

A National Conversation to Inform a new Dementia Strategy for Scotland – What People Told Us

March 2023

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Introduction

We are grateful to everyone who contributed to our National Conversation. The range of voices we heard, whether it be in writing, online or in-person, provided an incredibly strong basis on which to consider what a new Dementia Strategy for Scotland can and needs to achieve.

The engagement work was led and delivered by Scottish Government policy teams, working with a number of organisations who went to great lengths to engage communities across Scotland and to enable their voices to be heard. Such efforts have been essential in broadening out this conversation on what a new Strategy could look like, and we will continue to encourage these efforts as we progress from developing the Strategy and its outcomes to identifying and delivering on actions.

What is this?

Our ambition with this document is to collate and share an overarching, high-level summary of the collective written and oral evidence we received.

We also want to outline the range of responses received, as well as the evidence-based rigour we brought to this analysis through using thematic analysis techniques.

What people told us

People who participated in our National Conversation focused on:

- **The need to change how we talk about dementia** – There is a negative and stigmatising view of what dementia is and what a diagnosis means. This negative societal perception can mean people ‘putting off’ seeking a diagnosis or asking for help, and can limit the type of support made available to people when they need it.
- **Community** – The importance of community in the lives of those living with or caring for someone with dementia came through strongly, as did the need to leverage a community-led, peer-support ethos wherever possible.
- **Policy into practice gap** – There is a gap between Scotland’s world leading commitments on dementia policy and people’s experiences of receiving support (‘what it feels like’). This includes a lack of person-centredness towards individuals, their families and their carers in delivering or tailoring support that works for them.
- **The ‘postcode lottery’** – The availability and provision of support, including the commitment of a minimum of 12 months Post Diagnostic Support (PDS), is inconsistent.
- **Workforce issues** – The challenge in providing care which support people where and when they need support in a way that works for them is a consistent message.

- **Education and training** – A lack of education and training about dementia is resulting in an underskilled workforce in both social care and health.
- **Other key issues include:** The trauma of diagnosis; the perception that dementia should be seen as a ‘brain health’ condition rather than a mental health one; the need for an upscaling of preventative and early intervention activities (to reduce demand at the crisis end), and; the prohibitive cost of seeking specialist care and support.

What’s next?

- We have collated these responses to shape an initial outline draft of the new Dementia Strategy with which to engage our National Dementia Lived Experience Panel with.
- We will work with the National Dementia Lived Experience Panel to ensure, as our governance partner, it fully reflects their experiences and their views on what needs to change.
- We will also work in partnership with COSLA to ensure this is a Strategy that sets a new, long term agenda for change in dementia policy across society.
- Our Strategic Advisory Group will also play a critical role in evaluating further drafts of the Strategy.
- We have also commissioned a review of available evidence from senior academics. This will provide an evidence base with which to test the priorities which have emerged from our engagement.
- Accounting for all of this work, we will publish the Strategy in Spring 2023.

What will this Strategy look like?

Reflecting what we have heard, there is a clear need for **a long-term vision and set of priorities**. This reflects the extent and scope of change which people who have contributed to our National Conversation have called for, while being realistic about how long that change will take to deliver.

We will be informed by the large-scale independent evaluations of key commitments from previous strategies in assessing **whether these commitments contribute to a better life experience for those living with dementia** and those who provide care and support for them.

To begin to deliver a longer-term vision and in addition to continuing to deliver on our world leading commitments such as a year’s Post-Diagnostic Support for people living with dementia, we need **to engage further following the launch of the Strategy around the immediate to medium-term actions** we can take forward and how we will do this. This process will be captured in an initial strategy delivery plan, which we will publish by the end of 2023.

Our National Conversation

With our National Dementia Lived Experience Panel and Strategic Advisory Group providing oversight and governance to the strategy development, we announced an open 'National Conversation' on dementia running from 30 September to 5 December 2022.

The engagement approach is based around a small number of clear, open and easy to understand questions that allow people to offer their experiences.

The consultation questions were:

1. What does dementia mean to you and those around you?
2. What supports work well for you?
3. What challenges need to be addressed?
4. How would addressing these change lives?
5. What do we need to build on/learn from what has been done before?
6. What else would you like to tell us?

Formal responses

We had 139 responses via CitizenSpace, with an additional 22 from organisations and 6 from individuals after the deadline closed, giving us 167 in total. Of these, 64 were from organisations (around 38% of responses).

The type of organisation was mixed, with health and social care providers, third sector, professional organisations, and community support groups among those who have contributed.

For individuals, the majority (65%) were from people who are caring/have cared for someone living with dementia

Previous dementia strategies have not used a formal written template for response, so we do not have a prior comparison.

Type of respondent (N=167)	Number	Percentage
Individuals	103	62%
Organisations	64	38%

Type of individual (N=103)	Number	Percentage
Living with dementia	7	7%
Unpaid carer/ family/ loved one of someone living with dementia	67	65%
Caring professional	22	21%
Person with an interest in dementia	4	4%
Unknown	3	3%

Type of organisation (N=64)	Number	Percentage
Third sector	25	39%
Of those third sector orgs that are groups of lived experience/ Community Groups (N=25)	4	16%
Public sector	16	25%
Professional organisation	16	25%
Private sector	5	8%
Academic organisation	2	3%
Equalities groups	8	12.5%

Informal responses

We held or joined our partners to deliver a number of in person engagement sessions on the strategy in various locations across Scotland, including Orkney, Dunoon, Aberdeen, Dundee, Whitburn, Kirriemuir and Peebles. Events were designed to ensure that people can offer their views in places and environments that are comfortable for them, rather than asking them to travel to central locations to engage. This led to 110 separate engagements with a wide range of organisations and groups, reflecting our commitment to hearing a wider and more diverse range of voices.

In addition, we have held numerous online meetings and sessions with a wide range of organisations including Alzheimer Scotland, About Dementia within Age Scotland, British Deaf Association, Minority Ethnic Carers of People Project (MECOPP), Social Work Scotland, Allied Health Professionals Directors, Scottish Dementia Working Group (SDWG), National Dementia Carer's Action Network (NDCAN), the Mental Welfare Commission, Scottish Social Services Council, Scottish Care and the Care Inspectorate. Officials have also run a number of online sessions at various times which anyone can sign up to and attend. These sessions have also been well attended and have included people living with dementia, carers, and professional staff.

All of these engagements have been summarised, with these written summaries used to supplement the formal written responses as part of this analysis.

Online engagement

We also held four online public engagement events. These were attended by 33 people in total, with a collective summary of these used as part of the analysis.

The role of our governance groups

National Dementia Lived Experience Panel

The establishment of a National Lived Experience Panel, appointed by an independent group on behalf of the Scottish Government, has formed part of the formal governance which oversees the development (and subsequent delivery) of this strategy.

The Panel comprises 22 people:

- 11 with a diagnosis, and;
- 11 as care partners.

The questions for our National Conversation were developed in collaboration with the group, and initial findings were presented to them prior to the full analysis.

As well as working with the new National Lived Experience Panel, we have and will continue to engage with pre-existing lived experience groups as reflected during the National Conversation.

National Dementia Strategy Advisory Group

A new National Dementia Strategy Advisory Group has been established to inform and oversee the development of this strategy, chaired by the Scottish Government's Chief Social Work Advisor. The group is multi-agency, bringing together a wide range of backgrounds and interests including clinicians, the Third Sector, local government, providers of residential care, academia, and Scottish Government colleagues covering areas such as planning and the National Care Service.

The group helped inform our engagement efforts round the National Conversation, and how we could support the fullest range of people and organisations to contribute.

Analysing responses

To bring scientific rigour to the process, we used a thematic coding structure for our analysis. This saw us:

- Take all of the formal written responses into a single excel sheet
- Conduct an initial analysis for words and key themes which kept being repeated across the responses.
- From a long list of codes which emerged, we combined these into a core list of headings, providing us the basis for categorising the responses and comments received.
- An equal weighting has been given to all responses, with particular quotes and points raised utilised.
- Points raised have also been quantified in some way. For example, we use the terms "all", "most", "many", "some", and "few" to articulate the strength of opinion.

Points to Note

The following points should be noted:

- The analysis we have developed highlights those key issues and themes which emerged from our coding analysis at a high level. It does not reflect the totality of contributions and views which have been utilised to develop the Strategy itself.
- Respondents to any public consultation or engagement event are self-selecting, and the responses may not be representative of the population as a whole.
- Some organisations who attended a virtual or in-person engagement event also submitted a written response to the public consultation.

- The National Conversation was structured to allow respondents to answer questions independently in recognition that respondents may want to respond on one or some of the questions without wishing to express views on the others. All views have been carefully considered.
- Not all submissions to CitizenSpace, the portal that stored written responses, were presented in line with the Conversation questions.
- There does not appear to have been a campaign response, albeit there are some responses from individual respondents that use the same or similar wording. In part this likely reflects people operating/interacting with similar organisations in what is a small stakeholder pool and said stakeholders sharing the National Conversation out to their members and/or wider networks. Further, some organisations worked with others to prepare a joint response in addition to submitting a response from their own organisation.
- All responses, where the respondent has given permission for their comments to be published, will be made available on the Citizen Space website.

What people told us

Below is an overarching summary of the key themes which emerged from our analysis. These are illustrated by quotes from people living with/caring for someone living with dementia.

This does not represent the totality of contributions. Each of the contributions received has been used to inform the development of our strategy, the priorities it will focus on, and the actions we will consider in delivering this Strategy.

1. What does dementia mean to you?

“Dementia is like having a hole where someone used to be.

They are gone, but you can't mourn them, and you can't move on. The lives of those closest to them is held in limbo, with guilt affecting every decision of every day.”

“Dementia is an unexpected cross roads in the highway of life.

It doesn't necessarily mean the end.”

- **Community** – Framed as critical to a strengths-based approach to people living with dementia, the importance of developments like Dementia Friendly Communities could not be overstated for people. This also applied for minority communities with communication difficulties (such as people with Down's Syndrome or for whom English was not their first language).
- **Stigma** – Stigma was said to impact those living with/caring for someone with dementia in many guises. It started with the language used to describe dementia (particularly in other languages), the stigma shown publicly and within communities (that in turn reduced people's willingness to seek a diagnosis or support from communities). It was also felt clinicians could be guilty of taking a limited view of the capabilities of someone living with dementia, impacting the care they receive and engendering a focus on what they can't do rather than what they can.
- **Public health** – Recognising dementia as a public health issue, in both a preventative and awareness raising sense is critical. In doing so, this can leverage a societal-wide response to ensuring the lives of those living with dementia and their carers are enabled to be fulfilling.

- **Trauma** – This took a multitude of forms, but this was the most apt term for the wellbeing impacts of dementia:
 - For people living with dementia, this trauma presented in the impact of diagnosis, the impact of the condition on how your family and your community engaged with you, as well as the fear of ‘losing yourself’, your identity, and your livelihood. As the disease progressed, it was the loss of self, and the fear of requiring more and more assistance to be able to do less. The impact at an advanced stage of having to stay in residential care, away from their communities, was also seen in some instances as traumatic.
 - For those caring for someone living with dementia, it was the fear of what was to happen to the person they were caring for that came through strongest. This included how they would be able to ensure they can meet that person’s needs and, as the disease progressed, the sense of “loss” as the person they care for changed and their need for greater support grew. The scope of their own lives was also felt to reduce to meet additional need, with guilt felt among those who were unable to.
 - Other key points included: How the trauma was multiplied for minority communities; the difficulty in receiving what remains a palliative diagnosis; the failure to provide adequate care pathways which recognised dementia as a brain disease; the trauma of professionals feeling powerless to help, and; the potential loss of a brighter future
- **Relationships** – How people came into contact with dementia shaped their perception of those with the condition. Those in our communities who engage with people living with dementia through spaces like Meeting Centres were much likelier to form a positive and understanding perspective towards people living with dementia, and what they can achieve. In contrast, people with limited interactions or only interactions as the condition advances will take a less enabling, more limited perspective.
- **Finance** – The loss of a person’s economic contribution post diagnosis, as well as that of their family members/unpaid carers, was frequently cited.
- **Loss of independence** – There was a sense of life becoming much more limited post-diagnosis despite people feeling they have “so much more to give”. Communities and how they were designed were seen as playing their part in limiting people’s independence, as well as the lack of communication around the opportunity to continue to participate in communities post diagnosis.
- **Nature of condition** – How it is perceived and its impact on day-to-day life was detailed, with its impact extending to every facet. The range of co-occurring and/or exacerbating conditions alongside it, from Down’s Syndrome through to Parkinson’s, were also cited.

- **Supports** – The need for a much greater and more nuanced understanding of what supports was required across the dementia journey. This included for people caring for someone living with dementia, and the role of organisations more widely on this journey.

2. What supports work well for you?

“I had this huge desire to just to be able to be in the company of somebody who was going through the same process as me. Someone who was having similar experiences, who had similar hurdles to climb over and whose mountains to climb were just as high as mine. I needed to hear their experiences, I wanted to find out how they overcame them, how they overcame their difficulties.”

“Go to a meeting centre, people are interested in you. Meeting other folks is the most important thing. There's no better person than your friends to get you out the house and meeting other people.”

- **Person centred, skilled and continuous care** – A range of positive care experiences were cited, centring around PDS, personal assistants via Self Directed Support (SDS), forward planning of an individual's care needs across settings and continuity. The latter was seen as a key principle, enabling personal and trusting relationships to be built between people living with dementia, their families/carers, and professionals.
- **Coordination** – Key to better care and support outcomes was well planned, coordinated support across a range of professionals to meet the multiplicity of need. This includes third sector signposting, both formally through organisations and informally through communities.
- **Communities** – This was the most positive element of people's experience of living with/caring for someone with dementia. It's benefits as a space/forum to access advice, support, care, companionship and purpose were detailed across a range of settings, from local music groups to more formal meeting centres and dementia resource centres. It was framed by many as the foundation stone of good, positive support, and maintaining a sense of self beyond their diagnosis/carer status.
- **Lived experience and peer support** – A critical means of overcoming self-stigma following diagnosis was simply talking to others who had gone through the same process. The knowledge they possessed of where to go for support and the ability to connect people into new communities was not felt to be sufficiently utilised, but where it was, it was a highlight of people's experiences of support. This included for minority communities (such as Deaf Dementia Cafes), and in advocacy through campaign groups like the Scottish Dementia Working Group.

- **Volunteering** – As a conduit for participation for people living with dementia, it was potentially the only space available where they could find a purpose and value to society approximate to what they may have held prior to their diagnosis. It was also an avenue for carers to share their vast knowledge and to contribute to community efforts and understanding.
- **Workforce training** – While there are gaps in the workforce, a range of practitioners highlighted the greater range of training now available and increased awareness across professions. This included developments for specific communities, such as health checks for people with learning disabilities/autism, and how such a system could benefit people living with dementia. A greater range of multidisciplinary professionals to meet a person's multicuity of need was also seen as essential, as was the co-location of care and support practitioners.
- **Prevention** – Prevention was framed around: preventing potential factors which may increase the likelihood of dementia; preventing it becoming severe more quickly, and; preventing the need for in-patient care through community interventions. The progression in the brain health space, and the creation of these centres in Scotland, was both seen as a powerful anti-stigma tool and as a means of ensuring new preventative treatments could be brought into play at an earlier stage. Education of young people around potential factors which may increase likelihood was also welcomed. In terms of preventing admission, a greater range of professionals in communities and new models of support like rapid intervention teams were highlighted.
- **Innovative practice** – There were people who cited experiences where their care and support had been rooted in taking time to listen and to adapt to a person's individual preferences, as well as needs. This was underpinned by a balance of formal and informal supports as well as consistent ongoing outreach and communication with the person and their carers/families. Other innovative practices included memory clinics being delivered in communities and home-based rehabilitation techniques that enabled support to be delivered in homes.
- **Family/carer support** – Ensuring families/carers received sufficient support and had their rights upheld, including for their own wellbeing, was seen as paramount. Supports that worked included advocacy, timely development of an Adult Carer Support Plan (ACSP) and the allocation of Carer's Allowance. Day to day living adaptations, bereavement support and continued efforts to enable the person they are caring for to live well at home were all welcomed, and seen as crucial to avoiding the need for residential care until absolutely necessary.

3. What challenges need to be addressed?

“Treated like a set of symptoms, rather than a person.”

“I don’t want or need to leave my house just now. It just needs a few small changes to keep it working for me. That seems to be impossible though”

- **Challenges in accessing diagnosis and support** – A range of issues around diagnosis and accessing support at an early stage were highlighted:
 - **Diagnosis** – This started from a lack of awareness from professionals of the symptoms of dementia. There was also a lack of qualified professionals to diagnose (particularly in rural areas), driven in part by the continued ‘medicalised’ nature of the diagnosis process. That it continued to be based around a series of tests which were not accessible for many, and only captured a person on a particular day rather than cognitive deterioration over time. The lack of a national screening programme and campaign was also cited as a concern, as it led to people needing to ‘know’ themselves what symptoms to look for. Stigma in this process also existed, with some carers suggesting GPs had expressed an attitude that a diagnosis “*wouldn’t make a difference*” as the condition was at an advanced stage.
 - **Post-diagnosis** – Following diagnosis, the lack of automatic supports (such as blue badges and council tax exemptions) was criticised, as was the drop off in support following a year of PDS. As the condition advanced, it was also felt current provision for specialist care, in communities and in in-patient services, was inadequate to meet the extent of need.
 - **Exacerbatory factors** - All of these were said to have been exacerbated by the pandemic, which had led to many people ‘not wanting to bother’ healthcare services. All of these issues were also exacerbated for those with additional conditions/protected characteristics, in particular with communication difficulties.
- **Mental health and wellbeing** – Differentiating the debate around dementia not being a mental health condition and the mental health and wellbeing impacts of a dementia diagnosis was urged. The impact of a diagnosis on a person’s independence and self-worth could be stark, and it was urged dementia services and supports become more mental health literate to support people when they were struggling (including with anxiety, distress, depression, delirium and suicidal thoughts).

- **Person-centredness** – People’s experiences all too often were of systems unable to meet their/their family member’s needs and preferences. There was a real gap between aspirations in policy through initiatives like a year’s PDS support, and how people experienced them. The lack of person-centredness was the consistent rationale given.
 - **Capacity** – Consistently, one size fits all rather than person centred approaches were experienced. Much of this was driven by a lack of resource and capacity across public services. From PDS not adapting to individuals needs and preferences to a lack of co-ordinated and consistent social care (with Self Directed Support (SDS) in reality not expanding many people’s options). A consistent lack of communication and time for staff to meet people’s personal needs was reported. This also extended into community and housing design, neither of which sufficiently and consistently adapted to the needs of those living with dementia. In in-patient settings, the inability to provide appropriate packages of support in communities then led to people experiencing delayed discharges. Both in physical and mental health, in-patient care was unable to adapt to a person’s needs and preferences, in particular when they presented with an additional communication difficulty.
 - **Attitudinal** - There was felt to be a need to tackle the feeling of hopelessness which comes with a diagnosis, driven by self-stigma brought about by societal attitudes to the disease that extends to ‘shunning’ people with the condition. This led in some cases to people avoiding diagnosis so that they were not subject to a ‘death sentence’. All of this leads to a system where a person feels care and support focuses on what individuals can’t do, rather than enabling them to do what they can. These issues were exacerbated for those with other conditions such as learning disabilities, Down’s Syndrome and sight loss.
- **Experiences of equality groups** – the negative experiences of our ethnically diverse, our deaf, and our LGBT+ communities in relation to living with and caring for someone with dementia were highlighted. This extends to people with learning disabilities and Down’s Syndrome, as well as other protected characteristics/conditions. The multiplying impact of stigma and difficulties within systems to effectively engage and understand these communities’ experiences were detailed, including in relation to accessing diagnosis. Many reported feeling ‘invisible’ to services and supports. There was felt to be a need for greater societal understanding of the range of people who make up our dementia communities, and for workforce training to reflect this diversity. It was also noted women represented both the majority of the carer population (both paid and unpaid) and of those living with a diagnosis. This needed better understood, including connecting to emerging evidence about life events such as menopause and domestic abuse.

- **Workforce challenges** – From education and training through to pay and esteem, the challenges facing the workforce that inhibit its ability to fulfil its role in providing care and support are profound.
 - **Core workforce** – For those working directly with people living with dementia and their families/carers among their primary duties (AHPs, Care at Home support workers, dementia nurse practitioners, old age psychiatrists, social workers etc), there are significant gaps in staffing availability. There is also stigma towards these professions working with a community assumed to be ‘suffering’ and unable to recover. Negative variations in the makeup of the workforce were also experienced in some local areas. These reduced the availability of alternative supports and pushed people towards more specialist care before they may have required it. There was also said to be barriers for people working across health and social care when trying to prioritise the ‘human interactions’ and the importance of relational care (in particular in community and social care settings). Finally, the lack of professional leadership in in-patient settings to drive forward the uptake of the Promoting Excellence Framework was highlighted.
 - **Wider workforce** – For those who work with people living with dementia, the lack of training and awareness of dementia left them generally unable to understand and/or meet the person’s collective needs. A stronger training programme was called for, with input (and ideally co-produced) with people with lived experience, and an express understanding of different communities and how their experiences should be accounted for alongside their dementia.
- **Lack of advocacy** – The legal protections provided in law, including access to independent advocacy, did not translate to the reality of many people’s experiences. This was in part due to a lack of knowledge of these protections (including within the legal profession) which led to infringements (including around visitation to care homes, the rights of carers and maintaining people’s dignity). Also reported was a lack of forward planning to establish a Power of Attorney and advance statements.
- **Stigma & discrimination** – Until societal attitudes did not portray dementia as simply a ‘death sentence’, it remained difficult for people with a diagnosis to step past this and be active participants in their communities. It was urged this stigma was reframed as discrimination, from which greater legal powers could be utilised to leverage change. Community participation for people living with dementia was also said to be curbed by these societal attitudes.

- **Residential care** – As the condition advanced people called on residential care sooner than they needed to, and often found these settings were unable to adapt to their needs and preferences. A lack of access to community-based supports was detailed, including befrienders, as well as issues with cultural competency in the support provided (including in additional language provision and cultural understanding of communities such as people who identify as LGBT+). This was attributed by some to the lack of funding arrangements to build up specialist provision, as well as debates over whether residential care costs should be framed as healthcare costs to be met by the state. The subsequent loss of connections with wider society following admission was highlighted, as was the resulting financial impact on families to pay for what can be highly expensive care they perceive as disproportionate.
- **Sustaining innovations** – Efforts to advance new technologies and methods of care were stymied. This included through current funding criteria and annual budgeting placing an emphasis on low-cost, high-density interventions over more bespoke community set ups. This led to initiatives like SDS not fulfilling their potential.
- **A ‘mental health condition’** – While dementia continues to be perceived as a mental health condition, interventions will not adequately meet the ‘whole’ person’ needs, which living well with dementia demands.
- **Advanced dementia** – The ‘circle’ or range of supports available was felt to shrink as the condition advanced, with very limited options beyond residential care or in-patient care available. This was exacerbated by co-occurring conditions like delirium, which could be mistakenly assumed to be a symptom of dementia rather than a separate condition.
- **Impact on families (including loss of home)** – The ‘moral injury’ faced by families and professionals unable to enable a person to recover from the condition was clear. The experiences of the pandemic were said to have been harrowing and exacerbated issues around communicating with families as their loved one approached end-of-life care. Aspects like Carer’s Allowance and Carer’s Assistance also needed to become more person-centred, and the roll-out of Anne’s Law, enabling people to receive visits from family members on a human rights basis, was urged.
- **Pathways** – Without a consistent pathway or series of responsive supports, people will continue to experience a disconnected and fragmented response and potentially fall through the cracks. Significant variations in the experience of the initial year’s PDS were detailed. Without linkage to further supports and pathways, these supports were also too often not meaningfully continued after the one year. It was also urged a clearer, more holistic pathway post-diagnosis needed established, integrating community supports so that people living with and caring for someone with dementia were connected in from an early stage.

- **Data** – There was a lack of reporting and accountability from relevant bodies on what we know in terms of data on people’s experience with a dementia diagnosis. Additionally, there was a lack of data on who has dementia, when they are getting diagnosed, and the impact of treatments for their dementia (including antipsychotic drugs for people with advanced dementia).
- **Location** – Where someone lives has a significant impact on the range and type of supports available, as well as the ease with which they and their family/carers can travel to access or provide support.

4. How would addressing these challenges change lives?

“In my humble opinion, focus has to move away from entertaining people with dementia to empowering people with dementia by putting the foundations in place to allow someone like me to be more independent which in turn will enable me and my family to contribute both socially and financially to society and to live well as a family with dementia.”

“Less embarrassment and an ability to converse more effectively with friends and family.”

- **Greater societal awareness** – This was seen as critical to addressing stigma, increasing earlier diagnosis, reducing isolation, and raising the esteem of those working with people living with dementia.
- **Better support for families/ unpaid carers** – By better supporting families and unpaid carers, their physical and mental wellbeing improves and they are better able to support themselves and the person living with dementia. It is also critical to enable family members to remain in touch with their communities, to have support signposted for them to avoid them having to constantly have to advocate and navigate a complex care system, and to have appropriate care breaks (including a more reactive short break provision).
- **Improved quality of life** – Through a greater range of more co-ordinated support, people can be enabled to live the highest attainable quality of life, within their own communities. This includes upscaling the availability of rehabilitation support, as well as actively connecting people to community and peer supports.
- **Equality in access to the right support and care** – A range of options were suggested for how more equitable access could be delivered, including enhanced insurance schemes used internationally. Expanding the capacity and range of community-based supports was also critical to ensure more people can live well at home.
- **Reducing need for specialist care** – It was urged the ‘grey bit’ between the initial year of PDS support and the condition reaching an advanced stage was addressed. By increasing signposting and access to a wider range of supports in this period, this would both potentially slow progression of the illness, as well as ensuring those crisis services were only called on when absolutely necessary. Instead, people could live well for as long as possible in their own home and community. Explicitly mapping out in each community available supports, both formal and informal, was suggested.

- **Address delayed discharges** – Building capacity in social care through workforce investment and development would contribute to people leaving hospital in ways that are planned, timely and supported. Additionally, streamlining the guardianship and Power of Attorney processes in terms of administration and cost was advocated to enable family members to more effectively participate in decisions about the person’s care, while needing to maintain in-built protections for the individual’s welfare.
- **Enabling personal choice** – It was urged the Strategy genuinely consider people ‘in the round’ and focus on enabling preferences as well as needs to be met.
- **Belonging and connectedness** – By unlocking the ‘natural assets’ of communities and peer support early, self-stigma and fears of a ‘death sentence’ can be challenged. More widely, raising societal expectations for what people living with dementia and their carers can achieve would help challenge stigma. In turn, this would lead to more empathetic responses from communities and a more empowering experience for people living with dementia.
- **Person centred care** – The promise of SDS needs to be fulfilled, with a truly person-centred focus adopted across services and settings so that they follow and adapt to the person, rather than expecting it to be the other way around. Replacing the current ‘just in time’ model for commissioning social care support was identified as a contributor to a shift towards more consistent and higher quality, outcomes-based, relational support.
- **Palliative care** – Streamlining access to appropriate supports as the condition advances was urged, recognising changing demographics will likely result in more people dying due to dementia. Greater scrutiny of these supports at the palliative stage, and communication with families/carers at this highly sensitive time, was proposed.
- **A better trained workforce** – Greater specialisation, an increase in new and different types of roles, targeting recruitment campaigns for key professions and raising the value and esteem they were held in were all suggested as part of boosting the workforce. In turn, this would increase the range of choice of care and support available. Cultural gaps between professions also needed to be addressed through more integrated working, utilising the knowledge and skills of the collective workforce.

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

“We should treasure our care staff, and not treat them as deserving the same salary as someone who stacks shelves!”

- **Lessons learnt from pandemic** – There was a need to be vigilant of the continued impact of Covid on the dementia community and the potential for further protections being put in place. It was urged that this be balanced with respecting the full range of human rights for those in residential care.
- **Making PDS commitment meaningful for all** – Raising the numbers accessing PDS would be a critical step, as well as linkages to community supports in order to ensure people continue to access advice and support after the one-year delivery. The role of Link Workers in providing holistic support during this period was urged, as well as considering whether the trigger for a year’s PDS needed to be automatically upon diagnosis, or whether people could wait to decide when and intensive support would be most valuable.
- **Meaningful community participation** – This included within the current strategy, in particular for those with advancing dementia whose voices might not be heard through the Lived Experience Panel or the National Conversation. Cross-agency community support through initiatives like the Herbert Protocol were praised. Also cited were community participation opportunities, such as money advice services that enabled the dementia community to ‘take care of its own’. Greater cultural participation through dementia friendly spaces, such as theatres, cinemas, choirs and Scottish Ballet, was also urged.
- **Multidisciplinary care models** – Taking good practice, establishing the principles for its success, and implementing these across other areas was urged. This included the use of multidisciplinary teams, the creation in some settings of dementia ambassadors/champions, and balancing the development of new care models with ‘traditional’ supports, such as day centres.
- **Address staffing gaps** – Elevating the esteem of the ‘dementia workforce’, enhancing learning opportunities and making better use of existing skills and knowledge was called for. There was said to be untapped potential among the existing AHP workforce in areas including diagnosis, maintaining physical and cognitive capacity and supporting carers to adopt a re-ablement role. Utilising these roles effectively could contribute to a more responsive and innovative system of supports.
- **Tackling postcode lotteries** – Recognising the principles of good support and enabling these to be delivered to fit local need was seen as a means of addressing negative local variation.

- **Dementia-friendly communities** – These were seen as a critical initiative for building connections across people and place, fitting with wider policy initiatives (such as 20-minute neighbourhoods). This included the Meeting Centres model, with many participants in our National Conversation calling for greater support for these. Learning from communities that understand, welcome and are inclusive of people living with dementia was urged. To deliver this work, the Scottish Government was urged to listen to and enable bottom-up community development from local areas. Nationally, messaging around communities could be targeted to persuade wider society of the importance of communities being dementia-inclusive and enabling.
- **Return of agency** – The progress being made to do so was recognised but needed further amplification. This included through the Strategy’s development, co-produced by the Lived Experienced Panel, and how this return of agency to the dementia community needed to continue as part of care and support delivery.
- **Prevention agenda** – Enabling participation across the range of preventative activities, from the great outdoors to physical health activities (under a social prescribing banner) was urged, as well as leveraging resources within communities to keep people well at home for longer. New developments such as community-based specialist dementia care and brain health clinics could also create a more connected system of support and prevent the progression of the disease, including through new and emerging treatments. Raising understanding of potential ‘risk factors’ was called for, while balancing and avoiding messaging which imparted any sense of ‘blame’ towards people for their lifestyle choices contributing to them developing dementia.
- **New innovations and technologies** – A more joined-up approach to identifying and utilising new technologies was urged. This included commercially available hardware like Fitbit to enable the monitoring of activities, in partnership with the person being supported. Learning was also offered from global developments.
- **Increased involvement of families** – Through clear material and signposting from diagnosis onwards, it was hoped families’ contribution would be heard and valued. The benefits of developments like Meeting Centres to families of people living with dementia needed to be better recognised. Communication with families at key junctures such as hospital discharge needed to be overhauled to reflect the central role of families in supporting people to stay well in their communities, as well as legislative duties under the Carers (Scotland) Act 2016.

6. What else do you want to tell us?

“If you treat anyone as if they don't matter they will soon deteriorate physically and mentally. They do matter, they are people, those who have brought us up and contributed to society. And we will be them in the future.”

- **Learning from previous strategies** – Taking on the work of previous strategies to deliver more person-centred care to keep people well for longer at home was urged. Also critical was measuring progress made as a result of these and future strategies, to give confidence progress is being made. Having a robust governance structure with lived experience voices to hold people to account would support this. Being more systematic in evidence gathering was called for, including in relation to equalities issues. Other lessons highlighted were: the impact of austerity on maintaining innovative supports locally; the issues caused when strategies are not in accessible formats for all, and; the need to embed human rights across the work of the strategy.
- **Accessing supports** – The role the National Care Service could play in ending the complexity of accessing the right supports was highlighted. These supports extended to advocacy, with the importance of financial/legal support at critical junctures not to be underestimated.
- **What people ‘put in’** – A sense that what people have ‘put in’ to the system in terms of economic and social contributions was not reflected back in the cost of residential care for them and their families was highlighted.
- **Cycle of perception** – Frequently spoken of was the ‘untrodden path’ of diagnosis for many who have no immediate peer support to call on and the ‘unwritten’ requirement for many people living with dementia to have a strong and articulate carer to help them get the right care. These heightened negative perceptions of the capabilities of people living with dementia. The need to address this through mainlining lived experience voices in how the Strategy will be delivered, improving reporting and monitoring of strategy implementation and building awareness of the condition to enable a climate of change was urged.
- **Sport** – The links to some sporting activities and dementia prevalence was highlighted, as were the benefits of physical exercise for people living with dementia.
- **Rare types of dementia/symptoms** – The experiences of families with genetic-based childhood dementia were highlighted alongside other rare types of the condition. Services were felt to be unable currently to adapt to such need.



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