

Glasgow City Dementia Strategy 2016-19

Acknowledgment

This strategy was developed in partnership between Alzheimer Scotland, Glasgow City Council and NHS Greater Glasgow and Clyde.

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All quotations throughout the report are from actual responses received in the questionnaire.







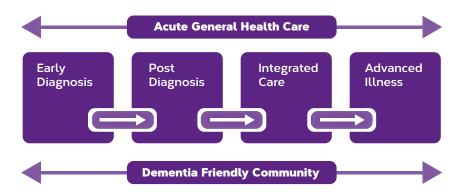
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"Glasgow should aspire to be a place where people can say we look after our own."

Foreword

Alzheimer Scotland welcomes Glasgow City Health and Social Care Partnership's Dementia Strategy for 2016-19. This strategy has been developed in partnership and we have welcomed the opportunity to shape its development. Importantly, this has included facilitating the involvement of a range of people with dementia, their carers and families as well as a really wide range of other stakeholders to inform the key themes for Glasgow's first Dementia Strategy.



Alzheimer Scotland has a clear vision for the change required if people with dementia and their partners, families and carers are to be properly supported in Scotland, and if their human rights are to be respected. Timely, skilled and well-coordinated support for people with dementia, and those who care for them, throughout the illness is essential if we are to avoid the human, societal and financial costs of crisis-driven care. Alongside that we must continue work to improve the care of people with dementia in hospital, and other care settings, and we must support our communities to be able to respond better to people with dementia so that they a can continue to live well for longer and be included in their own community.

We are pleased that these key elements are set out in the commitments of this dementia strategy for the city by Glasgow Health and Social Care Partnership and we welcome the plans in place for evaluating and monitoring these priorities. We look forward to continuing to work in partnership, and supporting the involvement of people with lived experience of dementia, to ensure that these commitments are delivered for people with dementia, and those who care for them, in Glasgow.

> **Jim Pearson** Director of Policy and Research Alzheimer Scotland

Foreword

We are delighted to introduce the Glasgow City Dementia Strategy. This important document has been a year in the planning; however, it builds on many years of work within Glasgow City to improve the lives of people affected by dementia. People with dementia attempt to live ordinary lives within our communities, but are at risk of disadvantage because the nature of dementia means that everyday activities such as shopping and socialising are more difficult. The Strategy seeks to engage with everyone in Glasgow - including businesses, organisations and agencies – to support people affected by dementia to stay in their own homes and communities safely.

People Make Glasgow, and we need to ensure that the people of Glasgow with dementia, or who care for someone with dementia, are fully included in Glasgow life. We commend this Strategy, and encourage everyone to use the information and good practice it contains to help our communities and organisations to become 'dementia friendly'.

"There is no 'one glove fits all' method of dealing with dementia."



Councillor Archie Graham OBE

Chair, Glasgow City Integration Joint Board

Trisha McAuley OBE

Vice Chair, Glasgow City Integration Joint Board

Executive Summary

"There is a need to ensure that services are locally responsive to make sure that the benefits of being an active citizen within a community can be protected for people with dementia and their carers."

This 3 year strategy and overall vision has been developed by Glasgow City Health and Social Care Partnership (GCHSPC) in collaboration with Alzheimer Scotland, and co-produced with people with dementia, their families, carers and a wide range of stakeholders.

The strategy outlines the commitments from GCHSCP to improve health and social care services for people with dementia; recognising that a diagnosis of dementia should be the gateway to information, support, care and treatment. Additionally the strategy aims to encourage and strengthen communities to ensure that over time, there is capacity to support people affected by dementia so they can enjoy the best possible quality of life. This will require a change in attitudes and behaviours towards dementia at all levels of society. People with dementia, and those who care for them, should have access to the support they need, when they need it and be treated with dignity and respect.

The strategy provides a framework for action for the whole community. It offers suggestions, sign-posting and good practice examples to stimulate activity throughout the city.

"Care and support should be person centred and based on the needs and preferences of the individual."

Introduction

This strategy originated from a recognition of the increasing numbers of people with dementia, and the developing policy context which illustrates that people can live well with dementia with the right support.

The number of people in Scotland with dementia stands at around 90,000 and is expected to double in 25 years. Policy at national and local level has therefore reflected a need to respond to this and plan for the future.

Dementia is a national priority, and the Scottish Government's National Dementia Strategies (2010-13/2013-16) and the proposed third National Strategy (2016-19) (click <u>here</u> for further details) directly influence the development of support for people with dementia and their carers and families in Glasgow.

National policy focuses on a range of issues including improving diagnosis rates and the provision of post-diagnostic support, and ensuring the highest quality of care and support for people with dementia at every stage of the illness. This has also included improving service response in acute care and a new focus on supporting the growth of dementia-friendly communities.

Much of this work is already underway in Glasgow and there is a need to have a strategic approach to dementia for the city at a time when Health and social care services integrate to form the Glasgow City Health and Social Care Partnership. This new Glasgow strategy provides an opportunity for everyone to consider how they can play their part in ensuring that Glasgow is a great place to live for people affected by dementia. Whether you are a large organisation, a small community-based service, a shop, a business, or a neighbour or friend, you have a role to play.



Dementia in Glasgow

"My father had a very good local GP who supported our family and definitely felt the community mental health nurse was invaluable."

Dementia is caused by damage to and destruction of brain cells which gives rise to a number of symptoms including the gradual loss of memory, reasoning and communication skills. There are different types of dementia, with the most common being Alzheimer's disease and vascular dementia.

Dementia is not a natural part of ageing process but a progressive illness which usually affects the individual in a gradual manner, although sudden changes can be common in those with vascular dementia.

Dementia can present with a variety of symptoms, often starting with mild short term memory impairment, with disorientation but leading later to impairments in sophisticated brain functions such as speech, the ability to calculate or the ability to organise day to day activities. In the later stages of dementia, people can be very vulnerable as a result of the symptoms of their dementia.

Anyone can be affected by dementia, irrespective of age, gender or ethnicity. It can affect adults of

working age as well as older adults. Many people with dementia will also have other underlying health needs and conditions.

There is considerable evidence, in particular from people with dementia and their families, that where people receive an early diagnosis of dementia and are helped to access information, support and care, people are often able to adapt to living well with dementia.

Older People	Dementia is more common as people age. One in 14 people over 65, one in 6 people over 80, and one in three people over 95 has a form of dementia.
Learning Disability	Studies have reported increased rates of dementia in people with Down's syndrome.
Younger People	Cause of dementia onset in people under 65y may differ from those in older age groups and may require particular investigation, diagnosis and treatment.

Health records tell us that there are around 4,500 people known to be living in Glasgow with a diagnosis of dementia, although there are potentially many more who have not sought or received a diagnosis.

Research suggests that there may be around 8,000 people with dementia in Glasgow. For more information about dementia statistics in Scotland please click <u>here</u>. Each year around 800 people receive a diagnosis of dementia in the city.

Population projections for the city suggest that while the number of people aged over 65 is not expected to increase significantly over the next five years, there will be an 8.4% increase in the number of those aged over 85.

In the longer term there are expected to be more significant increases, with a 38.7% rise forecast in those aged over 85 years between 2017 and 2037. As such the number of older people with dementia is expected to rise

The Lived Experience of Dementia

The lived experience of dementia is a progression that is not always straightforward and is not uniform. It can be helpful to think about the services and supports that people may require before they are needed. Service provision is generally accessed through health and social care services in Glasgow. This includes diagnosis, post diagnosis support, increasing support for both the person and the carer as dementia progresses, and the care of people with dementia at home, in care settings and in hospitals.

More and more research is now being done to understand how dementia develops and what we can do to delay and prevent dementia, as well as providing the best treatment and care.

This research shows that there are some things we can do to reduce our chances of developing dementia. It is now widely understood that "What's good for your heart is also good for your mind". This means that the wider prevention and health improvement strategies already being taken forward in Glasgow, will also contribute to preventing dementia.

In Glasgow we will develop further programmes that

- Support people to stop smoking, and never start.
- Work to ensure that high blood pressure (hypertension) and diabetes are diagnosed as early as possible and treated to high clinical standards, enabling patients to manage their condition.
- Work with Glasgow's Alcohol and Drug Partnership (ADP) to rebalance our relationship with alcohol as a city, and support a norm of drinking less.

- Work with partners to support learning and development, particularly making it easier for us to stay connected to others and remain inquisitive as we age.
- Work with partners like Glasgow Life to enable more people to be more active, more of the time.
- Extend programmes that support people to remain at and return to a healthy weight at any point in their life.

Although we now understand more about what affects our chances of developing dementia, there is still a lot of learn and we will consider emerging research evidence and good practice as this strategy is implemented. However the six key prevention areas above are ones that we already know will lead to more of us being able to live longer, healthier and often happier lives, as well as protecting more of us from experiencing dementia.

The dementia journey often begins with concerns about memory problems. First contact is usually with the person's GP who will find out more about the memory problem and how it is affecting the person's life. The GP will also take account of other aspects of the person's physical or mental health which could be contributing to symptoms, and carrot a test of their memory. The GP may at this point be able to make a diagnosis of dementia but more often the person will be referred to specialist mental health services for further assessment, diagnosis and treament interventions if it is felt these would be beneficial for the person. At appropriate times, multi-agency specialist support for the person and their carer(s) may be offered. Appropriate interventions can have a significant impact on the quality of life of the person with dementia - enabling the person to live as independently as possible, be supported to make choices, have optimal control, and enjoy increased participation in activities. It is important that social, physical, spiritual and psychological aspects are considered, and that there is:

- A focus on the remaining abilities, skills and capacities of the person;
- Recognition of the stigma that can be experienced by people with dementia;
- An emphasis on listening to the person living with dementia;
- A focus on supporting the person with dementia to achieve the outcomes that are important to him/ her;
- A focus on supporting carers and families so that the best quality of life can be maintained for the person with dementia;
- Awareness of the influence of the social and built environment in enabling or disabling people with dementia.

To find out more about outcomes, see the following links:

<u>National Health and Wellbeing Outcomes</u> and <u>Talking</u> <u>Points</u>.

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Pathway Diagram

Health Promotion & Early Intervention

Accessing health promotion literature about healthy living. To reduce risk of vascular dementia.

Worried about your memory?

Getting information on dementia and speaking with your GP.

- Dementia Friendly Communities -



Delivering the vision

Health and social care services

Health and social care services make significant contributions to a dementia strategy. They have a key role to play in diagnosing, treating and supporting people with dementia and in supporting their families and carers, in order that the person with dementia is able to live well in the community and within hospital and care settings. They also have a role to play in promoting health improvement, since there is growing evidence that living a healthy lifestyle (including being physically and mentally active) is protective against developing dementia.

Health and social care services are also responsible for ensuring that each person gets good quality care in hospital or 24 hour care settings if this is required. There are a number of ongoing initiatives in our local hospitals aimed at further enhancing the quality of care delivered to people with dementia.

Health and social care services to people with dementia, their families and carers are delivered through GHSCP. GCHSCP, in partnership with housing, voluntary and other key stakeholders, has set out its vision and objectives to improve the health and wellbeing of all the city's citizens, which can be found in the <u>GCHSCP Strategic Plan</u>.

The ageing population, and in particular the increasing numbers of people with dementia, will challenge how health and social care services are planned and delivered in Glasgow:

- Expected increase in number of people aged 85+ over the next decade.
- Increasing numbers of people living with more complex conditions and co-morbidities alongside dementia.
- Impact of deprivation and health inequalities.

Our ambition must be to ensure that people throughout their condition are given the best chance to live well and to play an active role in family and community life. We must do all we can to ensure that people who need treatment receive it at the right time and in the right place.

The creation of GCHSCP provides a key opportunity to develop more closely integrated health and social care services, more comprehensive programmes of care and a greater awareness and understanding of the needs of people with dementia and those close to them.

The key principles of health and social care services for people with dementia, their families and carers are:

- Services work closely together across agencies.
- People are able to access the right information at the right time.
- Services are accessible and referral pathways are clearly defined.
- A person centred outcomes based approach is in place.
- Services continue to change and develop as new learning emerges.
- People affected by dementia are listened to, with their views informing service planning.

- The workforce is skilled and knowledgeable about dementia.
- Supports and services are available to carers.

GCHSCP is committed to providing support to people in the city with dementia and their families. This will be delivered through a range of service providers. Some of these may be dementia specific such as Post Diagnostic Support or support from Alzheimer Scotland whilst others may be more generic such as homecare. This support is planned, co-ordinated and delivered by GCHSCP.

The key priorities are:

- Prevention: support with general health and well being
- Health improvement
- Dementia diagnosis
- Post-diagnostic support
- Access to medication and/or psychological interventions for memory or other symptoms associated with dementia
- Social care Support
- Carer Support
- Adult Support & Protection
- Power of Attorney/planning ahead for future care needs
- Staff awareness and training
- Public awareness and support
- High quality care within hospital and 24 hour care settings
- A safe, dementia friendly community.

What people in Glasgow say about dementia

"Services should be shaped around the people they work for."

Initial conversations with dementia carers' groups in the city suggested a number of key themes. A full consultation process around these themes took place between September and December 2015. This included people with dementia, their families and carers and a wide range of stakeholders including housing and care providers, voluntary organisations and the business community.

As well as consultation events, an online questionnaire was sent out to health and social care staff. The questionnaire was also made available to members of Glasgow Council for Voluntary Services (GCVS), the Alliance and the Chamber of Commerce. 939 responses were received in total.

The consultation sought views on health and social care services, the thematic approach to the strategy and how well dementia is understood in terms of its impact on people with dementia, their families and carers.

Improved information about and access to health and social care services were identified as key themes, with carers in particular highlighting difficulties in navigating their way around complex systems when looking for support. A further key theme was the need for increased support to be provided by and within communities, with the voluntary sector, public and independent sectors working together through a dementia friendly community approach. Almost everyone who responded to the survey agreed that it is important for people with dementia to be supported to live well with their condition within their community.

Other important themes:

- Support for carers and family members, including peer support groups
- Awareness Raising
- Access to services
- Support in and from the community.
- People wanted to stay at home for as long as possible
- Practical information about the progression of dementia
- Training for all, including the community, health and social care staff and carers.

Further information on the consultation can be found in Appendix 1.

From the information gathered from people in Glasgow, we developed our Vision:

People affected by dementia in Glasgow will be able to live well, be included and have access to the right support at the right time.



A Dementia Friendly Glasgow

"Every person with dementia is an individual and needs to be treated as such."

Traditionally, the focus for dementia care has been NHS diagnosis and treatment, and care and support services delivered by local councils. Recently there has been a shift to a focus on how we can enable people who have been diagnosed with dementia to live as full a life as possible, and encourage communities to work together to help people with dementia have the best chance to live well.

A key aim of this strategy is to encourage, support and work with the wider community in developing awareness and understanding of dementia. This will help to broaden and enhance the support for people living with dementia and their families.

A dementia friendly community may be defined as being a place where:

- It is possible for the greatest number of people with dementia to live a good life.
- People with dementia are enabled to live as independently as possible and to continue to be part of their community.
- People are met with understanding and given support where necessary.

It is a place where the community acts consciously to ensure that people with dementia are respected, empowered, and engaged. To create a dementia friendly community, we need:

- Everyone to have a level of awareness and understanding of dementia.
- Employees to be appropriately skilled and effective in supporting people with dementia.
- The built environment to be designed to suit people with dementia.
- Transport to be easily and readily accessible.
- Businesses and organisations in the community to be at the heart of someone's support and to help them to keep active and get out and about.
- People's general health and wellbeing to be optimised, so that they can stay in their own home for as long as possible.
- To make the community as safe as possible for vulnerable people.

Achieving a dementia friendly Glasgow will take commitment and action from all sections of our communities. Drawing on the consultation, the policy direction, and good practice examples, the following sections describe areas for action.



Challenging Stigma and Awareness Raising

"Stigma seemed to act as a barrier to understanding and awareness."

A majority of those who completed the online survey agreed that there was not a wide understanding or acceptance of dementia.

Research also suggests stigma exists around dementia and is a key contributor to people with dementia and carers feeling marginalised by society, sometimes by their own friends and family members. This can prevent people from seeking help and discussing the issue openly.

Public awareness is an essential first step towards challenging, understanding and reducing stigma, supporting inclusion by increasing social connections and activity, all of which are important for physical and psychological well-being.

Ensuring that front line staff who come in to contact with the public are more aware and able to spot the signs of dementia so they can support people in their care and in their community. Other organisations might already provide training and services for people with dementia but want to do more.

Good Practice Point:

Dementia Friends is an initiative from Alzheimer Scotland that seeks to change people's perceptions towards dementia through activities that help participant gain a greater understanding point of view of the person with the condition.

Dementia Friends has been delivered to the fire service, pharmacies, museums, housing associations, shops and primary schools in Glasgow.

Questions for groups and organisations to consider:

- How dementia aware are your staff and/or members?
- Have you considered this as a contribution to the strategy?

Additional Resources

The Promoting Excellence Framework developed by the Scottish Social Services Council and NHS Education Scotland defines four levels of learning about dementia: informed, skilled, enhanced and expert. An overview of the framework and levels can be found <u>here</u>.



Physical Environment

Most people with dementia are older and often have additional physical health and frailty issues. Community environments that can be easily navigated, with good paths and walkways and good lighting, make it easier for people to get out and about in their community.

Some people with more advanced dementia can find it difficult to find their way around and can benefit from easy to read signs, for example adding symbols as well as writing, and way markers can be used to help people to know where they are.

Indoors, there are many examples including the use of contrasting colours, good lighting and the use of simple symbols on toilet doors.

Good Practice

Silverburn Shopping Centre has committed to becoming a dementia friendly environment over the next three years. This process will include an audit that looks at the physical environment of the complex.

Questions for organisations to consider:

- Is your local area or premises easy to navigate?
- Does your shop have suitable signage, colour contrast and lighting?

Additional Resources

Looking at dementia friendly design and making small changes can have a big impact. An example is this <u>virtual care home</u>. The basic principles of light, colour differentiation and simple functional layout can be used in all rooms. "Not everyone is patient or understanding and this can cause distress when pressing someone for information they aren't able to communicate."



Transport

"There are some excellent services largely succesful due to the commitment and passion of the staff."

Many people with dementia tell us that using public transport can be stressful. They may struggle to pay the fare, remember where they want to get off or just get disorientated.

Transport providers can help their staff to feel more confident supporting people with dementia and in turn enable people with the condition to maintain their independence for much longer by continuing to get out and about safely. Transport providers need to ensure that information is easy to understand and services are accessible.

Questions for organisations to consider:

Do your employees have an understanding about dementia?

Additional Resources

The pocket sized 12 helpful hints leaflet looks at the best ways to communicate with someone with dementia. For more information please click <u>here</u>.

In addition, the Scottish Dementia Working Group who are a campaigning group formed of people living with dementia have created a video about the issues when travelling with dementia and some solutions to these, which can be viewed <u>here</u>.

"There are many people in the community looking after relatives."

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Community Safety

A preventative approach to community safety for people with dementia should be a priority, for example offering help and support to those who are most vulnerable to causing a fire or becoming injured in a fire.

Telecare services can provide a range of useful equipment to enhance home safety.

In terms of the wider community and safety there is a range of considerations from well maintained and free from leaves, footpaths, pedestrian crossings with audible cues at a pitch and timing suitable for older people, and adequate street lighting.

Police, Fire and Rescue, Social landlords, council services and other services play a key role in improving community safety for all community members including those with dementia.

Good practice

The Scottish Fire & Rescue Service provides free home fire safety checks and smoke alarms, to keep people safe in their own homes. They have also started the process to ensure all staff are more dementia aware through Alzheimer Scotland's Dementia Friends.

Questions for organisations to consider:

- Can other organisations help or give advice?
- How safe is your environment?

Additional Resources

For more information about home fire safety please click <u>here</u>. For further information on the role technology can play with dementia click <u>here</u> to read the Technology Charter.

"Have enjoyed Dementia Friendly training and hope to learn more."

Opportunities for personal enjoyment and engagement in community life

"Sometimes all you require is someone to talk to and help them understand they are not alone."

Research indicates that participation in meaningful activity is beneficial for the health and well-being of people with dementia.

Having access to leisure, sport and other experiences that add meaning and are of interest to someone with dementia is valuable for promoting their well-being. People have told us that being accepted, understood and catered for by the community means that they can continue to stay connected to places that are meaningful or special for them.

Good Practice

Clincarthill Parish Church in South East Glasgow regards itself as a dementia friendly church running groups and activities for people with dementia and their carers through a team of volunteers who also undertake awareness raising work with members. The church youth organisations are involved in reminiscence work and providing musical playlists within local care homes.

Questions for organisations to consider:

- Does your organisation run activities that are inclusive of dementia?
- What can you do to make someone with dementia feel more comfortable when attending your organisation?

Additional Resource

The Alzheimer Scotland Active Programme was delivered in partnership with Glasgow Life. The objective of the programme was to promote sport and health activities to people with dementia by supporting leisure centres to be more dementia friendly and offering increased opportunities for appropriate activities.

Please click here to read the full report.



Housing

"[My nana] was in a specialised unit in dementia care, not only did they care for her, they supported my family and me through the journey."

Many people with dementia want to live at home for as long as possible. Often, this is with support from others. However, it can be difficult managing everyday situations if you have dementia, particularly as the dementia progresses and you get older. As a result, some people may not be as safe at home as they used to be.

With the right support, someone who has dementia may be able to continue living at home for a long time.

Although having dementia can reduce a person's ability to live independently, there is a variety of support available including equipment and adaptations that can be used to modify someone's home to make it more suitable for them.

Many social housing landlords are looking at how people with dementia can continue living safely at home by making the best use of equipment, adaptations and technology enabled care. There is also a willingness to make new builds more dementia friendly.

People who own their own homes should also be supported to access information about adapting their home.

Good Practice

Croftspar Place in the East End of Glasgow is a purpose built facility containing housing within a community. Everybody living in the housing has dementia. They are able to access as much or as little support as they want from the onsite team.

Questions for organisations to consider

- If you are a Housing Association, do you run activities that are inclusive of dementia?
- If you support someone with dementia, have you thought about whether technology or other environmental supports could be beneficial within the person's home?

Additional Resources

Please click <u>here</u> to read Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012 – 2021, written by the Scottish Government.

Click <u>here</u> to read Improving the Design of Housing to Assist People With Dementia which contains ideas and reasons for housing design suitable for people with dementia.



Carers and Family Support

"People should be more aware of their rights as a carer when holding PoA for their guardian and how they can enhance the life of the patient by making good well informed decisions for them."

Living with dementia can have a huge emotional, social, psychological and practical impact on families and carers as well as on the person him/herself.

It is important that carers are recognised for their contribution and as such are regarded as equal partners in the planning and delivery of care and supports for the person with dementia. Carers of people with dementia are often older people themselves, and will required their own supports and services to alleviate the impact of caring.

The Council's Cross Party Working Group on Caring for Someone with Dementia recognised that diagnosis is important as it is the gateway to information, support, care and treatment of the person with dementia, their family and carers. The report concluded that outcomes for carers can be improved through early identification and providing effective supports. The final report can be accessed <u>here</u>.

As such the key objective of dementia carer support in Glasgow is to provide the right information and support at the right time through increased partnership working between health, social work and the voluntary sector, leading to improved health and well being of the carer and in turn the person they care for.

A DVD 'It's OK to Ask for Help' has been developed to encourage dementia carers to refer into services. This gives carers access to dementia education, peer and emotional support, income maximisation, carer health reviews and emergency planning services.

Carers can also be referred onto the pathway via the NHS post diagnostic services, GPs, Community Psychiatric Nurses and other health and social work professionals, or through Alzheimer Scotland or other voluntary organisations that carers might be known to.

Good Practice Dementia Carer Pathway

More than 1,700 new carers have accessed the dementia pathway since 2011 and there is a wealth of evidence that the supports available are leading to good outcomes for both the carer and cared for. To read a further report please click <u>here</u>.

Carer Positive is a Scottish Government funded initiative established to support and recognise employers who offer the best support to carers, allowing them the flexibility they often need to provide care to friends and family at home. Glasgow City Council has attained Carer Positive 'engaged' status as have many other employers in the city. A full list can be found <u>here</u>.

Questions for organisations to consider:

- Are any of your of your employees carers?
- What changes or supports can you provide to someone who is a dementia carer?

Additional Resources

Click <u>here</u> to learn more about carers services provided through the carers partnership and to find how to access these. Training for carers is also available and is provided in partnership with Alzheimer Scotland.

Equality, Anti-discrimination and Rights

"We have made tremendous progress and should strive to continue this."

People with dementia can face discrimination for a number of reasons. There remains significant misunderstanding about and stigma attached to dementia that can manifest in widespread discriminatory attitudes. Most people with dementia are over the age of 65 and may also face issues of age discrimination.

Having a diagnosis of dementia when a person is under 65 brings particular challenges, especially for those who are still working or have a young family. There may be young carers in these situations.

<u>The Charter of Rights for People with Dementia</u> (2009) was developed to acknowledge the cultural, social and economic barriers faced by someone with dementia, and to empower people with dementia and their carers.

Rights are important but often rights are required to be upheld and promoted by all community members.

Good Practice

An employee who received a diagnosis of dementia was supported to stay in work at Rolls Royce. Management were able to modify his job, meaning he could still work there with responsibilities that were in line with his abilities as his dementia progressed.

Questions for organisations to consider:

- Are there small changes you can make for someone with dementia to continue working?
- Is the Charter of Rights displayed in your workplace?

Additional resources

To read the Charter of Rights please click here.



The Way Forward

"Stigma is mainly due to a lack of understanding."

The city with its huge diversity of communities and organisations is responding positively in many ways to the needs of people with dementia, but there is still much more that can be done to make sure that people can live well with dementia.

This strategy provides an opportunity for everyone to consider how they can play their part in ensuring that Glasgow is a great place to live for people with dementia. Whether you are a large organisation, a small community-based service, a shop, a business, or a neighbour or friend, you have a role to play.

The expectation is that this strategy will raise awareness of dementia within the city, building on the existing work in communities to make Glasgow more dementia friendly and to provide a basis on which more partners and agencies can consider their role and contribution towards the vision. Working together, we can:

- Achieve better outcomes for people with dementia, their families and carers.
- Increase awareness of dementia.
- Provide better information about dementia and local services.
- Develop Dementia Friendly Communities in Glasgow.
- Support people with dementia to live well at home or in a homely setting.

- Provide support and resources for carers.
- Co-produce services for people with dementia and their carers.
- Provide awareness raising and training for health and social care staff and staff from stakeholder organizations.

Actions for GCHSCP

Leading on from the development of this strategy, GCHSCP makes the following commitments:

- Continue existing work around diagnosis and post diagnostic support.
- Maintain levels of carers' support and information provision.
- Support workforce development including Promoting Excellence training.
- Increase the use of technology including telecare.
- Continued integrated working with acute services.
- Maximising the benefits of voluntary sector and independent representation within the GHSCP and Integrated Joint Board.
- Increased engagement with Glasgow Community Planning Partnership recognising the opportunities for wider stakeholder contribution to the strategy.
- Continue to raise awareness of dementia in communities through dementia friends and an

awareness campaign.

- Engage with people with dementia and their carers in decisions that will affect them, including service provision and development.
- Provide more integrated support to people living with dementia and their carers.
- Implement current dementia work plans in the city.
- Produce an annual report on what has been achieved.

Evaluation and Governance

The health and social care priorities and aspirations of the Dementia Strategy will be monitored through GCHSCP planning structures. Progress will be reported to the Integrated Joint Board of GCHSCP annually against a range of key indicators (for further details please click <u>here</u>)

The wider Dementia Friendly aspect of the strategy will require the various stakeholders to develop their own priorities and actions and provide annual updates to measure impact over the period 2016-19.

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Appendix I

Glasgow City Dementia Strategy Draft Consultation

Introduction

The purpose of this strategy is to ensure that the City of Glasgow is a good place to live for people with dementia and their carers who are trying to carry on with their lives as normally as possible. Agencies and partners in the city are responding positively in many ways to the needs of people with dementia, but there is still much to do to make sure that people can live well with dementia.

Vision: Glasgow will be a fully inclusive dementia friendly city.

What is Dementia?

Dementia isn't a specific disease, it is an umbrella term used to cover a range of different types of cognitive impairment. Dementia affects memory, thinking and social abilities severely enough to interfere with daily functioning. People with dementia have difficulty with carrying out everyday tasks such as finding their way around, paying bills and remembering appointments. Dementia is not a normal part of ageing, and it can sometimes affect younger adults.

Model of Support for Glasgow

The Strategy provides an opportunity for partners in all sectors to consider how they can make the city a place where people affected by dementia can live well. The focus is on people's lives, looking at the services and facilities which make for a good quality of life. The foundation for this approach will be a dementia friendly Glasgow, where everyone makes a contribution to supporting people with dementia. By working together and creating dementia friendly communities we are optimising a joined up response to people with dementia, their families and carers and using all resources – ours and theirs – to enhance their quality of life.

The key aims of a Dementia Friendly Glasgow are:

- To ensure everyone is aware of and understands about dementia and its impact on people's lives.
- To ensure that those living with dementia and their carers are able to fully participate in their community.
- To ensure those living with dementia have choice and control over their lives.
- To develop a broad and holistic response to support in the wider community.
- To have a more coordinated approach to existing activities and initiatives.

The views and aspirations of people with dementia and their carers should be at the heart of ensuring people

live well with dementia in Glasgow. Creating dementia friendly communities can reduce the barriers that people tell us they experience.

What does a Dementia Friendly Glasgow look like?

A dementia friendly city has been described as a city, town or village where people with dementia are understood, respected, and supported, and confident they can contribute to community life.

The components of a dementia friendly community have been described by people with dementia as one that enables them to:

- Find their way around and feel safe in their locality, community or city.
- Access the local facilities they are used to (such as banks, shops, cafés, cinemas and post offices, as well as health and social care services).
- Maintain the social networks which make them feel still part of their community.

This approach is based on inclusion and building on what people can do and the contributions they can make.

Emerging Themes for a Dementia Friendly Glasgow

Appendix I continued

National and local work involving people affected by dementia and other stakeholders has identified the following key themes:

Challenging Stigma and Raising Awareness

Research suggests that a lack of understanding about dementia is a key contributor to people with dementia and carers feeling marginalised. This can prevent people from seeking help and discussing the issue openly. Public awareness is the first step towards challenging and reducing stigma.

Good Practice

Awareness raising is happening in schools, with fire and rescue services, with staff from shops, banks and housing. This includes practical advice on the signs and symptoms of dementia, communication and practical supports.

Physical Environment

Easy to read signs (for example including symbols as well as writing) and way markers are recognised as good ways to help people to know where they are. Many people with dementia are older and often have additional physical health issues. Community environments with good paths, walkways and lighting make it easier for people to get out and about in their community and reduce isolation. Good, accessible public transport is also important – this includes having bus stops in convenient places, providing clear timetable information, and having dementia aware staff.

Good Practice

The Queen Elizabeth University Hospital in the South of Glasgow has been designed specifically to help people find their way around. For example there are numerous pieces of distinctive art to act as landmarks for people navigating the hospital. Each floor of the hospital has a dedicated colour.

Community Safety

A dementia friendly Glasgow will aim to make our communities safer for people with dementia. A number of different organisations support safety in our communities, including the police, council services and fire services.

Good practice

The Scottish Fire and Rescue Service is working to increase the number of home fire safety visits in the homes of people living with dementia in the city.

Social and community Participation

Having access to leisure, cultural and/or spiritual

activities is valuable for promoting physical and psychological well-being.

Knowing what is important to someone with dementia, and making sure that activities are accessible and inclusive, is a vital part of living well with dementia.

Good Practice

Glasgow Life in partnership with Alzheimer Scotland set up bowls and modified dance classes in the south of Glasgow, with the abilities of people with dementia in mind. Staff training was also undertaken to support accessibility.

Equality and Rights

Everybody has the right to choice and control within their lives and to be treated equally. People affected by dementia tell us that they sometimes face discrimination.

Good Practice

Clincarthill Parish Church in the South of Glasgow was the first dementia friendly church in the country. Groups are run for people with dementia and their carers. A team of staff who have experience of dementia provide support, and awareness sessions have been run for the local community and the congregation.

Appendix I continued

Existing services and supports

The lived experience of dementia is often described in stages although it affects everybody differently.

In Glasgow, people with dementia and their carers will come into contact with a range of formal and informal supports. Some of the stages and types of supports can include the following:

Getting information on dementia and speaking with your GP.	Care settings	Residential and nursing home settings which are suitable for people with dementia.
Getting access to a timely diagnosis.	Hospitals	Hospital environments which are suitable for people with dementia.
Support from named a link worker for at least a year following diagnosis.	End of life care	People with dementia have access to planned end of life care.
Access to carers support services.	Staff development	Staff have the appropriate level of dementia knowledge and
Being safe at home and in the		skills
Access to co-ordinated support from health, social care and other agencies.	A Dementia Friendly Glasgow	A Dementia Friendly Glasgow which will support people to live with dementia
	dementia and speaking with your GP. Getting access to a timely diagnosis. Support from named a link worker for at least a year following diagnosis. Access to carers support services. Being safe at home and in the community. Access to co-ordinated support from health, social care and	Getting information on dementia and speaking with your GP.HospitalsGetting access to a timely diagnosis.HospitalsSupport from named a link worker for at least a year following diagnosis.End of life careAccess to carers support services.Staff developmentBeing safe at home and in the community.A Dementia Friendly Glasgow

Legal and financial

Being at the centre

Keeping active and

of your care

issues

well

Power of Attorney, accessing

benefits and future planning.

Person centred support.

Working on what is most

Support to keep active and

connected in the community.

important to you.

The consultation

Here are some questions about the consultation document which we would like you to consider. Your feedback will shape the final strategy so please tell us what you think.

- Have we got the vision and aims right?
- Are the themes the right ones?
- Have we missed anything?
- In the final document, what would you like to see?
 For example, links to further information? More good practice examples? Resources?
- How do you think we can make this a reality?
- People with dementia have told us:
- They want to be involved in all aspects of their support.
- They want to be in control and able to make their own choices.
- It is important to focus on what is important to that person.
- Being Listened to is a key factor.

"Key health professionals within the communities to embed good practice models would leave a legacy for the future promotion and education of dementia as a way of life."

Appendix II

Questions from the online questionnaire

1. A fully inclusive, dementia friendly Glasgow is a good vision for the Glasgow City Dementia Strategy to have?

- Strongly Agree
- Agree
- Neither Agree or Disagree
- Disagree
- Strongly Disagree

2. Do you think it is important for people living with dementia to be supported by their community?

\bigcirc	Yes
\bigcirc	No

3. Do you agree or disagree with the following statements

- Agencies such as NHS and The Council can only do so much?
- Neighbours should look out for neighbours in need?
- Communities are familiar to someone so should play a role in supporting them?
- Voluntary and community services can't look after everyone?
- Voluntary, community and agencies such as NHS, The Council need to work together?

4. Do you think there is a wide understanding and acceptance of dementia?

- Strongly Agree
- Agree
- Neither Agree or Disagree

- Disagree
- Strongly Disagree

5. Please consider the key themes in the document and indicate how you would prioritise these. Please number the themes from 1-6 where 1 is the most important priority for you.

- Challenging Stigma
- Raising Awareness
- Physical Environment
- Community Safety
- Activities
- Equality and Rights
- Access to Services

6. Are there other themes or issues you think should be included?

7. What do you think the final document should look like?

- Links to further information
- Visual document
- More good practice examples
- Other (please specify)

8. Would you want to be involved in making your community dementia friendly?

Yes No

9. Would you like to make any other comments? For example please tell us about your personal

experiences of services, and access to them.

10. We just need a bit more information about you to know who we have talked to. This is just to get a general idea of who is responding:

- Which one of the following best describes you?
- A professional who works with people living with dementia and/ or their carers
- I have cared/ do care for someone with dementia
- I have experience through a friend or neighbour living with dementia
- I have both professional and personal experience of dementia
- I am living with/ filling this out on behalf of someone living with dementia
- I have no experience of dementia

11. Please identify the sector in which you gain professional experience?

12. How many combined years' of experience around dementia do you have?

13. I identify my gender as?

14. My age is? Under 40 40-50 51-55 56-60 61-65 66-70 71-75 76-80 Over 80

15. My postcode is? (Please do not give the last three spaces of your postcode)

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Appendix III

Results from the online questionnaire

939 people filled in the survey in a six week period, from 19th Nov – 31st Dec 2015.

Q1. A fully inclusive, dementia friendly Glasgow is a good vision for the Glasgow City Dementia Strategy to have?

Strongly Agree- **78.71%** Agree- **17.85%** Total- **96.56%**

Q2. Do you think it is important for people living with dementia to be supported by their community? Yes- 99.14%

Q3. Do you agree/ disagree with the following? Voluntary, community and agencies such as NHS, the Council need to work together. Agree 99.25% Communities are familiar to someone so should play a role in supporting them. Agree 90.29%

Q4. Do you think there is a wide understanding and acceptance of dementia?

Disagree- **52.74** Strongly disagree- **8.38%** Total- **61.12%** <u>Neither Agree or Disagree- **22.99%**</u>

Neither Agree of Disagree- 22.99%

Q5. Please consider the key themes in the document and indicate how you would prioritise these. Please number the themes from 1-7 where 1 is the most important priority for you.

Access to Services Raising Awareness Community Safety Equality and Rights Physical Environment Activities Challenging Stigma **Q6.** Are there other themes or issues you think should be included?

248 people answered

1. Carers- **37.15%**

Included support and respite for carers. Help and information, especially at times of crisis, better communication between services and carers regarding the individual with dementia. Consideration of carers working full time.

2. Services- **11.07%**

Included services for under 65's. More support in person's home, one point of access for services, services working together, making sure consistency and continuity of care is upheld, partnership between services.

3. Training- **10.28%**

- Included training for all; the public, health care including specific department like acute, care home staff and relatives/ carers.

Q7. What do you think the final document should look like?

- 1. Visual Document- **66.41%**
- 2. More good practice examples- **50.88%**
- 3. Links to further information- **50.44%**

Q8. Would you want to be involved in making yourcommunity dementia friendly?882 people answeredYes- 75.67%

Q9. Would you like to make any other comments? For example please tell us about your personal experiences of services, and access to them. 287 people answered

Access to services

Carers Support Resources and awareness

Q10. We just need a bit more information about you to know who we have talked to. This is just to get a general idea of who is responding: Which one of the following best describes you?

Both professional and personal experience - 33.97%

Professional who works with those affected by dementia – **24.81%**

Cared for/ do Care for someone with dementia – **19.91%**

No experience – **10.97%**

Q11. Please identify the sector in which you gained your professional experience? 645 answered

- 65.15% worked in a department within the NHS
- **12.75%** worked in social care
- **9.37%** did not identify a profession
- 7.2% identified various roles in the voluntary sector
- 5.53% worked in a care home

Q13. What gender are you?

81.79% were female

Q14. How old are you?

- 1st Largest group, 40-50 **33.8%**
- 2nd, 51-55 **24.3%**
- 3rd, Under 40 **21.92%**
- 4th 56-60 **15.12%**

Appendix IV

"Assumptions shouldn't be made about what people like to eat/drink, what they like to do and how they prefer to be addressed"

Questions asked to all those who took part in fact-to-face interviews

- Do you agree with the vision for a full inclusive, dementia friendly Glasgow?
- Why do you think a community based approach is important/ unimportant? Explain why you say that?
- Do you think there is wide understanding and acceptance of dementia? Explain why you say that?
- Describe your thoughts on the themes outlined in the strategy...
- Do you think anything has been missed out?
- What are your top three priorities around dementia in Glasgow?
- How do you think we can make a dementia friendly Glasgow a reality?
- What would you like to see in the final document? For example, links to further information? More good practice examples? Resources?
- Would you want to be involved in making your community dementia friendly?
- Use this space for additional comments about dementia in Glasgow city, personal/ professional experience or the dementia strategy...



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