care for Dementia in Scotland.
- The timeframe for this process will extend beyond the end-point of Scotland's 2017-2020 National Dementia Strategy

nn This is based on an estimated 560 people with dementia who require care and treatment in a specialist dementia unit.

Appendix 1: Key findings – Review of NHS specialist dementia care (April 2015 to March 2016)

Introduction

This report outlines the key findings from the review of NHS specialist dementia care environments. This review was conducted by Maureen Taggart, Alzheimer Scotland National Dementia Nurse Consultant, between April 2015 and March 2016. It included 10 NHS Health Boards, over 60 individual dementia specialist care environments and a wide range of stakeholders, including senior managers and executive leads, practitioners and people living with dementia. This unique insight was made possible by the engagement and commitment of NHS colleagues, for which our warmest gratitude is extended.

This report sets out the key issues identified through visits to care environments, discussions with NHS Boards staff and meetings with people with dementia and their families.
A more detailed report will follow outlining recommendations for action and a model of safe transition for people who do not need to remain in these care environments.

Background

The review of NHS specialist care environments resulted from:

1. Themed visits by the Mental Welfare Commission of dementia continuing care units which outlined 17 key areas for improvement (Mental Welfare Commission (2014) "The Dignity and Respect Report: Dementia Continuing Care Visits"
www.mwcscot.org.uk/media/191892/dignity_and_respect_-_final_approved.pdf

2. A roundtable discussion on NHS continuing care hosted by Alzheimer Scotland and University of West of Scotland in September 2014. This event was chaired by Professor Graham Jackson and attended by representatives from the Scottish Government, Royal College of Psychiatrists and NHS Boards.

The purpose of the round table meeting was to develop a better understanding of the issues and challenges within NHS continuing care and specialist dementia care settings and identify what could be done to remedy these.

- The discussion highlighted:
- The static nature of the population within these settings was a significant issue that causes pressure on resources.
- Estimates that around 40%[oo] of this population had no clinical need to be in hospital.
- The difficulty in organising and supporting discharge to appropriate alternative care settings.

oo This estimate was put forward as part of the roundtable discussion – the review by the Alzheimer Scotland National Dementia Nurse Consultant found this to be much higher in practice.

The reasons for the issues outlined above are complex, but were thought to include:

- Financial costs (social versus healthcare), leading to a resistance to move to an alternative setting.
- Continuing healthcare criteria not being applied in many cases (new guidance published in June 2015)[pp].
- Criteria being poorly understood among public and professionals.
- The expectation that NHS continuing healthcare is a "bed for life".
- Lack of alternative accommodation and support.

Approach to review

Ten NHS Boards have been included in this review, with over 60 individual specialist care environments visited by the Alzheimer Scotland Dementia Nurse Consultant with the purpose of developing understanding of the issues around transition and discharge.

Initial contact was made with the Executive and Operational Leads for Commitment 11. Visits were set up with a range of professionals involved in the care and treatment of people with dementia in specialist dementia units[qq] in the following NHS Boards:
Ayrshire and Arran
Dumfries and Galloway
Fife
Forth Valley
Grampian
Greater Glasgow and Clyde
Lanarkshire
Lothian
Scottish Borders
Tayside

Meetings within NHS Boards included: Directors of Nursing, Clinical Leads for Old Age Psychiatry, Consultant Psychiatrist, Associate Directors of Nursing, Senior Nurses, Senior Charge Nurses, Allied Health Professionals (Occupational Therapists, Dietitians and Physiotherapists), Consultant Psychology, Social Work, Nurse and Allied Health Professionals Consultants, Community Psychiatric Liaison Teams, Pharmacy, Service Managers and Professional Leads.

Additional discussion was held with people with dementia within assessment and specialist care units and their families. Staff within these care environments were also included in this review. Visits to NHS contracted bed locations in private sector care homes were conducted. Other key stakeholders were also consulted: Scottish Dementia Working Group, National Dementia Carers Action Network, Healthcare Improvement Scotland, Care Inspectorate, Mental Welfare Commission, Nurse and Allied Health Professional National Group, Alzheimer Scotland Dementia Advisors, Alzheimer Scotland Policy and Engagement Managers, Alzheimer Scotland Carers Reference Groups, Scottish Government Focus on Dementia Team, Advocacy Services, Alzheimer Scotland's Head of Operations and National Education for Scotland.

pp Scottish Government (2015) Guidance on NHS complex clinical care http://www.sehd.scot.nhs.uk/dl/DL(2015)11.pdf
qq The term unit is used throughout the findings section to describe the range of environments where assessment, transition and specialist dementia care is delivered.

Key findings

1. Admission Units

The main reasons for admission were 1) increase in distressed behaviour in the person with dementia 2) carer distress 3) failed discharge to a care home 4) risk behaviours that meant care could not be safely managed at home and 5) lack of a care package to support the person with dementia to remain at home.

Length of stay varied greatly across NHS Boards, with an average of 8 to 12 weeks – this was up to two years in some instances. Most discharges from assessment units (estimated 90-95%) were to a care home or NHS specialist beds in a hospital or contracted beds. The application for power of attorney and guardianship increased the length of stay significantly – this was generally by nine months.

Some NHS Boards transferred people to "transition units" as they were not clinically ready for discharge. These transitions could last two to three years, with subsequent move to a care home. There was a higher level of access to multi-professionals within assessment units compared with specialist dementia units. However, this higher level of access was not available in every NHS Board.

Most units held reviews once or twice weekly, with families invited as appropriate. Only two areas had a social worker attached to the ward, with all others having a referral system.

Each area attributed delayed discharges to lack of funding and care packages. A lack of care home places was evident for one NHs Board.

There was good practice in relation to pre-discharge noted in two Boards. In one Board, staff and the family would visit the care home to offer support to care home staff – with community mental health staff or liaison psychiatry attending the pre-discharge meeting.

Another NHS Board had consultant-led clinics within care homes which successfully reduced admissions to the ward. The new "Hospital Based Complex Clinical Care Guidance" (2015) was being used in three Boards. In these areas, the review team met with the family one week after admission to discuss the plan of care, hear their views or concerns and provide a copy of the guidance for patients and their relatives.

2. Specialist beds and transitions

Consultant psychiatrists and managers highlighted that they had experienced an increase in complaints in response to attempts to transition patients. Families sought the support of their local MSP, who issued a letter of complaint to the NHS Board.

There were issues around charging policy when provision comes from social care as opposed to health – the financial impact of transition and families viewing specialist dementia units as a "bed for life". In some instances, when the person had been moved from another unit or hospital, families were given a letter to say the person would remain there for the rest of their life.

In cases where discharge to another care setting was proposed, formal appeals from the family were lodged, requiring further review to be carried out by an independent consultant psychiatrist.

In many cases, staff knew the patients well and the family were happy with the care provided – this could result in a lack of motivation for the person to be moved from the unit. Failed discharge to a care home was a common reason why many people remained in NHS care. Length of stay varied from one year to up to 15 years, with an average of 4.5 years. There were diverse needs within the same unit – this ranged from psychological and behavioural issues to end-of-life.

Discharging people with dementia is perceived to be a low priority for social workers, who view the person as being in a place of safety. The local authority insisted on transfer of resources if the person had been in a unit for over a year, as this was classed as long-term care.

When consultants have attempted to discharge people on several occasions without success, it can be seen as a waste of their valuable time to continue to attempt discharge. Many of the NHS contracted out beds have been in place for 20-30 years, with limited reviews of the initial contract. Whilst many of the specialist beds are in community hospitals, some are managed within mental health services and others are primary care, where the GP has limited access to specialist dementia professionals.

There was a general consensus that between 60% and 80% of these beds are not required – the care of this client group could be met within alternative care environments.

Most of these specialist units for people with complex clinical care associated with advanced dementia had no access to the multi-professional team of psychology, pharmacy, AHP, advocacy, etc. The main people involved in care were nurses and the consultant – staff recruitment and retention is a significant challenge for many NHS Boards.

One NHS Board had successfully closed many of their specialist beds and reinvested into community services to support people with dementia and their families to remain in their place of choice. At present four NHS Boards are reviewing and implementing a bed remodelling plan – this is driven in part by low occupancy and units being housed in outdated buildings.

There is real concern, and some evidence, that savings will not be re-invested back into specialist dementia care but utilised instead as efficiency savings.

A further two Boards reported a significant reduction in admissions where psychiatric liaison teams had been established to support the care homes in their areas. The three Boards using the new guidance have noticed a change, with families being much more engaged in the planning and discharge of their family member. One Board had also been reducing their beds due to low occupancy.

3. Specialist bed costs

There was significant variation in the cost of providing a specialist bed – costs of units ranging from £525 - £1,450 were highlighted. It should be noted that although a bed may cost £1,000 per week, this did not equate to access to a greater number of specialist dementia professionals than the less costly beds.

Low occupancy was noted in three Boards of 67% to 71%, which was consistent with the 2014 bed census.

NHS contracted beds were visited in three independent care home providers. There were various models used in these environments such as private sector beds with NHS management and staff, or private sector beds and staff with no NHS management but who could attend NHS Clinical Governance and Quality Monitoring meetings.

Of the NHS Boards visited, two had transferred the care and treatment of a patient to a dementia specialist unit in England, at a significant cost.

Most of the contracted beds visited are involved with the Commitment 11 local groups and have completed self-assessment and improvement plans. One NHS Board is to bring the specialist dementia care beds back into the acute sector from next year, under mental health management.

4. Environments and therapeutic activity

There has been a marked improvement since the Mental Welfare Commission's "Dignity and Respect" report (2014). Many of the units visited by the Commission have been closed, with new dementia friendly units developed and others to be completed by 2019.

However, a significant level of investment is required to upgrade/maintain some of the older facilities. Specialist dementia units continue to be located on upper floors with no easy access to outdoor areas. Features such as long corridors mean these buildings are not fit for purpose, even with adaptations.

It was evident that Commitment 11 improvement plans are making a difference in relation to activities within units. Some NHS Boards have developed an activity room and areas for family to use or stay overnight. One unit evidenced a reduction in falls since the environmental improvements and increased therapeutic activity over the previous year. Some areas had activity coordinators, with volunteers and community groups providing support for activity and connection.

Although some units had some excellent facilities and activity rooms, the majority were locked, with no activity going on in the unit whatsoever at the time of the visit. Staff shortages and lack of time was normally the reason given for this lack of therapeutic stimuli. When activity was carried out, it was provided by nurses, with few units having access to specialist AHPs to offer support.

Some areas highlighted how healthcare associated infection regulations hampered activity due to the concern over cross infection – this was a huge frustration for staff.

Bed and toilet areas could be shared by up to six people, with no showers or personal wash areas.

Some units had lots of personal effects on display for the people with dementia - this included pictures and soft furnishing. There was also some good evidence of life story work and person-centred care. However, other units were very stark, with no personal affects and presented as very clinical areas.

The private sector units visited have upgraded some of their areas to be more dementia friendly, with the majority providing en-suite single room accommodation. There are also improved dining and lounge areas and access to garden and outdoor areas.

Many of the units visited had activity programmes planned. This included Playlist for Life, baking, pet therapy, gardening, art work, exercise and movement, cognitive stimulation therapy, reminiscence, social outings to places of interest and doll therapy. Some of these activities were supported by volunteers, local primary or secondary school children and nurses or occupational therapists. A few of the areas were in the process of evaluating the effectiveness of therapeutic activity in their units.

5. Specialist AHP, Pharmacy and Psychology

There was great variation between NHS Boards in relation to access to AHP specialists, pharmacy and psychology. Only 50% of the assessment units had access to AHPs and there was very limited access to pharmacy and psychology. The specialist and complex needs units had virtually no access at all.

Most health care was provided by the consultant psychiatrist and the nursing team. All areas could access an occupational therapist from an acute service; however, there was a waiting time issue. When a falls risk assessment highlighted further intervention and referral to occupational therapy or physiotherapy, this was made to acute or primary care teams for further assessment and management.

There was a process to be followed for access to dietitians, speech and language therapists, geriatrician, Macmillan nurses, dentists and podiatrists to mention a few. Only three Boards had access to psychology via a referral process. However, due to increased referrals from community teams, very few people with dementia in the specialist units were ever supported by the extremely limited psychological services.

Access to pharmacy was minimal and normally only to top-up, as opposed to review, medication. No area had a pharmacist who was present at the multi-disciplinary reviews. However, staff could telephone a pharmacist for advice. Dementia assessment units based within the acute general hospital site did tend to have quicker access to AHPs and geriatricians - units outwith acute had a significant wait for assessment.

The Alzheimer Scotland Dementia Nurse Consultant held a multi-professional meeting in each NHS Boards. During these, there was a general consensus that improving dementia care was a priority. However, it was evident that they still received the lowest budget compared with other mental health services.

NHS Boards have highlighted some improvements in investment since Commitment 11 was implemented in September 2014. There was additional funding in two Boards, with appointments to additional psychology and pharmacy welcomed.

6. Skills and knowledge and workforce

The Promoting Excellence Framework had been implemented in every NHS Board visited. The majority had an implementation plan that sat with self-assessment and improvement plans. These were reported to the Chief Nursing Officer Directorate - reporting had taken place in December 2014 and in February 2016.

Skill mix and staff ratio to patients was lower than all other mental health areas – in most areas there were 40% to 45% registered mental health nurses with 60% to 55% untrained staff. A small number of Boards had a skill mix of 55% to 60% registered mental health nurses with 45% to 40% untrained staff.

Not all staff within the community hospitals hosting the specialist dementia beds were registered mental health nurses; however, some did have Dementia Champions on site. Whilst there were Dementia Ambassadors in some of the NHS contracted bed units, there were low numbers of registered mental health nurses, with only three covering a 90-bedded area. NHS contracted bed care homes did evidence training in the Promoting Excellence Framework. This was particularly strong at the informed practice level and they were progressing with plans at the skilled practice level.

All areas visited agreed that staff required their skills and knowledge to be at a higher level –the enhanced and expertise practice levels of the Promoting Excellence Framework were considered to be appropriate. However, this was considered challenging to achieve because of being unable to release staff as staff ratios were too low. Training in responding to stress and distress was highlighted as a priority in all areas. Some areas provided additional resources to assist with the training needs, but many had utilised the "bite size" models from NHS Education for Scotland only and highlighted a lack of support and supervision from psychology as a major issue.

Limited knowledge and skills to support people with advanced dementia and other co-morbidities affecting physical health was a challenge in many areas. Those who had undertaken the "Quality and Excellence in Specialist Dementia Care" programme with NES demonstrated greater knowledge and confidence in caring for complex physical health and delivering end-of-life care.

Some Boards did not have Practice and Improvement Development Support – thus creating an additional obstacle to supporting training. A small number of Boards did train large numbers of staff in "The Journey of Care for Dementia" and had recently trained "Dementia Care Mappers". Some areas had supported staff to train in "The Best Practice for Dementia Care" with Dementia Service Development Centre at the University of Stirling.

7. Experience of people with dementia and their families

Meeting with the families of people with dementia who were resident within the specialist assessment units was, in the main, a positive experience. They talked about being included in care and treatment decisions and being encouraged to offer care and support to their family member. They were invited to review meetings with the consultant and nurse, had completed "Getting to know me" or life story work and enjoyed the freedom in most wards to open visiting times.

This was in stark contrast to the comments provided by family members where the person was within a specialist care environment or had been recently discharged from a specialist complex needs unit (transition and what was previously referred to as long term care). They had expressed concern about the attitude of some staff, lack of empathy and compassion, feeling that they were not actively listened to or that their views were not valued. Many of these wards did not have flexible visiting times and families were not supported to engage and support the person with dementia. They did not have access to specialist multi-professional teams and when attending a review or pre-discharge meeting, they stated that "decisions were made before they were invited to speak".

An issue raised by a number of families was the lack of support and services for younger-onset dementia. When assessment was required, younger people with dementia were admitted to acute adult mental health wards where staff had very little skills and knowledge of dementia care. Families did not consider old age psychiatry wards to be appropriate for younger people with dementia. A few areas did have specialist community services that are multi-professional.

Appendix 2: Transitioning and Specialist Dementia Hospital estimated numbers by NHS Health Board

Health Board	Estimated number of people who can be transitioned to community	Estimated number of specialist hospital beds required
Ayrshire and Arran	67	44
Borders	22	15
Dumfries and Galloway	31	21
Fife	60	40
Forth Valley	46	31
Grampian	86	58
Greater Glasgow and Clyde	164	109
Highland	59	40
Lanarkshire	94	63
Lothian	121	81
Orkney	4	3
Shetland	4	2
Tayside	76	50
Western Isles	6	4

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