



**A report in response to
the fourth National
Dementia Strategy
consultation.**



**Alzheimer
Scotland**
Action on Dementia

**Prevent.
Care.
Cure.**

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Foreword

Since the Scottish Government made dementia a priority in 2007, there has been a major shift in the depth and quality of national and local dementia policy in Scotland. This has been supported by the development of three National Dementia Strategies focused on the delivery of world-leading approaches and commitments to improve the lives of people with dementia, their families and carers. Alzheimer Scotland has sought to make a positive contribution to each Strategy based on a detailed assessment of the challenges faced by people living with dementia and their families and what we believe might be possible in terms of system transformation and improvement.

Previous National Dementia Strategies^{1,2,3}

Alzheimer Scotland welcomed the prioritisation of diagnosis, post-diagnostic support and general health care in the first National Dementia Strategy. This enabled a substantial roll out of a new evidenced-based approach to post-diagnostic support based on a complimentary bio-psychosocial 5 pillar model. It also allowed for shared investment in an Alzheimer Scotland Dementia Nurse and Allied Health Professional Consultants in each territorial NHS board supported by the new Standards of Care and the new *Promoting Excellence* Framework. Alongside the development of the Charter of Rights, this focused approach to delivering services moved the paradigm of dementia care and created a platform for human-rights and person-centred transformation within our system.

Despite the ambitions of the first National Dementia Strategy, implementation of the policy commitments and progress were never fully achieved. Even with the priority placed on post-diagnostic support, nothing really changed until the then Health Secretary, and now First Minister, Nicola Sturgeon, made the commitment that every person diagnosed with dementia would receive a minimum of one year support from a knowledgeable, named link worker. It is only now, some ten years on, that there is anything like enough link workers to meet this commitment, which was only made possible by recent direct Scottish Government funding. Sadly, this lack of investment and drive to deliver commitments related to post-diagnostic support services reflects the general story around our National Dementia Strategies.

The second National Dementia Strategy aimed to reinforce the initial commitments set out in the first Strategy and new commitments were made to test an integrated model of care proposed by Alzheimer Scotland. This model was accepted and supported by COSLA and sought to improve the co-ordination of care and support for carers through our 8 pillar model. Nonetheless, little progress has been made in delivering the transformation of services to meet the needs of people with dementia and their carers through integrated approaches to care.

The development of the third Strategy brought further commitments to test a model for advanced dementia care. This was supported by evidence-based reports on how to transform NHS specialist dementia care facilities. Again, the recommendations were agreed by Ministers and, despite initial plans being made to test and implement these services, no real progress has been achieved.

Looking to the future

Alzheimer Scotland still believes that the key policies and previous commitments made in each of the three previous Strategies are relevant and, even more so, they reflect solutions to the same issues and challenges that people with dementia and their families face within our communities and in our health and social care system. We submit that the vision for transformation outlined below, and the key areas of focus described in this, all of which have been backed up by evidence-based reports, papers and lived experiences, provide a strong platform for a consistent model of national and local implementation.

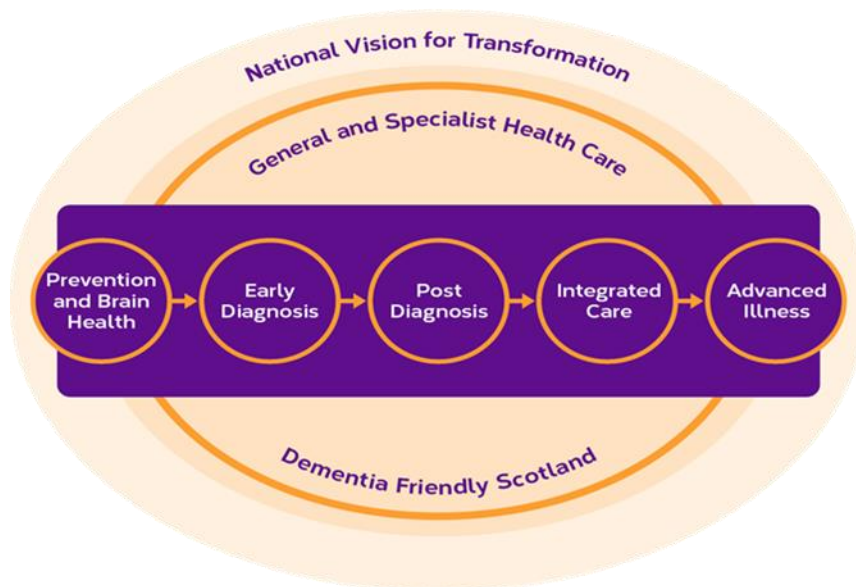


Figure 1: Alzheimer Scotland's vision of transformation

We now believe we can add new approaches of dementia prevention and brain health improvements to this model. Developing prevention strategies, followed by high-quality diagnostic services, exceptional quality post-diagnostic support, a well-supported integrated care journey and a person-centred approach to advanced care, should be the focus of both national and local strategy. Wrapped around this, we should be continuing the transformation of our acute and specialist NHS services and work towards achieving a Dementia Friendly Scotland. This vision reflects the aspirations, ambitions and firm commitments that have been made in the previous three Strategies. It is essential that they are woven into this fourth Strategy in the form of measurable commitments, with associated targets, funding and with a meaningful accountability and governance structure.

This report provides a detailed analysis of each of the areas of dementia care and highlights the current landscape of dementia services and delivery, and our view on how changes and improvements can be made. We share our recommendations for deliverable action within this fourth Strategy.

We recognise and appreciate that there will be new and emerging issues that need to be considered. We also recognise the need for this Strategy to link in with other developments and relevant policy. However, we must also look back to be able to move forward and

recognise the value of the work that has shaped dementia care as we recognise it today. How can we move forward effectively without addressing the undelivered high-quality policies and commitments from the past 12 years?

Henry Simmons
Chief Executive

Dementia Prevention and Brain Health

Alzheimer Scotland welcomes the Scottish Government's commitment to adopt a world-leading approach to dementia prevention and the promotion of brain health approaches that are designed to reduce the incidence of dementia. Evidence indicates that up to 40% of dementias might be preventable through specific actions to address identifiable risk factors⁴. With the prediction that the number of adults living with dementia worldwide is on course to nearly triple to 153 million by 2050⁵, it is vital to ensure that all opportunities to prevent or delay the onset of dementias are explored.

Brain Health Scotland

Brain Health Scotland, hosted by Alzheimer Scotland and funded by the Scottish Government, is leading the way in developing and delivering high-quality resources and services with the objective of reducing the incidence of dementia across Scotland. Alzheimer Scotland embraces this ground-breaking opportunity to change the future landscape of dementia in Scotland, and to set the example of positive policy and practice across international borders.

Our brain health engagement provides a platform to promote awareness of the principles of positive brain health across all walks of life. Brain Health Scotland works with partners in education, nutrition and fitness, as well as employers and sports associations to promote positive brain health. Our programmes include educational outreach from primary school years onwards, including the recent launch of their *My Amazing Brain* initiative⁶, health promotion campaigns and management of known risk factors such as diabetes and depression. Brain Health Scotland understands that it is never too early or too late to address dementia prevention.

Significantly, Brain Health Scotland places specific emphasis on equity of access, addressing the needs of people living in more challenging socioeconomic circumstances, thus providing the opportunity to tackle inequality and protect people with dementia. Deprivation and inequality are key drivers of the need for change in response to the challenge of existing responses to dementia prevention, intervention and care.

Brain Health Scotland is developing Scotland's first brain health clinics which will enable patients to access the information and interventions they need to protect their brain. It is essential to ensure that people across Scotland are provided with the opportunity to access services that enable them to begin the detection, prevention, and intervention of dementia earlier in the disease process. As such, it is imperative that steps are taken to test a robust care pathway for accessing brain health services in Scotland.

Brain Health Scotland has laid the groundwork for its future activities through the gathering of essential data to better understand the priorities it needs to address and through the development of a national brain health strategy that creates a clear direction and purpose. The strategy features four core commitments:

- Raising awareness of brain health and dementia prevention strategies;
- Targeted engagement;
- The establishment of open access services for personalised prevention; and,
- A system for disease and risk factor surveillance.

Through the delivery of these strategic aims, Brain Health Scotland can transform the approach to assessing and protecting brain health, and bring new opportunities for risk profiling, disease detection and early intervention to place Scotland at the forefront of the global effort to promote brain health and prevent dementia.

Recommendations

- ✓ Ongoing commitment to the delivery of brain health and dementia prevention policies and strategies through investment and funding
- ✓ A commitment to test and evaluate the delivery of brain health clinics within NHS settings

Early Diagnosis

Alzheimer Scotland recognises the importance of developing effective dementia diagnosis pathways. It is essential that individuals who experience cognitive impairment, or who suspect that they have cognitive impairment, have access to the right information, at the right time. A clear and consistent approach to diagnosis is necessary to streamline the process of diagnosis to ensure that an individual can access a timely diagnosis, led at their own pace and direction.

Access to an early diagnosis of dementia provides an opportunity for individuals to benefit from the treatment, care and support needed to let them live well with the condition and stay independent for longer. It also provides an opportunity for individuals and their carers to increase their understanding of dementia and to know what to expect through access to information, resources and support that meets their needs. Early diagnosis also offers the opportunity to become more actively involved in decision-making, including health and welfare decisions that can maximise quality of life, as well as to plan for the future, and also provides the opportunity to express your views and wishes more effectively with family, friends and professionals. Early diagnosis increases opportunities to benefit from drug and non-drug therapies that may improve cognition and/or other symptoms of dementia, as well as opportunities to participate in clinical research.

Current diagnostic pathways

Currently, diagnostic pathways for people with dementia are variable across a range of settings, including in primary care, acute care and residential care, often dependent on the age of an individual at the onset of symptoms. While most older people can expect to be referred from a primary care provider to specialist secondary care, most often in the field of old age psychiatry, those experiencing early onset of symptoms are more likely to be directed through various secondary care services including neurology, neuropsychiatry and neuropsychology.

A study of dementia diagnosis services across Scotland⁷ points to an inconsistency in the approach to the assessment of cognitive complaints in services across Scotland and there “appears to be a lack of uniformity in the implementation of the assessment and care pathway”. While data relating to waiting times for the assessment and diagnosis of dementia is unavailable, anecdotal evidence from Alzheimer Scotland’s public engagement with people with dementia and their carers in response to the National Dementia Strategy consultation⁸ highlights concerns across the whole of Scotland regarding delays and significant waiting times for assessment and confirmed diagnosis of dementia, including access to diagnostic scanning. The lack of a seamless diagnosis pathway acts as a barrier to early diagnosis and creates inconsistency within the delivery of diagnosis for people across Scotland which must be addressed.

Access to diagnosis in care homes is very limited and the Care Home Census for 2022 gives rise to “non medically diagnosed” dementia⁹ which falls far below the expected benchmark outlined in the *Standards of Care for Dementia in Scotland*¹⁰. Everyone with dementia has a

right to access a diagnosis regardless of where they live and should be supported to obtain a medical diagnosis.

The impact of the pandemic on diagnosis

Undoubtedly, the Covid-19 pandemic has had an impact on when and how people have been able to access a diagnosis of dementia. Interruption to services and delays to obtaining a diagnosis mean that people have received a diagnosis much later in their experience of the condition and their needs are more progressed at the point of diagnosis than would have been the case prior to the pandemic. It is inevitable that these delays have negatively affected people with dementia during this period, and beyond. We must acknowledge that aspects of their care needs are further advanced and that they are less able to benefit from the early interventions that are afforded by a more timely diagnosis. It is essential that a significant effort is made to provide the best available support to those who have been affected by the pandemic.

Data relating to the incidence and prevalence of dementia

Accurate data on the prevalence and incidence of dementia is unavailable since the relevant data is not collected across health boards or health and social care partnerships (HSCPs). Information relating to the prevalence and incidence of dementia is based on data that does not determine the actual number of people diagnosed with dementia. While the associated data indicates that more people are receiving a diagnosis of dementia, Scotland is still not achieving sufficient rates of diagnosis.

The lack of accurate data on the prevalence of dementia to inform and promote the delivery of the diagnosis target means that dementia continues to go under-diagnosed. In turn, this leads to a failure to address the needs of the population with dementia in terms of access to health care, social care and community supports that can improve the quality of life for people with dementia.

Recommendations

- ✓ Action to improve access to diagnostic pathways, particularly for people living in care homes, through the consistent implementation of assessment and care standards
- ✓ A commitment to the delivery of resources, infrastructure and funding to tackle delays and waiting times to receive a diagnosis
- ✓ Development of processes and mechanisms to capture, record and store accurate data relating to the incidence and prevalence of dementia to inform and guide services for people with dementia

Post-Diagnosis

Since the first National Dementia Strategy was published in 2010, the Scottish Government has recognised the value and importance of post-diagnostic support. Through the Scottish Government's guarantee to provide a minimum of 12 months support by a knowledgeable and skilled, named person, people with dementia have an opportunity to explore and develop supports that improve their quality of life.

The 5 pillar model

Alzheimer Scotland has strived to deliver high-quality post-diagnostic support through the implementation of our 5 pillar model. The 5 pillar model provides a framework for people living with dementia, their families and carers to access the tools, connections, resources and plans to allow them to prepare for the future. Our approach ensures that people with dementia receive a high-quality service that empowers them to develop a robust personal plan that utilises all their own natural supports, which maintains newly developed peer support mechanisms alongside existing and new community connections, and that supports each person to live well and independently with dementia for as long as possible.



Figure 2: 5 pillar model

The existing landscape of post-diagnostic support

Only in the last 12 months has the Scottish Government delivered sufficient funding and investment in the workforce needed to deliver effective post-diagnostic support. Alzheimer Scotland has been commissioned to provide post-diagnostic support services across many areas of Scotland and we now have 110 dedicated post-diagnostic support link workers

providing first-class care and support to people with dementia and their families. Nonetheless, challenges remain with the delivery of post-diagnostic support.

Figures suggest that less than 43% of people estimated to be newly diagnosed with dementia were referred for post-diagnostic support in 2019/20¹². This not only identifies a significant gap in the delivery of post-diagnostic support to people with dementia which must be addressed but also highlights issues around the availability of data relating to the delivery of post-diagnostic support. Firstly, the mechanism of data capture provides only an estimate since relevant data is not collected, and secondly, the data is reported retrospectively. Failure to record and report accurate, real-time data prevents a pro-active approach to meeting the post-diagnostic support needs of people with dementia.

Alzheimer Scotland has worked closely with Healthcare Improvement Scotland to develop and adopt a robust Quality Improvement Framework¹³ that is designed to drive up standards and that is measured against a Single Quality Question¹⁴. We are aware that these tools are used less consistently where post-diagnostic support services are provided through internal NHS mechanisms and standards of delivery are not recorded or reported equitably across all HSCPs.

The Covid-19 pandemic has had a considerable impact on people's experiences of post-diagnostic support. Increased waiting lists mean that people living with dementia have to wait longer for the support that they need, and subsequently, many people with dementia are presenting with more advanced illness which makes the delivery of the 5 pillar model less effective. Alzheimer Scotland anticipates that the implementation of workforce investment will act to resolve some of these concerns, but evaluation is necessary to ensure that improvements are being delivered through targeted investment.

The future of post-diagnostic support

While we welcome the Scottish Government's increased investment in the delivery of post-diagnostic support services, there remains ongoing uncertainties around future funding commitments. Short-term funding commitments and last-minute budget approval create insecurities for the future of post-diagnostic support and must be addressed to fulfil the guarantee to provide people with dementia a minimum of one year of post-diagnostic support.

Going forward, more needs to be done to fulfil the commitments to the delivery of high-quality post-diagnostic support services outlined in the previous Strategies. While significant progress has been made in post-diagnostic support, the implementation and delivery of the commitments has fallen short of expectations. Inconsistency in the delivery of the quality improvement framework, gaps in the data needed to effectively evaluate the delivery of post-diagnostic support, and increased waiting times mean that people are not feeling the benefit of the delivery of post-diagnostic support that could be achieved.

Recommendations

- ✓ Sustained funding and investment in post-diagnostic support services to secure the future of post-diagnostic support
- ✓ Develop processes and mechanisms to capture, record and store accurate data relating to the delivery of post-diagnostic support to anticipate future needs and focus service delivery
- ✓ Promote and consistently deliver the existing Quality Improvement Framework to increase the standard of post-diagnostic support

Integrated Care

The care needs of people with dementia are many and complex. They encompass a wide range of issues across the health and social care spectrum therefore an integrated approach to care is needed to provide holistic support to people with dementia to enable them to live well in the community. By enabling health and social care interventions to be brought together in a co-ordinated way, available resources can be used to the best possible effect in meeting the needs of the person with dementia living at home, within their own community along with their families and friends for as long as they choose.

The 8 pillar model

Alzheimer Scotland recognised the need to build the resilience of people with dementia and their carers to enable them to live in the community for as long as possible. We sought to develop a model that would build on the one year post-diagnostic support guarantee to ensure the impact of the investment in early intervention was not lost. The 8 pillar model¹⁵ was developed to provide a coordinated approach when people need support to live in the community. Although designed to follow on from the 5 pillar model for most individuals with dementia, there will be a proportion of those newly diagnosed who will require the 8 pillar model either immediately after diagnosis or in place of post-diagnostic support, as some people are diagnosed at a later stage, or progress more rapidly in their dementia.

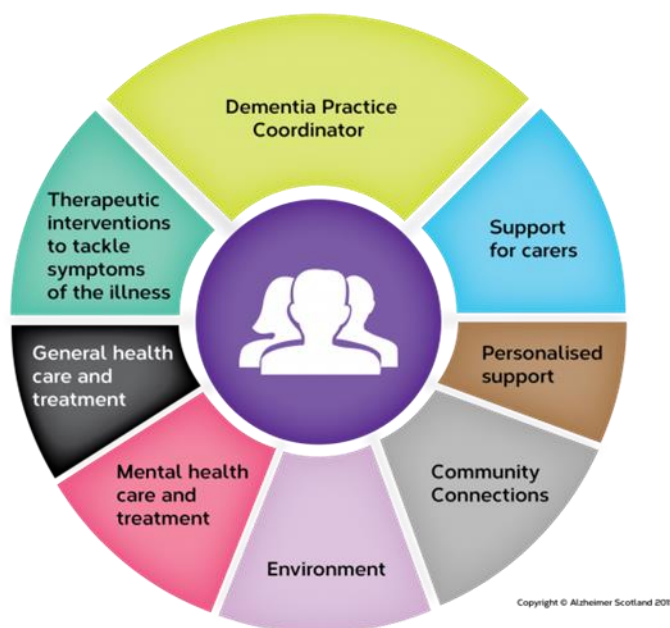


Figure 3: 8 pillar model

Failure to implement integrated care

The 8 pillar model has been tested across various settings in Scotland. Test sites have supported improvements and the redesign of community-based services to improve the

experience, safety and co-ordination of care for people with dementia from diagnosis to end of life care, with an emphasis on supporting people to stay well at home or in a homely setting for as long as possible. Evidence from the evaluation of these test sites¹⁶ strongly indicates the benefits of co-ordinated care approaches.

We acknowledge the need for vigorous testing of care models, and welcome current plans to further test the delivery of the 8 pillar model, however, we need real action to ensure that integrated care is implemented consistently across Scotland, and that people with dementia and their carers have fair and equitable access to co-ordinated support that better meets their needs. Despite significant testing of the 8 pillar model across various settings in Scotland, the Scottish Government has made no commitment to consistently roll out the 8 pillar model or any other integrated care model to meet the needs of people with dementia and their carers. This means that people with dementia and their carers do not have access to the continuous care and support that they need to live well in the community.

Integrated care and the National Care Service

The implementation of the National Care Service provides a platform to pursue further efforts to establish integration between health and social care services, a fundamental driver of the previous National Dementia Strategies. Alzheimer Scotland welcomes Scottish Government's commitment to an integrated approach between health and social care. In light of the ever-changing policy landscape, it is essential that every effort is made to ensure that the next National Dementia Strategy and future dementia policy are able to co-exist to achieve their individual and collective ambitions.

Recommendations

- ✓ Agree a plan to implement a co-ordinated approach to care in line with the learning from existing research and projects to test integrated care models
- ✓ Establish clear policy links between the principles of the National Dementia Strategy and the development of the National Care Service to ensure that the needs of people with dementia and their carers are met through the wider policy landscape

Advanced Illness

Increasing life expectancy means more of people in Scotland will experience dementia and the proportion of people dying with dementia will grow. Advanced dementia presents a range of complex health issues in addition to the social and psychological impact of the illness. This makes the transition to, and the experience of, advanced dementia both complex and challenging.

Advanced dementia practice model

In recognition of the multifaceted nature of advanced dementia, Alzheimer Scotland proposed an integrated and comprehensive approach to supporting people living with advanced dementia across all settings. The advanced dementia practice model¹⁷ responded to the need for a multi-disciplinary, co-ordinated and planned approach to support those living with the condition, as well as those providing day-to-day care, and provided a vision for how the care of people living in the community with advanced dementia could be transformed in Scotland. It was designed to build on the integrated approaches of care developed through the 5 pillar model of post-diagnostic support and the 8 pillar model of integrated care.



Figure 4: Advanced dementia practice model

Delivering advanced dementia care

Care co-ordination of palliative and end of life care for people with advanced dementia has been tested and evidence¹⁸ indicates that meeting their complex care needs can be mitigated by effective whole-system care co-ordination and identified that a co-ordinated approach to service delivery resulted in improved timely communication between staff and families to inform person-centred care planning. A further test of care co-ordination was carried out in Inverclyde to support improvements and redesign of community-based services seeking to improve the experience, safety and co-ordination of care for people with dementia from diagnosis to end of life care. The independent evaluation¹⁹ commissioned by the Scottish Government concludes that the programme successfully achieved its primary objective of delivering a personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer, and initial reporting indicates that short-term targets have been achieved in respect of improved quality of care and better outcomes for people.

Nonetheless, the Scottish Government has failed to adopt an integrated approach to palliative and end of life care that enables people with advanced dementia to access seamless care and support. There is no evidence that care standards for advanced dementia care have been implemented and the commitment to ensuring that more people get timely access to good quality palliative and end of life care has fallen significantly short of what could be achieved through the delivery of the advanced dementia practice model.

Given that the delivery of palliative and end of life care is inconsistent, people living with advanced dementia and their carers have become increasingly reliant on social care structures to provide support, even where existing services are unable to meet their needs. With the current social care crisis, people with dementia are struggling to access the type of specialist services that meet their needs and often need to seek alternatives, often at significant personal cost. Providing care for people with advanced dementia through a social care model that is not designed to manage and support the health complexities of their condition highlights the need to address the principles of fair dementia care.

Fair dementia care

Alzheimer Scotland recognises that people living with advanced dementia have specific health care needs that cannot be met by a predominately social care model. The Fair Dementia Care Commission²⁰ highlights the inequality that needs to be addressed to align the experience of people with dementia with other progressive and terminal conditions.

People with advanced dementia experience a lack of equal access to the health and specialist nursing care that they need to meet the complex health care needs that arise in advanced illness. Existing care pathways deny people with advanced dementia access to the expert dementia-specific health and palliative care required to meet their needs and are disproportionately subjected to social care charges. They face unfair charges for care in their own homes and in care homes for what Alzheimer Scotland has demonstrated are unequivocally health care needs. It is our view that these needs should therefore not be paid

for by the individual but by the NHS, and there must be an assessment to identify when someone with advanced dementia's needs change from social care to health care.

Recommendations

- ✓ Agree and implement the recommendations of the 'Advanced dementia practice model: understanding and transforming advanced dementia and end of life care' report published in 2015
- ✓ Recognise and agree that the needs of people with advanced dementia are fundamentally healthcare needs and provide access to health care assessment and treatment regardless of the care setting
- ✓ Remove the unfair charging practices for the care needed by people living with advanced dementia, both in the community and in residential care

General and Specialist Healthcare

Alzheimer Scotland's vision for delivering positive health outcomes for people with dementia includes access to the health care that people with dementia need, when they need it, delivered in a way which understands their dementia and its impact on their wider health care needs. Both primary care services and acute hospital care deliver vital services to people with dementia, so it is essential that both general and specialist services are designed to deliver person-centred, needs-led care.

General Healthcare Services

Primary care is the first point of contact with the NHS and includes contact with community-based services provided by general practitioners (GPs), community nurses, and allied health professionals. For people experiencing worries about their memory or other dementia symptoms, it is essential that they receive support from a skilled and knowledgeable primary care practitioner who can offer the reassurance and guidance needed as they take their first steps on the care pathway towards a diagnosis.

The first National Dementia Strategy¹ highlighted difficulties experienced by people with dementia in general hospital settings which resulted in the improvement of the practice of general healthcare supporting people with dementia being made a priority for action. It was evident at this time that very few staff in general hospital and healthcare environments had much training, skills or understanding of dementia and a significant paradigm shift was required to transform the delivery of general healthcare services for people with dementia.

There were three main components to this new approach. Firstly, a national, joint investment was made by the Scottish Government and Alzheimer Scotland to fund a Dementia Nurse Consultant in each NHS health board (this now also includes Dementia Allied Health Professional Consultants in some board areas). Secondly, these senior leaders were supported through the development of the *Promoting Excellence*²¹ framework and substantial investment in workforce development in partnership with the NHS, NHS Education for Scotland and the Scottish Social Services Council. This led to the third component which saw over 1,000 Dementia Champions trained across the country. These approaches have been transformational in improving and developing better standards of care in these environments.

In order to build on this, the 10 Dementia Care Actions were developed to support the delivery of the Scottish Government's commitment to improve care in acute general hospitals and were supported by all NHS territorial boards. The Care Actions provided a framework for transformational change in acute care settings and are as relevant today as they were when they were first published in 2013.



Figure 5: The 10 Dementia Care Actions

At present, the 10 Dementia Care Actions are not being fully utilised to their best effect but still have the potential to form the basis of a sensible improvement strategy in each board area. Alzheimer Scotland believes that the Actions should be refreshed and re-prioritised in the next National Dementia Strategy.

In recent years, the Dementia Nurse and Allied Health Professional Consultants have extended their roles to support improvements in specialist dementia care units. In a similar way to the Dementia Champions programme, the Specialist Dementia Improvement Leads programme has developed an extensive network of skilled improvement and change leaders in the NHS and care home sectors.

Specialist dementia care

Alzheimer Scotland outlined the nature and challenges of specialist dementia care across Scotland in their 'Transforming Specialist Dementia Hospital Care' report²². Commissioned by the Scottish Government, the report proposed a number of recommendations to improve the experience and quality of support for those individuals requiring specialist dementia care. The report introduces a vision of what a good specialist dementia unit should be, based on

the evidence and work of many committed practitioners and the views of people with dementia and carers. The report makes the case that these individuals should be supported and funded to make a safe transition to a more suitable form of care provision.

Although the Scottish Government accepted the report's recommendations, little progress has been achieved in implementing the therapeutic approaches underpinning specialist dementia care. Existing specialist dementia wards are frequently located in environments that do not support person-centred care and there is a lack of access to the multi-disciplinary professionals required to support the complex care required in dementia.

The goal of the recommendations in this report was to create a methodology for transferring resources from NHS facilities to create new, innovative community options for the longer-term care of people with complex needs. With the exception of one or two areas, no real progress has been made in this process. While we recognise the impact of the pandemic on the ability to drive change, we believe that now is the time to recommence this work with renewed vigour to introduce new models of community support and higher therapeutic residential care options that will support people to be enabled to return home and avoid unnecessary early admission to residential care. This Strategy must deliver on the implementation of the recommendations in the report to which the Scottish Government have previously committed.

Care homes (long-term care)

An estimated 33,000 people live in care homes in Scotland²³ at the current time and the main focus of previous National Dementia Strategies has been to support improvements in care through workforce development and training including access to the *Promoting Excellence* framework, the development of Dementia Ambassadors and access to Dementia Specialist Improvement Leads. Alongside the delivery of the Charter of Rights and new Standards of Care, this created a landscape for a potential positive future direction for improving practice. However, it is clear that the pressures in this sector, challenges that are well reported by the sector itself, in terms of delivering the right level of Promoting Excellence skills, mean that much work is required to continue to support staff in this area.

At the beginning of the pandemic, almost 20,000 people with dementia were resident in care homes²⁴ and it would be wrong to fail to acknowledge the horrific experiences of people with dementia during this period of time. People with dementia were disproportionately affected by Covid-19 and 1600 excess deaths of people with dementia in care homes were reported during the pandemic²⁵. We understand that staff in these environments make every effort to provide a warm, homely and therapeutic environment as far as possible and have done a remarkable job in supporting people to the best of their abilities during the pandemic. Nonetheless, we believe that now is the time for a rigorous debate and discussion about the future model of long-term care when we now know the added risks of group living when pandemics emerge. It is also the case that many of these residential care homes have developed over the years through entrepreneurial and market-based investments as opposed to strategically commissioned and co-designed long-term care models.

Improving the delivery of generalist and specialist dementia care

The previous commitments to the delivery of generalist and specialist dementia care have not been delivered consistently and significant improvements to dementia care could be achieved through a concerted effort to implement the policies designed to address the challenges experienced in delivering the quality of care that people with dementia should expect. The lack of data to track and monitor the delivery of key targets for people in acute care settings acts as a barrier to the delivery of informed, targeted support that meets the needs of people with dementia and this issue must be tackled to improve the information available to support the delivery of care. Moreover, steps must be taken to address the lack of consistency in the delivery of key quality improvement plans across the country. People living with dementia cannot be assured of the experience of high-quality care and are subject to the 'postcode lottery' so it is vital that a consistent approach is adopted to ensure equity of access to high-quality services irrespective of their diagnosis, age, socio-economic background or care setting.

Importantly, the Scottish Government has failed to act on, and implement, recommendations that it has agreed on providing high-quality specialist care. A renewed drive to deliver on the commitment to implement specialist care must be embraced to ensure that people with dementia are supported in a way that meets their needs most effectively.

Alzheimer Scotland is of the view that Scotland needs to re-imagine and re-design the long-term care options available to people with dementia, and that the Scottish Government should introduce and commission smaller scale, innovative and pandemic-safe environments going forward. Alzheimer Scotland will lead a commission to consider this position and we would ask the Scottish Government to support the opportunity to have this difficult, but essential, debate, and indeed, engage fully with us in this process.

Recommendations

- ✓ Develop processes and mechanisms to capture, record and store accurate data relating to the delivery of acute care to anticipate future needs and focus service delivery
- ✓ Develop a consistent approach to the delivery of high-quality care services through the implementation of national standards of care
- ✓ Refresh and re-prioritise the 10 Dementia Care Actions to improve the delivery of care in general healthcare settings
- ✓ Implement the recommendations of the 'Transforming specialist dementia hospital care' report published in 2018
- ✓ Support Alzheimer Scotland's Commission on the Future of Long-term Care

Allied Health Professionals

Allied health professionals play a significant role in providing support and making a positive difference to the lives of people with dementia. Their contribution to the care and support of people with dementia enables them to live well and live confidently in their own homes for as long as possible.

***Connecting People, Connecting Support* framework**

*Connecting People, Connecting Support*²⁶ was the first strategic allied health professional dementia workforce framework designed to maximise the impact of allied health professionals in response to the complex care needs of people living with dementia. The framework sought to ensure that people with dementia have better access to allied health professionals regardless of age or place of residence, from pre-diagnosis to diagnosis and throughout their illness and set out how allied health professional services in Scotland would be re-modelled to meet the needs of people living with dementia. The subsequent impact report²⁷ evidenced a range of activities that have supported implementation of this framework.

The reach of *Connecting People, Connecting Support* and the engagement of people with dementia and their carers with allied health professionals is a great success story. A committed and growing group of allied health professionals is building on allied health professional approaches at universal, targeted and individual/specialist levels within integrated health and social care services and the framework is promoting and developing collaborative and integrated ways of working. The framework has also raised awareness of the allied health professional role for people with dementia and their carers as well as providing health and social care partnerships with a framework for restructuring and integrating the contribution of allied health professionals to dementia care to enable these professionals to work to the greatest effect.

The implementation of *Connecting People, Connecting Support* is receiving interest locally, nationally and internationally from a broad range of health professionals. It is leading the way to transform the contribution of this specialist workforce to support people to remain in their own homes, reduce unplanned contact with primary care and help avoid unnecessary hospital and care home admissions.

The delivery of *Connecting People, Connecting Support* was interrupted by the Covid-19 pandemic so there is still much to do to close the gap between policy and practice. The four principles and ambitions for change remain unchanged and there is a renewed need to deliver the policy since the pandemic has exacerbated the need for access to allied health professional specialist skills in dementia at a local level and for enhanced access to rehabilitation. Work must continue to transform the allied health professional contribution to enhancing access and support to lifestyle changes that can potentially reduce the risk of developing dementia, delay progression of the illness and enhance quality of life. There is also a continued need to provide accessible and condition-specific signposting to allied health professional advice, self-management and rehabilitation to ensure that people with

dementia get the right allied health professional support, at the right time, and in the right setting.

The future of allied health professional support

There is a developing international evidence-base that highlights the benefits of allied health professional early interventions, supported self-management and rehabilitation as a means of supporting people to live well with dementia for longer. The allied health professional community in Scotland continue to work collaboratively and strategically to develop this evidence base. There is a drive to test, spread and scale a national approach to a tiered model of service delivery and to be more proactive in universal, targeted and integrated service delivery, promoting early intervention for prevention and direct access.

This move towards transformational change is set against a background of exploring technological and digital opportunities for innovations to transform service delivery. Allied health professional-led, evidence-informed, self-management resources for people living with dementia²⁸ have been developed and tested across Scotland to support self-management before specialist allied health professional interventions are required. Additionally, a whole-system approach to the allied health professional input to rehabilitation using the Balanced System Framework is being developed and tested.

Despite all the innovative, creative and evidence-based work, it is evident that access to allied health professional services remains inconsistent, challenging and, at times, simply not available. More must be done to raise the profile of allied health professional services and to improve access to these essential services.

Recommendations

- ✓ Ongoing commitment to the delivery of the *Connecting People, Connecting Support* framework to maximise the role of allied health professionals in dementia care through the delivery of the four ambitions that are integral to the delivery of this strategy
- ✓ Continued and strengthened clinical leadership from the National Alzheimer Scotland Allied Health Professional Consultant and the developing local leadership infrastructure
- ✓ A sustained commitment to improving access to the specialist support and treatment delivered by allied health professionals for people with dementia from the onset of symptoms to the end of life

Dementia Friendly Communities

Dementia-friendly community initiatives have been developed across Scotland to provide opportunities to increase understanding of dementia and to encourage people with dementia and their carers to participate in community life. This approach provides a platform for individuals and groups to explore peer support, and to prevent isolation and loneliness, while tackling stigma and ensuring equality for everyone.

Peer support and local activities

People with dementia can develop networks of support through participation in community-based activities and initiatives. Alzheimer Scotland has developed a significant network of local Dementia Resource Centres that provide a venue on the high street that will work to support and meet the social and cultural needs of people with dementia. Alongside our other third sector partners, people with dementia in Scotland can enjoy a wide range of activities that encourage and promote community connections.

Our local Dementia Advisors also provide advice and support to individuals, families and local communities and have a varied approach to local delivery based on local need and opportunities. They also provide an opportunity for ongoing support and involvement, fulfilling our goal of encouraging people to feel a long-term connection with us and creating that sense of security in knowing that we will be there to support them. Our Dementia Advisors also run a number of therapeutic groups, as well as carer support and education activities both within and out with our Dementia Resource Centres.

Technological innovation

The pandemic has provided the dementia community with an opportunity to develop advances in technological support and innovation. Digital communication technology has become an everyday tool for maintaining social relationships and a renewed openness to using technology has enabled people with dementia to discover the benefits of technology that can support them to live at home more independently, reduce their experience of stress and distress, and offer social interaction that improves their quality of life. Alzheimer Scotland highlighted the value of technology-enabled dementia care in their Technology Charter²⁹ and has committed to investing in digital solutions that promote opportunities to live well in the community.

Alzheimer Scotland has funded and developed the Virtual Resource Centre³⁰, an online space where people are able to benefit from all of the offerings of a Dementia Resource Centre in the comfort of their own home. There is access to our groups and activities, such as Music Memories, a zone specifically for carers, and the ability to chat to a Dementia Link Worker or Allied Health Professional. This accessible resource is available where and when people with dementia and their carers need it.

The Scottish Government funded the development of the About Digital and Me (ADAM)³¹ project, a platform to enable people with dementia and their carers to access tried and tested technologies that can improve their quality of life. The project provides an opportunity for a process of assessment that supports people with dementia and their carers to access digital products and services based on recommendations that are targeted at meeting individual needs. This intuitive approach to technology has proved invaluable for supporting people with dementia to live well in the community for longer.

Purple Alert and Herbert Protocol

Alzheimer Scotland launched Purple Alert³² in 2015 to harness the power of communities to make walking safer for people with dementia. Aligned with the newly published National Missing Persons Framework for Scotland, Purple Alert is a free mobile app which sends an alert to the community if someone with dementia is missing in their area. The app is successfully used throughout Scotland and is also an international benchmark in work to support people with dementia at risk of going missing.

It is important that we continue to build on the proof of concept that demonstrates the ongoing feasibility of this technology. Although Purple Alert's core functionality has remained consistent since it was launched, Alzheimer Scotland is working with partners including Police Scotland, the Scottish Government, Missing People, the NHS and local HSCPs to ensure that all the existing services are aligned before, during and after someone with dementia is missing. We are testing work on 'return conversations' that provide support to people with dementia and their families after a period of being missing with the intention of reducing the risk of further future incidences.

Working with Police Scotland and the Scottish Government, Alzheimer Scotland has also supported the development and use of the Herbert Protocol³³ that further supports people with dementia who are missing in the community. This collaborative approach to supporting people with dementia has provided opportunities to increase understanding of the condition and to provide positive interventions at a local level. Through building positive community relationships, the roll out of the Herbert Protocol has fostered the principles of dementia-friendly communities, ensuring that people with dementia are safe and well cared for in their local area.

Housing and transport policy

Dementia-friendly communities are supported by inclusive policies that enable people with dementia to live well in their local communities. This extends beyond the delivery of health and social care.

Housing policy has moved to support people with dementia living at home with the recognition that a more holistic approach to support is needed within the housing sector. The publication of best practice guidelines³⁴ highlights key areas of support that can be provided to people living with dementia at home, and this has been complemented by increased access to training through the *Promoting Excellence* framework to support housing

professionals to help people with dementia to live safely at home. However, limited adoption of the *Housing and Dementia Framework* creates inconsistency in the implementation of best practice, and there is no evidence of how many housing-sector staff have accessed training opportunities. Additionally, no work has been carried out to evaluate their learning or understanding of dementia.

Disabled people's needs, including those of people with dementia, have been included within national transport strategies and frameworks^{35, 36}. Recognising the inequalities experienced by people with dementia, these policies seek to remove barriers to public transport connectivity and accessibility within Scotland which further promotes the principles of dementia-friendly communities. However, work on the implementation and delivery of transport policy across priority areas stopped when resources were redirected during the Covid-19 pandemic so a renewed effort must be adopted to drive forward these changes.

The future of dementia-friendly communities

Dementia-friendly community initiatives require funding and investment to continue to achieve positive outcomes for people with dementia and their carers. At the current time, the third sector is filling the gap at a time when statutory services are struggling to cope with the pressures of moving on from the Covid-19 pandemic and managing the stark financial landscape. The third sector, including Alzheimer Scotland, brings a clear understanding and knowledge of the challenges faced by people with dementia and their carers but also has the capacity to provide solutions to address those issues. The need for investment in the delivery of dementia-friendly community initiatives is matched by the need for a commitment to the value and benefit of third sector delivery of these programmes.

As with other areas of dementia care and support, there is a lack of evaluation of the impact of community and peer-led approaches. This acts as a barrier to the duplication and replication of good practice more consistently across Scotland and must be addressed to resolve the inconsistent delivery of services that provide the most benefit to people living with dementia and their carers.

Recommendations

- ✓ Recognise the valuable contribution made by the third sector in the delivery of person-centred approaches to care and support in the community by providing a commitment to sustained, planned funding
- ✓ Agree to undertake an evaluation of dementia-friendly community activities to support future planning and the development of best practice guidelines
- ✓ Continue investment in new innovations and technological advances to support the delivery of community-based care and support
- ✓ Agree collaborative approaches to the delivery of initiatives that can reach the widest audience of the dementia community

Workforce Development

A well-informed and well-trained workforce is the most valuable resource to support people with dementia and their carers. Alzheimer Scotland acknowledges and promotes the need for health and social care providers to be educated to meet the needs of individuals experiencing complex care issues that improve their overall outcomes.

Promoting Excellence framework

The *Promoting Excellence* framework²¹ was ground-breaking as Scotland's first national workforce development framework, setting ambitious targets for the care and support of people with dementia, their families and carers across a range of services including in primary care, acute care and residential care. This framework continues to be implemented, reflecting wider changes to national policy context, including the integration of health and social care, the roll out of self-directed support and the legislation which expands support and entitlements for carers. It is complemented by the national dementia allied health professional framework, *Connecting People, Connecting Support*²⁶. This innovative approach to service delivery enables high-quality allied health professional interventions to support a co-ordinated approach to care.

Other programmes supporting workforce development

With the support of the Scottish Government and NHS boards, Alzheimer Scotland has established a network of Nurse and Allied Health Professional Consultants in direct response to the needs of people with dementia and staff in acute general hospitals. Available in every NHS board across Scotland, our skilled practitioners have driven the transformation of practice in general hospitals. They have supported the delivery of improvement programmes including the introduction of over 1,000 Dementia Champions and continue to support hospital staff to have improved understanding and ability to look after people with dementia. The Dementia Specialist Improvement Leads training programme demonstrates successful outcomes across its delivery in specialist NHS facilities and care home facilities.

Challenges to workforce development

Given the success of these development frameworks, there is no doubt about the value of investing in these programmes for staff employed by the NHS, social care providers and care home providers. However, it is clear that despite the availability of training and development opportunities, the health and social care sector is so stretched that there are gaps in the uptake of such opportunities. Attaining Promoting Excellence accreditation in the workforce is not achieved across all settings in health and social care.

In particular, resource challenges in social care and pressures on staff in health and social care settings mean that there is still a significant way to go to achieve a fully dementia-skilled

workforce to support people with dementia and their carers. The approach to commissioning home care services is a particular area for concern since staff who have achieved learning and skills through the Promoting Excellence framework and who are employed to work with people with dementia are never afforded time to dedicate to skills practice. Meanwhile, generic model commissioning that does not deliver the dementia-specific services underpinned by knowledge and understanding of the needs of people with dementia lessens the potential value of an intervention by asking staff with a lower skill level to provide support best provided by those with dementia-specific training.

Recommendations

- ✓ Ongoing commitment to the delivery of the Promoting Excellence framework and associated opportunities to participate in training programmes
- ✓ In line with the refreshed 10 Dementia Care Actions designed specifically to improve leadership and quality of care in the NHS, identify a Senior Improvement Lead to assume responsibility for the implementation of the actions

Research

Research brings hope for the future and there is a clear need to take steps to broaden opportunities to make advances in research, from developing improved social practices to medical and pharmacological advancement. Alzheimer Scotland continues to promote and invest in research opportunities that have the potential to improve the lives of people with dementia and their carers.

Investment in research has yielded significant progress in recent years, improving our understanding of the biology underpinning the diseases that can cause dementia and how these diseases can be diagnosed. We are now on the cusp of a new generation of treatments – industry has over 150 clinical trials focused on dementia globally and initial data from one recent clinical trial has shown that a drug, lecanemab, can slow the course of cognitive decline in Alzheimer’s disease³⁷.

Alzheimer Scotland understands the need for as many people as possible to get involved with dementia research to continue making progress towards a cure. Working alongside partners across research, Alzheimer Scotland is striving to encourage people to participate in research projects. We are proud to be part of Join Dementia Research which enables people to sign up to dementia research opportunities, and we have recently launched our ‘Confident Conversations about Research’ programme³⁸ with our partners at NHS Research Scotland Neuroprogressive Dementia Network to enable Alzheimer Scotland’s frontline staff to be trained to have the knowledge and skills to talk about research with the people they support, the benefits of it, and how they can participate in it.

The Scottish Dementia Research Consortium, with support from Alzheimer Scotland and Brain Health Scotland, has developed the Scottish Brain Health and Dementia Research Strategy³⁹. By creating an environment that promotes the conditions for the highest quality of brain health and dementia research, and the rapid implementation of research into practice, the strategy provides the foundation for Scotland to deliver a framework for meaningful brain health research that is driven by and meets people’s needs. The recommendations made in the strategy also lay the groundwork to engage more people in research activity across Scotland. This is supported by the work of Brain Health Scotland to promote opportunities to join research programmes, so everyone can join the effort to better understand brain health and disease.

Alzheimer Scotland has an active partnership with Alzheimer’s Research UK and the Alzheimer’s Society which is best demonstrated through our joint work on Join Dementia Research. We have consulted closely with our partners at Alzheimer’s Research UK, who specialise in research, and we both believe that Scotland’s scientific institutions and researchers make the country well positioned to be a global leader in dementia research. There is considerable opportunity for greater life science investment and for patients in Scotland to have early access to new therapies. To realise this potential, Scottish Government must not only continue to invest in and prioritise dementia research, but it must also engage with UK-wide funding bodies to ensure their decision-making reflects the needs of dementia research in Scotland. We agree that the key priorities for the Scottish Government’s approach to research are:

- Greater investment specifically in clinical research infrastructure. There are considerable challenges around the set up and delivery of clinical trials in dementia and we need to innovate to address these and support faster, more efficient trials.
- Horizon scanning the current industry pipeline and proactively working with clinical trial sites to ensure they are able to benefit from new commercial trials.
- Exploration of scalable diagnostics, such as blood-based biomarkers, to identify more people at the earliest stage of disease progression. A better characterised dementia patient population will speed up finding the right candidates for the right trials.
- Supporting greater participation in dementia research from as diverse a population as possible. Key to this will be enabling greater integration of clinical care and research as well as building on existing initiatives such as Join Dementia Research.

Clinical pathways and service delivery models

In line with our work in Brain Health Scotland, earlier, more accurate diagnosis of dementia and its underlying cause(s) is the key to improving the lives of people living with dementia. It will enable access to the care and support individuals need to plan for their future and give them the opportunity to participate in clinical research. Moreover, when they are available, disease-modifying treatments (DMTs) for Alzheimer's disease are likely to be most effective at the earliest stages of disease⁴⁰.

The Scottish Government must act now to ensure there is sufficient time to increase capacity, infrastructure and skills in the current dementia diagnostic pathway if people are to benefit from new DMTs when they become available. The new National Dementia Strategy offers an ideal opportunity to drive this work.

Recommendations

- ✓ Continued support and investment in research designed to improve the diagnosis, treatment and care of people with dementia
- ✓ Adopt a UK-wide approach to establishing funding opportunities meets the needs of dementia research in Scotland
- ✓ Explore opportunities to establish clinical trials and provide early access to treatments in Scotland through the development of infrastructure, capacity and skills

Equality and Diversity

Dementia affects people from all walks of life and their individual circumstances impact on their experience of dementia and the services designed to support them. Alzheimer Scotland believes that everyone with dementia deserves fair and equal access to human rights-based, person-centred care that meets their individual needs regardless of their socio-economic or cultural background. The current delivery of dementia diagnosis, care and support must be developed further to meet the specific needs of marginalised groups of individuals with characteristics that influence their experience of the condition as set out in the Equality Act 2010⁴¹, the European Convention on Human Rights⁴² and the European Convention on the Rights of Persons with Disabilities⁴³.

Age and dementia

Dementia is often assumed to be a condition of older people, and while it mainly affects the older population, it is not an inevitable part of the ageing process. Indeed, it is estimated that 7.5% of people with a diagnosis of dementia experience the first onset of their symptoms before the age of 65⁴⁴. However, the experience of young onset dementia is impeded by a lack of specialist services and support designed to manage the specific needs of the younger population. There are very limited opportunities for people with young onset dementia to access day services, respite care and residential care facilities that are aimed at meeting their unique range of needs and more needs to be done to address this disparity in the provision of dementia care.

People under the age of 65 must have access to services and resources that are relevant to them and their circumstances. They are more likely to experience issues around employment, education and training, and these challenges must be managed to allow these individuals to live well with dementia for longer. They also have age-specific needs that cannot be addressed through older people services and a detailed approach to meeting the needs of people with young onset dementia must be developed.

Women and gender

Dementia has a disproportionate impact on women. Dementia is the leading cause of death for women in the UK⁴⁵ yet dementia was not included within The Women's Health Plan⁴⁶. More must be done to address the health needs of women.

Women provide the majority of informal care for people living with dementia, accounting for 70% of carer hours⁴⁷. Providing care has an impact on women's opportunities in employment, training and education, as well as creating greater financial insecurity. This gender imbalance also creates barriers for women in terms of accessing support that reflects their additional needs and supporting them to manage the additional responsibilities that they carry. More must be done to support women in their role as carers. Support for carers must become a top priority to address the inequality experienced by women.

Ethnic minorities

Dementia rates have increased across all ethnic groups⁴⁸ yet people with dementia from minority ethnic groups do not access support and services to the same extent as the general population as a whole and are largely absent in residential care homes. Those who do, often find services limited and culturally inappropriate or of poor quality⁴⁹. They encounter barriers at individual, societal and structural levels and more must be done to address the barriers to accessing care and support. This should include improved information on living well with dementia and improved access to culturally appropriate services. It is important to recognise that people from marginalised groups may not feel comfortable in a generic service, even with additional support measures, and their needs should be recognised to ensure equality of access to services.

Further steps must also be taken to support health and social care staff to better understand the specific cultural needs of ethnic minority groups. Staff should have access to equality and diversity training as part of any continuous professional development to provide a good understanding of the challenges of delivering a service to minority or marginalised groups, and services need to make adjustments to their practice to accommodate the needs of those individuals.

The Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) community

Despite making up 1 in 15 people in the population, LGBTI people are relatively invisible, and that experience is magnified for LGBTI people with dementia⁵⁰. LGBTI people with dementia still face acute inequalities and discriminatory attitudes and their experience of not being accepted impacts on their trust and willingness to access services. Their expectation of equal treatment is relatively low. Older LGBTI people are more likely to live alone, be single as they age, not have children, and are less likely to be in regular contact with their biological family and have no-one to call on in a crisis which creates substantial inequalities in access to support.

More action needs to be taken to address the discrimination experienced by LGBTI people with dementia. A more inclusive approach to the LGBTI community must be adopted by dementia services that ensures that staff are informed, open and able to provide culturally appropriate care. Dementia services should be safe spaces for members of the LGBTI community that show a willingness to address issues of prejudice and discrimination.

Learning Disability

People with a learning disability are now living for longer and are therefore more likely to develop illnesses associated with age which puts them at an increased risk of dementia. A diagnosis of dementia complicates further the care needs of individuals with a learning disability and increases the need for specialist support. Alzheimer Scotland collaborated with the Care Inspectorate and Healthcare Improvement Scotland on guidance for staff to support people with a learning disability and advanced dementia moving into

a care home⁵¹ and further work needs to be carried out to ensure that this type of additional support is rolled out across the whole of Scotland to meet the needs of people with learning disabilities and dementia to ensure that those specific needs are met.

Sensory Impairment

Sensory impairment has a significant impact on people with dementia. Sight loss affects an estimated 250,000 people with dementia in the UK and is typically under-diagnosed because one condition can mask or be mistaken for another⁵². Meanwhile, hearing loss or impairment also affects a significant number of people with dementia, particularly acquired hearing loss that is more prevalent in older age⁵³. Sensory impairment impedes the ability to communicate and can lead to feelings of frustration and isolation for people with dementia. It is essential that inclusive approaches are adopted to ensure that people with dementia and sensory impairment feel included in everyday life across all the settings they find themselves in. Alzheimer Scotland has worked closely with the Royal National Institute for the Blind (RNIB) to raise awareness of sight loss among people with dementia and to promote the inclusion of people with dementia and sight loss and continued efforts in this field must be made to ensure ongoing support for those with a sensory impairment.

Tackling stigma

People with dementia experience stigma and discrimination as a direct result of their condition. They are often defined by their diagnosis and no longer seen as an individual. People lack understanding of what a dementia diagnosis means and make assumptions on pre-conceived ideas based on negative media stereotypes of dementia. Sometimes, people with dementia even feel stigma towards themselves and consider themselves to be 'stupid' or 'a burden' due to their diagnosis.

It is essential that action is taken to address the stigma experienced by people with dementia and their carers. Education and access to accurate information are essential to ensure that the wider public have a clear understanding of dementia and to tackle underlying fears or worries related to dementia. In turn, this can lead to improved interactions with people with dementia and their carers.

Recommendations

- ✓ Implement the essential infrastructure, resources and services designed to meet the specific needs of people with young onset dementia
- ✓ Address the inequalities experienced by carers through the delivery of flexible care and support, including improved access to day services and respite

- ✓ Improve access to culturally appropriate dementia information and services for people from marginalised communities, including those from ethnic minorities and the LGBTI communities
- ✓ Continue to implement existing programmes and policies designed to provide support to communities with additional needs
- ✓ Undertake a programme of public education and information to tackle stigma in the wider community

Accountability and Governance

The implementation of appropriate accountability and governance is essential to ensure the successful delivery of the next National Dementia Strategy. Previous Strategies have provided an opportunity to implement clear and effective dementia policy to provide the care and support that would empower and enable people with dementia and their carers to live well with the condition, however, failure to deliver the commitments of the previous strategies has resulted in the need to address the issues of accountability and governance.

A failure to evaluate the previous National Dementia Strategies indicates a short-sighted approach to the development of the fourth National Dementia Strategy. An evaluation of the work carried out to achieve the commitments set out in the first three strategies would clearly indicate that much work is still to be done to fully achieve the aims of the pledges made to people with dementia and their carers to ensure a more positive experience of services and resources to support them through their journeys with dementia. While the Scottish Government has indicated their desire to create a “new story”, it is clear that steps must be taken to ensure that previous promises are fulfilled to deliver a holistic approach to dementia policy that meets the needs of every person with dementia and their carers.

Future plans to ensure the delivery and implementation of the National Dementia Strategy

Alzheimer Scotland believes that the new National Dementia Strategy must learn from previous strategies and that a more robust approach to accountability and governance needs to be adopted. While previous strategies have referenced the importance of monitoring the outcomes of the strategies, the failure to address shortcomings in the delivery of the commitments highlights the ineffective approach to governance which must be addressed if the new National Dementia Strategy is to be delivered successfully.

Accountability comes from the development of a clear reporting framework that provides a mechanism to enable all stakeholders to know and understand what is being delivered, where, when and how, and to raise concerns when there is failure to do so. This will ensure that the delivery of the fourth National Dementia Strategy can be effectively implemented and will address the gap between policy and practice.

A fresh approach to data collection is needed to ensure a clearer understanding of the dementia landscape. The current approach to data collection is confused and needs to be addressed to enable the monitoring of service delivery and the experience of people with dementia and their carers. For example, there is no direct capture of data relating to the incidence of dementia, while data captured in relation to the delivery of post-diagnostic support is retrospective. Strategic planning and operational delivery of services is also carried out at different organisational levels so the available data does not provide a complete picture, and this creates a barrier to understanding the experience of people with dementia in a consistent manner.

Recommendations

- ✓ Deliver the commitments made in the previous National Dementia Strategies
- ✓ Agree an evaluation of the outcomes of the previous National Dementia Strategies
- ✓ Develop a strong framework of governance for the implementation of the fourth National Dementia Strategy based on accountability and transparency

Alzheimer Scotland's recommendations for the future of dementia care and support

- ✓ Action to improve access to diagnostic pathways, particularly for people living in care homes, through the consistent implementation of assessment and care standards
- ✓ A commitment to the delivery of resources, infrastructure and funding to tackle delays and waiting times to receive a diagnosis
- ✓ Development of processes and mechanisms to capture, record and store accurate data relating to the incidence and prevalence of dementia to inform and guide services for people with dementia
- ✓ Action to improve access to diagnostic pathways, particularly for people living in care homes, through the consistent implementation of assessment and care standards
- ✓ A commitment to the delivery of resources, infrastructure and funding to tackle delays and waiting times to receive a diagnosis
- ✓ Development of processes and mechanisms to capture, record and store accurate data relating to the incidence and prevalence of dementia to inform and guide services for people with dementia
- ✓ Sustained funding and investment in post-diagnostic support services to secure the future of post-diagnostic support
- ✓ Develop processes and mechanisms to capture, record and store accurate data relating to the delivery of post-diagnostic support to anticipate future needs and focus service delivery
- ✓ Promote and consistently deliver the existing Quality Improvement Framework to increase the standard of post-diagnostic support
- ✓ Agree a plan to implement a co-ordinated approach to care in line with the learning from existing research and projects to test integrated care models
- ✓ Establish clear policy links between the principles of the National Dementia Strategy and the development of the National Care Service to ensure that the needs of people with dementia and their carers are met through the wider policy landscape
- ✓ Agree and implement the recommendations of the 'Advanced dementia practice model: understanding and transforming advanced dementia and end of life care' report published in 2015

- ✓ Recognise and agree that the needs of people with advanced dementia are fundamentally healthcare needs and provide access to health care assessment and treatment regardless of the care setting
- ✓ Remove the unfair charging practices for the care needed by people living with advanced dementia, both in the community and in residential care
- ✓ Develop processes and mechanisms to capture, record and store accurate data relating to the delivery of acute care to anticipate future needs and focus service delivery
- ✓ Develop a consistent approach to the delivery of high-quality care services through the implementation of national standards of care
- ✓ Refresh and re-prioritise the 10 Dementia Care Actions to improve the delivery of care in general healthcare settings
- ✓ Implement the recommendations of the 'Transforming specialist dementia hospital care' report published in 2018
- ✓ Support Alzheimer Scotland's Commission on the Future of Long-term Care
- ✓ Ongoing commitment to the delivery of the *Connecting People, Connecting Support* framework to maximise the role of allied health professionals in dementia care through the delivery of the four ambitions that are integral to the delivery of this strategy
- ✓ Continued and strengthened clinical leadership from the National Alzheimer Scotland Allied Health Professional Consultant and the developing local leadership infrastructure
- ✓ A sustained commitment to improving access to the specialist support and treatment delivered by allied health professionals for people with dementia from the onset of symptoms to the end of life
- ✓ Recognise the valuable contribution made by the third sector in the delivery of person-centred approaches to care and support in the community by providing a commitment to sustained, planned funding
- ✓ Agree to undertake an evaluation of dementia-friendly community activities to support future planning and the development of best practice guidelines
- ✓ Continue investment in new innovations and technological advances to support the delivery of community-based care and support
- ✓ Agree collaborative approaches to the delivery of initiatives that can reach the widest audience of the dementia community
- ✓ Continued support and investment in research designed to improve the diagnosis, treatment and care of people with dementia

- ✓ Adopt a UK-wide approach to establishing funding opportunities meets the needs of dementia research in Scotland
- ✓ Explore opportunities to establish clinical trials and provide early access to treatments in Scotland
- ✓ Implement the essential infrastructure, resources and services designed to meet the specific needs of people with young onset dementia
- ✓ Address the inequalities experienced by carers through the delivery of flexible care and support, including improved access to day services and respite
- ✓ Improve access to culturally appropriate dementia information and services for people from marginalised communities, including those from ethnic minorities and the LGBTI communities
- ✓ Continue to implement existing programmes and policies designed to provide support to communities with additional needs
- ✓ Deliver the commitments made in the previous National Dementia Strategies
- ✓ Agree an evaluation of the outcomes of the previous National Dementia Strategies
- ✓ Develop a strong framework of governance for the implementation of the fourth National Dementia Strategy based on accountability and transparency

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