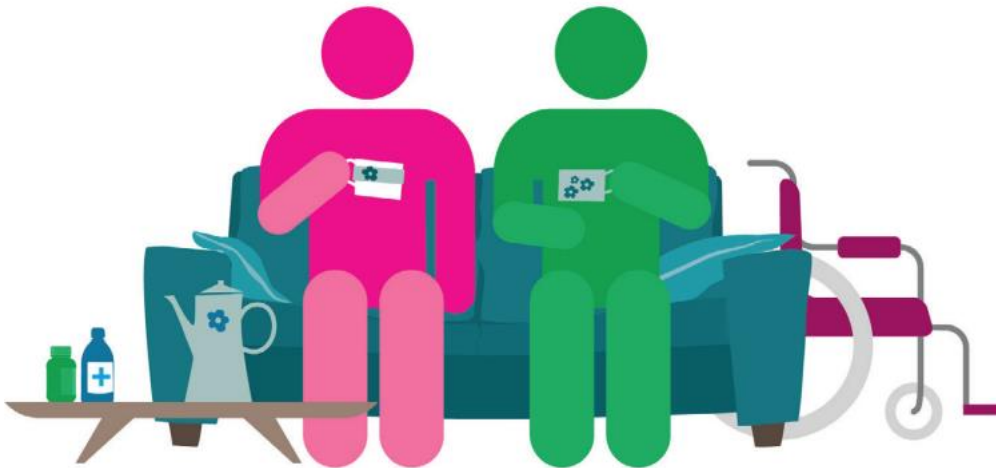




# Dementia Training Carers Engagement Report

November 2024



**‘Our lives have been turned upside down, but who’s looking after us?’**

(quote from carers at engagement events)



## Contents

<b>Key findings</b>	<b>Page 2</b>
<b>Introduction and Method</b>	<b>Page 3</b>
<b>Being a Carer</b>	<b>Page 4-5</b>
<b>What would have been helpful to know when you first became a carer? And what training do you think would be helpful?</b>	<b>Page 6-15</b>
Information on Dementia	Page 6
Dementia and communication/behaviour/mood	Page 7
Peer support available/appropriate sources of help/local knowledge	Page 8
Looking after yourself as a carer	Page 9
Finance/benefits	Page 10
Carers rights such as the Carers (Scotland) Act and Self-directed Support (SDS)	Page 10
How to care for someone living with dementia	Page 11-12
Ways of running courses/providing information for carers	Page 13
Pre-diagnosis	Page 13
Care Homes	Page 14
Hospital experiences/admissions/discharge	Page 14
Other points of discussion	Page 15
Input from people living with dementia	Page 15
<b>Would you like to have known about carers rights before you became a carer?</b>	<b>Page 16</b>
<b>What barriers exist for you to attend carer workshops/training?</b>	<b>Page 16</b>
<b>Would you be interested in attending a one off half day/day event for carers of people living with dementia?</b>	<b>Page 16</b>
<b>Policy issues raised in discussions</b>	<b>Page 17-19</b>
<b>Policy Response</b>	<b>Page 20</b>
<b>Policy Recommendations</b>	<b>Page 21-23</b>
General recommendations	Page 21
Fundings	Page 21
Care and Support for Carers	Page 22
Policy and Legislation	Page 23
<b>Acknowledgements</b>	<b>Page 24</b>

# Dementia Training Carers Engagement report

November 2024

**‘Our lives have been turned upside down, but who’s looking after us?’**

(quote from carers at engagement events)

## Key findings

### Training and education most valued by carers:

- Information about dementia – symptoms, signs, different types of dementia.
- How dementia impacts on communication, mood and wellbeing, and how to manage these changes.
- Knowledge about local peer networks and other dementia support.
- Support for carers - knowledge about rights, how to access support, how to care well for someone with dementia and how to look after their own mental and physical wellbeing.

### Key policy issues raised:

- Widespread frustration and anger about how carers consider that dementia is not treated like other illnesses. From being just left to get on with it post diagnosis, to the lack of ongoing check-ups/follow ups from medical professionals to the costs of residential care - many felt that this all places a huge burden on themselves as carers.
- There were mixed views about post-diagnostic support, with many stating that taking this away after one year leaves carers and people with dementia feeling unsupported.
- The impact of social care issues: a lack of knowledge about adult carer support plans and self-directed support plus long waits for support and/or respite were all raised.
- Many carers feel that they did not get sufficient information either about dementia or about their role as carers.
- Without the voluntary sector support experienced by the carers we spoke to, many carers feel that they would be completely unsupported.

## Introduction

The Dementia Training team were awarded funding from the National Lottery Community Fund starting from April 2024 to enable us to carry on and develop our work supporting unpaid carers of people living with dementia.

We were very keen to involve carers in the development and delivery of our workshops and we felt that a meaningful way of involving carers in the programme would be to carry out a series of conversations to determine what is important to carers in terms of training; where the gaps lie, and what we can develop to better support carers in terms of training and education.

A huge thank you to the groups that welcomed us across Scotland. We really appreciated their honesty, hospitality and willingness to speak to us.

## Method

Over the course of 4 and a half months, the Dementia Training team embarked on a tour of carers groups across Scotland to listen to their views and understand better about what types of training we could provide and develop as part of our new funding.

To identify groups to attend, we used a number of different methods. We contacted groups where we already had contacts. We spoke to Colm McBriarty, Dementia Friendly Community Development Officer who passed on contacts of groups in this network. We put a call for group leaders to contact us in our newsletter and we spoke to Age Scotland Community Development Officers to see if they had any particular suggestions or contacts, and we shared a paper and online survey.

From this process we set up 17 different engagement sessions, reaching 106 carers:

**AILN Saltcoats**  
**LEAP Cambuslang**  
**Dunbar Dementia Carers**  
**STAND Dunfermline**  
**STAND Rosyth**  
**STAND Kinghorn**  
**STAND Kennoway**  
**VOCAL Edinburgh**  
**Alzheimer Scotland group, Edinburgh**  
**Kirrie Connections, Kirriemuir**  
**Lochside Connections, Forfar**  
**Townbreak, Killearn**  
**St Andrews Dementia Hub, Carluke**  
**About Dementia Human Rights working group**  
**Dementia Friendly Pentlands**  
Online engagement open to all, using Zoom – x2



## **Can you tell us how long it took for you to recognise yourself as a carer?**

### **"Caring without realising"**

**"I retired just as we realised something was not quite right, didn't realise I was a carer, it is amazing how you start to adjust and it was a good bit further on, when I couldn't just pop out to the shops that when I realised I was a full-time carer."**

**"Grows on you bit by bit gradually, so you don't even notice"**

**"Still don't feel like a carer yet - it's just something you do"**

**"It wasn't until someone pointed it out to me"**

**"Don't like the word 'carers' – care supporters instead?"**

There was considerable variation in the length of time it took people to recognise themselves as carers. Some carers recognised themselves as such relatively quickly whereas others talked about how it was a process that had taken a number of years. For example, one group member said they had been a carer for 6 years before they recognised themselves as a carer. Many said it was such a gradual process that this is why it had taken so long to recognise themselves as carers. Many also said that as caring was just something that you do for your loved one, they didn't necessarily see themselves as carers.

One group also touched on how they did not particularly like the word 'carer' in this context. We have carried on using this word in this particular engagement report as it is a widely understood and used term, but we acknowledge this is something to address as a team and consider the alternatives.

## What do you think it would have been helpful to know when you first became a carer? And what training do you think would be helpful?

In practice, there was a lot of overlap between these two questions, so we have amalgamated the answers to these questions. The order below reflects the frequency which different topics came up with each group, from high to low.

### Information about dementia



**‘One of the helpful things I was told was that when people are being difficult it is important to remember it is not them it is the disease, and that was really helpful’**

**‘No one offered information until it was too late. It would have been useful earlier on’.**

Information about dementia was considered hugely important by every group we visited. Carers would like information about dementia, including how the illness would progress, and what to expect but also specific information about how to care for someone with dementia. For example, one person stated how the person they care for can get lost in their own house, and they would have liked some knowledge and understanding of how common this can be.

Carers wanted to know about the different types of dementia, including the rarer types. Carers who were caring for someone with a rarer form of dementia said this can be very isolating as people have less knowledge about it. People wanted to know about the causes of dementia and information about dementia for the whole family including children/grandchildren

#### Action points

We currently offer dementia awareness courses, but we will review current course content based on the areas carers are interested in. We will consider using practical examples from a carers point of view in Dementia Awareness.

We also need to ensure carer groups around Scotland know how to access these courses.



## Dementia and communication/behaviour/mood

**‘How to cope with mood changes and strategies - didn't expect these and wasn't prepared with these.’**

**‘Managing emotions for both the person you are supporting and as a carer’**

### Carers talked about:

- Behaviour: How to handle someone with delusions.
- How to cope with mood changes - strategies.
- De-escalation of aggression - dealing with someone who is stronger than you.
- How to deal with moods/sleeping patterns, toileting.
- How to cope with behavioural changes.
- Understanding different behaviours.
- Behaviour changes at night.
- Input of SALT into communication and what's helpful.
- How to talk/calming techniques.
- Knowledge of therapeutic lying.
- Playing music and the positive impact this can have.
- How to support the mental health of person with dementia, including depression and dementia

### Action points

Some of these areas are covered by our workshops Dementia and Communication and Dementia and Mood and Wellbeing. We suggest we review content to see the gaps that may exist with these workshops.

We also acknowledge that some of these requests for information may be more specialist than we can offer. We are considering whether we can invite guest speakers to one off events run by ourselves. We could explore running an online programme with outside speakers, and potentially record them as webinars, using Moodle as a vehicle to store the recordings.

Again, it's important for us to ensure that carer groups are aware of the range of workshops we offer – to publicise these and continue engagement where possible.

Ensure carers are aware of the local and national support networks that can also provide information and advice about these areas.





## Peer support available/appropriate sources of help/local knowledge

**‘Biggest help we got was joining this group - there was nothing else, no other help out there and this is a great support.’**

**‘If the council want us to provide care then they need to provide support and information’**

**‘We had to wait for the link worker because he was very busy, so before we got support from the local link worker it would have been helpful to have a checklist – you’ve got this diagnosis and life is going to be different – where do you get help – who do you speak to first’.**

The importance of peer support was acknowledged by every group we visited. Not everyone had found it straightforward though to find out about peer support. Sometimes health professionals did not always signpost to local support and people found out through their own informal networks. Similarly, a general lack of information/and where to seek further help for carers was often identified as missing.

### Action points

Ensure information about local support and national support is covered in our workshops for carers, with local contacts where appropriate.

We are currently reviewing what information the Age Scotland helpline holds about local groups and whether this is something we need to update.



## Looking after yourself as a carer

**‘Coping mechanisms, very hard to cope when they change so quickly.’**

**Carers raised these following areas where they would like more training:**

- How to look after yourself as a carer.
- Coping mechanisms.
- Mental health support for carers - dealing with your own emotions in the early stages of diagnosis.
- How to cope with the changing situation.
- Assertiveness and strategies to learn how to get your voice heard.
- How to manage emotions of loss/self-control, living grief and bereavement.
- Support for carers after the person they care for dies or moves into residential care.

### **Action points**

Some of these areas could be potentially offered by the health and well-being team at Age Scotland – we will be speaking further to this team to see if we could collaborate on offering webinars/training to carers.

We are also aware that some other organisations also offer information and courses relating to these topics: for example, tide/local carers centres/Dementia Carers Count/Alzheimer Scotland.

However, we acknowledge the link between effective, timely support for carers and improved health and well-being. Simply put, without proper support for carers, health and well-being is always going to be affected. This feeds into a wider concern about lack of support for carers. Our policy team at Age Scotland are aware of this, and have responded to this – see the policy section for more detail.

## Finances/benefits

More information about finances/benefits would be welcome. In particular, carers raised that they would have liked to have known that carer's allowance/carer support payment stops at state pension age.

### Action points

We currently offer training on this subject. We need to ensure that carers groups are aware of this, and other sources of support around finances, such as our helpline and Age Scotland factsheets. In particular, ensuring carers are aware of the 1:1 support that can be out there in relation to benefit advice.

## Carers rights such as the Carers (Scotland) Act and Self-directed Support (SDS)



**'I didn't know what my rights were but knowing your rights - knowledge is power'**

Many carers felt unaware of their rights as carers, and in several groups, no carers present were aware of adult carer support plans. Knowledge about SDS was limited, with one group in particular raising issues about SDS in their local authority.

### Action points

These are topics we already offer so ensuring that carers groups are aware of these and that we can deliver these face to face as well as online.

We feel generally that part of our role is to continue to promote carers rights and all settings that we work in, to ensure a broader knowledge not just for carers but for those who work with carers.

Ensure policy team are aware of the lack of coverage in relation to adult care and support plans, and issues relating to SDS.



## How to care for someone living with dementia

**‘You don’t know if you’re doing it right or wrong.’**

**‘I was never offered any training. I did have some meetings at the start which are very helpful but you have to do a lot yourself.’**

**‘Would have been useful to have information on how to look after him properly, times when you lose the place’**

**‘My personal experience has been there is nothing available (about end of life care) -needs to be sensitive as to when people are ready for that’**

Carers often felt they had not received sufficient information following the diagnosis about caring for someone living with dementia – in many cases they received information about the condition, but not how to care for someone, and all that this encompasses. For example:

- What adaptations to the home might be helpful/sources of support with this (e.g. how to fit lock/alarm to gas hob)
- Health and safety, first aid, moving and handling
- How to support someone with personal care
- How to support the person living with dementia with living well
- How to access respite
- Importance of Power of Attorney
- Information about end-of-life care
- Information about medication available

 **Action points**

We currently offer workshops on some of these topics e.g. Dementia and the Home Environment. We will review these to ensure they continue to meet carers' needs.

Health and Safety, First Aid, Moving and Handling: some carers centres offer these to carers. Carers' lack of knowledge of these areas also ties into Adult Carer Support Plans not being completed, because ideally gaps in knowledge and confidence in these areas should be addressed through this process. We address this further in the policy recommendations – see below.

We will also review the Age Scotland publication **Caring for someone with early stage dementia** to look at whether this publication needs some further development.

Regarding end of life care the organisation EASE offer the opportunity to explore this further: [Good Life, Good Death, Good Grief :: End of Life Aid Skills for Everyone \(EASE\) \(goodlifedeathgrief.org.uk\)](http://goodlifedeathgrief.org.uk)

Ensure workshop participants are aware of the support offered by Alzheimer Scotland: [www.alzscot.org](http://www.alzscot.org).

The charity Marie Curie are there for anyone with an illness that they are likely to die from: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Medication: this is not something we have specialist knowledge about. We are aware that the Alzheimer's Society has information about this, and we know also that the organisation tide also held a webinar about this subject: <https://www.tide.uk.net/resources/a-simplified-guide-to-dementia-drugs/>

## Ways of running courses/providing information for carers:

- One carer attended a 6-week course organised by the NHS after husband first diagnosed - found this really helpful but it doesn't run any more
- Some carers said there is a need for a 'one stop shop' for all things carer related
- Full day workshop for new carers with respite provided would be helpful
- Some carers in the west of Scotland had taken part in the Carers Academy - appreciated this opportunity.

### Action points

We are considering developing a course along the lines of 'new to caring for someone living with dementia', as we recognise that this is a time where people often feel underserved in terms of knowledge and training. This course would also be aimed at people who may be caring for someone without a diagnosis but with concerns around memory loss and/or cognitive change.

Each local authority is required to provide an information and advice service for carers. Some carers may not be aware of this - ensure we include this in workshop information.

## Pre-diagnosis

Some people can wait a long time for diagnosis. For carers in this situation, access to support and information at this point would be helpful.

### Action points

Make it clear that all of our carer workshops are open to people who are caring for someone with dementia or to anyone who is waiting for a diagnosis/concerned about possible dementia. In our workshops descriptions ensure this is clear - for example, stating no dementia diagnosis is required to attend the workshop, even if someone just has concerns or want to learn more, it's fine to join.



## Care homes

**‘What were the things to look out for if you're visiting a care home and how to try and build relationships with staff so that they will welcome you.’**

Carers wanted to know more about care homes such as: what happens in a care home; how to support someone in that environment; what activities might be offered; what does a good care home look like? The cost of residential care was also something people look for information on.

### Action points

We currently offer a workshop around the subject of residential care costs so this is something that we can provide for interested carers groups.

Caring for someone in a care home is not a topic we currently offer through our workshops but is an area we would like to explore further. We are hoping to invite an outside speaker for a webinar/Coffee Conversation on this subject.

## Hospital experiences/admission/discharge



**‘(Knowledge) gives you that power when you're dealing with authorities and particularly in hospital settings and around things like hospital discharge.’**

Carers stated it is helpful for carers to understand that they should be considered an equal partner in care. Some carers stated that they had completed a form at their GP practice to speak on behalf of the person they care for (a proxy form) and would like this more widely known, however there is no information about this on NHS Inform. Knowledge of John's Campaign was also recognised as being important.

### Action points

Hospital admission and discharge is a topic we currently offer and so ensuring carer groups are aware that we can offer this for their members, both online and face to face.

We have raised with our policy team the lack of information about proxy forms within NHS Scotland.



## Other points of discussion

The meetings offered groups an opportunity to talk more generally about particular concerns as carers, and another theme that emerged was the loss of friendships that can occur, both for the person with dementia, and the carer, and how often family and friends don't understand the illness or the caring role. For example, friends/family often see carers 'coping' and assume all is well. 'You find out who your real friends are,' stated one carer we spoke to.



### Action points

We are looking into running a one-off session around the subject of friendship and dementia, to help challenge the stigma and fear around dementia.

Friends and family members are also always welcome to take part in our dementia workshops.

The new Scottish government campaign Rethink Dementia has been launched and we will be referencing this in our workshops.

## Input from people living with dementia

Whilst our engagement primarily focused on listening to the views of carers of people living with dementia, two groups we visited had the idea of also asking people living with dementia what they thought carers could benefit from in terms of education and training. It was really interesting to hear their views about what was important: we have shared some of these views here:

People living with dementia valued patience, understanding, trust and openness. People recognised the important role carers played in supporting them with all sorts of issues both practical and emotional.

**'Need to look after yourself too - your health matters!'**

**'Find it hard to ask - can family and friends recognise this and maybe offer'**

**'Make sure I eat and drink I've become bad at drinking - need prompted'**

**'While I still can, support me to continue to do the things for example cooking, but please recognise when you need to do it for me'**



## **Would you like to have known about carers rights before you became a carer?**

We asked carers if they would like to have known about carers rights before they became carers of someone living with dementia. Overall, most people felt that they wouldn't have been receptive to this information prior to becoming a carer.

## **What barriers exist for you to attend carer workshops/training?**

The main barrier for carers was no respite for the person they care for. Carers also mentioned other responsibilities such as work, childcare and time. For many carers, attending events is only possible where there are arrangements in place for the person they care for.

Many of the groups we attended were run in a format that allowed both the person living with dementia and the carer to attend. People with dementia were offered an activity to take part in, whilst carers got the chance to speak to each other alone and share thoughts. The carers whose groups did this really valued this opportunity.

## **Would you be interested in attending a one off half day/day event for carers of people living with dementia?**

Most carers were positive about this, but also raised the concern about the barriers in attending. For many carers this would only be an option if there was respite provided for the person they care for. It became clear also that for many carers this would only be possible if such an event were relatively close to their locale.



### **Action points**

We are open to working with local organisations to support a one half day or day event for carers - something we can potentially promote in our newsletter. We have already started discussions with some local organisations to do this and would welcome more such opportunities.

## Policy issues raised in discussions

**Many policy issues came up in our discussions, and we have summarised these below, followed by our policy team's recommendations:**

### Employment

Not being viewed as a carer by certain employers and not granted carers leave. Giving up work to care, and the financial/emotional impact of this, and feeling unsupported to do so.

### Government policy in relation to dementia

There was a widespread feeling that the government doesn't put enough money into dementia, and nor does it prioritise it in the way it should. There is a sense of frustration and anger that dementia is not considered like other illnesses. For example, typically there is no follow up after the dementia diagnosis, and people feel like they are just left to get on with it. 'Dementia is just like any other illness, and should be resourced as such,' stated one carer. There is also unfairness at how much someone may pay towards residential care. Carers also feel in general unsupported after a diagnosis: 'It's scary how you're just left without support', said one carer, and another said, 'you are given the diagnosis and left to it.' There can be considerable waits for scans and access to psychiatric support.

Carers also stated how they find it very unfair that most people claiming a state pension who are carers will not be able to claim Carer's Allowance/Carer Support Payment. Some carers mentioned their fears about Carer's Allowance after reading the news about carers having to pay money back.

### NHS experiences

Carers we spoke to reported how GP/health professionals do not always signpost carers to sources of support, carers stating 'GP's don't want to be part of the process' and 'Found STAND by chance not through nurse'

Some carers related long waits for diagnosis (3 years in one situation).

Poor experiences in hospital - hospital staff not using the 'getting to know me' information, even getting the name of the patient wrong (using a formal name instead of nickname always known by); carer having to remind staff that patient has coeliac disease, and not being seen as an equal partner in care. One carer told us 'I said to the healthcare assistant oh her name is actually and gave the abbreviated version and the healthcare assistant looked at me, shrugged her shoulders and continued to pour the tea as if, well, what does it matter?'

## Post diagnostic support

There were mixed experiences of post diagnostic support, and a lack of consistency. Many groups raised the fact that PDS generally stops after a year, but as carers said, 'it's not like the person gets better after a year'. People felt that PDS should start when needed, not just at the start of the journey. Some groups also felt that PDS focuses on the person living with dementia, but should also provide support for the carer. There was some criticism of PDS as having a rigid check list.

Many carers raised the fact that they felt there was a lack of information post-diagnosis, both for the person with dementia but also for themselves as carers. One person commented how they had found out about local support by chance, not through the professionals who were supposed to be supporting them.

## Social care issues

Adult carer support plans were not widely known about in the groups we visited. Some people stated that earlier support should be provided, before waiting for a crisis to occur. Carers stated that they felt unsupported from the start and just left to figure it out on their own. "Had a bad experience with social work and so didn't want to ask". One carer had waited six or seven months and had still not been allocated a social worker.

Some specific social care issues related to issues finding the right care home, or getting an assessment for a care home place when required. For example, one person told us how the person being cared for needs to go into a care home, and professionals are in agreement about this - but the wait for an assessment will take months, despite the carer experiencing their own physical health issues, and being at risk of burnout.

There was also dissatisfaction with self-directed support. One group in particular were very vocal about how difficult it was to access SDS in their area, stating 'no-one tells the truth about SDS - it's a fight, lots of us don't know where we stand. No-one tells you, frustrating.' Another stated that there's too much red tape. In another group, the carer wanting SDS felt a lack of guidance in the process, meaning she was turned down, despite a real need for assistance. 'Applied for SDS to cover costs but were told they were not critical.' And one carer said, 'All services want to just pass you on to someone else.'

## Local support

Every group we visited acknowledged the significant part played by the voluntary sector in provision of services and the huge boost peer support gave them. For many of these groups, the feeling is that without these voluntary groups, there would be no support locally at all.

## Transport

Cuts to buses and the impact this has was raised by one group - no longer available to take people living with dementia to events. Transport is very important (and local

support) - we heard an example of someone having to get 3 buses to the nearest support group.

### **Support/information for carers**

A few different groups talked about their fears as carers when they have their own medical issues – they had no confidence in how the person with dementia would be supported if a carer needs treatment and how carers feel their own health and wellbeing is de-prioritised.

Accessibility was also mentioned - a carer with dyslexia was given lots of written information but this was not suitable for them; and accessibility of access was also mentioned in relation to carers who may have their own accessibility requirements.

Carers expressed how they often feel they are passed on to the next person, and a feeling that no one seems to want to have responsibility to help.

The issues around rural isolation - one carer reported how social work could not provide any paid carers to support as where the person lived was too isolated. (This was in the central belt of Scotland).

Admiral nurses were mentioned and their role south of the border was mentioned - carers stated how they would welcome this in Scotland.

## Policy Response

Following the engagement with carers of people living with dementia across Scotland by the Age Scotland Dementia Training team, the key issues relating to policy arising from the discussions were passed to Age Scotland's and About Dementia's policy team. This aims to ensure that the key concerns raised by carers, which relate to policy and legislation in Scotland are used as insight to inform Age Scotland's policy, influencing and campaigning work, closing the feedback loop between what we hear are the issues impacting older people, and how we try to influence change.

The following action statement outlines some of the key actions the policy team will aim to take and policy recommendations for public bodies, including the Scottish Government, COSLA, health boards and local authorities.

What has been most striking from the training team's engagement, is the distinct lack of progress since About Dementia initially carried out engagement via carers working groups in 2019/20. Key themes from this early engagement included:

- Need for a **centralised point of information for carers**
- Lack of post-diagnostic support for carers
- Lack of **practical education** for carers e.g., medication administration
- Desire to return to employment but cannot due to caring responsibilities and lack of support
- Need for more support available **before crisis-stage**

It is disappointing that in the last 5 years, little appears to have changed for those caring for people living with dementia. Whilst the covid pandemic undoubtedly had a significant impact on the progress of many areas of health and social care policy, this engagement shows that these challenges still face unpaid carers of people living with dementia. With the new ten-year National Dementia Strategy published in 2023, and the first delivery plan (2024-26), currently in progress, this is the window for putting policy change into practice.

The Independent Review of Adult Social Care (2021), and the subsequent plans to reform social care in Scotland via the creation of a National Care Service is a positive step. However, the lengthy delays to this process has created further feelings of frustration and discontent across those who deliver and access social care, as well as third-sector organisations supporting these individuals, including unpaid carers. Urgent reform is needed, as it is evident the situation for unpaid carers is worsening. There are already numerous pieces of legislation in place for unpaid carers (Carers Act 2016, Carers Charter, National Carers Strategy) but what is needed now is the action to ensure these do not end up shelved with all the ideas and promises, but no positive impact felt in reality.

A key promise of the National Carers Strategy was that *"carers voices are heard, and their views and experiences are taken into account in decisions which affect them"*. If the Scottish Government mean what they said, then what we have outlined in this report needs to urgently be considered and actioned.

# Policy Recommendations

## General recommendations

### The Scottish Government should:

- Lead and deliver a coordinated approach to **change the narrative of dementia** as a critical condition which deserves appropriate, equitable and sustainable funding in line with other incurable conditions
- Make dementia care and support for unpaid carers a **key policy consideration** for all parties in forthcoming Scottish Parliament election campaigns
- **Fundamentally reform the way social care is delivered and funded.** Ensure the necessary resources and activities to improve social care are not wholly reliant on the introduction of a national care service as people cannot wait
- Uphold the promises outlined in the **National Carers Strategy (2022)** action plan, especially in relation to Health and Social Care Support. Annual reviews and progress towards these commitments should be published to hold Scottish Ministers to account

## Funding

### By the end of the current parliamentary term (May 2026), the Scottish Government should:

- Consider their **funding priorities** so that for aspects of dementia care most critical to supporting unpaid carers such as peer-support, community groups, Meeting Centres and other grass-root organisations are prioritised
  - This must be a **long-term commitment** to ensure sustainable funding and planning

### All public bodies, including the Scottish Government, COSLA, local authorities, NHS Boards, integration authorities and others should:

- **Ring-fence Carers Act Funding** to ensure that all allocated funds for supporting the implementation of the Act are used for this purpose
  - Implement **financial reporting duties** for local authorities and HSCPs to ensure accountability and transparency
- Re-prioritise funding to **adult day care centres** to provide critical support for unpaid carers to enable them to attend medical/personal appointments and have a moment to themselves to avoid crisis situations

## Care & Support for Carers

**By the end of the current parliamentary term (May 2026), the Scottish Government should:**

- Use the **independent evaluation of post-diagnostic support**<sup>1</sup> as an opportunity to **drive meaningful change** in how it is implemented and delivered. This must ensure that carers receive their own high-quality support
  - Improve **training and guidance** for post-diagnostic support workers to be inclusive of unpaid carers
- Take urgent action to **improve social security support** for older unpaid carers by addressing the **overlapping benefit rule** between State Pension and Carer's Allowance (now Carer's Support Payment)
  - Either by allowing older unpaid carers with an underlying entitlement to Carers Support Payments who receive State Pension to receive this support or by creating a new specific recognition payment for these individuals<sup>2</sup>
  - Public awareness of the underlying entitlement rule must also be raised to ensure unpaid carers are aware of any changes to their entitlements

**All public bodies, including the Scottish Government, COSLA, local authorities, NHS Boards, integration authorities and others should:**

- Collaborate to offer **regular check-ups** for people living with dementia and their carers beyond the 12 months of PDS, bringing dementia care in line with other terminal illnesses
- **Review referral pathways** into support for people living with dementia and their carers so that staff are clear about where to direct service users and take responsibility for offering support where appropriate

---

<sup>1</sup> Dementia in Scotland: Everyone's Story Delivery Plan 2024-2026. [Link](#)

<sup>2</sup> Recommendations based on findings from Carers Trust Scotland Report (2023). 'Experiences of older adult unpaid carers in Scotland'. [Link](#)

## Policy and Legislation

**By the end of the current parliamentary term (May 2026), the Scottish Government should:**

- Introduce a **Right to Care Breaks** as part of the National Care Service (NCS) Bill. This must be supported with sufficient funding for this right to be obtained in practice
  - Include in the NCS a **duty** on Scottish Ministers to ensure sufficient funds are available to local authorities for the right to be met
- Reduce and eventually close the **implementation gap** between key Carer's legislation, policy and strategy,<sup>3</sup> and the reality experienced by unpaid carers which is only worsening

**All public bodies, including the Scottish Government, COSLA, local authorities, NHS Boards, integration authorities and others should:**

- Set out a clear commitment to **review the implementation** of **Adult Carer Support Plans** and implement actions to increase awareness, uptake and accountability for councils who are not meeting required standards

## Age Scotland and About Dementia will:

- **Write to MSPs** outlining the key issues raised from this engagement and our key asks. This will include pivotal players in health and social care and those with a demonstrated interest in dementia and/or unpaid carers
- **Research** the situation of obtaining and implementing Adult Carer Support Plans across Local Authorities and use findings as a **tool for influencing** national and local government
- Continue to **pursue key stakeholder relationships** with organisations supporting unpaid carers including Carers Trust Scotland and Carers Scotland
- Use our position to influence the development of the **National Care Service** whilst campaigning for action to be taken immediately to address key concerns for people living with dementia and unpaid carers
- Provide an update to carers at **Carer Conference Events** run by STAND in October/November 2024
- Start work early to ensure that dementia, including support for unpaid carers, is prioritised in parties' manifestos for the 2026 Scottish Parliament Elections

---

<sup>3</sup> This includes Carers (Scotland) Act 2016; Carers Charter (2018); National Carers Strategy (2022)



## **Acknowledgements**

**‘Your life revolves around theirs and you really don’t have a life of your own.’**

**Thank you to everyone who took part in our carer engagement.**

**AILN Saltcoats  
LEAP Cambuslang  
Dunbar Dementia Carers  
STAND Dunfermline  
STAND Rosyth  
STAND Kinghorn  
STAND Kennoway  
VOCAL Edinburgh  
Alzheimer Scotland group, Edinburgh  
Kirrie Connections, Kirriemuir  
Lochside Connections, Forfar  
Townbreak, Killearn  
St Andrews Dementia Hub, Carluke  
About Dementia Human Rights working group  
Dementia Friendly Pentlands  
Online engagement open to all, using Zoom – x2**

**We’d love to hear feedback so please get in touch with us if you have any comments or would like a visit from our team to your group. Get in touch with us at:**

**[dementiatraining@agescotland.org.uk](mailto:dementiatraining@agescotland.org.uk)**