

Alzheimer Scotland's Public Engagement Response

About Alzheimer Scotland

Alzheimer Scotland is Scotland's national dementia charity, and our aim is to make sure nobody faces dementia alone. We do this through providing support and information to people with dementia, their carers and families, campaigning for their rights and funding vital dementia research infrastructure.

We have over 9,000 members, over 90,000 Dementia Friends and we are supported by over 1,000 volunteers. We employ around 400 full and part-time staff, mainly in our service-provision projects across Scotland.

We have Brain Health and Dementia Resource Centres in 24 different locations across Scotland. Those centres provide a safe and friendly environment for people with dementia and their carers to access support and take part in a wide variety of activity groups.

Based within the Dementia Resource Centres are a network of Dementia Advisors, funded by Alzheimer Scotland. Dementia Advisors work with people with dementia and carers. They provide tailored support, information, and advice as well as signposting to other organisations and agencies and work in local areas across Scotland to raise awareness of dementia and help communities understand how to become more dementia friendly.

We employ a group of Dementia Link Workers across Scotland who are commissioned to provide at least one year of post diagnostic support for those people who have newly received a diagnosis of dementia.

We provide a Freephone Dementia Helpline, which is available 24 hours a day 7 days a week providing information and emotional support to people with dementia, carers, families, friends, and professionals.

About the Scottish Dementia Working Group (SDWG)

The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. The group was set up in 2001 and has gone from strength to strength since it was established.

SDWG is funded by Alzheimer Scotland and the Scottish Government, and are the independent voice of people with dementia within Alzheimer Scotland. SDWG is an inclusive group, led by, and for, people with dementia. The group has a wide membership and dedicated members of staff who support the group's activities.

The remit of the Scottish Dementia Working Group is to:

- Campaign and raise awareness at a national and local level.
- Engage with, and inform, Scotland's National Dementia Strategies.
- Promote, and raise awareness among health, social care and related professions, as well as the wider public.
- Work with all stakeholders at a national and local level, including national and local government, private and voluntary providers of health, social care and housing, and other relevant bodies.
- Work with other representative groups, in particular our sister group, the National Dementia Carers Action Network (NDCAN).
- Work alongside Alzheimer Scotland to ensure coordinated and effective campaigning activities.

About the National Dementia Carers Action Network (NDCAN)

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group for carers of people with dementia. NDCAN was formed in 2011 and exists to make the voices of carers heard and raise awareness of the issues impacting on carers. NDCAN has a committee and a wide general membership that works to promote and support the rights of carers of people with dementia. Each year the group decides on the priorities that NDCAN will work on for the coming year.

Since NDCAN was formed, they have:

- Influenced Government and Parliament - NDCAN members have met regularly with the Minister for Mental Health, fed into government consultations and spoke to MSPs at Parliamentary events and Cross Party Groups. Members also sat on the national boards for both the latest National Dementia Strategy and the Carers Act to ensure carers voices were heard.
- Helped to improve the quality of care - NDCAN worked with Focus on Dementia to improve the quality of post diagnostic support and specialist dementia units to ensure that professionals know what support carers need. NDCAN also participated in the Fair Dementia Care commission to support carers as the person they care for enters the advanced stages of dementia and end of life.
- Helped to train workforces - Each year, NDCAN members help to train health and social care professionals. This includes providing their own personal views and experiences of caring for someone with dementia to the Dementia Champions programme. Members have also contributed to the Dementia Ambassadors programme.
- Raised awareness at a local national and international level - NDCAN members have attended and spoken at a wide range of conferences in Scotland, the UK and abroad such as Alzheimer Europe and Alzheimer Disease International. NDCAN participate at the Alzheimer Scotland Annual Conference and use this opportunity to talk about the work of the group.
- Helped other carers – Members have helped to develop new resources for carers on a range of subjects, including early onset dementia, continence and speech therapy. In 2016, members of NDCAN developed a series of eight booklets, 'For Carers, By Carers',

explaining what has helped carers of people with dementia to get through the day and cope with difficult times.

Responding to this call for evidence

Alzheimer Scotland welcomes the opportunity to respond to the National Conversation on a new National Dementia Strategy. We acknowledge the importance of placing the voice of lived experience at the heart of future policy and, in line with our own values, we have been keen to enable people with dementia and their carers to get involved in the conversation.

Alzheimer Scotland has facilitated a programme of public engagement to gather the views and opinions of people with dementia, their families and carers across Scotland. We have hosted a number of national engagement sessions throughout the country, both online and in person, to encourage a broad discussion of individuals' experiences of dementia and their views and opinions on the future dementia policy in Scotland. We have also supported engagement across all of our localities through existing activities and groups facilitated by our frontline staff. We have consulted directly with members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) to understand their views regarding the development of the next National Dementia Strategy. We have supported 127 people with dementia and 171 carers and former carers to have their say across 30 facilitated sessions.

We have adopted an inclusive approach to gathering the views of the public and facilitated the opportunity to provide feedback about the next National Dementia Strategy through an online webform. This was made available on the Alzheimer Scotland website. A further 45 people provided their views using the online facility.

In an effort to provide a comprehensive understanding of the experience of dementia and the current landscape of dementia services, Alzheimer Scotland has also sought input from members of our frontline staff from across Scotland who work directly with people with dementia and their carers, including Dementia Advisors, Post Diagnostic Support Link Workers, and Community Activity Organisers. They offer a unique insight into the challenges of delivering services for people with dementia and their carers. We also facilitated feedback from our 24 hour Freephone Dementia Helpline volunteers who are able to share their experiences of supporting people with dementia and carers, particularly at times of significant crisis.

We have provided a response based on the questions posed in the Scottish Government's discussion paper. Our response seeks to comment on the key issues and themes that have emerged from our public engagement sessions and to highlight those responses that can guide and direct the Government's response as it seeks to develop the next National Dementia Strategy.

1. What does dementia mean to you and those around you?

"Dementia is all encompassing – it affects absolutely every aspect of my life".

Person living with dementia

"My life [as a carer] has been completely turned upside down – it just takes over you".

Carer

The responses received in respect of this question were wide and varied which reflects the unique experience of dementia for everyone who receives a diagnosis or who cares for someone with dementia. The views expressed were also reflective of the diverse socio-economic and cultural backgrounds of the individuals who participated in our process of engagement.

The general consensus among participants, both people with dementia and their carers, was that dementia affects every part of their lives and that no aspect of their, or their families', lives goes untouched by dementia. People were keen to share their own thoughts and feelings around how dementia has impacted them, taking the time to express the real challenges that dementia brings.

Dementia and identity

"For me dementia means that continuing change in relationship with my husband which is very difficult...I feel like I'm losing him"

Carer

Dementia has a significant impact on an individual's sense of identity and sense of self. Throughout our engagement process, people with dementia expressed the challenges of living with the changes caused by dementia. From being increasingly forgetful and less able to focus, to experiencing difficulty with communication and changes to temperament, it is clear that people with dementia must navigate difficult experiences around how they view themselves and how they perceive that they are viewed by others. Some expressed an ability to reach acceptance of the 'new person' they had become, while others expressed continued frustrations and an inability to reach acceptance, or maintaining a position of denial about the impact of their condition on themselves.

Carers also consistently provided the message that it is difficult to witness the changes in their loved ones as they move through their journey with dementia. Being a bystander with no control over these changes often results in feelings of loss and grief, not only in terms of what has changed from life before dementia but also in respect of the uncertainty of the future.

Carers themselves also identified changes in how they viewed themselves and reflected on how they have had to change in an effort to approach the challenge of caring for someone with dementia. Some of our participants felt that they had lost confidence due to constantly

questioning their actions and motivation throughout the caring process, while others shared that they felt pushed into becoming more assertive in order to manage the responsibility of caring. Overall, they felt that the changes to who they considered themselves to be led to a loss of identity, further impacted by the need to constantly place their loved ones front and centre at all times, sometimes to the detriment of their own emotional and physical wellbeing.

The social impact of dementia

"Meeting with others really helps, it makes me feel like I am not alone"

Person living with dementia

The social impact of dementia is immense for people with dementia and their carers, and links significantly to their emotional wellbeing. Most significantly, people with dementia and carers reported the substantial impact of dementia on their social relationships, both with each other and with their wider circle of family and friends. Close personal relationships change when there is a diagnosis of dementia – people often referred to no longer being 'husband and wife' or 'mother and daughter' but rather 'person with dementia and carer'.

People shared their experiences of feeling afraid to share their diagnosis with people they knew because they feared their reaction. Some people even said that they chose to avoid social situations to avoid having to deal with the challenge of having to address their condition with someone else.

Isolation and loneliness were a persistent feature of conversations with people with dementia and their carers. Many noted that this was magnified by the impact of the Covid-19 pandemic. Many people spoke about the impact of losing their job and the loss of social connection that came with the regular opportunity to engage with others. Others felt that they were less included and more likely to be left out of social gatherings that were once a typical part of their lives.

Financial challenges

"Money is always at the back of my mind... everything is much more expensive now and I can't care for my mum full-time and go out to work. I'm in a 'Catch-22' situation."

Carer

Much of our public engagement spent time reflecting on the financial impact of a diagnosis of dementia. Many people see loss of employment not only as a loss of social opportunities but also as a significant challenge to their financial situation. Loss of income alongside increased costs for care poses a significant challenge for people with dementia and their carers.

Carers in particular expressed frustration at the lack of value placed on the role that they play in providing support for people with dementia. Many highlighted the lack of financial support for carers and benefits being insufficient to cover the actual cost of caring. A significant number of carers pointed to the savings that carers make to public spending through the provision of informal care.

Participation in education, training and employment

"I used to enjoy going out to work... now I have nothing."

Person living with dementia

People with dementia and their carers highlighted significant inequalities that they experience as a result of being unable to fully participate in education, training and employment. People with dementia highlighted the challenge of stigma and discrimination as they attempt to access or remain in this sector. This was a particular issue for people with young onset dementia. People with dementia spoke of the challenge of coping with the symptoms of their condition at work both before and after their diagnosis, a lack of understanding of dementia by employers and the devastation of being unable to continue in the jobs that they had done for many years. Some of our participants spoke about the frustration of being unable to carry out tasks that they had previously done with ease, and the added frustration that their employers did not recognise their additional support needs. Many expressed feelings of worthlessness which was compounded by the lack of routine and focus in their day-to-day living following the end of their employment.

Carers shared their experiences of having to give up work or reduce their hours, and the need to abandon opportunities in training and education. They highlighted the impact on their career progression and the financial impact on their pensions; impacts that are felt far beyond the end of their caring journey.

Emotional and psychological wellbeing

"To me caring means feeling anxious all the time - and isolated."

Carer

Every participant emphasised the negative impact of dementia on their emotional and psychological wellbeing, either as a person living with dementia or as a carer. Both groups talked openly about the fear, anxiety and constant worry that comes with a dementia diagnosis. Their language was blunt and honest.

There is a significant amount of uncertainty around dementia and a fear of the unknown is a feature of life for the people with dementia and carers that we engaged. Everyone wants to live well with dementia but the challenges are sizeable to achieve that, and when that is not possible, this has an even greater emotional and psychological impact. People with

dementia do not want to be a “burden” while carers are anxious that they are “not doing enough”. Both groups spoke about their feelings of loss and grief, as well as guilt.

People with dementia and their carers spoke about the changing nature of their emotions and feelings – “good days and bad days” – and highlighted the need to make the most of the positive times.

The impact on time

“I had big plans for my retirement... now it feels like I’ll never get to do what I always wanted...”

Person living with dementia

Dementia has an inevitable impact on people’s time. People with dementia expressed the feeling that time is “stolen” from them because it takes longer to do things. Carers also feel that their time is redirected to providing support and managing their loved one’s care. Generally, our participants felt that they had less free time and that their time was focused on dealing with dementia. Many participants were also very aware of their, or their loved one’s, lifetime being shortened by dementia.

Participants spoke about having less time to participate in enjoyable activities. They also felt that they had fewer opportunities to achieve their goals and ambitions. This was often linked to feelings of loss – thinking about what they cannot do now or will not be able to do in the future.

2. What supports work well for you?

“You feel like the only person in the world but now you know you’re not”

Carer, discussing the benefits of going to a carer support group

“I find with the Dementia Resource Centre an acceptance, it’s like visiting a club. Friendships are developing with lovely staff and members.”

Person living with dementia

Again, the responses to this question are varied, reflecting the different needs of people with dementia and their carers, as well as their individual preferences. The process of engagement has highlighted excellent examples of local practice which has enabled people with dementia and their carers to benefit from the supports and services available to them in their communities.

It is clear that there is no one particular type of care or support that can meet all the needs of someone with dementia or a carer of someone with dementia. A multifaceted approach to care and support is needed to meet the specific needs of each individual.

Approaches to care and support

"People need to realise that we're all different... they need to listen to us..."

Person living with dementia

People with dementia and their carers agree that care and support is best received when it is person-centred and needs-led, and that a 'one size fits all' approach does not provide the standard of care that is required. Both people with dementia and their carers want the care and support available to them to reflect their individuality, and to be able to address their specific needs. They want a choice of services and the flexibility to be able to dip in and out of services as they need to, or as they wish.

Throughout our engagement with people with dementia and their carers, we heard that consistency in the availability and delivery of services was important. People with dementia identified the importance of routine and dependability in supporting them to maintain positive connections and good rapport with the support workers involved in their care. Carers, meanwhile, were keen to ensure reliability of services that in turn leads to reassurance.

Post-diagnostic support

"Post-diagnostic support has been really helpful, the link worker told me about Power of Attorney, Attendance Allowance and introduced me to Alzheimer Scotland."

Person living with dementia

In cases where post-diagnostic support is available and delivered using Alzheimer Scotland's 5 pillar model, the intrinsic value of post-diagnostic support was a key theme throughout our process of engagement. People with dementia and their carers report a positive experience of post-diagnostic support. Many people with dementia valued the relationship they established with their post-diagnostic support link worker and highlighted the importance of the role that they played in providing support. They also felt reassured by the role the link workers play in providing information, advice and guidance.

For those who had a positive experience of post-diagnostic support, people with dementia and their carers reported that they continue to feel the benefits beyond the immediate delivery of support. Individuals reported that they were able to reflect on the advice and support that they received during their 12 month period of post-diagnostic support and continue to feel reassured and guided by the knowledge and understanding of dementia and the availability of support structures that was delivered through their post-diagnostic support.

Self-directed Support

"The care service that was offered to me didn't fit in with my life... it's been great to have some choice."

Person living with dementia

A small number of participants identified the value and benefit of self-directed support. These individuals felt that they had been informed and supported to obtain a self-directed support budget and to exercise their right to choose how they receive their care. One participant with a self-directed support budget highlighted the flexibility and choice that is offered through this method of commissioning care, while another participant pointed out the ability to focus specifically on their individual needs that would not be available through statutory services available in their area. One participant who makes use of their self-directed support budget to employ a personal assistant noted that this enables them to receive consistent care and support, and also highlighted the positive relationship that they had built with their personal assistant which provides an opportunity for positive social interactions.

Statutory care and support services

"Day centre support works well for mum especially as they have their own transport in place – it also gives me a sense of security and much needed relief".

Carer

Many participants spoke about the endeavours of the social care workforce to provide support through the delivery of home care services. Many of our participants highlighted the carers delivering home care at an operational level as being assets to the service, and were appreciative of their caring and respectful approach to their work, even under the enormous pressures that they face.

The availability of, and access to, day services and respite is an invaluable tool for some carers in supporting them to carry on with their caring roles for much longer than they would otherwise manage. Respite offers an opportunity to "recharge the batteries" and ease the stress and exhaustion associated with caring.

Residential care

"I just felt so reassured that I knew that the staff were going to take good care of my mum."

Carer

A number of our participants expressed the wonderful care and support provided by residential and nursing care facilities looking after their loved ones. Carers highlighted excellent examples of individual practice within facilities across the country to meet the specific needs of people with dementia. Examples included carers in one care home singing through all personal care tasks to offer comfort and reassurance to one resident and the

carers in another care home enabling a resident to have a very early breakfast since they enjoyed the routine of an early start, having been a postman prior to retirement.

Local groups, activities and services

"I enjoy coming here [Dementia Resource Centre] every Thursday. I wouldn't miss it. I feel comfortable and not alone."

Person with dementia

Many of our participants highlighted the enormous benefits of local activities and groups that provide a social outlet, as well as a facility to support their needs and access useful information. Many people highlighted the wonderful community services provided by Alzheimer Scotland colleagues including dementia cafés, carer support groups, music and film-based activities, physical activities and drop-in sessions with Dementia Advisors and Post-Diagnostic Support Link Workers. They felt welcomed to Alzheimer Scotland's Dementia Resource Centres and at ease with the staff and other group participants. They found that the groups offered an opportunity for company but also a safe space to be relaxed and to seek advice or information.

Many participants highlighted opportunities offered by other third sector providers and the value that this brings to their lives. Local organisations and charities, churches and other national charities provide community-based groups and activities designed to improve the lives of people with dementia and their carers. Many people with dementia and their carers felt that these groups and activities offered further opportunities to participate in local activities and be involved in community life.

Many people highlighted the value of peer support and sharing experiences with someone who has a clear understanding of your own challenges. The ability to be in the same space as someone who has been through the same things or who has experience of overcoming a particular challenge offers a level of support that can only come from someone with a personal understanding so it is important that these opportunities for interaction are encouraged.

The pandemic has meant that services and supports have had to change and evolve to manage restrictions placed on communities. While some individuals have struggled to cope with the move to digital services, others have embraced it. Opportunities now exist online and in-person and for those who live rurally or remotely, this has opened up avenues to participate in groups and activities with no geographical boundaries. We have heard from people who participate in online groups and activities with members from all over the world, linked only by their experience of dementia or caring for someone with dementia.

Alzheimer Scotland 24-hour helpline

"The Alzheimer Scotland helpline was a total lifeline..."

At times of crisis, some people spoke about the invaluable support and assistance that they have received from Alzheimer Scotland's 24 hour Freephone Dementia Helpline. People spoke warmly about the reassurance of knowing that someone is on the other end of the telephone at any time of the day or night. People spoke about the excellent knowledge of the volunteers who provide the service but were most complimentary about their ability to listen, without judgement, and to provide a calm response, sometimes at times of crisis.

Family and friends

"Family are a great support to us."

Carer

Many of our participants value the support of friends and family. They feel that family and friends provide the most consistent and dedicated support. They feel more comfortable sharing their difficulties with someone they know and who they are familiar with. They also feel that family and friends are more able to be flexible in their approach to providing care and support, and that they have a greater understanding of their needs. Many people spoke about family and friends coming together as a collective group to provide care and support. Others spoke about their reliance on a partner or close relative to manage the everyday challenges of living with dementia or caring for someone with dementia and considered that they would otherwise be unable to cope without that support.

Access to information

"It's knowing about what support is out there and being directed to this at the point of diagnosis. Signposting is crucial."

Carer

People with dementia and their carers spoke about the importance of having access to information throughout the dementia journey. There is a belief among some individuals that "knowledge is power" so they find it beneficial to have access to information as they need it. There was agreement from participants who were less reliant on having access to information that it was reassuring to know that it is available to them if they decide that they want it.

Many participants found that their local Alzheimer Scotland Dementia Advisor provided an invaluable source of advice and information, in a similar way to the service provided by post-diagnostic support link workers. Most people feel that they can approach their Dementia Advisor to discuss all aspects of their life, from health and social care issues to finances and access to local activities. Dementia Advisors are key players in the delivery of local information and play a central role in providing a constant source of advice and support to people when they need it most.

Non-specific dementia supports

"My faith has been a huge source of comfort to me."

Person living with dementia

A number of our participants highlighted some of the non-specific dementia services that provided them with additional opportunities to receive support. Some individuals highlighted churches and other religious organisations that provided faith-based activities which were described as "comforting and enriching". Others highlighted access to sports and social activities provided out with dementia services. The importance of good transport links was highlighted since, for many, a lack of transport would act as a barrier to these opportunities. These opportunities all provided participants with opportunities to improve their lives and to participate in community life and activity.

3. What challenges need to be addressed?

"I feel as if we are waiting for a crisis to happen before any help will be offered".

Carer

"The challenges are like a snowball – they keep getting bigger and bigger as time goes by."

Carer

It is clear from our engagement with people with dementia and their carers that there are a significant number of challenges that need to be addressed to improve the care and support of the dementia community. These challenges are longstanding but many of the issues have been magnified by the Covid-19 pandemic. We heard harrowing stories of people who have experienced the most difficult circumstances and how they felt abandoned by the services designed to support them. It was difficult to hear their stories but much more difficult to live through them. The people we engaged feel that now is the time to drive forward the changes that are needed to address the inequalities that they experience across all aspects of their lives.

Understanding dementia

"We need a 100% improvement in educating all staff within the caring profession on every aspect of how to properly deal with those living with dementia."

Carer

Our participants highlighted the continued failure of the public to understand what dementia is and what it means for people living with the condition and their carers. People spoke about the negative connotations associated with dementia and how this impacted

how they are viewed and perceived by others. People spoke about how these negative views made them feel “worthless” and “useless”.

People highlighted the need to address pre-conceived ideas and assumptions about dementia. Ill-informed ideas such as dementia being a disease of only older people, that it only affects your memory and that people with dementia lack ability or capability to do things were regular issues raised during our discussions. Many people felt they were unable to address these beliefs because they feel that they exist across the whole of society and are reinforced by the media.

Many people spoke about the experience of dealing with health and social care professionals who lack a clear knowledge and understanding of dementia and the impact this has on their experience of services. A common example of this misinterpretation is the notion by medical professionals that “there’s nothing we can do for dementia”. People who experienced this approach from their medical professionals went on to explain that they received little or no input into their care which compounded their feelings of isolation.

Those involved in our discussions agreed that more needed to be done to raise the profile of dementia among the public, and that by doing so, more could be done to challenge the misinterpretation of what the disease is and tackle those negative attitudes.

Access to information

“So many carers don’t know how to obtain information.”

Carer

Access to information was a frequent issue raised in almost all of the conversations that we facilitated during our process of engagement. People felt that “you don’t know what you don’t know” and that there was a lack of information made available to them throughout their journey with dementia. From the point of raising concerns about the onset of dementia symptoms, through the process of assessment, obtaining a diagnosis and beyond, people felt that there were many missed opportunities to access information that would support them. Overall, they felt that they had to seek out information and take on the responsibility, and often challenge, of finding information that they needed. The lack of a proactive approach to providing information was a persistent feature of our discussions.

People felt that the process of receiving information was very inconsistent and dependent on the support and services that were available to them locally. Some people expressed that they had received no information about services and that they did not know where to go to find out about what support was available to them. A significant number of people with dementia and carers highlighted the need for a more consistent approach to the provision of information and suggested that there were key points where they needed to receive information, namely at the beginning of the assessment process, at the point of diagnosis, and at points of change within their condition after diagnosis. They noted that in the existing landscape of dementia pathways, these opportunities are the responsibility of a number of

key players but that there is no consistent approach to how that is delivered, if at all. People highlighted the need for improved signposting to sources of support, such as Alzheimer Scotland and other local supports and services.

Accessibility of information was another issue that was raised by people with dementia and their carers and some participants highlighted the need to improve accessibility to some types of information. Many people with dementia highlighted the challenges of reading, either in respect of the type or size of font or the challenge of focusing on the words caused by their dementia, and welcomed the opportunity to access large print versions of leaflets or audio and audio-visual formats rather than solely written word documents. Access to translated, non-English language documents would be similarly welcomed as an extension to inclusive approaches to information.

Diagnosis

“The amount of time to get a diagnosis was extremely distressing which causes a delay in getting the correct help and medication.”

Carer

Our public engagement sessions were attended by a number of people who had recently received a diagnosis or were near the beginning of the assessment stage. They highlighted their own challenging experiences and a significant number of these features were reflective of experiences across the whole country.

Many of the people we engaged raised concerns about the lack of knowledge and understanding of dementia by their GP. This included examples of individuals being advised by their GP that dementia was not a viable diagnosis because they were “too young”. They felt that this lack of knowledge and understanding delayed their diagnosis and made the path to diagnosis unnecessarily difficult.

Waiting times for obtaining a diagnosis is a consistent barrier to obtaining a diagnosis. We heard examples of people waiting for a year or more for scans to inform their diagnosis across a number of areas in Scotland, and we heard that, in some cases, individuals were choosing to remove themselves from NHS and seeking a diagnosis through private healthcare providers. This creates further implications for accessing follow-up support since care pathways are linked to the NHS model of care.

Healthcare services following a diagnosis

“People should have some sort of timely check-ups as this is so important – people get a regular check up with other health conditions so why not dementia?”

Carer

A significant number of individuals highlighted ongoing concerns at the lack of follow-up care by a medical professional following their diagnosis. With the exception of individuals who received follow-up care in the event that they were prescribed medication for the treatment of their dementia, the vast majority of individuals highlighted that contact with their diagnosing-consultant stopped almost immediately. Similarly, a significant proportion of participants indicated that they did not receive a follow-up contact with their GP regarding their dementia.

Our participants reported that annual check-ups or reviews were not routinely carried out by a medical professional after a diagnosis and many felt that this was a missed opportunity to address issues and concerns that inevitably come about with a progressive condition like dementia. Some participants gave examples of other health conditions that were reviewed more frequently such as diabetes and asthma but suggested that dementia was consistently overlooked and that more needs to be done to meet the ongoing health needs of people with dementia. It was felt that a clearly defined process for ongoing assessment would provide the most benefit for people with dementia and their carers, and that the onus of pursuing a review should not fall on people with dementia or their carers since they already carry a significant burden of responsibility in managing their condition or supporting someone with dementia to manage their condition.

Post-diagnostic support

"We had to ask for a [post-diagnostic support] Link Worker and eventually got one [from the Community Mental Health Team] but were left disappointed as we only got 2 visits from them in the whole year"

Carer

While post-diagnostic support provided using the Alzheimer Scotland 5 pillar model was welcomed, it was clear from our discussions that access to post-diagnostic support was not consistent across the country. Some individuals indicated that they had not received post-diagnostic support but indicated that a Community Psychiatric Nurse (CPN) or other mental health professional from their local Community Mental Health Team had been in contact with them. On further exploration of these examples, it was evident that some post-diagnostic support had been delivered but that it was not recognised as such.

People who received post-diagnostic support during the pandemic discussed the limited support that they felt at this time. They felt that they were unable to fully benefit from their post-diagnostic support since much of it was delivered later than would be expected, which resulted in their condition having progressed, and they felt that phone contact was less helpful than face-to-face interactions. They also felt that managing interruptions caused by the changing rules on contact during the pandemic also limited the benefits of the support that they received. This impact continues to be felt even now for those individuals.

Waiting times for post-diagnostic support are a continued hangover from the pandemic. Some of our participants were still waiting, in some cases for more than 10 months, for post-

diagnostic support. They feel concerned at the lack of support they have received and feel that they do not know where to turn for advice or support about their symptoms and conditions while waiting for contact from their local post-diagnostic support provider.

For those who had received their 12 months of post-diagnostic support, some felt that they did not benefit from a high-quality post-diagnostic support service. Some participants felt that the support did not meet their needs and indicated that they had received only 3 or 4 visits across the year. Some reported that they were never asked about what support they needed or what they thought about the support they received. Many spoke about the "postcode lottery" of post-diagnostic support with the quality of support sometimes being determined by what services are available in an individual area.

Some discussion was held regarding the timing of post-diagnostic support, with some individuals preferring it to be delivered almost immediately following their diagnosis and others highlighting their preference to receive a more flexible service that would enable them to choose when to start their support. Others highlighted the need for the support provided to continue for longer than 12 months given the progressive nature of their condition and the need for support further into their journey.

Overall, our participants indicated that a more consistent approach to the delivery of post-diagnostic support would be beneficial across the whole of Scotland. They felt that replicating areas of good practice which was well-received by people with dementia would benefit everyone who needed post-diagnostic support.

Support after post-diagnostic support

"I feel like I'm managing well with my dementia at the moment, but I just don't know where to get support if I ever need it – this frightens me".

Person living with dementia

Many individuals felt that support following the period of post-diagnostic support was very limited and that more needs to be done to provide a more continuous approach to care and support for people with dementia and their carers. Many people described the need for a single point of contact to guide them throughout their dementia journey, including access to information and access to support provided across the health and social care sector. Most people felt that they are "just left to get on with it" and that a more proactive approach to support, where the emphasis is placed on the offer of support rather than the need to seek it out, would be beneficial for both people with dementia and their carers.

Home care services

"We've had no help for the past 2 years, except for close family."

Person living with dementia

Some of our participants are in receipt of home care services as part of their package of care provided on the basis of their needs assessment, however, it is evident that there are a number of issues around both access to home care services and the delivery of those services.

A number of individuals highlighted the challenges of accessing a care needs assessment to obtain access to home care services. Lengthy waiting times for a care needs assessment were referenced throughout our process of engagement meaning delays to the delivery of essential support services.

Delays are further compounded by the lack of available services due to staff shortages. Many spoke about being unable to receive services, or the right amount of services assessed as being needed, because there is a lack of social care staff to deliver the care. This means that people are simply not receiving the care and support that they need. This was further highlighted by examples of people with dementia remaining in hospital longer than necessary because there are no services available to allow them to return home. Many of our participants suggested that the workforce crisis in social care needs to be addressed and that the value of social care workers needs to be re-evaluated. They also need access to education and training that can support them to understand and meet the needs of people with dementia.

Many people highlighted the challenges of accessing alternative approaches to social care provision. A large number of people who engaged in our discussions indicated that they did not know about Self-directed Support and what alternative options were available to them, assuming that local authority-commissioned care was the only option available to them unless they were in a position to self-fund a private provider. Of those who were aware of Self-directed Support, most felt that the process of obtaining and managing a Direct Payment was too complicated and time-consuming. They felt that they would need support that is simply not available in most parts of Scotland.

Day services and respite

"I can't get access to the day centre... it was shut down because of Covid and it hasn't opened up again."

Carer

Day services and respite provide a vital lifeline for both people with dementia and carers yet our participants report severe issues in accessing these services. Across the whole of the country, we heard that these services are being scaled back and that availability of these services is severely limited.

People with dementia highlighted the loss of social connection and interaction that day services affords them and carers feel that they have lost an opportunity for an essential break from caring with the lack of flexible day services. This increases the stress experienced by people with dementia and their carers.

Longer-term respite, often facilitated through residential care homes, is also unavailable. The value of respite cannot be overstated as a means to ensure that people with dementia and their carers are supported to remain in the community. We heard an example of one participant who indicated that had the opportunity for respite been made available, their partner would not be in full-time residential care since they now felt ready to care again after a week of rest and recuperation. Sadly, this experience is not unique.

People with young onset dementia highlighted that they were very disadvantaged by the current provision of day services and respite since there are very few specific services designed to meet the needs of younger people. They feel that they miss out on these opportunities or have to fit in with older people services which are unsuitable.

Residential care

"I'm just in despair – high turnover of staff and not knowing who will be looking after him."

Carer

The move to residential care is a challenging step for people with dementia and their carers. Many people are worried about the ability of residential care facilities to meet the very specific needs of people with dementia, particularly in light of the experience of care home residents with dementia throughout the Covid-19 pandemic. While the care home workforce were rightfully lauded for their response during the pandemic, some people highlighted the lack of training and knowledge among care home staff, and the increasing challenge of staff turnover in care homes in light of the challenging environment that they present.

The lack of available spaces in residential care facilities was highlighted as a problem, particularly in rural and island communities. We heard examples of people being unable to access local residential care and being asked to move to a facility more than 150 miles away. This means that people are unable to remain within the familiar environment of their local community and that additional burdens are placed on carers who are expected to travel to visit their loved ones.

Additionally, the cost of residential care for people with dementia was highlighted as a serious cause for concern. Weekly fees in excess of £1,000 were frequently quoted during our discussions, and many feel that the costs are excessive and place a financial burden on people with dementia and their families. Rising costs are a continuing challenge for many and create uncertainty around the viability of continued access to residential facilities with some individuals expressing their concern that their loved one will need to move since they are unable to meet the additional care home fees as the country tries to navigate the cost of living crisis.

Financial support

"Carer's Allowance is like a drop in the ocean... does anyone really believe that [£67.90] is enough for providing care? We [carers] save the government a fortune."

Carer

The lack of financial support for people with dementia and their carers is a considerable challenge that results in significant inequalities that must be addressed. The need for greater, more targeted financial support was a key theme that emerged from our discussions with people with dementia and especially with carers.

People with dementia raised the cost of additional care services as a barrier to accessing the amount and type of support that they require to manage their needs. They feel that there is no financial support beyond the availability of disability benefits (Adult Disability Payment, PIP or Attendance Allowance) and that this is not sufficient to cover the real world costs of supplementary support services that are needed to cover the aspects of care that are unavailable through social care measures, need to be paid for as part of their existing package of support or because of the shortage of social care services that means that they have unmet need.

Carers were keen to highlight the poor level of financial support that is available to them to help them to manage their caring responsibilities. Many carers told us that they had to give up work or reduce their hours at work to enable them to provide the level of care that their loved one with dementia needed. They highlighted the additional cost of caring such as extra costs associated with travelling to and from their loved one's home. A reduction in income and increase in their costs mean that carers often need to turn to the benefits system for support but feel that it does not meet their needs either.

Financial support for carers through the benefits system is limited, principally to Carer's Allowance and Carer's Allowance Supplement, to those who qualify. Eligibility for Carer's Allowance is linked to the person with dementia making a claim for a disability benefit. This means that for those who choose not to claim, their carer is unable to access Carer's Allowance. Carers expressed their frustration at this criteria since they told us that the people with dementia that they care for did not claim disability benefits because they did not understand what it was or felt that they did not need it because they did not accept their condition.

Carer's Allowance is also limited due to the eligibility criteria which excludes individuals who provide care but who earn more than £120 per week and the overwhelming majority of the carers we spoke to expressed that they felt that this was unnecessarily strict in light of the demands placed on them even if they remain in employment. This limited access to benefits means that many people are not in a position to provide the amount of care that they would like to. There was also significant concern around the lack of financial support for carers who are of retirement age since they are ineligible to claim Carer's Allowance and only those pensioners on a very low income may be eligible for a top-up of existing benefits if they provide care. Carers were keen to highlight the need to provide financial support to all carers, regardless of age, since they perform the same caring duties.

Moreover, the amount of Carer's Allowance is considered to be too low and does not reflect the amount of effort that goes into caring. Even with the payment of a Carer's Allowance Supplement, carers feel that this does not go far enough to meet the actual costs of caring for someone with dementia. A significant number of carers highlighted the additional challenge of Carer's Allowance not being paid if their loved one is in hospital for more than 4 weeks. They still provide care even when their loved one is in hospital and the financial impact of losing income at an already challenging time can be "devastating".

Carers feel that the entire approach to financial support does not place real value on the contribution that they make to improving the lives of their loved ones and to society as a whole. They feel that the system around financial support needs to be reviewed and delivered more fairly to acknowledge the importance of the role that they play. They feel that their contribution should have greater value placed on it and that they need to be fairly supported to continue to deliver their caring duties and responsibilities.

Progress in research

"Being given the diagnosis was like being handed a death sentence because you automatically know there is no cure"

Person living with dementia

A number of individuals discussed the lack of progress in research and the need for more to be done to find treatments and, ultimately, a cure for dementia. Some participants highlighted the lack of availability of clinical trials for dementia treatments, and one participant highlighted the challenge of accessing such opportunities due to the lack of ongoing medical input after the period of diagnosis. Many people felt that more needs to be done to improve opportunities to participate in dementia research.

Prevention approaches

"What about the future? I worry about my children and my grandchildren."

Person living with dementia

Some people feel that "prevention is better than cure" and believe that more needed to be done to prevent others getting dementia in the future. Our discussions highlighted the need for early intervention and the need to use opportunities to educate people about dementia at a younger age in an effort to increase their understanding of the condition and also to take a more proactive approach to make decisions that could positively impact their future brain health.

4. How would addressing these challenges change lives?

"I'm looking for a feeling of assurance and calmness, and not feeling so different and apologetic."

Person living with dementia

"It would be a great relief and help to the family... just knowing that mum is being well looked after."

Carer

From our interactions with people with dementia and their carers throughout our period of engagement, it is evident that the challenges and barriers that they face need to be addressed to improve their lives. Our participants believe that people with dementia should be striving towards living well with their condition and that carers feel supported to carry out their role to the best of their ability.

Improved understanding of dementia among the wider public

"I wish people would give me more time to do things... I can do everything if I just have the time to do it."

Person living with dementia

People with dementia and carers recognise the importance of educating the wider public about dementia. They experience first-hand the challenges of ignorance and the need to tackle misconceptions about dementia, including the widely-held view that dementia is a disease of older people. By providing easily-accessible information about dementia to people in their communities, people with dementia and their carers want to reduce stigma around dementia and remove the taboo of openly discussing dementia. By tackling fear and uncertainty around dementia, we heard that improved understanding would support the ability to deliver dementia-friendly communities and dementia-friendly spaces, even outwith dementia-specific settings. People with dementia and their carers hope that this would in turn lead to reduced isolation and segregation of people with dementia and encourage and enable them to play a more active part in their communities.

Improved information and knowledge about dementia

"It makes sense to have an early initial conversation when diagnosed to get some advice..."

Person living with dementia

The lack of information about dementia available to people with dementia and their carers disempowers them. By improving the availability of information, people with dementia and their carers can feel more assured about the future by increasing their understanding of the condition. By improving their knowledge, people with dementia and their carers feel that they have the ability to plan ahead and be involved in informed decision-making that

supports their wishes and desires, as well as addressing their specific needs. The people that we spoke to wanted to have the ability to anticipate at least some of their futures needs and to have the opportunity to consider how they would like to manage their concerns or issues before reaching crisis-point, or before it is too late to make an informed choice.

Improved information and knowledge about services and support

"There needs to be more information given to families about the support services available to them. There are a lot, and most go under the radar because we are not told about them."

Carer

People with dementia and their carers are seeking reassurance that there is support available that can meet their needs. Providing better, *consistently* delivered information about services and support can provide that safety net that people are trying to find, particularly as they navigate the early stages following their diagnosis and at times of crisis. Access to information about accessible, local support early in the period following their diagnosis means that people with dementia and their carers have the ability to plan ahead and have the tools to be able to direct their own support, at a pace they feel comfortable with and in a way that is beneficial to them.

Improved diagnosis experiences

"Help doctors to understand the signs of early onset dementia as it was years before my partner was diagnosed..."

Carer

It is clear from our engagement with people with dementia that their experience of obtaining a confirmed diagnosis reflects on their entire experience of their journey of dementia. Negative experiences of interacting with medical and healthcare professionals, delays in receiving a diagnosis, and subsequent delays to treatment and support must be addressed to improve the process of obtaining a diagnosis of dementia. Better education of medical professionals, from GPs to consultants, about dementia and the impact of dementia is necessary to avoid instances of patients feeling dismissed in healthcare settings. We heard about the need to address delays in obtaining a diagnosis to reduce the amount of worry and concern experienced by individuals and their families, as well as ensuring that the follow-up support provided post-diagnosis is received in a timely manner that enables the most benefit to be felt by those in receipt of services.

Improved health services

"My doctor sees me for my diabetes but not for my dementia... my dementia affects me more than my diabetes."

Person living with dementia

Most of the people we engaged highlighted concerns about the need to address shortcomings in the delivery of health services for people with dementia. The view that healthcare “just stops” following diagnosis means that people feel that they do not benefit from the input of healthcare professionals. By addressing this concern, the people we engaged with thought that they would experience better physical and mental health and that they would feel more supported.

Improved social work and social care services

“Better care at home support needs to be provided especially to the unpaid carers.”

Carer

Again, the individuals that we engaged with identified significant challenges in their access to, and experience of, social work and social care services. By tackling the issues across this sector, people believe that they would feel better supported to stay at home. They also feel that their wellbeing would improve.

Improved opportunities for respite

“If I had a break every now and again then it wouldn’t feel quite so difficult... I would manage better, I would cope better.”

Carer

Access to opportunities for respite was a significant challenge highlighted across the engagement process. Respite provides an opportunity for a break from caring for carers and needs to afford carers the opportunity for a flexible approach to support that meets their needs, as well as the needs of their loved ones. In accessing adequate respite support, carers observed that they would have an opportunity to exercise self-care and take time for themselves. They believe that they will feel less stressed and less pressured which would in turn enable them to continue caring for someone with dementia at home for longer.

Improved residential care services

“Less turnover of staff would give peace of mind to the carer or family, and be less stressful for the person with dementia... seeing a familiar face. This gives both a chance to build a relationship with carers, nurses, etc.”

Carer

More targeted support for people with dementia in residential care homes is necessary to address the unique needs of these individuals. Our participants believe that increased staffing levels and an educated workforce would enable people with dementia the opportunity to have access to the quality and standard of care that they deserve.

People from all backgrounds need access to residential care support so work needs to be done to enable better access to age and culturally appropriate services that are better placed to support people's specific needs. This would reduce the inequalities experienced by specific groups of individuals.

Improved social opportunities

"My husband had stopped going out, but since he went to Football Memories, his confidence has increased and he looks forward to it, he asks when is it on"

Carer

The availability of accessible, local groups will provide more opportunities for people with dementia and their carers to participate in community-based activities. People with dementia and their carers feel that there would be greater opportunities to meet their peers and share similar experiences. They would be able to widen their shrinking social circle and spend time with people who have an understanding of their experience.

Improved approaches to equality and diversity

"Everyone deserves to be treated fairly... no-one should be disadvantaged because dementia doesn't discriminate."

Carer

It is essentially important that people from marginalised groups, including people from ethnic minorities, the LGBTI community and those with a learning disability and sensory impairment, have fair and equitable access to dementia services. A better approach to equality and diversity will lead to improved cultural awareness among dementia communities, and can also improve access to more culturally appropriate services. A more inclusive approach can encourage those who may not typically access services feel more confident to do so going forward. The example of Alzheimer Scotland's approach to services for Gaelic speakers in the Highland area, and beyond, shows the benefits of inclusive approaches bringing together communities with similar experiences to explore new opportunities and link with other groups together.

Improved financial support

"The benefits system needs addressed. I eventually got PIP when I stopped working but it took 6 months to get any money – something needs to be put in place much sooner"

Person living with dementia

Addressing the financial inequalities experienced by people with dementia and their carers would result in less worry about money, particularly in light of the cost of living crisis. People

with dementia and carers highlighted the significant financial burden they experience and believe that more appropriate financial support would enable them to focus their energies on more pressing issues involved in their care.

Our participants also believe that removing financial barriers will also increase opportunities to purchase services or resources that are more targeted and better able to meet their needs, thus leading to increased choice and flexibility for everyone.

Improved support to access education, training and employment

"My employer lacked awareness – I knew I couldn't continue working after my diagnosis but was devastated to be given 10 days' notice that I was getting 'retired'"

Person living with dementia

Our participants believe that more needs to be done to support people with dementia to participate in employment, education, and training. The availability of support to address stigma and discrimination in the workplace will lead to greater opportunities to remain in employment.

Carers face significant challenges by being unable to access fair opportunities to work flexibly and to have their caring responsibilities recognised legitimately by employers. By enabling carers to remain in employment, they will be able to achieve better career progression and have access to the other benefits of employment including secured pension rights.

Availability of a cure or other treatments

"More money for research, particularly early diagnosis and a preventative... response. Earlier diagnosis and earlier treatment."

Person with dementia

Inevitably, the availability of a cure will lead to improved physical and mental health and wellbeing. Our participants believe that other treatments have the potential to improve their physical and mental health and wellbeing but may also improve day-to-day living by managing specific symptoms or limiting progression of their condition.

Improved brain health and dementia prevention approaches

"Prevention is better than cure, that's what I say!"

Person with dementia

Our participants are hopeful that young people can benefit from improved brain health and dementia prevention approaches that will provide an opportunity to reduce the impact of

dementia on future generations They believe that improved education about the importance of looking after your brain will secure better outcomes for those who learn about brain health at an early age.

5. What do we need to build on/learn from what has been done before?

"It's not a "new story" – this has been my life for more than 5 years."

Person living with dementia

"We need to learn from the pandemic. Too many of us [carers and people with dementia] have struggled during the last few years. We're still struggling now."

Carer

Our participants highlighted the need to build on existing policy and practice that has been proven to improve the lives of people with dementia and their carers. They want a commitment for action to implement the change that is needed, and some even questioned the need for a new National Dementia Strategy when previous promises have not been delivered. Many participants noted that, in the long-term, dementia care and support has improved but that it has now stalled and even gone backwards due to the pandemic. Our participants want to see a renewed enthusiasm for implementing change.

Implement existing policies

"Expectations and should be's" are all very good but in reality who has the responsibility and the correct level of influence, accountability and authority to turn "expectations and should be's" into reality."

Carer

Many individuals brought forward concerns that the three previous National Dementia Strategies have not been fully implemented. Many people we spoke to felt that the previous Strategies had a positive plan to address and tackle the inequalities experienced by people with dementia and their carers but that this has never been achieved in the way that it originally set out. People highlighted the lack of consistency in service access and delivery across the country and gaps in the care that they have experienced. They highlight the ongoing challenges that they face in everyday life, including getting access to GP appointments, knowing who and where to turn for advice and support, and finding services that are designed to meet their specific needs.

Other policies that affect people with dementia and their carers were also highlighted as failing to meet the needs of these individuals. The most significant examples that were highlighted were the inconsistent delivery of Self-directed Support and inconsistent access to carer support plans both made available through existing legislation. Many people felt

that if more was done to implement these policies fully and effectively, then more people would have their needs met.

Duplicating examples of positive practice

"The "Boogie Night" that Alzheimer Scotland put on is brilliant, it's something we can go to as a couple and have a really good time meeting new people – everyone should be able to go to an event like this."

Person living with dementia

Many of our participants shared examples of local practice that are positive and make a difference to their lives. Most people felt that it was important to learn from these examples and understand more about what makes them work well in order to spread them around the whole country. People felt that there were missed opportunities through failing to replicate the best practice on a larger scale and developing the services that work well.

Joint-working and collaboration

"It would be great if all the services talked to each other... the doctors, the [post-diagnostic support] link workers, the physio[therapist]s, the Dementia Advisors... things would run more smoothly if everyone just talked to each other."

Carer

Many of our carers highlighted the need for services to work together and to work collectively to achieve better outcomes. They believe that better communication is essential to ensure that people with dementia and carers get a joined-up service. Previous attempts at integrating care and sharing information has largely failed but this needs to be addressed to improve the experience of people with dementia and their carers.

The voice of lived experience

"We've done this all before... why are they [Scottish Government] reinventing the wheel? They just need to listen to us."

People living with dementia

Many of our participants have joined in with previous consultation work on previous National Dementia Strategies and felt frustrated that they are being asked the same questions for the current National Dementia Strategy. They feel that they have not been listened to since they feel that the same topics are still being covered by the current discussion paper and are concerned that the involvement of people with lived experience is very tokenistic. They feel that much more has to be done to capture the views of people with lived experience and make them an integral part of future policy.

6. What else would you like to tell us?

The consultation process

"How can I answer the questions if I don't have time to think about the answers?"

Person living with dementia

Throughout our process of consultation with people with dementia and their carers, concern was raised about the time being afforded to engage with people with lived experience. Individuals raised concerns about the lack of time for the consultation since it acts as a barrier to participation for people with dementia in light of the additional needs and support required by individuals to access, dissect and consider their responses. People with dementia noted that they need more time to reflect on how they will respond to questions or ideas put forward in the discussion paper, and require additional support and input to be able to express their views. While this additional support was provided by Alzheimer Scotland staff, they felt that they were unable to participate in a way that was supportive of their needs and enabled them to meaningfully engage with the consultation by allowing them adequate time. We heard from various participants that it would have been more helpful to discuss the individual questions on a weekly, or even monthly, basis to enable them to feel more engaged in the process. They felt that the short timescale to gather views and opinions acted as a barrier to enable the voice of lived experience to be "fully heard".

Data and measures of success

"I'm afraid that my dementia bus is stuck at a red light that won't change. We've had 3 Strategies so far and these have never been evaluated to identify any improvements. In my opinion, there are specific measurable targets needed because if we don't know where we are, then we can't possibly know where we're going".

Carer

A number of our participants highlighted the difficulty in evaluating services and resources due to the lack of data and information around dementia. Many pointed to the lack of basic information relating to how many people had a diagnosis of dementia and how they are spread across the country. They felt that without this information, it was hard to focus services where and when they were needed most. Some individuals also questioned the measures of success being applied to dementia services and highlighted the need for an evaluation of the previous National Dementia Strategies before being able to move on to the next Strategy.