Aberdeenshire
Health & Social Care
Partnership

Making Connections - Aberdeenshire Dementia Strategy 2021 - 2030

Our priorities for integrated health and social care support for people living with dementia in Aberdeenshire

Aberdeenshire COUNCIL

NHS Grampian

Contents

Executive summary	4
What is dementia?	6
Introduction	8
Plan on a page	10
The wider picture	12
How has this strategy been developed?	16
Strategic priorities	19
Being well informed	19
Getting a diagnosis of dementia	20
Knowing who to turn to	24
Living Well with dementia	29
Developing health and social care support for people living with dementia	31
Caring for Carers	35
How will we know we have made a difference?	37
Language and terminology	38
References	39

1. Executive Summary

There are approximately 3000 people living with dementia in Aberdeenshire. 'Making Connections', The Aberdeenshire Health and Social Care Partnership's Dementia Strategy 2020 - 2030 outlines our approach to the requirements of Scotland's National Dementia Strategy in a local context.

Development of the strategy has been informed by research, learning from prior projects and engagement with people living with dementia, their families and carers, our wider communities, third sector partners and the health and social care workforce.

Dementia can happen to anyone therefore getting it right for people living with dementia will benefit everyone.

We have identified six key priorities for dementia care and support in Aberdeenshire. These are accompanied by key outcomes which identify what we hope to achieve within each priority. Our strategy will be accompanied by an Action plan detailing how we are working towards these priorities and this will be reviewed every 3 years.

Our priorities and key outcomes

Being well informed

- People feel knowledgeable about dementia and are not afraid to talk to someone if they are concerned that they, or someone they care about, are experiencing the symptoms of dementia. (Locally identified).

Getting a diagnosis of dementia

- More people have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning. (Nationally identified)
- More people get earlier access to good quality, person-centred post-diagnostic support in a way that meets their needs and circumstances. (Nationally identified)
- People living with dementia receive a timely diagnosis and can access post-diagnostic support. (Locally identified)

Knowing who to turn to

- People living with dementia understand what support may be available to them and are able to link into support as and when it is required. (Locally identified)

Living well with dementia

- There are more dementia-friendly and dementia enabled communities, organisations, institutions and initiatives (Nationally identified)
- The use of technology is promoted with people living with dementia. (Locally identified)
- People living with dementia do not experience barriers to accessing their chosen communities and living a happy healthy life. (Locally identified)
- Developing health and social care support for people living with dementia

- People living with dementia are supported to maintain independence and where support or services are required this is appropriate, proportionate and person-centred. (Locally identified)

Caring for carers

- During the process of diagnosis and through all parts of the care journey, the critical input of carers is encouraged and facilitated, and carers own needs are recognised and addressed. (Nationally identified)

Achieving these priorities depends on everyone working together. This includes people living with dementia themselves, unpaid carers, health and social care staff, the independent and third sector and our partners in the wider NHS and Aberdeenshire Council.

Dementia and the COVID-19 pandemic

This strategy was engaged upon and developed prior to the COVID-19 Coronavirus pandemic we have experienced in 2020. When consulting on this final version it was important therefore that we acknowledge the significant impact the pandemic has had on people living with dementia in the community, in hospitals and in Care Homes as well as unpaid Carers, families and the health and social care workforce. This has been an extremely challenging time with changed or reduced services available, increased isolation as a result of social distancing restrictions and in some cases, loss of life as a result of COVID-19.

We cannot underestimate the impact the pandemic has had. As we begin the process of recovery we have the opportunity to reconsider how we support people with dementia and carers. Many aspects of this strategy have been progressed during the pandemic, including increased use of digital methods of support. We believe that the priorities within this strategy are still the right ones for the people of Aberdeenshire and will continue to progress them over the next ten years.

Throughout the strategy we have included **'spotlight on....'** sections which are there to highlight additional resources and information linked to the topic.

2. What is dementia?

"Dementia is an umbrella term for over 100 different types of diseases and symptoms, and it's possible to have more than one type. What all these diseases have in common is that they damage brain cells, so that the brain cannot work as well as it should.

Dementia can affect every area of human thinking, feeling and behaviour, but each person with dementia is different - how the illness affects someone depends on which area of their brain is damaged."

Alzheimer Scotland[iv]

Dementia is not just memory loss, although this may be a symptom, and it is not an expected part of ageing. The most common types of dementia are Alzheimer's disease and vascular dementia though there are many other rarer types.[v]

Spotlight on most common conditions causing dementia

Alzheimer's disease

An illness of the brain which causes dementia. Alzheimer's disease gradually destroys brain cells and their connections. Symptoms are gradual and affect a person's ability to carry out everyday tasks. Everyone is different and it is not possible to predict which symptoms will develop. Very often a person's short-term memory is affected.[vi]

Vascular dementia

Caused by problems in the supply of blood to the brain cells due to conditions, for example, high blood pressure, irregular heart rhythms, damage to brain arteries from disease. People with vascular dementia often have a series of small strokes. These can interrupt the supply of blood to the brain and cause dementia. If strokes are the cause symptoms can get worse suddenly. Like Alzheimer's disease Vascular dementia affects the memory and the person's ability to recognise people and things.[vii]

Dementia can happen to anyone therefore getting it right for people living with dementia will benefit everyone.

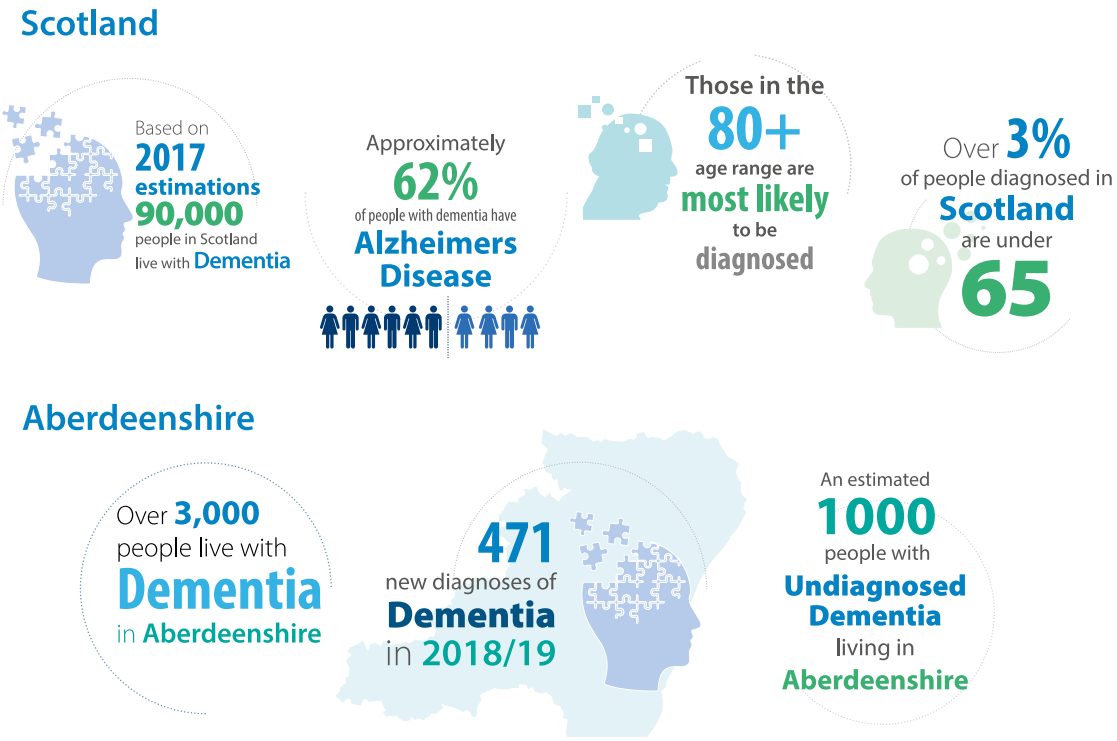
How common is dementia? Who is affected?

Scotland

- Based on 2017 estimations, there are 90,000 people in Scotland living with dementia.[viii]
- Dementia is more common in women than men with 67% of those diagnosed being women.[ix]
- The risk of developing dementia increases with age. Those in the 80+ age range are most likely to be diagnosed.[x]
- Over 3% of people diagnosed in Scotland are under the age of 65.[xi] A diagnosis under the age of 65 is often referred to as, 'early onset' or 'young onset' dementia.
- Dementia rates are higher for people with a learning disability.[xii]
- Approximately 62% of people with dementia have Alzheimer's Disease.[xiii]

Aberdeenshire

- There are over 3000 people living with dementia in Aberdeenshire.[xiv]
- During the period 2018/2019 there were 471 new diagnoses of Dementia in Aberdeenshire.[xv]
- The population of Aberdeenshire is projected to grow over the next 20 years. The largest increase will be in those of pensionable age with more than half of this group aged over 75. It is predicted that the number of people living with dementia will therefore increase.[xvi]
- There are estimated to be 1000 people living with dementia in Aberdeenshire who have not received a diagnosis.[xvii]



3. Introduction

Welcome to Aberdeenshire Health and Social Care Partnership's Dementia Strategy. This strategy sets out our dementia support priorities over the next ten years.

This strategy is for everyone affected by dementia. The Aberdeenshire HSCP believe that people should not be defined by their dementia diagnosis and we recognise that people living with dementia are individuals with a range of aspirations, personal goals and needs.

The vision for this dementia strategy shares Aberdeenshire Health and Social Care Partnership's wider vision

"Building on a person's abilities, we will deliver high quality person-centred care to enhance their independence and well-being in their own community."

We recently published our Strategic plan for the delivery of health and social care across Aberdeenshire.[i]

In addition to this separate strategies and action plans for mental health & wellbeing, learning disabilities, alcohol and drugs, autism, adult protection, unpaid carers, palliative and end life care and primary care improvement are currently in place or being updated. We recognise that there are many interlinking priorities and that people living with dementia may also be affected by these. We will work to ensure effective links with these strategies when implementing this dementia strategy.

This dementia strategy aims to focus in on key priorities where progress is required specifically for the purpose of improving the lives of people living with dementia in Aberdeenshire.

This is a ten-year strategy reflecting our long-term commitment to the improvement of health and social care services for people living with dementia and their families. The accompanying Action Plan is initially for 1 year and will then be reviewed and refreshed. This will allow us to identify initial key priorities whilst keeping a view on the longer term and changing priorities both locally and nationally.

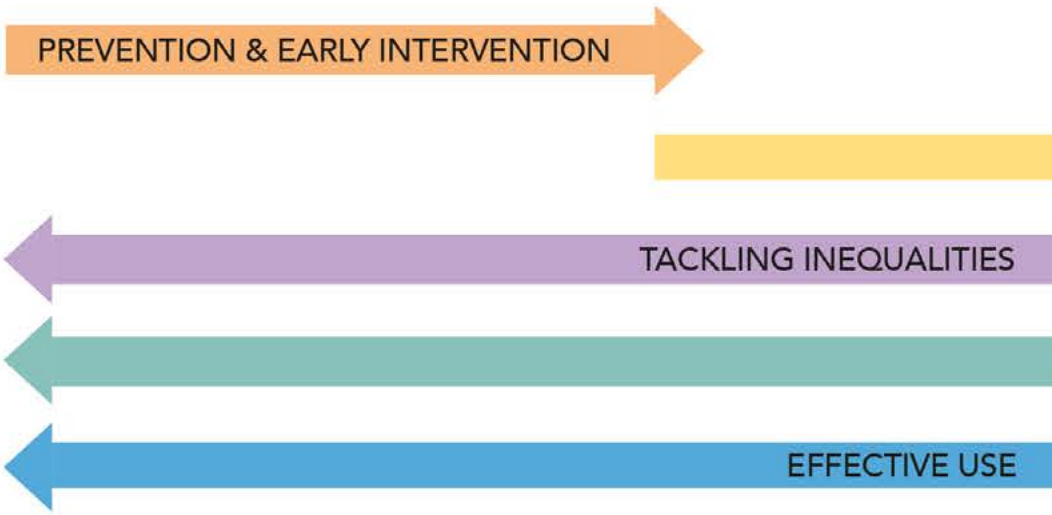
This strategy reflects our approach to the requirements of Scotland's National Dementia Strategy and has been informed by research, learning from the evaluation of the dementia friendly Aberdeenshire project, feedback from the Life Changes Trust, 'Community & Dementia': Creating better lives in Grampian Event and engagement with people living with dementia, their families and carers, our wider communities, third sector partners and the health and social care workforce.[ii]

Our priorities are:

- Being well informed
- Getting a diagnosis of dementia
- Knowing who to turn to
- Living well with dementia
- Developing health and social care support for people living with dementia
- Caring for Carers

Scottish Government have identified key outcomes within Scotland's National Dementia Strategy 2017 - 2020 and these have been included.[iii] In addition we have identified local outcomes through our engagement on this strategy.

4. Plan on a page

Aberdeenshire Dementia strategic priorities	Being well informed	Getting a diagnosis of dementia	Knowing who to turn to
Aberdeenshire HSCP Strategic priorities These priorities cut across all aspects of dementia support			
Expected outcomes for people living with dementia in Aberdeenshire	People are knowledgeable about dementia and are not afraid to talk to someone if they are concerned that they, or someone they care about, are experiencing the symptoms of dementia.	People living with dementia receive a timely diagnosis and can access post-diagnostic support.	People living with dementia understand what support may be available to them and are able to link into support as and when it is required.
Caring for Carers Expected outcomes for unpaid Carers	During the process of diagnosis and through all parts of the care journey, recognised and addressed.		

	Living well with dementia	Developing health and social care support for people living with dementia.
RESHAPING CARE & PUBLIC PROTECTION ENGAGEMENT OF RESOURCES	People living with dementia do not experience barriers to accessing their chosen communities and living a happy healthy life.	People living with dementia are supported to maintain independence and where support or services are required this is appropriate, proportionate and person-centred. The right support is available at the right time from dementia diagnosis to end of life.

the critical input of carers is encouraged and facilitated, and carers own needs are

5. The wider picture

National priorities

Scotland's national dementia strategy 2017 – 2020 is their third dementia strategy and determines the Scottish Government's key priorities for dementia support.[xviii] There is a focus on improving support following dementia diagnosis (post-diagnostic support) as well as ensuring high quality support is available at every stage including the provision of end of life care.

We have considered the recommendations of the National Strategy in the context of Aberdeenshire. Building on feedback and the experience of other Health and Social Care Partnerships since the launch of the national strategy in 2017 we believe the development of our pathway (Page 28), is a starting point to ensure provision of good quality, consistent support in line with the Scottish Government's expectations.[xix]

The Scottish Government has identified that they will commence engagement on their 4th dementia strategy in 2020. The priorities within this strategy outline our position on the delivery of dementia support in Aberdeenshire. We look forward to engaging with the Scottish Government on future developments nationally.

We also expect to be given further direction from the Scottish Government on their position with regard to Alzheimer Scotland's 'Fair Dementia Care' Campaign.[xx] This campaign outlines Alzheimer Scotland's position that people with advanced dementia experience inequality in being able to access healthcare support in Scotland. It raises a number of points with regard to charges for social care. It is expected that these recommendations will be considered nationally as part of the Scottish Government's Reform of Adult Social Care programme.[xxi]

Local priorities

Since 2016 health and social care services in Aberdeenshire have been provided by the Aberdeenshire Health & Social Care Partnership (Aberdeenshire HSCP). This Partnership brings together NHS and Council staff and offers new opportunities to develop and improve support for people living with dementia. We aim to ensure the best possible experience for people living with dementia and those who love and care for them.

The Aberdeenshire HSCP Strategic Plan outlines the Partnership's five strategic priorities. As indicated in our 'plan on a page' (page 10) dementia care and support cuts across all of these priorities. Below we describe each priority (as determined in the Partnerhip's 'strategic plan on a page' and its links to dementia care and support.[xxii]

Prevention and Early Intervention

- We will support people to live healthy lifestyles. We will support people to self-manage conditions. We will work to help people avoid preventable conditions.

This strategy highlights the importance of dementia post-diagnostic support as a key early intervention with the aim of ensuring better long-term outcomes for people living with dementia as well as potentially reducing the likelihood of crisis interventions at a later stage.

Spotlight on Public Health

Aberdeenshire HSCP Health Improvement Delivery Plan[xxiii]

This plan has a key focus on improving the health of everyone in Aberdeenshire and promoting healthy lifestyles. Many people who took part in the discussions on this strategy indicated that improving the health of older people and reducing the risk of dementia should be a priority. We are also aware of increasing evidence that healthier lifestyles contribute to a reduction in risk of developing dementia and therefore this strategy supports the actions within the Health Improvement Delivery Plan with a view to reducing the risk of dementia in the longer term.xxiv

Reshaping Care

- We will support people to remain in a homely environment. We will ensure people can access the right support when they need it. We will support people to live happy, healthy independent lives.

People living with dementia are likely to require additional health and social care support at some point. There is considerable work underway within this priority to develop our overall provision of social care support with projects looking at the future provision of care at home and the development of technology enabled care. These aim to have a positive impact for everyone who access these, including people living with dementia.

Priority 6d. (page 24) within this strategy 'developing health and social care support for people living with dementia' focuses specifically on areas where people living with dementia experience gaps in provision or barriers to accessing support. It is important to understand that beyond these priorities a range of developments are being progressed by the Partnership which will have additional benefits for people living with dementia.

Engagement

- We will be clear and transparent in our decision making. We will listen to and be responsive to what individuals and communities say. We will be open, honest and transparent when communicating with individuals and our communities and continue to engage with our staff.

This priority has been a central component in the development of this strategy. An overview of our engagement on this strategy is included in section 6, 'How has this strategy been developed?'. Where quotes are used within this strategy these are from this feedback.

"Include people with dementia – don't exclude us!"

We will explore options for people living with dementia and their carers to have a direct involvement in monitoring the Action Plan for this strategy.

Effective use of resources

- We will work to ensure we have the right amount of staff with the right skills. We will focus our resources where they are most needed. We will manage our budget against increasing need.

It is important that the delivery of this strategy is mindful of the challenges we face particularly in ensuring the most effective use of our limited financial resources. We expect to see a rise in the number of people living with Dementia as a result of predicted changes in life expectancy. This rise is likely to result in increased demand across health and social care services.[xxv]

This increased demand places significant financial pressure on the Aberdeenshire Health and Social care Partnership and as a result we must continuously review the delivery of services, including those aimed at people living with dementia, to ensure they are appropriate, desirable and affordable going forward.

Tackling inequalities & Public Protection

- We will work to make sure that everybody is able to access the service or treatment that they might need. We will work to remove barriers to accessing services.

This strategy aims to improve the experience of all people living with dementia in Aberdeenshire. It is important to recognise that the aims of this strategy are not specifically linked to an area of service delivery, for example, those who receive older people's services. They represent an approach which should be equally applicable to people in other circumstances, for example, people with learning disabilities who receive a dementia diagnosis and people in prison who receive a dementia diagnosis.

We will work to keep vulnerable people safe. We will work with partners to ensure that Aberdeenshire is a safe and happy place to live for everyone.

The safety of people living with dementia and the potential risks people face are often a key concern of people receiving a diagnosis and their families and this has been reflected in discussions when developing this strategy.

Being diagnosed with dementia does not, on its own, mean a person is at risk of harm or not able to make decisions about their own safety. Where risks to a person's safety have been identified those working within health and social care are expected to take a 'risk-enablement' approach to supporting people, including those living with dementia.[xxvi]

Spotlight on 'risk-enablement'

What is risk enablement?

"The supported person should be assisted to feel safe and secure in all aspects of life, to enjoy safety but not to be over-protected and, in so far as possible, to be free from exploitation and abuse."

Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013 xxvii

This strategy focuses on taking a preventative approach by increasing dementia awareness within communities, and enabling people living with dementia and carers to consider their future needs at an early stage. This will usually include consideration of measures under the Adults with Incapacity (Scotland) Act 2000, for example, power of attorney. This enables the person living with dementia to choose who they would wish to support them with decisions, including those involving their safety, in the future.[xxviii]

Where there are concerns that an adult is at risk of harm the Adult Support and Protection (Scotland) Act 2007 enables us to intervene to keep them safe.[xxix] The Aberdeenshire Adult Protection team can advise and investigate any alleged incidents of harm. This might include physical harm, psychological harm, financial harm and conduct causing self-harm.[xxx]

Spotlight on The Herbert protocol

The Herbert Protocol is a simple form which can be completed in advance by the person with dementia, family or professionals. Its purpose is to aid the police in finding someone if they go missing. It includes a photograph, descriptions of the person and information on favoured places and hobbies.

6. How has this strategy been developed?

Our understanding of the priorities for dementia care and support in Aberdeenshire have been informed by:

- Engagement and consultation with our communities, including people living with dementia and unpaid carers
- Knowledge and experience of staff working across health and social care including those from the independent and third sector.
- Analysis of national and local data and statistics.
- Priorities identified in Aberdeenshire Health and Social Care Partnership's strategic plan.

Over 470 people have engaged in the development of the strategy to date. Engagement events and targeted engagement sessions took place throughout Aberdeenshire in summer 2019. This was accompanied by a survey which was available online and in paper copy.

Spotlight on engagement

Dementia Storytelling sessions

In March 2019, the Life Changes Trust hosted a three-day collaborative dementia learning event for Grampian. They used the 'village storytelling' model for engagement sessions with very useful feedback. As a result, we were lucky enough to have a member of the team from the 'village storytelling centre' train staff in Aberdeenshire on their method of engagement.

'The Village Storytelling Centre' is an organisation based in Glasgow who, "believe that everyone has a story worth hearing, yet nobody's is written in stone. We help people to find, shape and share their voices, and to tell, reflect on and reframe their narratives." In Aberdeenshire we used this method to prompt discussion in our sessions both to discuss the theme of a dementia friendly community and to create characters whose experiences of dementia we could then discuss.[xxxi]

Our aim was to engage with people with dementia and carers in a way that was enjoyable and non-confrontational. The use of storytelling proved to be an informative and generally enjoyable experience for those who took part whilst also enabling very personal discussions to take place based on the experiences of the 'characters' that were created.

Case studies included within the strategy (pages 18 & 26) are based on these discussions. They are not real people but incorporate real experiences of living life with dementia in Aberdeenshire.

Engagement themes

Getting a diagnosis of dementia

- Stigma and fear of dementia. People are frightened of being labelled. They are frightened there is no support available.
- Anger at receiving the diagnosis. Many people spoke of the loss of future plans they felt following their diagnosis or that of a family member.

- Diagnosis taking too long – particularly for those with young onset dementia.
- People believe in the value of dementia post-diagnostic support and want it to be consistently available across Aberdeenshire.
- Living well with dementia
- People living with dementia want to be able to access dementia friendly community spaces where their specific access requirements, including dementia friendly signage, have been considered.
- People expressed difficulty in accessing community transport and feeling lost if they are required to give up their driving licence.
- People reflected on positive experience in rural communities with good neighbours who look out for one another.
- People don't know enough about Telecare / Technology and how it could be helpful to them.
- People can feel lonely and isolated. They want personalised support options – both 1:1 and in groups.
- Support beyond Post-diagnostic support. People want to know what support is available to them beyond their post-diagnostic support period.
- People want to be able to take risks and to live safely. There can be tensions in families and between professionals around how much risk is acceptable, e.g. for people with dementia living alone.

Care and support for people living with dementia

- People with a young onset diagnosis want support which recognises their individual needs.
- People are concerned about the risks to people living alone with a dementia diagnosis for example being targeted by scammers.
- People with multiple conditions can find it difficult to access support, for example, people with substance misuse issues, can feel excluded from mainstream support.
- People's experience of hospital discharge varied, both negative and positive experiences highlighted.
- People do not understand the routes to dementia support. It is not clear who is responsible for supporting at different points.
- Many people felt that support for people with dementia was only available in a crisis and that it was not responsive enough.
- People did not feel that dementia support options were consistent across Aberdeenshire.
- People wanted staff to take a person-centred approach to their support. People reported that self-directed support options are not always considered for people living with dementia.
- Specialist dementia care – Not enough specialist resource for people living in the community and in care homes.

- Charging Policy – A number of respondents felt the non-residential charging policy prevents people from accessing support.
- Care Homes – not enough homes for people with advanced dementia.
- People felt that care staff make a positive impact on people's lives and that they are often undervalued and underappreciated. They also felt there are not enough care staff to meet the demand.

Support for unpaid carers and families of people living with dementia

- Respite – A significant proportion of respondents highlighted that appropriate respite options for carers of people living with dementia were a priority.
- Carers Act / Carer Support plans - Of those who indicated knowledge of the Carers Act many were not aware of how it is being implemented locally.
- Carer support - emotional support to carers was a strong theme with many highlighting the personal impact and stress involved.

These initial engagement themes were based on the main themes identified within the national dementia strategy. For the purposes of this strategy we have considered all our feedback and developed our strategic priorities for dementia as below;

a. Being well informed
b. Getting a diagnosis of dementia
c. Knowing who to turn to
d. Living well with dementia
e. Developing health and social care support for people living with dementia
f. Caring for Carers

7. Strategic Priorities

7a. BEING WELL INFORMED

What people told us:

"The experience has been much improved since my grandfather had Alzheimer's 30 years ago. The problem is that we didn't know that. We were terrified that what we'd previously experienced was going to play out again."

Why is this a priority?

Many people experience symptoms as they age that are associated with dementia, for example, forgetfulness. Often there are other physical reasons for these symptoms and it is important to always check with your local surgery if you are worried for yourself or someone you care about.[xxxii] Where dementia is suspected the GP will advise you on the process for diagnosing and the support available.

Scotland's National Dementia Strategy 2017 – 2020 focuses on support from dementia diagnosis onwards. Discussions about the development of this strategy in Aberdeenshire showed that stigma and fear of dementia were very strong themes. People are scared that they will be labelled, treated negatively and that there is no benefit to seeking a diagnosis. The number of people being diagnosed with dementia in Aberdeenshire is below what would be expected. [xxxiii] We believe that stigma and fear is holding people back from seeking a diagnosis.

We need to take a strategic approach to raising awareness of dementia to ensure that everyone who could benefit from available support can do so.

The benefits of an earlier dementia diagnosis include;

- Access to medications and treatments (where appropriate)
- Advice and support on what to expect from your diagnosis
- Practical tips on how to live well with your diagnosis
- Time to plan for future support and decision making.[xxxiv]

What we will do

- Improve access to information on what dementia is ensuring it is visible and readily available online and in our local communities.
- Promote and encourage the positive benefits of an early diagnosis of dementia.
- People, including our young people, are encouraged to talk about dementia and understand the effects of dementia and how we can all contribute to supporting people living with dementia to live well in our communities.

Key Outcomes

- People feel knowledgeable about dementia and are not afraid to talk to someone if they are concerned that they, or someone they care about, are experiencing the symptoms of dementia. (Locally identified).

Spotlight on existing resources

Dementia Aberdeenshire Website - http://www.dementia-aberdeenshire.org/

This website is for anyone in Aberdeenshire who would like to access more information on support for people living with dementia. It is split into sections so that people can look at what is most relevant to their situation. The section on 'who might support you as your dementia progresses' has been welcomed in helping people to understand the roles of professionals involved in dementia support.

The website also directs people to other trusted sources like the Alzheimer Scotland website.

7b. GETTING A DIAGNOSIS OF DEMENTIA

What people told us:

"My experience of dementia diagnosis and support afterwards is that it can be very varied depending on where you live and when you access services."

"A member of my family has been diagnosed with mild dementia. The support he has received since his diagnosis has been great."

Why is this a priority?

We support the Scottish Government's view that an early diagnosis and good quality support after that diagnosis improves the quality of life for people living with dementia.[xxxv]

In Aberdeenshire a diagnosis will usually be made by a psychiatrist or a GP with additional specialist training (Dementia Scholarship).

Feedback from our communities indicates that where possible people would prefer to be diagnosed and receive their support in their own communities. Over recent years the Scottish government have been supporting pilot projects in other parts of Scotland on post-diagnostic support in primary care (local GPs and Health centres).[xxxvi]

We want to ensure that there are no unnecessary barriers to dementia diagnosis for people living with dementia and that where possible diagnosis can be made locally.

Scotland's national dementia strategy guarantees a minimum of 1 year of support once a dementia diagnosis has been made.[xxxvii]

This is referred to as post-diagnostic support (or PDS). We report progress on the delivery of this guarantee locally to the Scottish Government. In Aberdeenshire this is usually provided by a link worker or mental health Nurse. We want to make sure this support is offered in a consistent manner across Aberdeenshire and that any variation is based on the needs of the individual.

The benefits of this support are demonstrated through the 5 pillars model below;

Alzheimer Scotland 5 pillars of Post-diagnostic support[xxxviii]

- Supporting Community Connections (Accessing groups, keeping in touch with friends, meeting new people)
- Peer Support (Support from and with people who are also experiencing dementia)
- Planning for future care (Planning for what support you would like in future, including understanding self-directed support)
- Planning for future decision making (Consideration of who you would wish to support you, including, agreeing Powers of Attorney)
- Understanding the illness and managing symptoms (including the use of technology)

CASE STUDY – Maggie

Maggie (75) is widowed. She lives alone in her own home in Maud, Aberdeenshire. Maggie is a retired nurse. She has always been a self-reliant person with a large circle of friends. She has Son who lives in London and a daughter, Phoebe, who lives in Aberdeen with her 2 young children. Maggie was diagnosed with frontotemporal dementia 5 years ago.

Scenario 1 – Without post-diagnostic support

At the time of her diagnosis Maggie was not aware of any support on offer to help her understand her diagnosis. She felt embarrassed and scared about what her future may hold. She told Phoebe she had been diagnosed with dementia but didn't give her much details on how it would affect her. Phoebe hadn't noticed her mum having memory problems.

Over time Maggie's dementia began to affect her personality and she was known to say things to her grandchildren which Phoebe felt were inappropriate. Phoebe did not realise that this was related to her Mum's dementia and was increasingly reluctant to take her children to visit her Mum. Maggie's relationships with friends also changed and it was rare that anyone passed by or invited her out. Maggie felt lonely and depressed.

Phoebe had been keeping contact by phone and hadn't noticed any significant changes in her. Maggie always indicated that she was fine. Phoebe went out to visit her Mum and discovered that her home was very untidy with dirty dishes and out of date food in the fridge.

This was not like Maggie who had always kept a very neat home. Maggie herself appeared unkempt. On the table she noticed credit card bills which indicated large donations to various charities. Maggie appeared to be in a lot of debt, but she appeared to not be concerned at all.

Phoebe was upset and tried to contact the bank to stop her Mum from using her card. They refused to discuss anything with her as she did not have any legal powers in place. Maggie did not wish to speak to the bank as she did not recognise there was anything to be concerned about.

Phoebe contacted Maggie's GP who made a referral to the local Care Management Social Work Team. In order to support Maggie with her financial issues Financial Guardianship had to be pursued.

This involved an assessment of Maggie's capacity and a mental health officer visiting and completing reports for the court. After 3 months Phoebe was appointed financial Guardian for her Mum.

They both found the experience very stressful.

Scenario 2 – with Post-diagnostic Support

Maggie was offered post-diagnostic support at the time of her diagnosis. Janine, a Mental Health Nurse, met with Maggie and Phoebe. She began by discussing Maggie's specific diagnosis of frontotemporal dementia. She explained that it is an uncommon type of dementia and that it mostly affects the front and sides of the brain, symptoms can include changes in behaviour, personality and language. Phoebe and Maggie were surprised to hear changes in her memory may not be the main symptom.

Janine worked with Maggie and Phoebe early on in her diagnosis to consider her future decision making. Maggie discussed her wishes with her family and agreed for Phoebe to be her financial and welfare powers of attorney.

Janine supported Maggie to link in with local social groups for people living with dementia and connected Phoebe with the Carer support service who had a support group for carers of people living with dementia. As Maggie's dementia began to affect her personality her friends were able to make contact with Alzheimer Scotland's 'dementia friends' training to help them to understand how to support her with this. Maggie felt happy that she had friends who understood her and continued to enjoy a good social life.

Phoebe supported her mum with managing her money and noticed that credit card payments were being made to charities. As her power of attorney, she was able to contact the bank and blocked these payments. She also set up call blocking on Maggie's phone to prevent cold callers.

What we will do:

- Where possible a diagnosis is given locally by a psychiatrist or GP (with specialist training).
- There are no unnecessary delays to receiving a diagnosis of dementia.
- Everyone newly diagnosed with dementia is offered post-diagnostic support.
- Everyone newly diagnosed with dementia has access to post-diagnostic support which is appropriate and proportionate to their needs and circumstances.

Key Outcomes

- More people have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning. (Nationally identified)
- More people get earlier access to good quality, person-centred post-diagnostic support in a way that meets their needs and circumstances. (Nationally identified)
- People living with dementia receive a timely diagnosis and can access post-diagnostic support. (Locally identified)

Spotlight on practice

Home based memory rehabilitation programme (HBMR)[xxxix]

Aberdeenshire based Mental Health Occupational Therapists (or OTs) have been trialling this intervention. The Occupational Therapist teaches techniques, personalised to the individual, to compensate for everyday memory difficulties and supports the individual to continue with the activities that are important to them in their home and community. These can range from use of memory prompts and diaries to involving technology, such as the use of tablets and smart speakers, to provide reminders.

Spotlight on research

Aberdeenshire HSCP continue to support the Government position of offering everyone diagnosed with Dementia, the opportunity to take part in local, high quality Dementia research through the Neurodegenerative and Dementia Network for Scotland.

7c. KNOWING WHO TO TURN TO

What people told us:

"Information about services [was] difficult to find until we had a Care Manager and contact with Alzheimer Scotland - both were like passports to services."

"Can be difficult knowing who to speak to."

"Care Staff need to be trained to high standards."

Why is this a priority?

The support a person living with dementia may require is varied depending on their diagnosis, personal circumstances and how they are affected. The Aberdeenshire HSCP vision highlights the importance of a person-centred approach to care and support.

Spotlight on national policy

Connecting People, Connecting support[xl]

This provides a framework for integrating the work of Allied Health Professionals (AHPs) in dementia care. It details how AHPs can improve their support for people with dementia, their families and carers (people living with dementia) to enable them to have positive, fulfilling and independent lives for as long as possible.

In Aberdeenshire considerable progress has already been made in implementing changes to how health and social care is delivered by health and social care staff. This has included the introduction of a 'Core Team' approach to ensure anyone who requires support can access this in a co-ordinated way from the right people at the right time. This type of co-ordinated approach for people with dementia is echoed in the existing national dementia strategy.[xli] As a Partnership we have gone beyond the recommendations of the national dementia strategy to extend this approach to everyone who will benefit from it.

Despite this progress people told us that the routes to accessing health and social care support for people living with dementia in Aberdeenshire appear confusing. It was clear form our discussions that when to seek support and from who is not widely understood. We don't believe that people living with dementia should have to struggle to understand where the support they need will come from. Instead there should always be someone they can contact to connect them to what they need.

Spotlight on Practice

The Dementia Outreach Teams

There are Dementia Outreach Mental Health Nursing Teams for in North, Central and South Aberdeenshire. Each team is enhanced with integrated support from an Alzheimer Scotland Link Worker. The teams provide both post-diagnostic support and clinical support to people living with dementia across Aberdeenshire.

It was highlighted that many people who have received post-diagnostic support for a year then don't understand what other support could be available and how to link back into it. Identifying a lead worker in this circumstance whilst continuing to support people with dementia to remain independent for as long as possible will be a priority of this strategy going forward.

Discussions with people living with dementia highlighted both good and bad interactions with health and social care staff across a range of settings including hospitals, the community and care homes. Often this was down to how informed they found them to be on dementia as well as the type of care or support the person is looking to access.

There was also a strong view that health and social care staff should be more highly valued for what they do, particularly home carers and nurses who provide support in, often, very rural places.

Spotlight on training

Dementia Champions[xlii]

Dementia Champions are nurses, social workers and allied health professionals trained to an enhanced level to influence dementia care in their workplaces across Aberdeenshire. They meet twice a year to share good practice and plan continuous service developments for people with dementia across Grampian.

Examples of how the Champions have influenced practice include promoting the use of 'Getting to Know Me'. This document is used to ensure nurses have information on what is important to the person with dementia on admission to hospital and the development of a leaflet highlighting how Speech & Language Therapists can support people with dementia in eating and drinking and communicating.

People indicated to us that for those types of support where an 'eligibility criteria' is in place, for example, Social Work, they did not understand what this meant and how this is applied.[xliii] This led to people feeling upset and confused if they were not offered these services.

The dementia pathway on page 28 highlights examples of the support that may be available to people at different points dependent on their individual needs. It is not an exhaustive list and we do not expect everyone to follow the pathway exactly as it is described. It serves as an illustration to highlight the range of options available from the Health and Social Care Partnership and our partners in the independent and third sectors. It also demonstrates how the pathway links to the recommendations made by the Scottish Government and Alzheimer Scotland specifically the 5 pillars and 8 pillars models of support.[xliv]

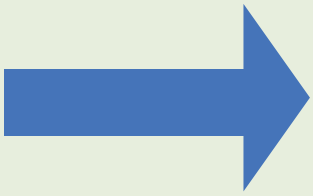
What we will do

- Implement the dementia pathway and work to ensure appropriate support is available to everyone diagnosed with dementia.
- People diagnosed with dementia who are receiving any type of support have an identified 'lead worker' who will support them to access any additional support from across the Health and Social Care Partnership.
- Those people who are living independently with dementia know how to link back into support if they need it.
- If relevant, the 'eligibility criteria' for accessing the support is readily available to everyone.
- All health and social care professionals, including those in the independent sector, receive appropriate training on dementia related to their specific role. We will also support those who seek to further develop their professional practice to benefit people living with dementia in Aberdeenshire.

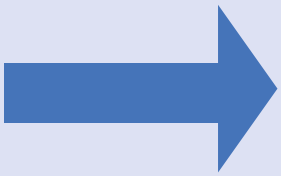
Key Outcome

- People living with dementia understand what support may be available to them and are able to link into support as and when it is required. (Locally identified)

Dementia Pathway

	Prevention & Early Intervention	
Lead practitioner	**Practitioner delivering post-diagnostic support**	**To be considered and developed as part of Action Plan**
Stages of support	Alzheimer Scotlands 5 pillars of dementia support 	
Support available (dependent on circumstances)	Diagnosis (Early to mid-stage dementia) • PDS lead worker (Outreach Nurse or Link worker) • Occupational Therapist - including 'Homebased memory rehab' • Groupwork • GP • Psychiatrist • Psychologist • Allied Health Professionals • 3rd sector group & Activities • Telecare service • Family & Friends	Self Management • Outreach Nurse/Psychiatrist (where there is a clinical need) • GP • Allied Health Professionals • Hobbies/community groups • 3rd Sector Groups & activities • Alzheimer Scotland Dementia Advisor • Accessible written resources • Community / GP link worker • Telecare service • Family & Friends
Eligibility for Care Management	Low	Low/moderate

[1] Diagnosed at this point (no previous PDS) - Lead practitioner must ensure appropriate actions from 5 pillars are covered. This may include the involvement of the dementia advisor and where appropriate access to groupwork sessions.

	Reshaping Care	
Lead practitioner	**Practitioner providing main support (MUST be identified as lead)**	**Practitioner providing main support (MUST be identified as lead)**
Stages of support	Alzheimer Scotlands 8 pillars of dementia support 	
Support available (dependent on circumstances)	Increase in need for support[1] • Outreach Nurse/(where there is a clinical need) • Care Management staff (eligible need) • GP/Psychiatrist • Allied Health Professionals • Community Nurses • 3rd Sector Groups & activities • Telecare service • Care providers (Care at home, day service, respite etc) • Family & Friends	Advancing Illness/End of Life • Outreach Nurse(where there is a clinical need) • Care Management staff • GP/Psychiatrist • Allied Health Professionals • Community Nurses • 3rd Sector Groups & activities • Telecare service • Care providers (Care at home, day service, respite etc) • Care Home/Specialist Housing Staff • Family & Friends • Palliative Care e.g. Macmillan/ Marie Curie
Eligibility for Care Management	Moderate/Substantial/Critical	Substantial/Critical

7d. LIVING WELL WITH DEMENTIA

What people told us:

"Peer support – it's your 'family of choice'"

"There is a lack of dementia signage in public buildings"

"Personal care (physical care) is obviously a huge necessity, but why isn't social interaction (mental care) seen as being just as important?"

Why is this a priority?

Living well means different things to different people. For us it is about removing barriers to a having a happy healthy life. This means ensuring that people living with dementia can participate in their local communities, access local amenities and feel safe.

On a practical level this involves considering whether our physical environment, including public spaces, are dementia friendly as well as ensuring there are options available for people living with dementia to continue to enjoy the things that are important to them and, if they wish, to make new relationships and develop new interests.

Spotlight on technology

In 2016 Scotland's, 'Technology Charter for People Living with Dementia' was launched.[xlv]

It sets out a commitment to incorporating technology into the pathway of support for people living with dementia. We support this charter and are committed to further promoting the use of technology in Aberdeenshire. Often, we are told that people would use technology if they were shown or that people are not interested or able to use it. We believe that ensuring information is available on how technology may be useful gives people living with dementia more opportunities to choose to use technology to enjoy life.

Some examples include;

Independence – There are a range of devices that can be used to maintain independence for people living with dementia including methods to remind people of appointments or medication.

Fun – Technology can enable access to our favourite music and contact with family and friends. Recently there has been increased use of virtual reality devices to enable people with dementia to participate in new experiences like scuba diving or travelling to different countries.

Safety – GPS devices can be a useful tool to support people living with dementia to get out and about and enjoy life whilst also providing them with reassurance that this could be used to find them if they lose their way.[xlvi]

Healthcare – There are a range of ways to interact with health professionals and monitor health from home. The use of 'Attend Anywhere' can enable people to have face to face appointments with health professionals from home.

People told us that public spaces in Aberdeenshire were not always dementia friendly or dementia aware and there were additional barriers including challenges using public transport, particularly in circumstances where people are advised they can no longer drive.

A lack of accessible toilets was also highlighted. We are aware that these issues have been raised by people during engagement on other strategies including the learning disability strategy and the mental health and wellbeing strategy.

This is an area where we as a Health and Social Care Partnership must be proactive in working with our partners in the wider NHS, Aberdeenshire Council, the Police, independent sector and third sector to link together existing good practice and encourage inclusive communities across Aberdeenshire.

Many people we spoke with highlighted the benefits of peer support and spoke highly of community groups available locally both aimed at people living with dementia and more generally. Tackling loneliness and isolation is a national priority. People living with dementia are at higher risk of being socially isolated or lonely than other social groups. We will work to support people with dementia to enjoy social activities.[xlvii]
It has been highlighted that this can be more challenging for people living with more advanced dementia who require support. This is further considered in priority 7e. 'Developing health and social care support for people living with dementia.'

What we will do:

- People living with dementia live in an Aberdeenshire that is inclusive and safe.
- People living with dementia are supported to stay a part of their chosen communities.
- We work with partners, including the independent and third sector to maintain and develop social opportunities for people living with dementia, including those with advanced dementia.
- There is increased use of technology to aid people living with dementia to live independently, have fun and maintain social connections.
- We work with partners, including Aberdeenshire Council and Live, Life Aberdeenshire to ensure the needs of people living with dementia are considered when designing public spaces and offering community activities.

Key Outcomes

- There are more dementia-friendly and dementia enabled communities, organisations, institutions and initiatives (Nationally identified)
- The use of technology is promoted with people living with dementia. (Locally identified)
- People living with dementia do not experience barriers to accessing their chosen communities and living a happy healthy life. (Locally identified)

7e. DEVELOPING HEALTH AND SOCIAL CARE SUPPORT FOR PEOPLE LIVING WITH DEMENTIA

What people told us:

"Self-direct support is good and works well but there is still a feeling with social work which means that care homes and traditional care at home services are used rather than more creative and flexible options which might suit needs better."

"There is not a uniform approach over the whole of Aberdeenshire. Some areas have fab resources and support whilst others don't."

"Need for better services for those who are young and have a diagnosis of dementia"

Why is this a priority?

As described in section 5. 'The wider picture' one of the Partnership's overall priorities is 'reshaping care'. For the purposes of the strategy and action plan we have identified areas where development is required to ensure people living with dementia are able to access a range of health and social care support which meet their needs.

People have told us that those with a young onset dementia diagnosis and those with moderate to advanced dementia experience particular challenges in accessing support that meets their needs. For the latter there may be a requirement for support with personal care or supervision in order to maintain their safety.

Charlie & Mary

Charlie (55) and Mary (53) live in Banchory, Aberdeenshire. Charlie is an architect and Mary is a housewife. They have two adult children and a young grandson who lives nearby.

Charlie had been having difficulty at work. His ability to react and respond to situations was noticeably slower and his colleagues had noticed a change in him. At first Mary thought he was feeling stressed, but she also began to notice changes and whilst driving back from the local shop Charlie missed the turn off for their street and didn't appear to realise. Mary became increasingly worried and took Charlie to see their local GP.

Due to his age the doctor considered and ruled out a range of other conditions before he was referred to Psychiatry and diagnosed with young onset Alzheimer's. The diagnosis was a shock. They didn't know it was possible to get dementia at 55. They worried about how they would tell their children. Charlie's first instinct was to deny the diagnosis. He didn't want to talk to Mary or anyone else about it.

Mary worried for the future. They were both dependent on Charlie's income to pay their bills. Mary already had responsibility for caring for other family members. She worried she wouldn't be able to cope with caring for him too. They were both angry and felt that his diagnosis changed everything they had planned for the future.

James, a dementia link worker, visited them at home. Charlie was reluctant to discuss things with him and Mary was visibly very stressed. James explained his role and talked about their money worries. James supported Charlie to discuss his diagnosis with his employers. They were able to make some adaptations to his role to enable him to continue to work. James also provided advice on powers of attorney and Charlie and Mary decided to include their children as their powers of attorney.

With some encouragement Charlie and Mary attended a local social group for people with young onset dementia. James also supported Mary to contact the local Carers support service.

As indicated in the Case Study people with a young onset diagnosis often have different support needs from those who are diagnosed at an older age. They are more likely to still be in active employment and have dependent family members. A young onset diagnosis is rarer and as such there are fewer people who are in similar circumstances.[xlviii] People with young onset dementia indicated that care and support is often targeted at older people and that they can face challenges as the wider public are not always aware of young onset dementia. We aim to learn from good practice in other areas and engage directly with people with a young onset diagnosis to develop a better understanding of their support needs. We aim to work on this together with our partners in Aberdeen City, Moray and NHS Grampian.

Developing a range of support

The introduction of self-directed support in 2015 brought new options for people eligible for social care services. This includes the ability to have more choice and control over the way support is provided including how care at home is delivered and a move away from 'service-led' to 'outcome-focused' models of support.[xlix] This means developing a package of support tailored to what is important to the individual. For people living with dementia this has enabled some people to remain at home in circumstances where they might otherwise have moved into residential care.[l]

Those who took park in the development of this strategy indicated that innovative approaches to care and support are not always considered for people living with dementia. This may be attributed to people being less able to participate in plans for their care and support as their dementia progresses. We believe that ensuring that people living with dementia and their carers know about self-directed support at an earlier point (during their post-diagnostic support) will enable people to be more informed when planning for their future care.

Spotlight on free personal care

'Frank's law'

In Scotland anyone who has an identified need for personal care is entitled to this free of charge. Personal care refers to support with tasks including personal hygiene, food preparation and medications. When it was introduced free personal care was available to everyone over 65. This was extended to everyone with an eligible need in April 2019 following campaigning by Amanda Kopel and her late husband Frank, a former footballer who was diagnosed with young onset dementia[lilii]

As people look for different options to what we have traditionally provided we have seen marked changes in who is accessing those services and when. We have seen decreases in the availability of specialist dementia units in Care Homes whilst also acknowledging that people who do choose to move into a care home are doing so at a more advanced stage of their dementia than had been the case in the past.

An example of these changes is decreased attendance at traditional day care services.[liii] There have been closures of dementia day services across Aberdeenshire in recent years due to low attendance. People indicated reasons for this including changing ideas about what should be offered, charges for attendance and the option to do things differently through self-directed support. We are supportive of people choosing alternative and more personalised options of support however this poses challenges for us in ensuring appropriate support options are available for people living with advanced dementia for whom day care services are often an essential source of support. Going forward we will be required to consider more different and innovative options to ensure a range of support is available to people living with dementia in Aberdeenshire.

Acute Hospital and specialist NHS Care

The national dementia strategy makes a specific commitment to improving support for people living with dementia in acute and specialist NHS Care. In Aberdeenshire there is ongoing work to improve the experience of people living with dementia in our community hospitals and our three specialist dementia units. This includes a phased implementation of 'experience based co-design' in specialist dementia units.[liv] This is an approach that enables service users / patients, family carers and staff to work together to design services. This work builds on a piece of work that already took place in Strathbeg ward (Royal Cornhill Hospital) with Healthcare Improvement Scotland (HIS)'s 'Focus on dementia' Team which had positive feedback.

In addition Rothieden ward in Huntly has been chosen in Partnership with Orthopaedic Trauma (Aberdeen Royal Infirmary) to work together on a quality improvement project designed by the HIS, Focus on Dementia team that will build on current practice to improve services for people living with dementia who have been admitted into general hospitals.

Housing and residential care

Ensuring there are appropriate housing and residential care options available to meet the future support needs of people living with dementia is being considered as part of a wider 'homely setting' project being taken forward by the Aberdeenshire Health and Social Care Partnership and Aberdeenshire Council. We aim to contribute to this work highlighting the perspective of those who have taken part in the development of this strategy. We also aim to work with Care Homes, both those operated by Aberdeenshire Council and independent care providers to ensure support for people living with dementia, who represent a significant proportion of residents, are met. This includes a focus on dementia friendly environments and community connections for those living in residential care.

Spotlight on palliative care and end of life care

We believe in high quality palliative and end of life care for people living with dementia who live in the community and residential care. Our dementia pathway highlights what support should be expected at this point. We believe the vision outlined in the draft Grampian framework reflects the expectations of the National Dementia Strategy and specifically seeks to ensure that "Palliative and end of life care is supported as a whole system, rather than a collection of individual services or teams". We believe in this approach and will work to ensure the specific needs of people living with Dementia are always a central consideration of this approach.

Aims

We will work to ensure that;

- People living with dementia are supported to be as independent as possible. Where there is the opportunity to improve or maintain independence, we will always consider this before introducing any type of care service.
- Innovative approaches to supporting people living with dementia are considered including through self-directed support.
- We are responsive to the changing demands of our local population whilst also considering the best use of our limited resources.
- Appropriate health, social care and housing options are available to people living with dementia and unpaid carers.
- We learn from good practice in dementia support nationally and in other Partnership areas and actively seek to incorporate this within the range of health and social care support we provide.
- The experience of people with a 'young onset' dementia diagnosis is actively considered when developing dementia services and health and social care services more widely.
- High quality palliative care and end of life care is available to people living with advanced dementia in residential care settings and our local communities.

Outcome

- People living with dementia are supported to maintain independence and where support or services are required this is appropriate, proportionate and person-centred. (Locally identified)

7f. CARING FOR CARERS

What people told us:

"We need more effective coping strategies such as carer support and respite."

"I'd like to have someone to understand what I'm going through, I'm not a trained nor natural carer & I do sometimes get feelings of resentment… then deep guilt for feeling this way."

Why is this a priority?

A carer is a person who provides, or intends to provide, care for another person who is unable to live independently without assistance. Unpaid Carers provided detailed and moving accounts of their experiences of caring for a loved one who is living with dementia when discussing the development of this strategy.

Unpaid carers are husbands, wives, sons, daughters, neighbours and friends. Often an unpaid carer is a spouse who is older and may have their own health and social care needs.

There have been significant changes to the legislation regarding carers support following the introduction of the Carers (Scotland) Act 2021.[lv] This introduced new rights for carers, including young carers.

Spotlight on practice

Adult Carer Support Plans

These were introduced by the new legislation and our local carers support service supports carers to use them to identify their personal support needs as an unpaid carer. The legislation also enables those with eligible needs to access a budget for support in their own right through self-directed support.[lvi]

Unpaid carers are vital to the sustainability of health and social care services, and the health of carers is as important as the health of those they provide care for. A lack of appropriate short breaks and respite options to enable unpaid carers to take a break was a very strong theme from the engagement on this strategy.

What we will do

- Carers support services will continue to be available, including emotional support to carers to enable them to continue to care.
- Provision of short breaks and respite services for people living with dementia and their carers both at home and in residential settings are available, desirable, appropriate and fit for the future.

Key Outcomes

- During the process of diagnosis and through all parts of the care journey, the critical input of carers is encouraged and facilitated, and carers own needs are recognised and addressed. (Nationally identified)

8. How will we know we have made a difference?

Our Delivery plan is reviewed regularly and is published as an accompaniment to this strategy.

9. Language and terminology

Allied health professional (AHPs) – A group of various health professionals who use their professional skills to improve health, diagnose, treat and rehabilitate people of all ages and conditions across all sectors and specialities. Professions considered to be AHPs include, for example, Occupational Therapists, Dietitians, Physiotherapists & Speech and language therapists.

Care Management – A social work department consisting of professional Care Managers and, in some teams, Enablement and Support Coordinators who carry out assessments and develop support plans with people with eligible care and support needs or those requiring a period of rehabilitation and enablement.

Carers support service – Provides support and advice to Adult and Young Carers in Aberdeenshire.

Dementia friendly – refers to anything which is inclusive of people living with dementia. For example a dementia friendly environment is one that has been adapted to take account of the impact it may have on the person, for example, lighting, colour contrast and the use of assistive technology.

Eligibility Criteria- a nationally agreed method for allocating social work resources to meet people's needs based on levels of risk. Eligibility criteria assist local authorities to demonstrate equity, consistency and transparency in how decisions about resource allocation are taken.

Integration Joint Board (IJB) - The Integration Joint Board (IJB) is a joint board of Aberdeenshire Council and NHS Grampian. It oversees the Aberdeenshire Health and Social Care Partnership. The IJB manage adult Social Care and Health services in Aberdeenshire.

Live Life Aberdeenshire - Aberdeenshire's sports and cultural services are operated by Live Life Aberdeenshire on behalf of the council. This is an innovative approach to delivering services including libraries, museums, arts developments, sport programmes and development, community sport hubs, leisure and sports facilities, support to clubs and grants.

Mental Health Officer (MHO) - A Mental Health Officer is sometimes known as an MHO. A Mental Health Officer is a Social Worker who has specialised training, education, experience and skills to work with people with a mental disorder. A mental disorder is legally defined as any mental illness, personality disorder, or learning disability and includes someone with dementia.

Promoting excellence framework – A skills and knowledge framework for health and social care professionals supporting people living with dementia.

Technology enabled care – The use of technology to support health and care needs. This includes telecare, telehealth and telemedicine.

10. References

[i] Aberdeenshire Health & Social Care Partnership, Strategic Plan 2020 – 2025, http://publications.aberdeenshire.gov.uk/dataset/92dd401b-c939-4b2d-a804-e556a8fa9b69/resource/e7a18b76-77b8-40ca-87c1-36916c7300f5/download/ahscp-strategic-plan-2020---2025.pdf (Accessed 04/02/2020)

[ii] Life Changes Trust, Human Rights, Community and Dementia: By local people for local people in Grampian, (2019)

[iii] Scottish Government, National Dementia Strategy: 2017 – 2020, https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/ (Accessed 04/02/2020)

[iv] Alzheimer Scotland, About dementia, https://www.alzscot.org/what-is-dementia/about-dementia (accessed 04/02/2020)

[v] Alzheimer Scotland, Rarer forms of dementia, https://www.alzscot.org/what-is-dementia/rarer-forms-of-dementia (Accessed 04/02/2020)

[vi] Alzheimer Scotland, What is Alzheimer's disease?, https://www.alzscot.org/what-is-dementia/what-is-alzheimers-disease (Accessed 07/02/2020)

[vii] Alzheimer's Scotland, Vascular dementia, https://www.alzscot.org/what-is-dementia/vascular-dementia (Accessed 07/02/2020)

[viii] Alzheimer Scotland, Statistics: Understanding the prevalence of dementia in Scotland, https://www.alzscot.org/our-work/campaigning-for-change/scotlands-national-dementia-strategy/statistics (Accessed 04/02/2020)

[ix] NHS Health Scotland, Dementia: Dementia and health inequalities, - http://www.healthscotland.scot/health-topics/dementia (Accessed 01/10/19)

[x] NHS Health Scotland, Dementia: Dementia and health inequalities, - http://www.healthscotland.scot/health-topics/dementia (Accessed 01/10/19)

[xi] Alzheimer Scotland, Statistics: Understanding the prevalence of dementia in Scotland, https://www.alzscot.org/our-work/campaigning-for-change/scotlands-national-dementia-strategy/statistics (Accessed 04/02/2020)

[xii] NHS Health Scotland, Dementia: Dementia and health inequalities, - http://www.healthscotland.scot/health-topics/dementia (Accessed 01/10/19)

[xiii] Alzheimer Scotland, What is Alzheimer's disease?, https://www.alzscot.org/what-is-dementia/what-is-alzheimers-disease (Accessed 07/02/2020)

[xiv] Base on World Health Organisation, Dementia, https://www.who.int/news-room/fact-sheets/detail/dementia##targetText=Rates%20of%20dementia,is%20between%205%2D8%25 (Accessed 04/02/2020) .

[xv] NHS Grampian Health Intelligence

[xvi] Aberdeenshire Health & Social Care Partnership, Strategic Plan 2020 – 2025, http://publications.aberdeenshire.gov.uk/dataset/92dd401b-c939-4b2d-a804-e556a8fa9b69/resource/e7a18b76-77b8-40ca-87c1-36916c7300f5/download/ahscp-strategic-plan-2020---2025.pdf (Accessed 04/02/2020)

[xvii] NHS Grampian Health Intelligence Performance Matters November 2019 using local and national source data

[xviii] Scottish Government, National Dementia Strategy: 2017 – 2020, https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/ (Accessed 04/02/2020)

[xix] Based on interactions with the Focus on Dementia PDS Forum

[xx] Alzheimer Scotland, Delivering Fair dementia Care for People with Advanced Dementia, https://www.alzscot.org/sites/default/files/2019-07/McLeish_Report_updated_24.01.19_Web.pdf (Accessed 04/02/2020)

[xxi] Scottish Government, Policy - Social Care; Reforming adult social care support, https://www.gov.scot/policies/social-care/reforming-adult-social-care/ (Accessed 04/02/2020)

[xxii] Aberdeenshire HSCP, Plan on a page – Strategic Plan 2020-2025, http://publications.aberdeenshire.gov.uk/dataset/92dd401b-c939-4b2d-a804-e556a8fa9b69/resource/d260c468-c554-48f4-a51e-700c3a2c4929/download/plan-on-a-page---ahscp-strategic-plan-2020-2025.pdf (Accessed 04/02/2020)

[xxiii] Aberdeenshire HSCP, Public health improvement plan 2019-2020, http://aberdeenshirecommunitysafety.org.uk/download/health/delivery_plan_2019_20.pdf

[xxiv] NHS, Nine Lifestyle changes may reduce risk of dementia, (2017) https://www.nhs.uk/news/neurology/nine-lifestyle-changes-may-reduce-risk-of-dementia/ (Accessed 04/02/2020)

[xxv] Aberdeenshire Health & Social Care Partnership, Strategic Plan 2020 – 2025, http://publications.aberdeenshire.gov.uk/dataset/92dd401b-c939-4b2d-a804-e556a8fa9b69/resource/e7a18b76-77b8-40ca-87c1-36916c7300f5/download/ahscp-strategic-plan-2020---2025.pdf (Accessed 04/02/2020)

[xxvi] Kennedy, L., (2016) Risk enablement in dementia care (DSDC) https://dementia.stir.ac.uk/blogs/dementia-centred/2016-10-09/risk-enablement-dementia-care (Accessed 04/02/2020)

[xxvii] Scottish Government, Social Care (Self-directed Support) (Scotland) Act 2013 : Statutory guidance, https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013/ (Accessed 04/02/2020)

[xxviii] Adults with incapacity (Scotland) Act 2000 https://www.legislation.gov.uk/asp/2000/4/contents (Accessed 04/02/2020)

[xxix] Adult Support and Protection (Scotland) Act 2007 http://www.legislation.gov.uk/asp/2007/10/contents

[xxx] https://aberdeenshire.gov.uk/social-care-and-health/community-care/protection-and-support/adult-protection-and-support/ [accessed 26/11/2019]

[xxxi] The Village Storytelling Centre, http://www.villagestorytelling.org.uk/ (Accessed 04/02/2020)

[xxxii] NHS Health Scotland, Worried about your memory (2018), https://www.alzscot.org/sites/default/files/documents/0003/2783/Worried_about_6019.pdf (Accessed 04/02/2020)

[xxxiii] NHS Grampian Health Intelligence Performance Matters November 2019 using local and national source data

[xxxiv] NHS, Benefits of early dementia diagnosis: Dementia Guide, (2017) https://www.nhs.uk/conditions/dementia/early-diagnosis-benefits/ (Accessed 04/02/2020)

[xxxv] Scottish Government, National Dementia Strategy: 2017 – 2020, https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/ (Accessed 04/02/2020)

[xxxv] Alzheimer Scotland, About dementia, https://www.alzscot.org/what-is-dementia/about-dementia (accessed 04/02/2020)

[xxxvi] Healthcare Improvement Scotland, Dementia Post-diagnostic Support in Primary Care – update, (2018) https://ihub.scot/media/1421/20180419-pds-in-primary-care-april-flash-report-v1.pdf (Accessed 04/02/2020)

[xxxvii] ISD Scotland, Dementia Post-diagnostic Support, https://www.isdscotland.org/Health-Topics/Mental-Health/Dementia-Post-diagnostic-Support/ (Accessed 04/02/2020)

[xxxviii] Alzheimer Scotland, 5 Pillar Model of Post-diagnostic support, https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support (Accessed 04/02/2020)

[xxxix] NHS Scotland & Alzheimer Scotland, The Home Based Memory Rehabilitation Programme in dementia – an update on the Occupational Therapy Improvement Journey in Scotland, https://www.alzscot.org/sites/default/files/2019-12/HBMR%20RCOT%20poster_June%202019_FINAL.pdf (Accessed 04/02/2020)

[xl] Alzheimer Scotland & Scottish Government, Connecting people, Connecting Support: transforming the allied health professionals' contribution to supporting people living with dementia in Scotland, 2017 -2020, https://www.alzscot.org/sites/default/files/images/0002/9408/AHP_Report_2017_Web.pdf (Accessed 04/02/2020)

[xli] World Health Organisation, Continuity and coordination of care, (2018), https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?ua=1 (Accessed -04/02/2020)

[xlii] Alzheimer Scotland, Dementia Champions Programme Recognised in UK's breakthrough List, (2018) https://www.alzscot.org/news/dementia-champions-programme-recognised-in-uks-best-breakthrough-list (Accessed 04/02/2020)

[xliii] Aberdeenshire Council, Eligibility for care services, https://www.aberdeenshire.gov.uk/social-care-and-health/community-care/living-independently/eligibility/ (Accessed 04/02/2020)

[xliv] Alzheimer Scotland, 5 Pillar Model of Post-diagnostic support, https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support & Alzheimer Scotland, 8 Pillar model of Support, https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/8-pillars-model-of-community-support (both Accessed 04/02/2020)

[xlv] NHS Scotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue, Tunstall & Tynetec, Technology Charter for people living with dementia in Scotland, (2015) https://www.alzscot.org/sites/default/files/images/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf (Accessed 04/02/2020)

[xlvi] National Lottery community fund, William Grant Foundation & Life Changes Trust, Dementia and Technology: a literature review and qualitative study, (2019) https://www.lifechangestrust.org.uk/sites/default/files/publications/LCT_Qualitative_Study_report_WEB.pdf (Accessed 04/02/2020)

[xlvii] Scottish Government, A Connected Scotland: Our Strategy for tackling social isolation and loneliness and building stronger social connections, (2018) https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/ (Accessed 26/11/2019)

[xlviii] SCIE, Young onset dementia, (2015) https://www.scie.org.uk/dementia/symptoms/young-onset/ (Accessed 04/02/2020)

[xlix] Miller, E., Cook, A., Samet, W. (2009) Philosophy and Principles Underpinning a Personal Outcomes Approach. Joint Improvement Team. https://content.iriss.org.uk/careandsupport/assets/docs/3_service_led.pdf (Accessed 04/02/2020)

[l]Scottish Government, Self-directed support, https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support (Accessed 04/02/2020)

[li] Scottish Government, Frank's Law, (2017) https://news.gov.scot/news/franks-law (Accessed 04/02/2020)

[lii] Scottish Government, Free Personal and Nursing Care, https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care/Free-Personal-Nursing-Care (Accessed 04/02/2020)

[liii] Information provided via the Carefirst Care Management system

[liv] The Point of Care Foundation, Experience-based Co-design toolkit, https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/ (Accessed 04/02/2020)

[lv] Carers (Scotland) Act 2016, https://www.legislation.gov.uk/asp/2016/9/contents/enacted (Accessed 04/02/2020)

[lvi] Aberdeenshire Council, Support for Carers, https://www.aberdeenshire.gov.uk/social-care-and-health/community-care/caring-for-others/support-for-carers/ (Accessed 04/02/2020)

Aberdeenshire
Health & Social Care
Partnership

Aberdeenshire
COUNCIL

NHS
Grampian

Produced by Aberdeenshire Council GDT25300