

New National Dementia Strategy

Consultation Response

December 2022



Contents

Overview	3-8
Who we are	3
How we have approached this consultation	3-5
Our methods of engagement	5-6
Social Model of Dementia	6-7
Our aspirations for policy design	7-8
Summary	9-12
Key Messages	9-11
Specific Asks	11-12
Community and Friendship	12-30
Supporting and Enabling Dementia Friendly Communities	12-17
Community as a form of Post Diagnostic Support.....	17-21
Grants and Funding	21-23
Limitations to the current funding model	23-25
Case Study 1: Celebrating the voices of lived experience	25-28
Case Study 2: The power of Peer Support and Representation	28-30
Post Diagnostic Support	31- 43
Access to Post Diagnostic Support	32-33
Continuity of care throughout the dementia journey	33-35
Transport	34-37
Housing And Independent Living	38-42
Information and advice for the dementia journey	42-43
Care	44-53
Stabilising workforce to enable person centred care	41-46
Dignified Continence Care	46-48
Self-Directed Support	49-51
Independent Advocacy	51-53
Unpaid Carers	54-
Post Diagnostic Support For Unpaid Carers	57-59
Adult Carer Support Plans	59-61
Right to breaks from Caring	61-63
Conclusion	64-65

1. Overview

1.1 Who we are

About Dementia is Age Scotland's Forum for Policy and Practice for people living with dementia and unpaid carers. Funded by Life Changes Trust, we bring people affected by dementia together with professionals in the public and third sector to influence change around policy and practice in Scotland. We strive to create an environment in which people with lived experience lead the discussion and set the agenda on areas of change.

In recent years, our core activity has focused on both of our lived experience Human Rights groups, creating a safe space for people living with dementia and unpaid carers respectively. Members work together to highlight the impacts to their human rights by sections of society. Both groups have been actively engaged with influencing our response to National Care Service and our submission for the new National Dementia Strategy. We have also explored particular policy areas through a number of thematic 'sub-groups'. The groups gathered evidence and proposed policy improvements around the following: Housing, Transport & Mobility, Human rights of Unpaid Carers, Prevention & Living Well, Technology, and Befriending & Peer Support.



Fig 1.0 About Dementia's Working Groups

1.2 How we have approached this consultation

Our starting point, as with all of our activity, has been the voices of people living with dementia. Over the first three years of our project, we collected a wealth of evidence from our members about the challenges facing them in daily life, both pre and post lockdown. However, given the importance of the new strategy, we have been keen to ensure that we widen the representation of voices within our submission. To enable multiple opportunities to share views, we organised five online engagement sessions and fourteen in-person

sessions. Additionally, we launched an interactive National Dementia Strategy Engagement Pack, to enable community groups to conduct their own engagement activity.

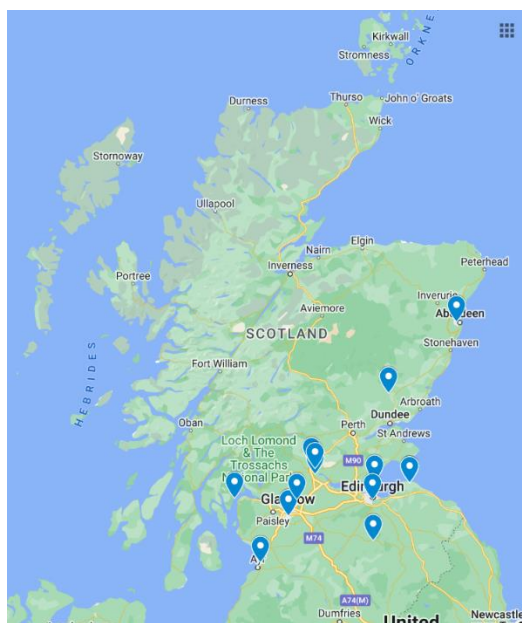


Fig 1.1 Geographical Plot Map of In-Person Engagement

Engagement took place between the end of September and the end of November 2022. Recognising the importance of ease of engagement, we took a hybrid approach to our workshop activity. Four online sessions were held; two for members of About Dementia's Human Rights Working Groups, an online event for stakeholders who were unable to attend our in-person event, and a workshop at the Carers' Parliament. The vast majority of our engagement activity has taken place in person, and in communities that people living with dementia are already a part of. About Dementia's organised engagement sessions reached approximately 267 people living with dementia (N=83), unpaid carers (N=84), and professionals (N=100). More details about our engagement events are available in Figure 1.1 and 1.2 below.

Location	Person(s) Living with Dementia	Unpaid Carer(s)	Professional(s)	Total
September Online Engagement	1	5	0	6
October Online Engagement	1	5	0	6
November Online Engagement	1	3	0	4
Carers Parliament Engagement – Online	0	3	4	7
Carers Parliament Engagement – In Person	0	1	5	6
Stakeholder Engagement – Online	0		4	4
Stakeholder Engagement – In Person	3	1	30	34
Ceartas – Kirkintilloch	5	6	2	13
Kirrie Connects – Kirriemuir	16	0	5	21
Meeting Centre – Prestwick	3	4	3	10

Dementia Friendly Tweeddale	5	23	5	33
Cowal Befrienders – Dunoon	9	0	3	12
Carers Parliament – Edinburgh	0	2	6	8
Eric Liddell Centre – Edinburgh	0	5	3	8
ACE – Aberdeen	7	0 (+7 children)	4	20
Townbreak – Stirling	6	3	7	16
Glasgow’s Golden Generation	6	7	2	15
STAND – Kinghorn	4	6	3	13
Dementia Friendly Dunblane	-	-	-	43
Extended Engagement - St. Andrews Carluke	16	10 (+3 children)	14	42
	83	84	100	267

Fig.1.2 Breakdown of Engagement Attendance, Septemeber 29th to Novemember 30th.

Our ‘National Dementia Strategy Engagement Pack’ was designed to empower community groups to carry out their own engagement activity. Our launch for the pack was attended by 41 people, and it was distributed to approximately 160 people afterwards. As well as professionals, we invited people living with dementia, and unpaid carers to attend. The Engagement Pack contained two interactive session plans designed to encourage discussion with people living with dementia, and unpaid carers. The policy areas covered in the session plans were Friendship & Community Support, and Care & Complaints. The pack was based on the methods we developed for our own engagement activity and was based on two of the topics we used.

We feel the extensive level of community-based engagement organised by About Dementia was warranted given the gravity and impact that a new National Dementia Strategy may hold. The willingness shown by our contributors to engage with the consultation response demonstrates their determination to see significant improvements made across Scotland for people living with dementia and unpaid carers.

1.3 Our methods of engagement

To cater the in-person sessions to a mixed audience of people living at various stages of dementia, current and former unpaid carers, and professionals, we took a novel and creative approach. We designed interactive workshops featuring icebreakers, songs and games to gently orientate and introduce a set theme. Over the course of 2 months, we delivered sessions which covered:

- Finance
- Independent Choice and Self-Directed Support

- Friendship and Community Support
- Care and Complaints
- Human Rights
- Primary Care

We adopted a storytelling methodology to our engagement in an acknowledgement that many of the topics we were addressing could be sensitive and raise personal or emotive issues for participants. This approach depersonalised the topics and requested that attendees give tailored advice to a fictional character experiencing dementia. Workshop participants were able to choose how much of their own story they wanted to share, this prevented anyone feeling ‘put on the spot’. This ‘one step removed’ approach created a cathartic environment for people to talk about dementia, and participants expressed their thanks to the About Dementia team for enabling a safe space to hold such important conversations.

1.4 Social Model of Dementia

About Dementia adopts a Social Model approach to dementia, and it is from this perspective that this response is framed. The social model is drawn from an understanding that the challenges faced by people living with dementia are often caused by the organisation and structure of support, rather than from the disease itself. The Dementia Friendly Communities we visited during our engagement provided ample evidence in support of this approach over a medical approach.

When people see the word ‘dementia’, they make a variety of assumptions that are not accurate – people assume that if you have dementia you can’t think. And that’s rubbish.

– Person Living with Dementia, Cowal Elderly Befrienders, Dunoon

When medical professionals see the word ‘dementia’ on your file, they are unable to see anything else. Treat you like a set of symptoms, rather than a person.

– Person Living with Dementia, Cowal Elderly Befrienders, Dunoon

Our engagement revealed concerns that taking a strictly medical approach to dementia can be de-personalising and lead to the individual being overshadowed by their disease. This is not to say that we do not accept the need for medical intervention, particularly in the later stages of dementia. All people living with dementia are entitled to excellent medical care and treatment, and as much choice and involvement as possible in their end of life care decision. However, the overarching view is that taking a social model approach enables one to see a person with dementia as an individual and reframes opportunities to engage in therapeutic and social activities. Such interventions can help to enable people to live active, connected lives following a diagnosis, which can help them to remain well for longer. This

approach may also enhance the visibility of dementia and reduce the stigma that continues to be associated with it.

1.5 Our aspirations for policy design

We were pleased to welcome members of the Dementia Policy Team from the Scottish Government to many of our in-person sessions. This was a mutually positive experience for all involved, allowing the Dementia Policy Team to witness the instrumental value of community-based support first hand, alongside being available to answer any questions directly from workshop attendees. We welcome this integrated approach to engagement; it echoes commitments made by Minister for Mental Wellbeing and Social Care, Kevin Stewart MSP, to prioritise the voices of people with lived experience. We would hope that this sentiment is shared and continued by others responsible for the National Dementia Strategy's development and hope there will be further opportunity for it in the future. Feedback from several attendees towards the presence of a government official was very positive.

This time, someone is listening – that's all we can ask.

- Unpaid Carer, Prestwick Meeting Centre

With rates of dementia diagnosis set to increase by over 50% in the next 15 years, we ask that adequate thought for the unique circumstances of people living with dementia and unpaid carers is given when designing the new strategy (Public Health Scotland, 2022). This includes providing help and support for those who are currently living with the condition, as well as looking to the future at those who will inevitably need help after diagnosis. As we've heard many times throughout the lifespan of About Dementia, 'If you've met one person living with dementia, you've met one person living with dementia'. There is a huge diversity in the experience of dementia, with people being diagnosed at a much younger age.

For many, this will be the biggest opportunity for influencing change in relation to dementia that they have experienced since their diagnosis or connection to dementia began. We received overwhelmingly positive feedback from the organisations that we engaged with, with many emphasising the way the sessions enabled both meaningful engagement, as well as being good fun for participants.

We have been very encouraged by the approach of your team - despite the seriousness of dementia and its effects on people, you are demonstrating that it is possible to have positive and optimistic conversations on the subject and this is proving to be infectious!

- Cowal Elderly Befrienders, Dunoon

We hope this response will serve as precedent for future strategies, shining a light on the many experts-through-experience who were generous enough to contribute to it.

Given the breadth and depth of responses we received through engagement with our members, we have taken the decision not to respond directly to the questions contained within the consultation document. Instead, we present an analytical overview that demonstrates the range of views expressed by our members and allows their voices to be communicated directly through extensive quotations.

2. Summary

In the remainder of this submission, we present a thematic overview of some of the evidence from our engagement. This is backed up with both academic and grey literature from the significant work carried out in the dementia field in Scotland. From this we have drawn a number of key messages, and specific asks that we believe should be at the heart of the next dementia strategy. The key messages describe our vision for dementia policy in the coming years, based on the evidence we have presented in this paper. Our specific asks outline some of the actions we believe need to be taken in order to enable the realisation of our vision. The list of asks is not comprehensive or exclusive, and there may be other actions required that we have not included here.

2.1 Key Messages

We believe in a Scotland that provides the best quality, most innovative and evidence-based support for people diagnosed with dementia and their families and enables the full realisation and enjoyment of their human rights. A number of things need to change about the way that policy is currently delivered in order to achieve this. Our vision for the next strategy is one that has:

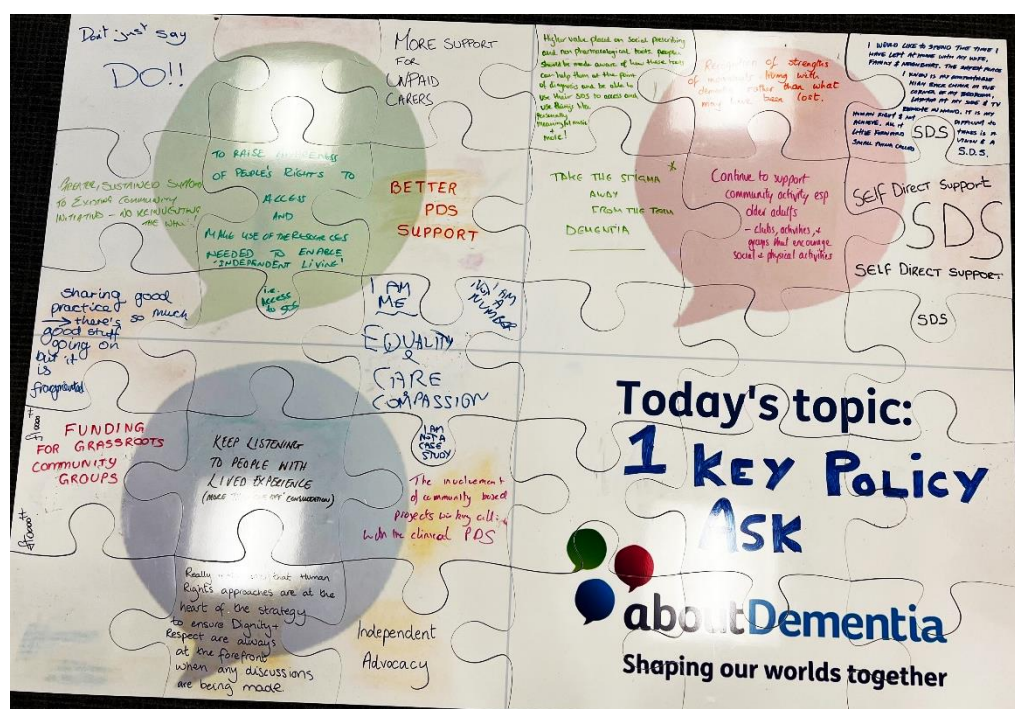
- Truly person-centred Post Diagnostic Support, based on choice, available at any time in a person's journey, and includes a recognition that peer support and community-based initiatives may be more appropriate for the individual.
- Increased and sustained funding for peer and community-based support that acknowledges the integral role this support plays in helping a person to stay connected and informed, and live well. Additionally, a recognition that these initiatives are a part of social care.
- A larger focus on the social model as an enabling way for people living with dementia and unpaid carers to live well. Emphasising benefits of non-pharmaceutical interventions such as playlists or social prescribing and taking a holistic and person-centred approach to what dementia care involves.
- Improved advocacy for people living with dementia which includes independent, specialist dementia advocacy available at all points in the journey, but particularly when someone seeks social care or enters hospital.
- Improved access to SDS, with reduced inhibitive eligibility criteria, to enable aspirational care for people living with dementia and unpaid carers.

This vision was drawn from the evidence we collected throughout our engagement. We shared an overview of our findings with attendees at our Stakeholder Engagement meeting in Stirling in late November 2022. A morning of workshops concluded by asking participants what their one policy ask would be for the new strategy. A summary of their responses is below.

Fig 1.3 – During our Stakeholder Engagement event in Stirling, each discussion table were asked to name one policy ask to bring forward in the strategy. Table displays a summary of those asks.

One Policy Ask From Each Table, Stakeholder Engagement Stirling	
Improved Access to Self-Directed Support	<ul style="list-style-type: none"> · Promote SDS over full-time care, as a preventative measure. · More accessible Self-Directed support. · Better understood and managed service.
Focus on Social Model	<ul style="list-style-type: none"> · Reduced focus on the medical model of dementia. · Goes some way to removing stigma of ‘terminal illness’ diagnoses. · Social Model is more socially inclusive, and less isolating.
Increased Funding	<ul style="list-style-type: none"> · Across all sectors of care, and in particular community led projects/hubs which aim to help people live independently for as long as possible.
Continued Meaningful Involvement of Lived Experience	<ul style="list-style-type: none"> · Those with lived experience are the people that will have to live with the decisions made in this strategy. · They know their circumstances best, and so they should be talked with, not at.
Availability of Information	<ul style="list-style-type: none"> · Information is useless if it isn’t relevant to you. · Often, timely information delivered by peers during informal conversation is more accepted and appreciated. · Carefully co-ordinated information which is kept up to date and available from all sources possible from diagnosis moving forward.
Easily accessible Post Diagnostic Support	<ul style="list-style-type: none"> · PDS should not be a postcode lottery.

Fig 1.4 – Participants at our Stakeholder Engagement wrote policy asks on a puzzle piece.



2.2 Specific Asks

In order to achieve our aim, we call for the following measures:

Community	<ul style="list-style-type: none"> Increased and sustainable financial support for community-based services across Scotland Recognition that community-based services are a form of Post Diagnostic Support for people living with dementia and unpaid carers. Utilise intergenerational spaces to promote awareness, education, and support around dementia within a community.
Post Diagnostic Support	<ul style="list-style-type: none"> Improved access to Post Diagnostic Support through expansion to forms of community-based support. Improved policy connections between different government departments and Dementia, including Housing and Transport. Continuity of access post diagnostic support information and advice throughout the journey. Again, this should recognised community based approaches as part of the plurality of options and choices available. Access to flexible and varied Post Diagnostic Support to suit individual needs and preference. Home adaptation assessments to promote independent living being carried out at point of diagnosis as a preventative measure. Explicit and improved connections between housing and social care irrespective of the mode of governance (IJBs or Local Care Boards)

	<ul style="list-style-type: none"> • Accessible information about services and support at the point of diagnosis.
Care	<ul style="list-style-type: none"> • Investment in a high quality, well remunerated and qualified workforce to enable truly person-centred care. • Commitment to ensuring dignified and better understood continence care. • Improved access to and understanding of Self-Directed Support. • Enable independent advocacy for those living with dementia to ensure their needs and wishes are being met at all stages of the journey.
Unpaid Carers	<ul style="list-style-type: none"> • Right to flexible breaks from caring. • Equip unpaid carers to better understand their rights and entitlements. • Effective training and support to the workforce to ensure that all agencies are aware of and working to implement carer's rights. • Enhance funding for and access to community-based peer-to-peer networks for unpaid carers (former and current). • Continuation of Carer's Allowance after care home or hospital admission, recognising that the caring role does not stop at the point of admission. • Full implementation of Carer Support Plans and the Carers Act across all local authorities and agencies. • Scottish Carers Assistance should continue to be available after state pension age. State Pension should not be classed as a benefit but an entitlement. • A flexible and easy to access Carers' Development fund to enable carers to undertake training related to their caring role and beyond.

3. Community and Friendship

A community-based approach to dementia

Age Scotland has a long and rich history of supporting and enabling grassroots community-based activity and continues to operate as a membership organisation made up of community-based older people's groups. As one of the National Legacy Partners for Life Changes Trust, we are also the repository for their vast bank of evidence and learning around Dementia Friendly Communities. Since January 2022, we have been funded by the Dementia Policy Unit at the Scottish Government to embed and enable grass roots approaches to community-based support for people living with dementia. This has included funding for the Scottish Meeting Centre Network, work to establish the Scottish Dementia Friendly Communities Network, and two grant funding programmes. The work is subject to a robust external evaluation by Blake Stevenson, the learning from which will be presented to the Dementia Policy Unit separately from this submission. Early evaluation suggests this work is already improving wellbeing of lived experience panel members and increasing the level of community-based and local support.

This section shares some of our learning from this work, as well as through our engagement, to demonstrate the critical centrality of grassroots community support to people living with dementia. Though this approach has not been recognised in previous Dementia Strategies, we demonstrate that community organisations provide a vital safety net to people living with dementia, papering over the cracks between formal dementia support, social care, and clinical care.

3.1 Supporting and Enabling Dementia Friendly Communities

Fig 2.1 Life Changes Trust key principles for dementia friendly communities



There is no single definition of a Dementia Friendly Community (DFC), however, there is consensus that they include both geographical communities (a village, for example, or a neighbourhood within a larger town or city) as well as communities of interest which focus on a common activity (for example walking, sport, or singing). The Life Changes Trust funded 40 DFCs in Scotland between 2015 and 2020 and an evaluation of the programme identified the nine principles, as seen above, which contribute to a successful community.

While Dementia Friendly Communities are often informal networks, there is a growing movement towards formalising the support they provide by establishing Meeting Centres. Five of the DFCs we visited during our engagement classify themselves as Meeting Centres.

Meeting Centres are a form of hyper-localised, community driven Post-Diagnostic Support (PDS). They are designed through co-production with a range of different community members and stakeholders, and often involve statutory services, though they are not driven by these. In contrast to day centres or more traditional approaches, Meeting Centres are not regulated services, but instead are community-led and driven by the needs and wishes of the membership, who attend on a regular basis. The focus of support is also on both the person living with dementia and family members.

The model emerged in The Netherlands in the early 1990s and has since gained international relevance with centres emerging on every continent (Brooker et. al 2017). The approach has been so successful that the Dutch Government have recently committed to 80% of the population having access to a Meeting Centre by 2030. The creation of Meeting Centres in the UK has been supported by research taking place at the University of Worcester, England, with the first Scottish Meeting Centre opening in 2019 in Kirriemuir, Angus. The research in the UK and internationally has demonstrated considerable positive outcomes from involvement in meeting centres, including prevention, brain health, international cooperation, and the provision of meaningful opportunities for people living with dementia through the 'Dementalent' volunteering programme.

Alongside the creation of the first Meeting Centre in Scotland, Life Changes Trust has provided funding and support to Kirrie Connections, Scotland's Meeting Centre Demonstrator Site, to enable the expansion of this model across other areas the country. Since 2022, About Dementia has provided funding to Kirrie Connections to facilitate the Scottish Meeting Centres Network through our partnership with the Scottish Government. There are now 11 meeting centres open or shortly due to open in Scotland with a further 13 community groups exploring the potential of forming a meeting centre.

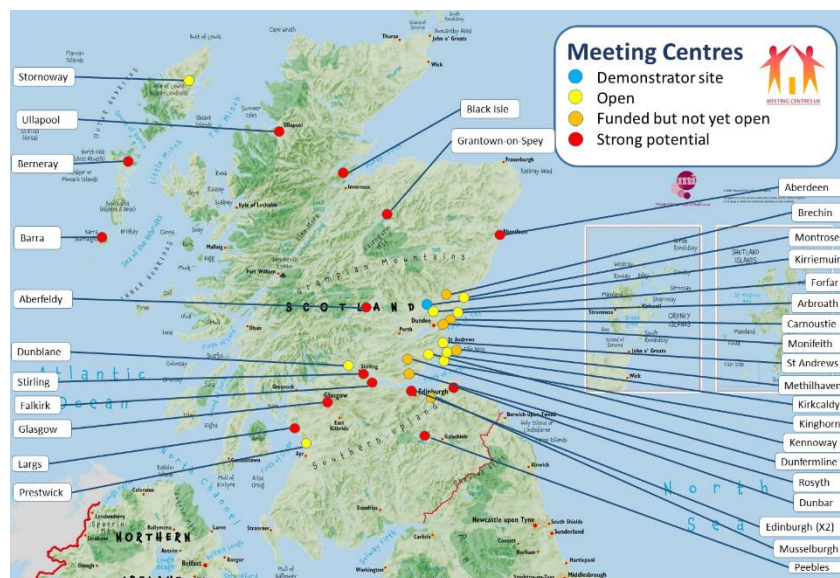


Fig 2.2 Plot Map of Scottish Meeting Centre Network Vision

The Scottish Meeting Centres Network are in the process of formally constituting as a SCIO. About Dementia are currently running an open call to provide seed corn funding to a further 5 meeting centres in Scotland.

Each group we visited during our engagement activity, irrespective of the model they adopted, provides vital support to people within their locale. The benefits reaped by participants who utilised the resource was evident beyond measure. In the majority of cases, people cited their local group as a source of advice, a social connection, support, and a place of friendship.

I come here once a week and it's a lifeline. Yes, I have family nearby who I like seeing, but I love the friends I have here. I really enjoy the social interaction. Getting up to no good! My wife is in the hospital at the moment, has been for weeks, and coming here to a friendly face and good food beats sitting in the house by myself. It's a nice change.

– Person Living with Dementia, ACE Aberdeen

These services prove to be a vital salvation for many people, their value being especially apparent during the pandemic. When other services had shut up shop, community-based initiatives stepped in to fill the gaps of care that were previously delivered by registered services. Examples of this include the Braeport Memory Café in Dunblane who delivered fish and chips to members throughout the 2020 and 2021 lockdowns. While adhering to social distancing regulations, they stayed for a quick catch-up chat, which maintained essential social contact when the Café members were unable to meet.

Services based in the local area enables members of a DFC to stay connected to other resources nearby. In our session around community, when asked what services are essential to a prosperous and supportive community, participants included suggestions of a library

(Aberdeen), open park space (Glasgow) and easily accessible shops (Kinghorn). Most importantly, each group confronted with this question highlighted the importance of having ‘one of these’ (Participant at Kirriemuir engagement session) – implying that every community should have a Meeting Centre of some sort.

Participants in our engagement identified community groups as a vital form of Post Diagnostic Support. One piece of advice, which ran throughout our engagement, was linked to finding a service like a meeting centre within your community as a valuable first step in accessing support.

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.

– Postcard Feedback, Kirriemuir Meeting Centre

These communities within communities, are invaluable networks to help people maintain links to their local area. This was further evidenced from our visit to Aberdeen to observe and engage with an intergenerational partnership between a Heathryburn Primary school and Kingswood Day Centre. The visits are facilitated by a volunteer from ACE Voices and take place throughout the entire school year with the same children visiting each time. Our Influencing & Engagement Officer shared her reflections from the visit:

We worked in small groups to create posters designing our ideal community.

The children used their imagination including everything from cats, a pub, a donut shop and unicorns. One group drew a football pitch as a man in their group had been a professional footballer in his youth.

The kids behaved exactly as you would expect them to. It was chaotic, loud and they cheekily poked fun at the older adults. To my surprise, the adults loved it. When I asked everyone what their ideal community would look like, children and adults alike said “here”.

Intergenerational connections within the community had been viewed as a great success in this project for both age groups: connecting and educating younger people within the community, while stimulating those living with dementia. The benefits of these intergenerational connections for people living with dementia is well established, and a growing area of interest (Christie et. al, 2021). Indeed, during Deepness Dementia Media’s 100/6000 gathering, we were heartened to hear of an initiative in Fife in which new care homes will be built with a children’s nursery attached, again bringing the wider community into the lives of older adults.

The ability to create a welcoming and inclusive environment is another essential feature of DFCs recognised in our engagement. Contributors made clear that these services are not

exclusive to support people with a diagnosis of dementia, they also act as crucial support for current *and* former unpaid carers. Additionally, several people attending our sessions had not yet had a formal diagnosis of dementia. The groups we visited were accepting of anyone who needed support; they did not discriminate.

Due to their inclusive nature, Dementia Friendly Communities cast a wide net throughout the local community itself. We were encouraged to see such a wide range of attendees at Dementia Friendly Dunblane's Braeport Memory Café. Throughout the session, the café was attended by; mothers and toddlers, a primary school class, secondary school pupils completing their Duke of Edinburgh Awards, a master's student studying dementia, a Ukrainian refugee, and volunteers with past experience of family caring. Dunblane's Braeport Memory Café serves as a true example of the reach and opportunity DFCs have to bring in all members of a community, and situate people living with dementia as full citizens and active agents within that.

A natural benefit of the local groups is that they allow people to come together socially over a long period of time, providing changing and flexible support as people move along their dementia journey or their lives as unpaid carers. People also pointed to social support as a way to maintain independent relationships, outside of the family home, in later life. Having a wider social circle and feeling positive about the local group had a dual benefit of allowing unpaid carers necessary breaks and peace of mind when a person living with dementia was at their group. While there was much discussion about the availability, duration and quality of formal Post Diagnostic Support and Self-Directed Support, the community group provided ongoing and dependable support and friendship:

I don't know what I would do if this place closed. After my husband died, I had no one. I was a mess before I came here, it really changed my life. Staff are accommodating and kind.

– Person Living with Dementia, Aberdeen

3.2 Community as a form of Post Diagnostic Support

Over the past decade of Dementia Friendly Community activity in Scotland, there has been an ever-growing call for community-based initiatives, including peer support and Meeting Centres, to be rightfully recognised as integral to the delivery of dementia support. This was echoed throughout the engagement we have conducted on this strategy. The sentiment perfectly captured at our Stakeholder engagement event in Stirling in November, when one participant commented that community led initiatives are not merely a 'fluffy add-on', but instead a potent and cost-effective form of providing relevant and person-centred support throughout the journey of dementia.

A model of dementia Post Diagnostic Support delivery which works with people in a community-based and/or group environment, as we will show, is not only cost effective, but throughout our engagement we have found it is often the preferred option for people living with dementia and unpaid carers. Sadly, loss of friendship and social connection due to

stigma and misconceptions around dementia are all too common. Despite attempts to maintain or rekindle friendships, many people, including unpaid carers, find themselves isolated and lost.

I got diagnosed at 54. Lost my job, lost my friends.

My partner of 10 years walked out.

My peer support group gave me a purpose in life.

- Person living with dementia, speaking at the 2021 100/6000 Conference, delivered by Dementia Deepness Media

Members of About Dementia's Befriending and Peer Support group shared their honest acceptance of this loss, though also pointed to a hopeful opportunity for new connections to emerge. One unpaid carer referred to this experience by using the Japanese word 'Kaizen', explaining it meant 'change, but for the better'. Other descriptions and meaningful associations to peer support can be viewed in our word cloud below. The word cloud was created from engagement from our Befriending and Peer Support workshops, highlighting the many meaningful benefits the group attributed to peer support.



Fig 2.3 Word Cloud, Befriending and Peer Support Working Group

The section on Post Diagnostic Support below outlines some of the challenges faced by the existing formal model of delivery in Scotland. We contend that despite these challenges support both pre, during and post diagnosis has taken place through other means. In the absence of traditional and structured Post Diagnostic Support, communities and individuals affected by dementia have created their own due to necessity.

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.

- Founding member of STAND, a peer support group for people living with dementia

Peer support offered an alternative avenue for people living with dementia and unpaid carers to speak openly about the raw aspects of dementia, without fear of repercussions:

*People can talk about the really difficult issues ...
such as suicide without thinking; 'Oh they are gonna safeguard me? [sic]*

- Unpaid Carer, Befriending and Peer Support Working Group

This authentic interaction is also evident in other forms of community-based support, such as Meeting Centres, where *“people open up because they know you’re not from a statutory body”*.

Yet, as we will demonstrate, community-based support, such as Peer Support and Meeting Centres, remains a silent and underfunded linchpin in the management of dementia in Scotland. This neglect of recognition not only adds to a false impression that community-based initiatives are secondary or lesser than formalised support, but inhibits successful signposting to effective approaches, preventing a much-needed blending of medical and social models.

It’s vital that we make sure that the community and the third sector are properly appreciated. It’s lunch clubs, it’s memory cafes, it’s all those things that are happening in our community and I think they really need to be properly valued, which I don’t think they are right now

- Third Sector Professional, National Care Service Engagement, 2021.

We really need to appreciate how vital communities in the third sector are [to] that preventative approach... often being the first point of contact.

- Third Sector Professional, National Care Service Engagement, 2021.

Community-based supports are enabling the exploration of new approaches to practice in dementia care. They have also provided fertile ground for the exploration of new partnerships. One such example is the collaboration between Dementia Friendly East Lothian and the Health Board and Health and Social Care Partnership to support memory clinics being conducted within community buildings – bringing healthcare professionals to where people already are. This not only enables diagnosis to take place in a safe, familiar, and non-clinical environment, but also allows newly diagnosed individuals to be signposted to community-based forms of support. A similar model is in existence in NHS Orkney, where the Consultant Older Age Psychiatrist holds diagnostic clinics in the offices of Age Scotland Orkney in Kirkwall. Individuals and families are then referred immediately on to staff in the organisation for the provision of Post Diagnostic Support, and to join their meeting place for peer-to-peer support.

Similarly, the growing movement of Meeting Centres in Scotland, supported by the Scottish Meeting Centre Network, is creating more opportunity for traditional health initiatives to meet people in their own community. Meeting Centres are based on a model developed in The Netherlands and strengthened by the evidence generated there over 25 years, Meeting Centres are essentially social clubs for people and families affected by dementia which are based in local community buildings. A key strength of Meeting Centres is their ability to help people living with dementia and family carers adjust to change, following the adaptation and coping model (Brooker, 2021). Important features of these are; the opportunity to build strong new social networks and friends, to prepare for an uncertain future, and learning how to get onto an even keel emotionally, assisted by the lived experience of others. Members meet several times a week and benefit from social activities, a shared lunch and peer support, including expert, informal and practical advice from trained staff and volunteers.

Kirrie Connections, based in Kirriemuir, have hosted Dementia Link Workers, offering a weekly slot as an informal drop-in for dementia curious or concerned local people. In a similar vein, Prestwick Meeting Centre have entered into a partnership to support externally led Cognitive Stimulation Therapy (CST). CST is an evidence-based treatment recommended by the NHS which has been found to improve general cognitive function, language comprehension and quality of life in those living with dementia. Prestwick Meeting Centre have given the NHS use of the room free of charge and ask only that anyone from the Meeting Centre is welcomed to seek information about the treatment themselves. Please note, our engagement workshops were built around the principles of CST, showcasing the progress that can be made when blending evidence-based research with community led approaches.

The benefits of a community-based approach are evident not only in the social benefits to the individuals involved, but, as we have indicated, in cost-effectiveness. The evaluation of the Life Changes Trust Dementia Friendly Communities projects conducted by Hammond Care included a Social Return on Investment analysis. This calculated that the average cost per person per year of supporting people living with dementia and unpaid carers to be an active part of their local dementia friendly community was £694.29 (Yates-Bolton and Thompson-Bradley, 2021).

Number of people with dementia reached:	12,374
Number of unpaid carers reached to date:	4,471
Average cost per head per year:	£694.29

Fig 2.4 Life Changes Trust Social Return Report Statistics

Further Social Return on Investment analyses were carried out on two Dementia Friendly Communities. The first case study focused on Dementia Orkney, a geographical DFC developed by Age Scotland Orkney, NHS Orkney and Dementia Friendly Orkney. It was assessed that the social value contribution for every £1 invested was estimated to be £5.16. The second, at Badenoch Shinty Memories Group, found the social value contribution for every £1 invested was estimated to be £4.83. We have seen throughout our engagement that smaller community-based projects work tirelessly to deliver significant impact on often very tight budgets.

3.3 Grants and Funding

About Dementia's contribution to Dementia Friendly Communities

About Dementia have been grateful to be able to play a small part over the past year to provide much needed funding to Dementia Friendly Communities through our partnership with the Scottish Government.

The challenges facing the sector have been evident in both rounds of our grant funds, though most evident in our most recent, having been targeted at smaller community groups. The Encouraging and Supporting Grassroots Activity Fund (ESGA) launched in late summer of this year with £145,921 available to support community-based approaches to dementia support. Overall, 78 applications from local, grassroots community groups were received. The applications supported a vast array of community-based services, with the majority focusing on social and community activities.

Fig 2.5 Blake Stevenson ESGA Fund Evaluation Report Statistics

Applicant activity	Applied	Shortlisted	% applied
Social & community activity	37	13	47%
Creative	18	12	23%
Reminiscence	7	2	9%
Movement	6	1	8%
Therapeutic	5	2	6%
Befriending	5	0	6%
	78	30	100%

The ESGA Fund was oversubscribed by £979,869, with the total requested figure standing at £1,125,780. Applications were submitted by community groups from various local authority areas across Scotland, as demonstrated in the map below, and shared many common themes despite their geographical diversity.

Post Covid-19 recovery was an important element of this. Many applications mentioned loss of social confidence and reluctance to re-engage on the part of previous clients, as well as a decline in mobility and physical confidence to get out and about. As we highlighted in our report into the experiences of people living with dementia 'Lockdown Down by Not Forgotten Report', the pandemic and lockdowns exacerbated isolation as people were unable to socialise in the way they had previously. Many core and voluntary services closed their doors or had to adapt to delivery to doorstep or telephone provision. Whilst this maintained contact in some form, it was often brief and transactional.

Applications frequently referred to the need to combat isolation and loneliness as a driver for a project: many of their clients live alone or are a sole carer for their partner.

There was also a clear indication that projects centred around activity are needed to promote reablement, enhance health and wellbeing, and to create a sense of self-worth. This goes beyond addressing isolation and loneliness and looks at helping people not just to exist but to live well with dementia.

The majority of projects were prompted by a desire to address poor mental health and feelings of obsolescence, giving people living with dementia and their carers access to meaningful activity and a sense of purpose. It was notable the extent to which project leads highlighted that many participants avoid activities that have medical or social care overtones, further evidence for the benefits of adopting a social model approach. People want to take part on their own terms and not feel they are being cared for or accessing a formal service.

Fourteen projects were awarded funding out of the 78 who applied to the fund. These decisions were made in collaboration with our lived experience funding panel who also worked with us to co-produce the criteria for the fund. These projects were decided based on how well they demonstrated meaningful involvement of people living with dementia and unpaid carers in the development of the work, as well as demonstrating the gaps in support that the work would address in the local area. All projects demonstrated the importance of grassroots community-led work in covid recovery, with a recurring theme of intergenerational work emerging as an important part of reconnecting people with their local community. The successful applicants include projects working with communities in



Fig 2.6 Geographical Plot Map of ESGA Funding Applications

rural locations such as Uist and Ullapool, where community-led work is particularly important in addressing a lack of services and isolation compounded by Covid.

3.4 Limitations to the current funding model

Availability and sustainability of funding is a significant challenge facing community groups across Scotland and was an important topic of discussion at both our in-person and online stakeholder engagement sessions. Twelve years of fiscal austerity has seen increasingly stretched local authorities cut statutory services, and the third sector has often been expected to step in to fill the gaps. However, without dependable and reliable sources of funding, this creates an incredibly challenging environment for community groups to operate within. Given the evidence presented above of the enormous contribution being made to supporting people living with dementia and family members following a diagnosis, this is a significant risk factor.

Two of the projects we visited for engagement told us they were unsure if they would be open, or have regular premises, in the new year. Our session at Dementia Friendly Tweeddale involved a group that was attended by over 40 people and continues to grow weekly, with ambitions of spreading into other areas of the Scottish Borders. The group was established by volunteers who recognised a gap in support across the area and is still staffed entirely by volunteers. At one community group we visited we spoke to the only paid staff member who had become unemployed several times in the past few years due to uncertainty of funding. They shared that they were once again at risk of redundancy should the project fail to attract sufficient funds.

Both projects rely on volunteers and are a lifeline for people living with dementia and their families. The possibility of them not continuing into the year ahead should cause concern and will no doubt leave a gap in support in the area and put families into crisis.

Relationships with local authorities and the mismatch between funding and expectations of delivery was another theme that came up in our engagement. At Cowal Elderly Befrienders, during a conversation around referrals, it was revealed that around 70% of referrals for the service come from local council or social work. However, only 20% of Cowal's funding comes from the local council, an amount that has not changed in 13 years despite obvious energy and cost of living increases. Cowal's remit covers a large geographical area, with transport provided as a necessity for many to attend, yet the minibuses were purchased entirely by the project itself.

Numerous groups we engaged with had sought funding through trusts and other sources outwith the statutory sector. Others, such as STAND in Fife, depend upon fundraising activities, seeking support from their local community. Other groups such as Dementia Friendly Prestwick have spent time fostering local relationships and relying on goodwill. Dementia Friendly Prestwick had recently entered a partnership with their local Royal Air Force Association who had offered offer premises for a peppercorn rent. The commitment from the local community to support such initiatives should be celebrated. The ingenuity of the groups mentioned should be admired, alongside their ability to take very small amounts of

money to deliver the extraordinary. However, it cannot be ignored that these groups are delivering a vital support that will evaporate without sustainable funding.

During a conversation, in Kirriemuir, about how community support should be funded, a group of people living with dementia suggested various avenues, such as local businesses, fundraising and charging a small daily fee to members. Not one person in the group suggested that the Scottish Government, or local government, should fund community initiatives such as Meeting Centres. When asked by the facilitator if Scottish Government funding could be a viable option as a funding stream, the group felt strongly that it should, 'we're still here', inferring that in terms of funding, this group felt invisible.

Challenges in the post-Covid-19 funding landscape were very much front and centre in our thinking when we were developing our approach to the Scottish Government partnership grants we developed. Often, project funding will require funds to be spent on project activity, rather than running costs, such as electricity or rent. We were concerned that if our grants did likewise it would inhibit many projects from applying, as they struggle to keep the lights on. With many projects supported entirely by volunteers, securing premises via goodwill, and relying on the support of their local community to donate food or funds, there is no margin for security and no more costs to be saved. In such a scenario, it may only take one volunteer becoming ill or one rejected funding application for an entire project to fold.

Time-limited funding can also cause challenges with attracting suitably qualified staff. This has been evident in the projects funded under the Empowering Dementia Friendly Communities Fund with several projects affected by delays in recruitment and all other projects being impacted by staff turnover throughout their funding period. This inevitably impacts on projects ability to deliver on their stated outcomes and was an evident cause of frustration expressed at our Stirling Stakeholder Engagement event. The frustration felt by projects around their ability to deliver outcomes was expressed during our stakeholder event in Stirling. Many attendees who supported local community-based initiatives pointed to their achievements with pride yet raised how much more value in return for investment could be achieved if sustainable and longer-term funding was given. Participants also commented on the detrimental impacts a scarce funding environment can have, causing projects to compete rather than collaborate. This does not always have to be the case, however. The Life Changes Trust worked hard to develop a collaborative atmosphere among projects and provided significant support to smaller projects who may have been unsuccessful in gaining funding first time around. While we are unable to address the funding environment alone, we are keen to foster this culture of collaboration through our work on the Scottish Dementia Friendly Communities Network in the coming two years. The network may also provide support to enable projects to combine forces through consortium applications, providing more opportunities to bid for greater sustainability.

Overall, throughout our engagement there has been an awareness shared by community-based initiatives that they are filling an increasing gap in support for people living with dementia and their families. Such projects are already turning every penny they receive into much needed and specialised dementia support, often to a larger group than one-to-one support offers. If we are to help people living with dementia stay part of their communities,

then we must trust the approach of community-based initiatives, fund them, and recognise their contributions appropriately – before they cease to exist.

3.5 Case Study 1: Celebrating the voices of lived experience

The contribution of the voice of people with lived experience is gaining increasing recognition at a policy level, both in the development and design of this strategy, and the National Care Service. Healthcare Improvement Scotland have also taken a similar approach in the development of the new SIGN Guideline on Dementia which is due out next year. Our involvement in the Empowering Dementia Friendly Communities partnership with the Scottish Government has given us the opportunity to test out new approaches to involving the voices of lived experience in grant-making, and we are keen to share our learning from this in the hopes of informing the approach that will be taken within the new strategy.

Having people with lived experience of dementia at the heart of activity was a core feature of the Life Changes Trust approach to Dementia Friendly Communities. We were keen to honour this in our approach to designing our own grants programmes. This experience has reinforced the belief that communities are not only geographical, as our panel has quickly become a firm and well-connected community of interest.

Our first funding program under the partnership was ‘Empowering Dementia Friendly Communities Fund’ delivered in March 2022. We recruited a panel of five people with lived experience of dementia to assess the applications for this fund support the decision-making process. We took the decision to create these as remunerated posts, paying a consultancy fee of £20 per hour to each panellist. This was an approach that had been successfully piloted by Life Changes Trust during their final year. It was also an important principle that those involved in making and supporting decisions had their expertise recognised and appreciated. This was greatly appreciated by the panel members, many of whom had felt undervalued and deskilled since their dementia journey had begun:

I am so honoured to be invited to do this and wish to accept,
with pleasure. It is a rare occurrence to be offered to be paid
and I cannot tell you just how much that means time, for which
I thank you most sincerely.

– Panel Member, Unpaid Carer

Our funding panel were joined by four new panel members for our second fund, Encouraging and Supporting Grassroots Activity, where we co-designed the fund from the ground up. We explored community support for people with lived experience of dementia during our panel meetings in detail, specifically:

- What does community support mean for the panel?
- What is needed within the community to improve the lives of people living with dementia and their unpaid carers?
- What should this look like? What values should the organisation have?

We drew upon the panels personal lived experience and concluded that community support is an integral part of strengthening communities. There was recognition that often the simple, small-scale activities make the most difference and that a small investment can go a long way:

Sometimes fairly small sums of money could make quite a big difference.

– Panel Member

In addition, the panel felt that community support should allow the everyday, simple, social interactions to take place. ‘Enable the ordinary,’ by removing the barriers for people with lived experience of dementia to get together and take part in groups and activities.

One of my hopes for this funding is that it could enable the ordinary activity that then becomes hard for people because of dementia, to take place.

- Panel member

These findings formed the key elements of what we were looking for from applicants in the ESGA fund. Alongside the above themes, several others emerged from the panel meetings:

- Addressing gaps in support for people with lived experience of dementia within local communities.
- Trialling new approaches and activities that will include and empower people with lived experience of dementia.
- Supporting intergenerational activity – this could be work with young carers of people living with dementia or work with young people in the community.

The importance of peer support was another key theme that came out from the panel meetings, and how integral that peer support had been for many panel members throughout the years. We witnessed first-hand the panel meetings themselves becoming a space for peer support and a supported learning opportunity. One of the panel members, who had never been involved in work like this before, was unsure if they had enough experience to be on a funding panel. The reply from another panel member follows:

When I was involved with the last panel, I knew nothing about assessment panels, but I learned so much. What was important was the panel value each other's contribution, and ideas...you have plenty to offer, don't undersell yourself.

The involvement of people with lived experience of dementia within these funds has been crucial in so many ways. Most importantly it ensures that the criteria for the fund have been co-designed with people’s real-life experiences of engaging with community support, what has worked for them and what is missing. This is an invaluable contribution and alongside the involvement in the decision-making process, it ensures that the investment into community support is impactful and based on people’s experiences.

We have witnessed a real appetite from our panel members to be meaningfully involved in all stages of the funding process. Similarly, our engagement has shown how important it is that community support is designed with the meaningful involvement of people living with dementia and their unpaid carers and supporters from the beginning. This ties into how any community support should be empowering for people, as explained by one of our panel members:

It's all about empowering [in reference to projects that entertain people]. I think projects that empower people, both the carers and the people with dementia, are important.

For these reasons, we contend that any funding or investment into community support should always have active engagement and involvement of people with lived experience of dementia built in from the beginning to ensure that the investment will be able to fill the gaps in support, strengthen sustainable development of community support and meet the needs within the community.

3.6 Case Study 2: The power of Peer Support and Representation

Whilst we have detailed the impact of peer support to people living with dementia and unpaid carers, it is worth celebrating the additional outcomes that can arise when people living with dementia experience this form of support post diagnosis. In recent years, thanks to the activism of those with lived experience, the dynamic between professionals and people living with dementia is changing. As one professional who attended the 100/6000 Conference expressed, the shift can be categorised as one which *“puts the role of professionals in perspective. We should be the pillars of support. Not doing for but supporting”*.

100/6000 is an annual event which is designed and delivered by people living with dementia. Organised by Deepness Dementia Media, a platform led by people with lived experience of dementia, only permits people living with dementia attending the conference speaking rights. Professionals are invited strictly as silent observers and in part, support a ‘pay it forward’ model by subsidising a free place for a person living with dementia when purchasing an observer ticket.

Having now delivered two events, a domino effect of representation has been palpably felt at each. Presenting and promoting people living with dementia, as experts in their own experience has inspired several attendees to accept their diagnosis: *“After 3 years of dementia, I’ve come to terms with it”* (Year one delegate at 100/6000 conference). From this acceptance, facilitated by peer support, conference attendees have continued to flourish and exceed outdated societal misconceptions of dementia.

Deepness Dementia Media who organise the conference, trailblaze and destigmatise with their offerings. Their Wellbeing College provides free resources and courses to families and individuals navigating dementia, with the aim of increasing autonomy, promoting better relationships, and instilling an often-lost sense of self purpose (Deepness, 2022).



'It's about enabling people, acceptance & recognition. Peer support has been a great lifeline. Post-traumatic stress after diagnosis can be converted into post-traumatic growth'

– Person Living with Dementia at the 100/6000 Conference, delivered by Deepness Dementia Media

Fig 2.7 The power of Peer Support in action, 100/6000 in 2021.

Their latest course, 'You Are Not Alone – Living Well with your Money', carries on their characteristic advantageous authenticity, being led by a former teacher living with dementia. Students learn from a community of people living with dementia about how to tackle often sensitive and potentially uncomfortable subjects, such as 'When do you know it's time to give up managing your money?'. The methodology behind peer given advice has merits, as many people living with dementia have told us they would trust guidance and information more if given by someone in a similar situation.

Indeed, education delivered by people with direct lived experience of dementia has continued to be championed by dementia activists. Requests for STAND, a self-funded peer support group in Fife, to present talks in their local community continue to snowball, with recent ventures including presentations to local GP practices and primary schools. It is clear that when we accept and enable people living with dementia to retain community citizenship, the benefits can pay dividends, increasing overall awareness of the condition outside of specific DFCs, whilst creating opportunities for self-actualisation. Yet, it is worth pointing out that not one of the groups or initiatives mentioned in the above, including Deepness Dementia Media or STAND, receive any statutory funding or external support to deliver their work. Instead, relying on funding applications and local community support to maintain existence.

**You are Not Alone:
Living Well with your Money**

Developed by
people living
with dementia,
for people living
with dementia.

FREE FREE

8 week online
course for people
living with
dementia.

Topics Include

- Coping at initial Diagnosis
- Benefits, Grants, Funding, Travel
- Planning your Money
- Living Alone
- When to give up managing your money

**Course starts
26th September
2022**

Find out more Email -
michael@deepnessdementiaradio.com




Fig 2.8 Promotional flyer created to publicise 'You Are Not Alone: Living Well with Your Money', A money management course created by Deepness Dementia Media

Supporting people in the early stages of life post diagnosis to remain stimulated and mentally active resets the relationship between dementia and the community, allowing people living with dementia to both give and receive care and education. Community-based initiatives offer a more holistic approach to Post Diagnostic Support, blurring social and medical models, whilst cross pollinating effective innovations from diverse pockets of dementia research, care and support.

4. Post Diagnostic Support

“A lot of people start having problems and there’s no one around them ... If everything goes well and you receive post diagnostic support you get a year... at most... but what happens 5, 10, 15 years down the line?”

“My needs are far greater than they were 20 years ago, but there is no support available.”

– Person Living with Dementia, Online Engagement (Diagnosed 1999)

Limitations to post diagnostic support and the lack of access to that support is an issue raised by many of our members since our project began three years ago. In collating these views, we ask that a truly person-centred approach is taken with post diagnostic support. Support based on choice, that is available at any time in a person’s journey (including in advance of formal diagnosis) is the main objective. It should be based on the goals or milestones of that individual, rather than based on a time restriction. This includes a recognition that peer support and community-based initiatives may be more appropriate for some individuals, as a form of Post Diagnostic Support.

We have spoken to both people living with dementia and unpaid carers about the initial stages post-diagnosis, with many reiterating that directly after diagnosis was too soon to be able to digest or take support on board. Inversely, many who sought Post Diagnostic Support after initial diagnosis found themselves abruptly lost without this level of support after their year had passed.

We also ask for consideration to be given to what is offered within the remit of Post Diagnostic Support. Our national engagement has highlighted several important factors that should be considered and supported at the point of diagnosis.

While the current approach to PDS was ground-breaking in its inception, in practice less than half of people diagnosed with dementia in Scotland have been able to benefit. To avoid a one size fits all approach, it should be recognised that there are many different avenues of long-term post diagnostic support that should be explored. We recognise the symbolic importance and significance of the year of support as a hard-won policy position – the first of its kind internationally. However, while there is significant good practice, too many people have not benefitted from accessing any form of post diagnostic support.

This lack of support is potentially life threatening, as research has found a conclusive link between dementia and suicide, finding people living with dementia are at a 2.82 times increased risk of suicide compared to those without the condition (The Guardian, 2022).

Anecdotally, this experience has been felt by many of our members. A founding member of the peer support group STAND shared their journey:

I lost a lot of human companionship and friendship. It felt as if the whole world just decided to walk away from me. I left feeling scared alone with no real future to look forward to and

to be honest I thought my life had ended. I got into such a dark place; I probably was that far away from actually ending it.

I had this huge desire to just to be able to speak to someone or talk to somebody, be in the company of somebody who was going through the same process as me.

Through that desire the group STAND was formed, and what a lifeline that's been.

- Person Living with Dementia

Our conversations with people in community settings has also demonstrated that there is more than one way to deliver 'good' or indeed 'excellent' PDS. This has likewise been robustly evidenced in the Hammond Care evaluation of Dementia Friendly Communities funded by the Life Changes Trust. However, at present these often vital services are not recognised within policy. The importance of proper transport, housing, peer support, and community-based supports are just as valuable, and may meet the needs of some individuals better. We have chosen to highlight several key themes within our response. It is our aim to present the wide variety of support as a cohesive unit of Post Diagnostic Support: one cannot operate affectively without the other.

4.1 Access to Post Diagnostic Support

After my mum was diagnosed, we were supposed to receive PDS, but we only received it 18 months later. It started as the pandemic started, so it was worthless to an extent. I therefore don't know what proper PDS entails, as it was through a pandemic. ... All she got was a once-a-week phone call ... The idea of PDS is good but in practice it's not what it's meant to be.

- Unpaid Carer

Nine years after the promise for post diagnostic support for all, the national figure of those receiving full support has never reached 50%. Only 42.9% of those people estimated to be newly diagnosed with dementia in 2019/20 were referred for Post Diagnostic Of them, only 81.3% go on to receive a full year of support (Public Health Scotland, 2022). Formal one to one Post Diagnostic Support as envisaged has not been the reality for the majority of people diagnosed with dementia in Scotland. However, these official figures disguise the extent of

the community volunteers, day centres, meeting centres and lunch clubs who have independently bridged the gap of post diagnostic support that has been missing for nearly a decade. From a financial perspective, peer support groups and Meeting Centres are delivering a form of Post Diagnostic Support to many people simultaneously with few or no paid members of staff. This approach is not only cost saving but has an additional benefit of reducing isolation and connecting people with peers facing similar problems and experiences.

The challenges with accessing Post Diagnostic Support were exacerbated during the pandemic. As evidenced in the quote above, we saw national services and support come to a standstill. In the early months of the lockdown, Age Scotland's National Helpline was promoted by the Scottish Government as a national advice line for older people in Scotland. Age Scotland Staff collated a spreadsheet with local support and contacts in each of the 32 local authorities to signpost to callers. The vast majority of these were community-based support groups including Dementia Friendly Communities. It was these communities who delivered a hot meal and a supportive face to people on their doorstep, who collected prescriptions and groceries as well as news from the outside world, and who welcomed those living with dementia and their carers back with open arms, long before the formal and statutory support services reopened their doors. Person-centred Post Diagnostic and Peer Support in a variety of different forms has been taking place at a community level for years. It is time to recognise this vital contribution in policy and offer sustainable funding for it to continue.

NHS Board	2018/19R	2019/20P
Ayrshire & Arran	40.5%	42.5%
Borders	29.9%	39.9%
Dumfries & Galloway	51.1%	58.6%
Fife	61.0%	58.5%
Forth Valley	43.5%	39.7%
Grampian	27.1%	34.7%
Greater Glasgow & Clyde	47.9%	43.4%
Highland	36.2%	36.3%
Lanarkshire	53.0%	48.1%
Lothian	43.2%	43.6%
Orkney	53.8%	36.8%
Shetland	67.9%	69.0%
Tayside	49.8%	32.9%
Western Isles	40.5%	28.5%
Scotland	44.8%	42.9%

Fig 3.1 NHS Board Level Performance (2018/19 - 2019/20)

4.2 Continuity of care throughout the dementia journey

One of our longstanding members, who was diagnosed with dementia in 1999, shares his experience:

I got support via Social Work funding until about 2005. The service was fantastic, then bad things happened... I asked social work to get me some support which stimulated me. After a month or so, they admitted defeat, and said they would return in a month.

They never returned since that time in 2005.

No support from anyone since that time. Nor any offers. My steadfast wife coped without any help from anywhere.

I am now approaching age 82. Naturally my dementia, a deteriorating illness, had worsened. In March 2020, I had a stroke. Now, I stagger, I need help to walk, rise from my seat, and need a hand or arm and a strong back to pick me up, if necessary.

The PDS, which I advocated for, for many years, came on the 1 April 2013 if I am correct. But it did not include us “oldies”, who were in a much poorer condition, than the young ones coming along. We are still to this day, abandoned and left to rot by the Government. Who advocates for us?

The dementia journey is seldom linear or predictable. We welcome the policy emphasis on living well with a dementia diagnosis, as well as the drive towards early diagnosis. A move towards early diagnosis could change the type of support that is required post diagnosis, moving from medical interventions to a social model which encourages retention of employment and connection to local community. Such approaches will enable people with dementia to remain independent for longer periods and continue the activities and lifestyle that is important to them.

During our engagement, we carried out several sessions across meeting centres in Scotland. The approach in each centre encouraged a care approach which is tailored to individual want and needs. Meeting Centres open the door to peer support, which ordinarily would not be available. Prestwick Meeting Centre, which is led by volunteers, work on the ethos of ‘What would my mum want?’, the staff understand the importance of individual preference and work hard to ensure no one feels forced into any activities, instead everyone has the opportunity to participate. Ensuring personal preferences are at the centre of the meeting centre approach, participants still able to exercise choice and preference while learning from each other about their own diagnosis.

I have learned more about dementia from Jackie and Gail (the meeting centre staff) than I've ever learned from any doctors.

They're angels.

– Person Living with Dementia, Kirrie Connections

In a similar vein, we asked the members of Kirrie Connections to finish the sentence:

‘If I was lost, I'd turn to...’

‘You're looking at ‘em. If I was lost, I'd turn to my friends’

- Person Living with Dementia, Kirrie Connections

At present, many individuals have no contact with any agency from the end of their year of support, until they reach a crisis point. While they may not need medical intervention during this period, we believe that there is a need for ongoing input and support that is flexible enough to meet individual needs. This could have the benefit not only of enabling signposting promptly when crises do occur but may also help to prevent them from taking place. Such support need not be supported by existing PDS practitioners but could take a variety of different forms and be personalised to the needs of the individual.

We believe that properly supported, many of the existing community-based support systems could enable this continuity of care to be delivered in a flexible way, that both signposts to formal services, and reduces pressure on them in the longer term.

4.3 Transport

I don't drive, and, for me, transport remains one of the biggest barriers to accessing dementia services. Taking my mum to clubs or class... at a cost of over £25 a time to use taxis is not feasible.

It is only because the local council-run Day Care and Glasgow's Golden Generation, a charity-run lunch club, both offer their own transport to pick up Mum from home and return her later in the day, that she is even able to access these opportunities. Otherwise, she would be stuck at home every day with no outside contact, community interests or stimulation.

It is all very well having dementia cafes and day centres specifically aimed at people with dementia, but without the access to transport to get there, such opportunities are effectively useless to people like me and my Mum.

Unpaid carer, About Dementia Policy Drop in, November 2022

Integrated transport is a key enabler of independence for many older adults within the community, but is rarely considered within health and social care beyond patient transport. All through engagement, we have seen that the backbone to the success of any service is accessibility. Transport can often be poor, and as the pandemic has highlighted it is often dependent on market demand rather than the needs of the community. This shift in availability takes access to services out of the control of its target demographic, shifting responsibility to a whole host of volunteers, good Samaritans, or self-funded transport.

Of the 78 applications we received for the Encouraging and Supporting Grass Roots Activity fund, 47% of those applications linked to a need for social and community activity, with a significant portion of those applications seeking funding for transport vehicles, and money towards providing a more accessible service. Highlighted within the applications was the glaring reality of lack of available services, as well as lack of access to those services.

Volunteer or charitable groups are trying to bridge the gaps where there are no core services available to provide transport. Following the Covid-19 lockdown reduced or ceased transport provision needed to bring people to activities, lunch clubs and for days out, and breaks in care for people living with dementia has simply not returned.

Members of our Transport and Mobility sub-group often framed access to transport as a human right's issue, citing the rights to freedom of association and home and family life. Access to transport and therefore available services ensures that a person's right to develop a personal identity and to forge friendships and other relationships is upheld. This includes a right to participate in essential economic, social, cultural and leisure activities.

Transport was an important theme in our discussions at our in-person and online Stakeholder engagement sessions:

Transport is an insurmountable challenge for us as a charity... and for many of my colleagues in the third sector. We are constantly coming up against this barrier of transport. A lack of transport and lack of access to transport that's affordable to be able to get to and from our services. I lived in the Highlands before moving to Dundee, and I really did think transport wouldn't be an issue in a big city, but it is just as bad. If not worse.

– Third sector professional, online engagement session

Transport is the biggest problem we have with regards to supporting our community and within with dementia cafes, or any cognitive stimulation situation whatsoever. It's a perennial problem, and something that we spend a lot of time organising the logistics of people who live in very remote areas to come together. There are only so many volunteers available to offer a lift, if we don't have enough drivers, people miss out.

- Third sector professional, online engagement session

It should not fall solely on voluntary and third sector professionals to uphold this right.

These sentiments were echoed in our community-based engagement sessions. Those in rural and island communities were keen to highlight the disparities between rural and urban areas, arguing that what works in the central belt may not work in the rest of the country. Public authorities have a duty to help unpaid carers, and people living with dementia to participate in society and that can take many forms. Targeting funding towards community transport or ensuring better access to Self-Directed Support to enable both unpaid carers and people living with dementia may be a way to enable both this and an individual's human right to the service.

We would love to be able to have a little bus, it's not always about the activity that you do, it's about the coming together in a shared experience. The short minibus ride home becomes part of the therapy. It becomes sightseeing, discussions around where people used to live. It becomes part of the day's activities.

Integrated working within the community would help. When we first started Dementia Friendly Prestwick, we approached our local taxi company, and we did some dementia awareness with them. It worked well. One of our members has an account now with that local taxi firm and they've been brilliant. The lawyer set it up, which means that she doesn't have to worry about paying for the taxi because money is a source of anxiety. Of course, it is. The fact that her journeys are all on account, and she doesn't need to worry about it. It's as though she's got a chauffeur, rather than she's getting public transports.

- Stakeholder Engagement Online

There is a robust evidence base drawn from the experiences of people living with dementia and transport, developed by the Go Upstream Project in 2017 (Hyde & Cassidy, 2017). About Dementia continued this work through our Transport & Mobility working group which met from 2019-2021. Our Better Buses report which emerged from this work called for all local authorities to work with people living with dementia in order to plan bus networks that meet the needs of the local population.

We are encouraged that despite delays due to Covid-19, the provisions of the Transport (Scotland) Act (2019) came into force last month, but believe that more must be done to provide support to third sector services who's residents cannot access support without aided transport. We cannot continue to underestimate the impact a well-supported transport system would have on those living with dementia, and their unpaid carers.

4.4 Housing And Independent Living

[Having support to be independent] gives you a sense that you're living a normal life. If I can come in and make a cup of tea, cook, Hoover, do proper tasks – that's going to make me feel better. [After diagnosis] you lose the feeling of worth. If you can maintain stability in life that can really help.

- Person Living with Dementia

Home and family life is as much about the community and relationships we have around us as the bricks and mortar that keep us warm and safe. Indeed, the concept of home and

neighbourhood is deeply porous and relational as evidenced in a multi-site research project on Dementia and Neighbourhoods (Clark et al 2020). This study has called for neighbourhoods to be reconceptualised as interconnected webs of support rather than simply geographical communities. People living with dementia and unpaid carers have told us of the pain and distress they've experienced when leaving a much-loved family home which has become unmanageable for them, and this is often as much about those connections that exist at a local level and the sense of home as the built environment. We recognise that in some instances, moving into supported housing is the best option for a person living with dementia. However, it has also been evidenced that simple changes to the physical environment can help people to stay at home for longer, and to keep the connections to friends and neighbours around them. Like any other citizen, people living with dementia deserve to live in accessible, adaptable, and well-maintained housing at the heart of integrated and thriving intergenerational communities.

Previous Dementia Strategies have referenced housing only briefly, though we believe that it should be a key element of the new strategy. Early intervention is key to enabling people living with dementia to live at home for as long as possible. Housing should be integrated into Post Diagnostic Support discussions, and explicit links should be made to agencies who can provide information and advice. Taking advantage of, and utilising, expertise of existing services such as housing officers, handyman services like Care and Repair and, for example, Age Scotland's free publication *'Creating an Enabling Home for Someone Living with Dementia'*, will ensure the enablement of independent living as a person's diagnosis progresses.

Research has demonstrated that over 50% of older adults live in owner-occupied accommodation (Brown et. al, 2017), and around 65% of people living with dementia reside in their own homes (Campbell & Palmer, 2022). This is an ageing population whose housing needs will be changing rapidly and will increasingly be seeking input from social care. Their needs must be considered and anticipated. By ensuring that an assessment of the home is carried out in the early stages of a diagnosis, the individual and their support network have time to put adaptations in place before the point of crisis. Adaptations do also provide a wider social and financial benefit. Empowering people living with dementia to remain at home independently not only enhances their wellbeing, but also provides significant cost savings to both individuals and the public purse as compared to residential care. Adaptations also act as a preventative measure reducing the risk of accidents, which might result in a hospital admission. Annually, emergency admissions to hospital by older people cost approximately £1.4 billion (Scottish Government, 2012). In a time of severe pressure on public spending, providing solutions that save money as well as benefitting lives needs to be a consideration (Scottish Government Adaptations Working Group, 2012).

The Care and Repair Scotland's Dementia Enablement Project (Blake Stevenson 2019), funded by Life Changes Trust, is just one such example of how integrated working and small changes in existing practice can have a significant impact on improving both housing and health and social care outcomes, including independent living. The project supported four regional Care and Repair services to train and upskill their workforce allowing them to carry

out safety checks while also reviewing the needs people living with dementia in their own homes. The project has received a favourable evaluation which emphasised the benefits to individuals in enabling greater confidence and independence, as well as preventing falls. We would urge the Scottish Government to explore the Dementia Enablement Project as an example of good practice that could easily be rolled out nationally, but crucially would deliver person-centred support at a local level.

A further hurdle which creates barriers to cohesive development in housing is that housing does not currently have a formalised place at the table in integrated health and social care.

There is a real need for housing and health and social care departments to talk to each other more clearly. Conversations may happen between housing officers and social workers (and these have been improving) but this is not necessarily always the case and there is a real need for this to be joined up better.

- Housing officer, Housing Subgroup Meeting 2019

We highlighted this deficit in our response to the Feeley Review in 2020. There is a significant body of evidence that demonstrates the need for greater integration of housing and social care in Scotland. We urged the review to examine this issue closely and to make firm recommendations, ensuring the inclusion of housing be placed at the heart of the integration project.

For those in the social rented sector, housing officers are well placed to identify unmet needs or suggest adaptations that would enable people to remain in their own homes for longer, but too often those links are not made, or rely on pre-existing relationships rather than strategic connections between services. Housing officers are well placed to identify social care needs and make interventions before a crisis is reached. Formal referral mechanisms and parity of esteem between these important professions and social work would enable early intervention. We are aware of a number of areas where good practice exists, for example Glasgow City Integrated Joint Board, who have a housing sub-committee to ensure strategic connections between housing and health and social care. Likewise, North Ayrshire have developed close working relationships between housing and social care that have also had benefits at a local level. There is, however, no mechanism to ensure that these relationships are taking place across the board, or to enable such examples of good practice to be shared with professionals in these sectors across the 32 local authorities.

Housing is not routinely on Integrated Joint Board agendas and when it is it is often left to the end or falls off completely. IJBs are driven by budgets and policies often don't reference each other.

- Online Housing & Home Sub-Group Meeting 6th May 2020

To uphold our Article 8 Human Right to respect for your family and private life, your home and your correspondence, a strategic and multi-agency approach is needed to ensure that housing meets the changing needs of a person living with dementia. While there are many initiatives that are exploring this challenge, such as Dementia Villages, or co-locating care homes and nurseries, these are often not connected to longer term strategic approaches and local development plans. The challenges are also unlikely to be resolved through a focus on new development. An emphasis on ageing in place and adapting and repurposing existing housing stock is going to be necessary.

The lack of integration is apparent in other areas of local government and impacts similarly on the suitability of housing stock for people living with dementia. Too often there is insufficient coordination between local government departments (planning and housing for example), let alone between different sectors such as developers, private rented landlords, social landlords and the local authority. Raising awareness of dementia and understanding the challenges people with lived experience face daily would help to ensure more coordinated thinking. In our early Housing Subforum, the notion of dementia friendly housing approaches was discussed at length. Creating a 'Care Village' model of residential care was discussed as a good example of having the right support and services available in one place, while making sure that it is a familiar and safe place. However, others problematised this approach, arguing that it can lead to people living with dementia being separated from the rest of their community.

A significant hurdle to introducing dementia friendly housing is the volume of different providers across Scotland. Some of our members have contended that if a national standard around dementia friendly building were to come into effect this could ensure developers consider people living with dementia more. Good practice exists in this regard for example in Fife, [Kingdom Housing](#) have embraced dementia friendly building standards, as well as becoming the first social landlords in the country to introduce dementia training courses for all staff.

It centres on the idea of community. The person living with dementia was able to live in their own home, adapted for their needs and with the people they love.

They were able to access services and supports in their local community, including their local shop and a Meeting Centre. They also had access to Self-Directed Support to make many of the interconnections possible (see section below). Note the importance of the safety net hanging from a tree which prevents anyone slipping through the gap of support within the community.

Fig 3.2 Poster, Stakeholder Engagement, Stirling



In addition to making savings to the public purse, this vision has a number of benefits including enabling independence through residing in familiar spaces, as well as ensuring continued access to local amenities. Planning decisions that locate new-build care homes on brownfield sites on the peripheries of towns run contrary to these aspirations. More appropriate has been proposals from the Scottish Government under Housing to 2040 for 20 minutes neighbourhoods. These emphasise the social and relational aspects of neighbourhood, while ensuring that adequate infrastructure from transport to shops are built in. People living with dementia have a right to continue living within diverse and supportive communities, and housing and planning policy should enable this.

I would like to spend the time I have left at home with my wife, family, and neighbours. The safest place I know is my comfortable high back chair in the bedroom, laptop at my side and TV remote in hand. It is my human right and not difficult to achieve. All it takes is a little forward vision.

– Person Living with Dementia, Stakeholder Engagement
Stirling

The Scottish Governments Co-Produced work ‘Living well at home: Housing and Dementia in Scotland’ stated; *“Failure to plan ahead by adapting and improving our housing is likely to lead to increasing disrepair and more people moving into care”* (Palmer & Campbell 2022). This principle was echoed throughout our engagement for this strategy, as well as in meetings of our Housing and Home Sub Group (2019-2021), supporting the belief that adapting the home environment is a significant contributing factor to ensure independent

living for people living with dementia, as it guarantees the home is fit for the person's needs. We endorse the recommendations made in this publication and urge for their inclusion in the new strategy.

4.5 Information and advice for the dementia journey

My husband was never told about power of attorney, by the time it was needed it was complicated to set up due to lack of capacity. It was yet another stress added to my role as an unpaid carer that I had to navigate with no support.

– Unpaid Carer

While ensuring that access to Post Diagnostic Support has been the primary goal, guaranteeing that the information and support provided is useful follows closely behind. There are several considerations which, at present, are not made at the point of diagnosis that we and our members would like to establish as important elements of successful support.

Recognising the reality that Post Diagnostic Support will not support the person through their entire diagnosis, we believe that many difficulties which may be faced as dementia progresses can be significantly mitigated through taking a preventative and upstream approach. As the quote above alludes, issues around power of attorney and many other things become blurred when an individual's capacity begins to decline. An individual approach will be necessary, as people will be at different stages in their journey at the point of diagnosis, but where possible we would like to see issues like Powers of Attorney, Wills, and DNARs (Do Not Attempt to Resuscitate) organised and discussed as early on as possible.

Established in the housing segment of this response, the health and wellbeing value of allowing someone with a diagnosis to remain in their home for as long as possible cannot be underestimated. We would like to see home adaptation assessments become standardised at the point of diagnosis. Independent Living needs to come from a proactive angle, not a reactive one.

Highlighted within the Unpaid Carers segment of this response, it is often difficult to identify and therefore support unpaid carers of those living with dementia. Our engagement has highlighted that many unpaid carers will begin their role years before a formal diagnosis, with others not identifying a caring need until years after dementia has been diagnosed, and even post diagnosis, they can slip through the gaps for support. We ask that the planning and support for unpaid carers begins at the point of diagnosis. Support for the carer must begin at the same point that the person living with dementia is supported. Behind every person living with dementia, while at home, there is likely an unrecognised unpaid carer who would benefit from support and guidance.

5. Care

We recognise that some of the challenges and recommendations related to care that are highlighted below may be outwith the scope of the Dementia Policy Unit. However, the interdependency between dementia and wider social care means that we cannot avoid raising these concerns. We welcome the unit's commitment to ensuring explicit linkages between the new strategy and plans for the National Care Service and offer these examples as contribution to that aspiration.

Dignity in Care, in line with our Article 3 right to not be subjected to torture or inhumane or degrading treatment, has cropped up time and again during engagement. Two of our engagement session plans focused discussions around care and what to do if things go wrong. One session covers hospital care, while the other explores at home care. We delivered the sessions on hospital care at Eric Liddell, Edinburgh and Cowal Befrienders, Dunoon. The at-home care sessions were delivered at Dementia Friendly Tweeddale, Peebles and in Kinghorn, with the STAND group. The need for dignity and person-centred care was a recurrent theme throughout all discussion, with specific focus on the need for a skilled workforce, recognition of the unpaid carer as a partner in care, and a proper complaints procedure which enables people living with dementia to advocate for their rights and needs.

Don't speak for us, but speak with us.

– Person Living with Dementia, Cowal Befrienders

It should be noted that everyone we engaged with on this topic were acutely aware of the challenges facing the workforce at this time and did not seek to apportion blame. These challenges must be addressed in order to deliver the high-quality person-centred care that people living with dementia are entitled to.

If I'm looking for one thing, I'm looking for a skilled, highly trained workforce across health and social care. As a carer, that's what I always wanted.

- Unpaid Carer, Online Engagement

5.1 Stabilising workforce to enable person centred care

It would seem more appropriate to stabilise the health and social care system before trying to implement new strategies.

- Unpaid Carer, September Online Engagement

Recruitment and retention problems in the social care sector continue to grow and dominated many of our discussions. Professionals that we spoke to during engagement were keenly aware of these challenges, both from first-hand experiences within their own

organisations and via conversations with their networks. The mainstream media is beginning to give greater focus to the issue, with the effects of Covid-19 and Brexit being cited as contributing factors for some of the most widespread staff shortages the sector has ever seen (BBC News, 2021).

The impact of staff shortages was something noted by our contributors, with some suggesting this would need to be addressed as a point of priority before any plans for the National Dementia Strategy can be achieved.

Another unpaid carer considered that the key may be to conserve staff resources by allocating services '*according to need, rather than location*', with towns with younger demographics having "*very different needs*" to those with a larger percentage of older people. Although such a suggestion may be noteworthy when considering strategies related to staffing, it is also worth pointing out that many people with early-onset dementia may find it difficult to access age-appropriate care in such a scenario.

We recognise the Scottish Government have responded to the staffing shortages by making multiple funding commitments to recruitment and retention in health and social care within an overall package of £300 million for this budget year. Measures included a commitment to recruiting 1,000 additional health and care support staff to deal with patient flow and delayed discharge, and the establishment of "new multi-disciplinary teams" to support people "as close to home as possible". The commitment that grabbed headlines was £48 million in funding to support employers to provide a minimum hourly rate of £10.02 for staff offering direct care within adult social care. (Scottish Government, 2021). Nevertheless, unions, opposition parties, and even some members of the government, have insisted that a £15 an hour wage is the least that is needed to attract and retain staff within the sector. (GMB Union, 2020; Scottish Labour, 2021; Scottish Greens 2021).

At the crux of most complaints shared though our engagement was a stretched and fatigued workforce. There was recognition of the importance of investing in workforce training and development, as well as opportunities for career progression:

Make caring a career. A more attractive profession with better growth. Growth doesn't have to mean moving to management. Growth could mean a wage increase after X number of years or after Y amount of training.

- Engagement participant, Dementia Friendly Tweeddale

Understanding the importance of the care profession and the value there is in a longer-term vision for recruitment may help to reduce several of the challenges we face across social care, especially towards those living with dementia.

Another participant during engagement discussed the idea of banding carers, similar to doctors or nurses, creating an infrastructure that allows manageable goals and progression. For example, if an entry level carer began as 'Band 1' they would have a standardised level of training for that band, and only work within their capabilities as a 'Band 1'. After a year or two of training and progression they could move to 'Band 2' or 'Band 3'. This would allow

them to care for higher risk and more time-intensive clients, with the pay increase and title to match. We have heard, across the board, that not all paid carers will want progression into the form of management. Often carers enjoy their current, more involved roles, but the demand and expectation on them to be capable of caring for such a diverse range of people is not sustainable and sees a considerable amount of people leave the profession for less taxing, better paid employment.

I love being a paid carer. I wouldn't want progression, but I only do paid caring as part-time job on the side now because it simply doesn't pay enough. If there was a way to be paid and appreciated more, I would go back to full time paid caring.

– Founder of Prestwick Meeting Centre

Short staffing was a recurrent theme in discussions about hospital care too. It was notable that these were often cited as arising from COVID-19 and Brexit. However, many of the key themes we heard during engagement have been long standing issues in the social care space. Participants reported being made to feel like *“a set of symptoms, rather than a person”* (Person Living with Dementia, Cowal Elderly Befrienders).

5.2 Dignified Continence Care

Access to dignified, appropriate, and hygienic continence care was one of the ‘stories’ we drew on for our in-person workshops. Unsurprisingly, this resulted in a rich discussion about this topic.

Continence is not only a matter of dignity or convenience, but when poorly managed can be a cause of serious medical complications. One unpaid carer shared:

My mum has constant urine infections, constantly on antibiotics, and I know that she is sitting alone in wet pads. I understand they don't have the time to change her regularly because of short staffing but it's not excusable.

A carer at our Prestwick engagement session shared his experience of caring for his wife after she moved into a care home:

I went in one day and she'd been in a wet pad for hours. I pointed this out to the staff, but they just said: 'It's fine, the pad holds a lot'. I was outraged, I asked the staff member: 'Have you ever wore one of those?'

They looked at me like I was mad. I told them:

'Well, I have. I took one home, filled it with salty water and sat in it for 8 hours, until I was stinging. It's not comfortable. So don't tell me 'It's fine, until you've worn one yourself!'

These examples illustrate the challenges faced by many care home residents across Scotland. Participants at our online stakeholder engagement session shared experiences of care facilities that openly rationed continence materials with residents entitled to only three changes per day. Attendees thought this was ‘absolutely ridiculous’ and it further highlights how staff need further support and resources to ensure that incontinence care improves in quality.

The issue of access to continence care provides challenge to the assumption that family member’s caring roles end following a move to residential care. We will illustrate the damaging effects of this this hurtful and inaccurate misconception in more detail under the focus of our section on Unpaid Carers, later in this response. Although, it is worth highlighting under the issue of dignified continence care that we regularly hear from unpaid carers of family members that they are still performing ongoing caring tasks, including personal care. Issues of continence and dignity in toileting was not only raised in the care home setting, but also featured in discussions around hospital stays. One carer commented of her husband’s hospital care:

What kind of care is that? Only when I made a fuss did they make a note in his plan to ask him regularly if he needed the toilet. Why did it take me asking? What would have happened if I hadn’t been there to ask?

– Unpaid Carer, October Engagement

Whilst the issue of continence care may seem from an outside perspective to be one small part in the management of dementia, for people living with dementia and unpaid carers, achieving person-centred continence care is an important mechanism to enable full realisation of the human right to dignity.

I had to put (husband’s name) into care and he suffered, can you just imagine the impact that would have on me? It’s the carer again who feels guilt, you’re grieving it. You’re handing them over to other people that are not doing it, and you’re breaching the human rights or every term by them lying in a wet bed. So, there’s something in here that we really need to get fed into the strategy.

- Former Unpaid Carer, October Online Session

A 2022 study on continence care (Northcott et. al, 2022) pointed to a phenomenon of hospital stays increasing levels of incontinence for people living with dementia. Citing what they referred to as ‘pad cultures’, the study highlighted an established routine of continence pads utilised as default in the care of a wider group of people living with dementia, regardless of continence status and independence (Northcott et al, 2022). Whilst the research suggested a rationale of staff may be to provide safeguards, ensure containment and prevent ‘accidents’ or incontinent episodes, our own engagement with carers and people living with dementia also pointed to a lack of appropriate staffing levels and training as an additional issue.

You don't go to the toilet on cue every two hours. There isn't enough staff and it's not allowing person centred. I go (to visit) and when my mum needs a toilet, there isn't enough staff...there physically isn't enough. It's this awful situation.

- Unpaid Carer, October Online Session

Sadly, the 2022 study mentioned above compounded this theory by pointing to a consistent reluctance of staff to assist a person to use the toilet if wearing a pad. Continence care was often deprioritised in order to meet organisational pressures, such as medicinal rounds. Forgoing physical visits to a toilet in favour of pad use was found to have both a knock-on effect to mobility and a potential stressor for agitation and anxiety in the person living with dementia (Northcott et. al, 2022).

Perhaps most detrimentally, the widespread use of 'pad cultures' were suggested as a key contributor to people living with dementia developing long-term incontinence issues that were then taken home as a result of the hospital stay (Northcott et. al, 2022). Anecdotally, we heard from one Meeting Centre Support Worker who was currently urging a family to seek legal advice due to life-changing continence care in hospital. The worker revealed a family member was pressured over the phone to enact Power of Attorney to overrule a person living with dementia's reluctance to have a catheter fitted. Sadly, the family agreed resulting in an individual receiving invasive medical treatment against their will.

Long-term incontinence could result in a need for establishing or increasingly personal care visits from paid care providers. When viewing the impacts through this lens, it reveals 'pad cultures' are not a time-saving measure on a hospital ward, but a costly factor in the demand for social care services across Scotland. If using the toilet is viewed as an act of independence on an individual level, the utilisation of pads by default for people living with dementia is a form of discrimination, which deskills the person and removes their dignity. It is unsurprising then that both people living with dementia and unpaid carers see person-centred and effective continence care as transparent indicator of human rights realisation.

5.3 Self-Directed Support

I was diagnosed with early onset dementia some years ago. All I want is to be able to hire someone who can get to know me in these early stages. Someone to build a relationship with me. Learning my likes and dislikes, my favourite songs and seeing me as a whole person. If I could access SDS now, that is what I would do with it. Create a comfortable home environment where my dementia could slowly progress, but where I would be reassured everything was in hand.

- Person living with Dementia, Stakeholder Engagement
Stirling

The Feeley Review (2020) has brought renewed focus to Self-Directed Support (SDS) and the gaps between the policy's aspirations, and the reality of its implementation. Our engagement with people living with dementia and unpaid carers over the past three years has demonstrated that these gaps are particularly acute for people living with dementia. Figures for 2016/2017 showed that less than 10% of people with a 'primary diagnosis of dementia'[sic] were using Option 1 or Option 2 (Scottish Government, 2018). This means that, the majority of people living with dementia will be accessing traditional homecare services via option 3. Our engagement for this strategy, as well as that we have conducted around the Feeley Review and subsequent National Care Service, has highlighted that for most people living with dementia, this was not an active choice, but rather all that was on offer.

Care Management [were] resistant to share all care options [with us]. Care manager just said care home or personal care, none of which was appropriate for mum. I did all the personal care to give mum her dignity.

- Unpaid carer

In August this year I got a visit by a Social Worker to discuss Self-Directed Support. They only stayed 5 minutes, if that. They didn't even sit down. I told them not to come back if today's 'meeting' was anything to go by.

– Person Living with Dementia

For those receiving Option 3 care at home packages, these are often reported to be brief and impersonal transactions. At our webinar on SDS in October 2020 one carer commented that paid carers '*can be there for 15 minutes, and then walk out the door – that starts your day*'. The pressure on care staff to achieve what they need to within such short timeframes is immense, particularly with many not being paid for travel between care visits. As a result, quality is jettisoned in favour of expediency. One carer at a recent engagement session at Dementia Friendly Tweeddale shared; '*I have a friend who has had to eat their breakfast on the toilet so that the carer could do everything in 15 minutes. It's just not right*'.

This narrow approach to social care means that it is impossible for many people to achieve their articulated outcomes. These then often fall to carers and family members to support their loved ones to realise:

Tasks like hygiene, taking our loved one for walks, helping them listen to the music they like etc are all tasks that us unpaid carers do day in, day out. Local council would never pay for a service like that, so who else does it fall to?

- Unpaid carer, Dementia Friendly Tweeddale

We believe that access to appropriate person-centred and personalised social care is an important solution to enabling people living with dementia to access their human rights and live with dignity. In the words of one carer, *“It’s not about any care, it’s about the right care.”* However, many of the people living with dementia we speak to do not access social care early enough in their journey to be able to get the full benefit.

When it comes to care, getting to know the person should be at the centre of it all. Learning the small things about a person is an act of care. Getting to know how they take their tea, or what foods they like, is a caring and person-centred way of caring. That should be the norm, not the exception.

– Unpaid Carer, Dementia Friendly Tweeddale

There are scattered good-practice examples where this has been able to work effectively. A person with dementia living in North Lanarkshire has used her direct payment to enable her to attend online yoga classes. This helps her to manage her breathing and enables her to focus more, while also relieving stress and anxiety. Another person living with dementia in Glasgow was able to hire a personal assistant to support him to go out on day trips and participate in hobbies. These examples take a creative and holistic approach to identifying and meeting people’s outcomes through social care. While having significant benefits to individuals, we contend that they also represent a preventative approach to social care that could have significant cost saving benefits to the public purse, if implemented early enough.

I can no longer do what I used to do. I need help to walk, rise from my seat, and need a hand or arm and a strong back to pick me up, if necessary. Who would a young girl phone to help get me up? Police, ambulance, or Fire Brigade? The Government isn’t around. All staff are supporters, not weightlifters. H&S would prevent them. My ambitions have shattered. I just need a run to places and a cappuccino.

- Person Living with Dementia – email response to call for views

SDS is also highly complementary to the community-based approach that we have advocated for throughout and could help to address some of the gaps that exist in transport or other services to enable a network of support to exist within the community. At our recent stakeholder engagement event in Stirling, we asked attendees to comment on the example of a carer who was unable to cover the £25 taxi needed to get her mother to the local day centre. As a result, her mother was becoming isolated at home. One of our stakeholders pointed out that if the carer had access to SDS through her Adult Carer Support Plan, she would be able to use that to pay for her mother’s taxi and be able to benefit from a care break, without worrying about her mothers’ continued wellbeing.

An important challenge to enabling people living with dementia to make the most of Option 1 and 2 packages is assumptions around capacity and ability to manage their direct payments. Indeed, at a recent SDS Scotland workshop on SDS and Dementia, the majority of practitioners did not believe that people living with dementia were entitled to the full range of options available. These assumptions are compounded by the lack of good practice examples of people living with dementia exercising choice and control in their daily lives.

We have already outlined our case for an approach to Post Diagnostic Support that enables greater flexibility for individuals and family members to choose the approach that is best suited to their needs. This approach could be framed similarly to SDS in emphasising choice and control, while helping to provide evidence in support of Option 1 and 2 packages. It could also facilitate information sharing for both staff and individuals around the benefits of Option 1 and 2, while enabling a genuinely preventative approach to social care.

5.4 Independent Advocacy

Information and advice to enable people to navigate the complexities of the social care system is another important deficit within the current system highlighted through our engagement. Access to independent advocacy is recognised in both the SDS legislation, and in the Feeley Review, as well as in the provisions for the creation of the Scottish Social Security System but is yet to be sufficiently realised. For people living with dementia, access to advocacy can mean the difference between being able to achieve the things that are important to them, and continue living well following a diagnosis, or not.

While SDS legislation made provision for advocacy, different service level agreements with health and social care partnerships have led to significant variation, often even within the same health board area. In Forth Valley, SDS Forth Valley are contracted to provide advocacy around SDS in Falkirk from an individual's first contact with social work services. They are able to support people to navigate and understand all four options, how the assessment process will work, and to explore their outcomes. By contrast, in Clackmannanshire and Stirling, which is a separate health and social care partnership within the same health board area, SDS Forth Valley are only contracted to provide advocacy to people who have already been assessed and have chosen an Option 1 Direct Payment Package. This inevitably leads to vastly different opportunities to explore the options available and make the most informed decision regarding how they want to arrange their care.

Advocating on behalf of someone living with dementia requires additional skills and competencies that generalist advocacy services may not have access to. At present there is a stark lack of specialist independent advocacy for people living with dementia. As a result, advocating on behalf of people living with dementia often falls to carers. This places a lot of pressure on family members who may not be fully aware of their own rights and entitlements. Community-based organisations already fill part of this important gap. At almost every in-person engagement workshop, when the fictional character asked for advice, they were told to: *"Get a Julie"*, *"Get a Jennifer"* or *"Get a Ruth"*, pointing to the

everyday advocates that had supported them in their journey. This specialism should be recognised and actively supported.

We are acutely aware that many people living with dementia will not have a family member or community helper to support them. This can be especially problematic in a hospital setting where family members may not be able to be present all the time but can be just as important in the community or in a care home setting. At a workshop at the Eric Liddell Centre, when presented with a fictional character who has raised concerns over their treatment in hospital, one unpaid carer suggested that independent advocacy should be automatic when a person living with dementia enters hospital. When the facilitator asked for clarification as to whether advocacy should be offered as a choice automatically, the unpaid carer corrected: *“No, not an offer, a right that happens as default.”*

During the first lockdown, Age Scotland, Life Changes Trust, and Alzheimer Scotland all raised concerns about the practice of issuing Do Not Attempt Cardiopulmonary Respiration (DNACPR) to people living with dementia without the input of family members, powers of attorney, or appropriately trained advocates. At the time, updated guidance was developed that reiterated the importance of conducting anticipatory care planning conversations with the support and input of powers of attorney, and ideally well before a hospital admission takes place. Unfortunately, this practice is still ongoing. An About Dementia member shared his experience during a recent hospital stay. He was approached while on strong pain relief medication, and during treatment for a systemic infection and asked to engage in conversations around anticipatory care planning. He was able to communicate his displeasure at being approached in such a way, without his wife being present, and when he was not well enough to sufficiently communicate his wishes. However, many people in a similar situation would not have been able to communicate their views as clearly. This is deeply concerning.

As part of our response to the National Care Service and the Feeley Review, we have called for the provision of dementia specialist independent advocacy to be available at all points during the dementia journey to empower individuals to express their wishes and preferences. We reiterate that call here.

6. Unpaid Carers

We have a right to know our rights, failure to educate people on these rights is a breach of the rights themselves. How can I implement my rights if I don't know them?

– Unpaid Carer, Eric Liddell Centre

As we are all aware, the Covid-19 Pandemic has brought unprecedented pressures on our social care services. But these pressures have been felt just as strongly (if not arguably more so) by unpaid carers. Crucial services, such as day centres and support groups stopped almost overnight, and in many cases, remain closed to this day due to infection control measures and lack of staff available. Many people living with dementia had their care at home packages reduced, which had a knock-on effect on carers, many of whom were also juggling family and/or work responsibilities. Providing support and gratitude towards a forgotten work force who, during the pandemic, saved the Scottish Government £43 million every day must not be overlooked (Collie, 2020).

There are over 90,000 people living with dementia in Scotland, with an estimated one in three people caring for someone living with dementia at some point in their lives. The Carers (Scotland) Act 2016 introduced important rights for those providing informal care to friends or family members. Our engagement with unpaid carers over the past three years, and during recent workshops, has shown that few carers are aware of their rights under the Act.

There are many barriers to carers claiming and understanding their rights. Throughout our engagement, we have run several rights-based sessions. Two of our more carer focused sessions were at Eric Liddell in Edinburgh and Dementia Friendly Tweeddale, however, we have heard powerful stories from unpaid carers across Scotland. Perhaps the most striking example of the pressure faced by carers can be encapsulated by the experience shared by an unpaid carer at our workshop in Stirling. The unpaid carer spoke of receiving very little external support and was extremely aware of their fragile role in keeping their wife healthy and settled at home:

I'm an unpaid carer and I'm 98 years old. I'll care for her till the day I die. As long as I live, she won't ever go to a care home.

- Unpaid Carer, Townbreak, Stirling

The same carer spoke of Townbreak in Stirling being a lifeline for connection and support, and due to age factors, it is fair to assume access to support via technology may not always be an option for older carers. The sessions brought into focus factors such as exhaustion, isolation, lack of formal care options, and not being well enough informed from the point of diagnosis as key factors for unpaid carers missing out on vital support, and benefit entitlement. Yet, in each session there was reason for hope. In the same Stirling session,

unpaid carers swapped telephone numbers, Carers Centre details and written advice, leaving one carer in tears due to the support they had received from their peers.

Time and time again during engagement, we saw the baton of support being passed from carer to carer. Unpaid carers, and former carers, spoke of being implored to share their story with others, giving people who are new to their journey a road map to navigate the unknown future of caring. This was often challenging for many former carers who had found themselves experiencing forms of post-traumatic stress disorder, compounded by a twin grief:

I was caring in grief for 7 years. Then when my husband died, I experienced a different kind of grief. I have never recovered from either type of grief.

- Former Unpaid Carer, October Online Engagement

Whilst, as we have illustrated, former unpaid carers have received some support as part of peer networks, we have also heard saddening examples of former unpaid carers being stopped from attending their regular dementia group after their loved one has passed away:

She was told she couldn't come anymore. She said: 'Why not? I've got all these skills and experiences to share.'

- Person Living with Dementia, 100/6000 Conference (Deepness, 2022)

This poor example highlights the years of experience gained through an unpaid caring role and also the great loss of purpose and connection that can be felt when their caring role comes to an end. We met countless volunteers who donated their time directly because of their connection to family caring, yet there is an unrecognised community of highly skilled and bereft former carers who have no avenue to seek or give support. Loss of sense of purpose can also arise when a person living with dementia moves to a care home.

I was amazed when my mum moved to a care home, no one ever asked how I was doing. It was a real struggle for me to see my mum declining.

- Unpaid Carer, October Online Session

Unpaid carers continue to air their frustration around the assumption that an unpaid caring role ends after a loved one has moved into a care home. While they may no longer have the resources to care for their loved one at home, their involvement in care rarely ends there. This assumption often sees carers lose access to the forms of support they had previously relied upon. At present, Carer's Allowance ceases when the cared for person moves into a care home. We welcome the Scottish Government's commitment to tapering this when the new Carers Assistance benefit is launched next year. However, we continue to contend that this payment should be accessible for those caring for loved ones in care homes or hospital settings. Many carers have shared that the financial implications of such a move would be significant too. Many carers incur additional costs during this period depending on public transport and how far they need to travel to visit family members in hospital. The loss of

Carer's Allowance can have a substantial impact on household finances at such a time. The ongoing cost of living crisis makes this loss of income more significant than ever, with many households unable to absorb unexpected external shocks. Given the ongoing staffing and workforce challenges, sustaining Carer's Allowance during care home or hospital stays would be a cost-effective measure, that would have a significant impact on family carers and go a long way to giving them the recognition they so richly deserve.

The input required by carers following a move to residential care may be particularly intense for carers of people living with dementia, who may experience confusion and distress as a result of the move to an unfamiliar environment. Having a family member there to advocate for them and provide reassurance is therefore often vital to support their wellbeing. During our engagement workshop in Dunoon, we were told of a shocking example of a husband not being allowed to accompany his wife living with dementia during a hospital admission: 'I felt like I was giving her away'. The lack of enabled advocacy from the husband resulted in their partner being given outdated medication, resulting in illness, due to historic and incorrect patient records. The carer spoke movingly of the misplaced guilt he still felt over the experience of being denied the opportunity to provide much needed support to his wife and the medical team responsible for her care.

The underappreciation of the role of carers proved deeply damaging during the Covid-19 pandemic, when relatives were effectively shut out of care homes for months at a time. One of our members, who is a member of the Care Home Relatives campaign group has argued that Anne's Law could afford additional opportunities to hold care homes to account, should the level of service not be met:

Personally, I see Anne's Law as much more than allowing essential visits in a pandemic. It's about [the] right to advocacy and POA (Power Of Attorney) rights for both named relative and resident as part of safeguarding, and ensuring adequate care is provided. I think Anne's law should be written into the Residency Agreement for everyone who enters a care home.

Residents should have more rights to receive the services they signed up for as per their social work review and funding agreement. [The] right to have adequately trained number of staff and skill mix.

- Unpaid Carer, November Online Session

Fundamentally, we need a more focussed and rigorous spotlight cast on the needs of unpaid carers of people living with dementia. A focus which acknowledges the broad spectrum of the journey of caring, from pre-diagnosis to post-grief, and puts trust in unpaid carers to take place as full partners in care. For carers' mental health to improve, and for their role to be sustainable, carers should be able to access support independently to the person they care for seeking formal support. Alongside a recognition that, for carers to achieve their Article 3 right not to be tortured or treated in an inhuman way, they must be able to access bereavement support to cope with life after caring.

We would like to see a push towards implementing Carer Support Plans fully, and effectively, for those caring for someone living with dementia, as well as allowing carers access to personalised care breaks. We would additionally ask that Self-Directed Support becomes more readily available to carers (independently from the person they care for). Caring duties do not end, and in some cases are only made more challenging by ageing, therefore Carer's Allowance should not stop when a person reaches state pension age.

To ensure carers access these strands of support, more must be done to raising awareness among carers of their own rights, and how to access support that they are legally entitled to.

6.1 Post Diagnostic Support for Unpaid Carers

When considering entitlement around Post Diagnostic Support, given that less than 50% of those living with dementia are able to access support, it comes with no surprise that unpaid carers are often inadvertently excluded from support as well. Taking on the role of caring does not come with a guidebook, and many carers spoke of finding their way by trial and error. As with people living with dementia, we have found that peer support can be a vital source of solidarity and empathy in a situation that can seem overwhelming. As one unpaid carer put it, 'Information is only useful if it's relevant', and many carers spoke of being overloaded with information leaflets at the start of their journey. Instead, being able to seek informal advice from peers on a specific issue as it arises was seen as a less daunting and more manageable approach.

Throughout our consultation response, we have argued for a truly person-centred form of Post Diagnostic Support for people living with dementia, and we propose the same approach for unpaid carers. Every person is different, every journey will be different and there is no one-size-fits-all toolkit that will prepare a person to undertake unpaid caring.

The [PDS] needs to come at an appropriate time. When we got our diagnosis, there wasn't a need for me caring. We got a letter through the post and I threw it in the bin. Couldn't get my head around it. Got angry, cos I was crying at everything anyway.

- Former Unpaid Carer, Human Rights Working Group Meeting 2020

Everything was just thrown at you. It was hard to deal with.

- Unpaid Carer, Human Rights Working Group Meeting 2020

It should be recognised that, much like an individual living with dementia, carers also need time to come to terms with diagnosis, and in most cases, advance towards a realisation that a caring role may develop as their loved one's condition progresses. For many, this can be a slow realisation, often being prompted by reaching a crisis point. Being able to access

relevant support and training, at any point in the caring journey is a necessity to sustain the many unpaid carers who save the government millions each day.

About Dementia's Manifesto for the 2021 Scottish Parliament Elections called for the creation of a Carers' Development Fund:

A Carers' Development Fund should be established, allowing carers to access funds at a time appropriate to them, to undertake training or research which improves the safety or quality of life for themselves or the person they are caring for.

- About Dementia Manifesto, 2021

To truly enable unpaid carers and recognise their expertise in their own experience, we must trust carers to choose the support that is right for them. Under the concept of a Carers' Development Fund, unpaid carers would be able to access training to support them in their caring roles such as moving and handling training or medication administration or opt for non-pharmaceutical initiatives like Playlist for Life or seated yoga classes to support their loved one. A flexible approach would also allow the carer to seek training to support their own personal needs such as a course on meditation or breath work for example, approaches which have proved successful for carers when offered by the Eric Liddell Centre. We would also envisage the fund being available to carers to enable them to access support to re-enter the jobs market following the end of their caring journey should they wish to do so.

It has been acknowledged in previous strategies, that the role of unpaid carers can be poorly defined. Additionally, as observed in the examples shared above, we have found a common misunderstanding around the recognition of period in which a person is unpaid caring. Many carers spoke, with sensitivity, of their loved one being in denial of symptoms for many years, and as a result refusing to seek diagnosis or downplaying elements of the condition to professionals. It is an extremely difficult tension to navigate whilst respecting the preferences of the person experiencing dementia, though carers often expressed their insight was rejected during diagnosis or social work assessments for support. This left carers feeling hopeless and unsupported:

My grandma had evaluation for dementia one month ago and was deemed not to have dementia because she scored too highly out of 75 on their assessment chart. She has now been moved into care, still undiagnosed, because she refuse to sleep next to a 'stranger'. Her husband of 65 years. We are still fighting for a diagnosis.

- Unpaid Carer of a person living with dementia

Whilst there has been an acknowledgement that unpaid carers may need support from Post Diagnosis, the example above highlights a need for carer support pre-diagnosis, support that can be accessed independently from the person living with dementia seeking formal help.

6.2 Adult Carer Support Plans

I have heard so many times since my mum moved into care that I am no longer a carer, so I shouldn't be entitled to a Carer Support Plan or any support. But I still visit her every day and run around for her every day, fighting in her corner for a basic level of care.

– Unpaid Carer

The Carers Act 2016, section 6(2) states ‘responsible local authority has a duty to offer adult carer support plans, regardless of the intensity of the caring role, or whether the carer’s identified needs are expected to meet eligibility criteria.’ Our engagement has displayed a substantial disconnect between statute and reality. The variation and support across local authorities but also between neighbours in community was distressingly common.

At the suggestion of one of the regular members of our Human Rights of Unpaid Carers group, we conducted a poll with participants at our engagement session at Dementia Friendly Tweeddale on their access to a Carer’s Support Plan. From a group of 33, of which 23 people identified as an unpaid carer, not one person was aware of having an Adult Carer Support Plan in place. Whilst some in the group were aware of their right, and a few carers had tried and failed to access a Support Plan, one carer scoffed at the idea that it was their right to receive one. To the carers of Dementia Friendly Tweeddale, an inbuilt right to receive a Carers Support Plan still seemed a pipe dream, further pointing to a growing implementation gap in carer’s rights.

We carers don't often know what we are entitled to! When you are in the thick of caring, your needs are second place. I don't have time to ask myself what I need.

- Unpaid Carer, Dementia Friendly Tweeddale

Other carers were concerned that an admission that they were struggling to provide the support their loved one needed would mean negative repercussions for both of them. A carer at our Prestwick engagement session shared an experience that seemed to confirm this for her:

I remember it well because it was Mental Health Awareness Week. I was speaking to a doctor for my mum, and he asked how I was, and I thought, you know – I'll just be honest. So I said; 'Not good, I'm stressed out.'

Next thing I'm contacted by a Social Worker saying they've heard I'm not coping, and suggested I put my mum into a care home! That was the first suggestion I got, before any other offers for support.

*I just thought after that – I’m not telling anyone how I feel.
That’s what that experience taught me. Just bottle it up.*

We shared this story with our online Human Rights of Unpaid Carers group, who reflected on their own experiences. Discussion highlighted there is long term grief, and emotional trauma that comes from caring for someone living with dementia. Grief was recognised as transitional and ever changing as the person living with dementia’s condition progresses. We are aware that recognition of pre-death/anticipatory grief will form key recommendations of the new SIGN dementia guideline due for publication next year, and warmly welcome this. There is much that can also be done at a policy level to provide recognition and support for carers experiencing this.

One unpaid carer pointed out that Adult Carer Support Plans should include financial, emotional, and practical support for carers. However, they also recognised that Carer Support Plans, especially for carers of people living with dementia, are not being created or understood clearly enough for them to be beneficial.

I have experienced this a lot of times when I was in tears and wasn’t coping. The first thing they say is “Maybe you need antidepressants”. ...I asked her if she had any suggestions for practical support. She told me to phone the Samaritans. I thought, if I have another phone call like this, I might just need to phone the Samaritans.

- Unpaid Carer, October Online Engagement

The group felt that providing easy to access and responsive mental health support is vital for carers and that this should be an integral part of the Adult Carer Support Plan. Many members of the group spoke anecdotally about the fact many carers either haven’t been offered a Carer Support plan or have one and it is largely redundant because it is not actionable.

As a carer it becomes very difficult to identify who you are and when you need support. It is a very complex task and the solution as a result will be very complex.

- Unpaid Carer, August Online Engagement

In order to uphold Carers Rights, access to a timely and useful support plan, regardless of individual location or circumstance, must be at the heart of support for unpaid carers caring for someone living with dementia.

6.3 Right to breaks from Caring

Everything compounds guilt.

- Unpaid Carer, Prestwick Meeting Centre

When discussing carer breaks¹, and the right to a break from care one word throughout our engagement rang time and again: guilt.

We commend the commitment to creating a right to care breaks within the National Care Service Bill. However, in addition to access to care breaks, there are a number of internal and psychosocial factors that can make taking breaks incredibly difficult, if not impossible, for unpaid carers. The experience of and internalisation of guilt is regularly discussed as an inhibiting factor from taking breaks at our Human Rights of Unpaid Carers meetings, and indeed was a recurrent theme for carers throughout our engagement:

I took a respite break in 2019. Left my wife for 3 days in a care home. I wish I had never bothered. The whole time away I was riddled with guilt about having 'put' her in a home, and when I returned? Well... She was in a mess. Hair a mess, soiled herself and agitated. I never took a break again.

- Unpaid Carer, Prestwick Meeting Centre

The care home phoned me two days into my break; 'you'll have to come and get your mum right now; she's being very aggressive, and we can't handle her behaviour'. I collected her and asked the staff what had happened. I could've cried. Turned out, she'd thrown a pillow at them because they were trying to move her in the bed, and it was hurting her. That was the last time I took a break.

- Unpaid Carer, Prestwick Meeting Centre

Lack of trust in the social care system was another key factor in unpaid carers not taking long stints of respite. When considering breaks for unpaid carers, we have called for a flexible and individual approach. Time away from the family home for a person living with dementia may be beneficial if there is good care in place, or they are in the earlier stages of dementia, however, it will not always be beneficial for someone with high care needs, or later stage dementia, which is often when entitlement kicks in at present.

¹ NB In discussing this topic we have chosen to use the term Care Breaks over 'respite.' Throughout our project, there has been a growing reluctance to use the term respite, with many inferring that it places the person living with dementia as a burden. The term 'care break' has been praised as a more inclusive term, which allows both the person living with dementia and an unpaid carer to be beneficial recipients of a break in intense contact. This is the definition we use here.

We have also been reminded throughout our project duration that there is a real lack of appropriate support for people living with young onset dementia, many care homes do not accept people younger than 65 years of age, and for those who do, the setting is jarring and inappropriate. The gap in suitable care break support for people living with early onset dementia, which in some scenarios may be home-based paid care, leaves unpaid carers unable to take a break.

In our response to the Feeley Review in 2020, and the National Care Service Consultation in November 2021, we called for an up-stream and preventative approach to care breaks, that focuses on the outcomes the individual carer may want to achieve. This might involve providing flexible care to enable them to take part in a course, or attend a fitness or wellbeing class.

As with other services, we believe that community-based organisations may be well placed to provide responsive and innovative solutions to care breaks. One such example is an initiative which has begun in Aberdeen, by Kingswood Day Centre, which offers outreach care breaks. They began offering at home care breaks for carers of people who are no longer able to attend the day centre. Instead, carers will visit for several hours a week, sitting with someone in their home, allowing the family member time to themselves to enjoy hobbies or company away from the person they are caring for. This initiative has provided vital support to those who are unable to attend the day care anymore due to higher care requirements. It has also provided input at a time in the dementia journey that has historically been challenging for carers to navigate, filling an important gap in the traditional care pathway, and working to avoid what the centre manager described as a ‘cliff edge of support’.

Similarly, in an online engagement session, the issue of what support might be available when someone’s needs exceed the capacity of a day centre or meeting centre weighed heavily in discussion. Not only do meeting centres and day centres offer social stimulation for the person living with dementia, but they offer direct care breaks for the unpaid carer. If those services are removed, as we saw during the pandemic, unpaid carers often reach ‘crisis’ points and the likelihood of care home admissions increase. By funding programmes like Kingswood Day Centre, to allow weekly breaks from care for unpaid carers, we may see people living with dementia able to continue living at home for longer, while ensuring support needs of the carer are met.

I came here for support, and that’s what I’ve got.

– Unpaid Carer, Eric Liddell, Edinburgh

Providing unpaid carers with a platform for discussion and support even in the setting of dementia-related activities encouraged peer support, informed discussions, and friendships. This access to support is often a crucial lifeline for former unpaid carers grieving for the person whom they had cared for. Providing a space for them to add value, experience and peer support is a crucial part of the dementia journey which cannot be overlooked. By ensuring access to adequate and flexible breaks from care, ongoing peer to peer support via community-based services, and ensuring unpaid carers are funded properly for the vital role

which they carry out, Scotland can continue its world leading work to enhance the lives of those living with dementia, but also enhance the lives of its, often forgotten, unpaid carers.

Conclusion

This document presents the findings of our extensive engagement with people with lived experience of dementia. By ensuring the voices of those with lived experience run through our response, we have demonstrated how much is to be gained from accessing information and experiences from those directly affected by dementia. We believe it is vital that this learning is integrated into the new National Dementia Strategy, and we urge the Scottish Government to continue to promote the involvement of lived experience in the development of guidance, which will work to enhance the support offered to both people living with dementia and unpaid carers.

Our engagement has shown the positive impact a community-based approach can have on improving the lives of people living with dementia, as well as former and present unpaid carers. Understanding that a person-centred, individualised approach is integral to establishing a diverse range of services and support networks must be an ethos at the heart of dementia support across Scotland. We believe the evidence presented first hand shows that the social model of care can serve as an invaluable resource and alternative to current Post Diagnostic Support, for both people living with dementia and unpaid carers. Enabling reliable support within a community-based approach should form an important part of the Scottish Government's commitment to strengthen and recover resilience in our communities.

We conclude this report with a synopsis of the recommendations people with lived experience have directly expressed to us, which we believe need to be embedded within the new National Dementia Strategy:

- Truly person-centred Post Diagnostic Support, based on choice, that is available at any time in a person's journey, and includes a recognition that peer support and community-based initiatives may be more appropriate for the individual.
- Increased and sustained funding for peer and community-based support, that acknowledges the integral role this support plays in helping a person to stay connected, informed and living well, as well as a recognition that these initiatives are a part of social care.
- A larger focus on the social model as an enabling way for people living with dementia and unpaid carers to live well. Asking that the application of non-pharmaceutical interventions such as playlists or social prescribing be improved.
- Improved advocacy for people living with dementia, that includes independent, specialist dementia advocacy.
 - As an additional caveat we could ask that this advocacy is automatic or offered when someone seeks social care or enters hospital to improve realisation of human rights.
- Improved access to SDS, with reduced inhibitive eligibility criteria, to enable aspirational care for people living with dementia and unpaid carers.

We are aware that we are advocating for a shift in the way in which dementia policy is designed and delivered in Scotland, at a time when public finances are under significant

strain. This is a significant ask and will require the reallocation of resources as well as a change of culture. We do not take this request lightly. The changes that we call for are not simply ideas plucked from the air, and we would strongly urge against policy changes for the sake of change alone.

What we have presented here has been drawn from substantial evidence of what has worked over the past decade of trial and error in the Dementia Friendly Communities sector in Scotland, backed by robust independent evaluation. We also draw on the voices of people living with dementia and unpaid carers who have engaged enthusiastically in our workshops both over the past three years of About Dementia, and in our recent intensive engagement activity.

Scotland has been ground-breaking in its approach to dementia policy since the first National Dementia Strategy in 2010. We believe that the new strategy is another opportunity to push forward along the path of innovation and excellence.

References:

About Dementia, (2021). A Manifesto for Human Rights for People Living With Dementia and Unpaid Carers. Available at: <https://www.ageuk.org.uk/globalassets/age-scotland/documents/age-scotland-projects/about-dementia/age-dem-manifesto-v5.pdf>. [Accessed Dec 2022].

Age Scotland, (2020). Locked Down but Not Forgotten. Available at: <https://www.ageuk.org.uk/globalassets/age-scotland/documents/age-scotland-projects/about-dementia/locked-down-but-not-forgotten-about-dementia-report-sept-19.pdf>. [Accessed Dec 2022].

Age Scotland, (2022). Creating an Enabling Home for Someone Living With Dementia. Available at: <https://www.ageuk.org.uk/scotland/information-advice/dementia/creating-an-enabling-home-for-someone-living-with-dementia/>. [Accessed Dec 2022].

Blake Stevenson Ltd., (2019). Evaluation of the Dementia Enablement Pilot Project. [online]. Available at: <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/DEMENTIA%20ENABLEMENT%20PILOT%20PROJECT%20final.pdf>. [Accessed Dec. 2022].

Brooker, D. (2018). The Meeting Centre Support Programme UK: Evidence-Based, Local Support For People And Families Living With Dementia The Association for Dementia Studies at Worcester University Our timeline with Meeting Centres. [online] Available at: https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/2018-forum-slides/the-meeting-centre-support-programme-uk---db.pdf?sfvrsn=21aa25af_4 [Accessed 3 Dec. 2022].

Brown, M., Tolson. S., Ritchie, L., Sharp, B., Syme, K., James, K., and Tolson, D. (2017). Being Home. Housing and Dementia in Scotland. Lanarkshire, University of the West Scotland. [online]. Available at: <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/Being%20Home%20-%20Full%20Report.pdf>

Campbell, A., Palmer, L. (2022). Living well at home: Housing and Dementia in Scotland. [online]. Available at: <https://www.cih.org/media/ay0mo1x4/living-well-at-home-2.pdf>. [Accessed Dec. 2022].

Collie, F. (2020) Unpaid carers save Scottish Government £43 million every day of the pandemic - Carers UK. Available at: <https://www.carersuk.org/scotland/news/unpaid-carers-save-scottish-government-43-million-every-day-of-the-pandemic>. [Accessed: December 6, 2022].

Christie, J., Yates-Bolton, N. and Thompson-Bradley, O. (2021). Dementia Friendly Communities: Evaluating the Impact of Life Changes Trust Funded Dementia Friendly Communities in Scotland. The Dementia Centre, Hammond Care. [Accessed Dec. 2022].

Clark, A.J., Campbell, S., Keady, J., Kullberg, A., Manji, K., Rummery, K., Ward, R. (2020). 'Neighbourhoods as relational places for people living with dementia', *Social Science and Medicine*, 252, p. 112927. [online]. Available at: <https://www.sciencedirect.com/science/article/pii/S0277953620301465>. [Accessed Dec. 2022].

Deepness Dementia Media (2022). Deepness Dementia Wellbeing College Prospectus. [online] Deepness Dementia Media. Available at: https://www.deepnessdementiamedia.com/shared/images/content/bus_54552/pdf/Deepness Dementia Wellbeing College - Prospectus 2022 - 13th May 2022.pdf

The Guardian. (2022). *People with recent dementia diagnosis found to have higher suicide risk*. [online] Available at: <https://www.theguardian.com/society/2022/oct/03/people-with-recent-dementia-diagnosis-found-to-have-higher-suicide-risk#:~:text=However%2C%20after%20taking%20into%20account> [Accessed 30 Nov. 2022].

Hyde, A. and Cassidy, S. (2017). Traveling well with dementia. [online]. Available at: <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/Upstream%20Final%20Report.pdf> [Accessed Dec. 2022].

Scottish Government, (2012). Maximising Recovery, Promoting Independence: An Intermediate Care Framework for Scotland. [online]. Available at: <https://www.gov.scot/publications/maximising-recovery-promoting-independence-intermediate-care-framework-scotland/pages/5/> [Accessed Dec. 2022].

Northcott A, Boddington P, Featherstone K. (2022). Pad cultures: An ethnography of continence care and its consequences for people living with dementia during a hospital admission. [online]. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9483683/>

Public Health Scotland, (2022). Dementia Post Diagnostic Support Local Delivery Plan Standard - Figures to 2019/20. [online]. Available at: <https://publichealthscotland.scot/media/12377/2022-03-29-dementia-pds-report.pdf> [Accessed Dec. 2020].

Scottish Government, (2018). Data under development – Health and Social Care: Self-Directed Support Scotland, 2016/17). [online]. Available at: [file:///C:/Users/A.Motion/Downloads/unseen-and-undervalued-embargoed-0001-26-november-2020%20\(1\).pdf](file:///C:/Users/A.Motion/Downloads/unseen-and-undervalued-embargoed-0001-26-november-2020%20(1).pdf). [Accessed Dec. 2022].

Scottish Government, (2021). Consultation on Proposals for Delivering Anne’s Law: Supporting People Who Live in Adult Care Homes to Maintain Family and Friendship Connections. [online] Available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2021/09/annes-law-supporting-people-live-adult-care-homes-maintain-family-friendship-connections/documents/consultation-proposals-delivering-annes-law-supporting-people-live-adult-care-homes-maintain-family-friendship-connections/consultation-proposals-delivering-annes-law-supporting-people-live-adult-care-homes-maintain-family-friendship-connections/govscot%3Adocument/consultation-proposals-delivering-annes-law-supporting-people-live-adult-care-homes-maintain-family-friendship-connections.pdf> [Accessed 1 Dec. 2022].

Scottish Government, (2022). NHS Scotland performance against LDP standards. [online] Available at: <https://www.gov.scot/publications/nhsscotland-performance-against-ldp-standards/pages/introduction/> [Accessed Dec. 2022].

Scottish Government Adaptations Working Group, (2012). Planning ahead: living at home. [online] Available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2012/12/adaptations-working-group-paper-planning-ahead/documents/adaptations-working-group-planning-ahead-paper-pdf/adaptations-working-group-planning-ahead-paper-pdf/govscot%3Adocument/Adaptations%2BWorking%2BGroup%2B-%2Bplanning%2Bahead%2Bpaper.pdf> [Accessed Dec. 2022].

Scottish Government (2021). Housing to 2040. [online]. Available at: <https://www.gov.scot/publications/housing-2040-2/>. [Accessed Dec. 2022].

Scottish Government (2020). Adult Social Care: independent review. [online]. Available at: <https://www.gov.scot/groups/independent-review-of-adult-social-care/>. [Accessed Dec. 2022].



To find out more about what we do: www.agescotland.org.uk/AboutDementia

Contact us at: AboutDementia@agescotland.org.uk

Tweet us at: [@AboutDementiaSc](https://twitter.com/AboutDementiaSc)

We would like to thank all of the people living with dementia, unpaid carers, About Dementia partners, professionals, academics and others who contributed their ideas to this consultation response.



Age Scotland is the national charity for older people. We work to improve the lives of everyone over the age of 50 so that they can love later life.

Our vision is a Scotland where everyone can love later life.

Contact us:

Head office
0333 323 2400

Age Scotland helpline
0800 12 44 222

Email
info@agescotland.org.uk

Visit our website
www.agescotland.org.uk

Follow us on social media:

 [/agescotland](https://www.facebook.com/agescotland)

 [@AgeScotland](https://twitter.com/AgeScotland)

 [@age_scotland](https://www.instagram.com/age_scotland)

 [/AgeScotland](https://www.linkedin.com/company/AgeScotland)

