

A Manifesto

for human rights for people living with dementia and unpaid carers

April 2021



Who we are

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.

Our mission is to inspire, involve and empower older people in Scotland, and influence others, so that people can make the most of later life.

Our three strategic aims are to:



Help older people to be as well as they can be



Promote a positive view of ageing and later life



Tackle loneliness and isolation

How we can help

We know that growing older doesn't come with a manual. Later life can bring changes and opportunities to your life and you may need to know about rights, organisations and services which are unfamiliar to you.

That's why we provide free information and advice to help you on a range of topics including benefits and entitlements, social care, legal issues such as Power of Attorney, housing and much more. All of our guides are available to download for free from our website, or you can contact our helpline team to have copies posted to you for free.

The Age Scotland **helpline** is a free, confidential phone service for older people, their carers and families in Scotland looking for information and advice.

Later life can bring times when you just need someone to talk to. Our **friendship line** is part of our wider helpline and older people can call us for a chat. We're here to listen, provide friendship and offer support.

For information, advice and friendship



Call us free on:
0800 12 44 222
(Mon – Fri, 9am - 5pm)



Visit [agescotland.org.uk](https://www.agescotland.org.uk)
to find out more.



About Dementia is Age Scotland’s Forum for Improving Lives. Funded by Life Changes Trust, we work with people living with dementia and unpaid carers of people living with dementia to shape the policy and practice that affects them in everyday life. The project covers many areas of life, including transport, housing, technology, financial inclusion and human rights.

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Our vision



Everybody has the right to live well, to be able to work. To move around from place to place if required, everybody. Just because you have dementia, it doesn't make it any different. It doesn't put us above anybody else, everybody in the world has human rights."

Person living with dementia

Human Rights are something that we all have and should be able to enjoy to the full. They underline what we are all entitled to and should be able to expect in life. However, so often the conversation around Human Rights takes place in terms that are distant and remote from the experiences of real lives. Over the past two years we have spoken to people across Scotland about the challenges facing people living with dementia and unpaid carers of people living with dementia. We believe that thinking about these challenges from the perspective of our Human Rights can help us to make the case for real change. This manifesto has been structured around 5 human rights with key asks related to each.

On May 6th 2021 the citizens of Scotland will vote to elect the next Scottish Parliament. The parliament has wide ranging powers that impact on people living with dementia including health, transport, housing, social care, some elements of social security and much more. The parliament was also founded with the role of upholding the human rights of the people of Scotland. We believe that this is a huge opportunity for the parties standing in this election to engage with the human rights of people living with dementia and unpaid carers of people living with dementia.

This manifesto is based on the conversations we've held over the past two years, and the priorities our members have raised with us. We hope that all of Scotland's political parties adopt it as a blueprint for making these rights a reality.

Our 5 key asks

- 1 An immediate end to DNAR (do not attempt resuscitation) without consent and an investigation into its use.**
- 2 A commissioner for Older People to advance the rights of people living with dementia.**
- 3 The introduction of an annual Carers' Consultation to attend to carer's physical and mental health.**
- 4 Guaranteed specialist independent advocacy to support access to Self-Directed Support as part of the National Care Service.**
- 5 A Carers' Development Fund to equip carers with the skills and support to care for themselves and their loved one.**

The right to life



Being diagnosed with dementia is so often about loss; driving licence, friends. You want to maintain a lifestyle that's as normal as possible and keep in touch with people ... keep active as much as possible to keep the brain going."

Person Living With dementia



[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

The right to life is the most fundamental of all rights. Narrowly drawn it means having the right to live at a most basic level, but it also relates to being able to live the kind of life you want to lead. The Covid-19 pandemic has seen a rolling back of this fundamental right. We recognise the importance of end of life and anticipatory care conversations, but they must never be allowed to take place under duress, without consent or without appropriate input from powers of attorney. The life of a person with dementia has as much value as any other life, whether we are facing a global pandemic or not.

Looking more broadly, following a diagnosis, dementia is too often viewed as a loss of all that came before. But with the right support, people living with dementia can continue to live a full and active life doing things that are important to them. Access to preventative, creative, and flexible Self-Directed Support can make all the difference to making this possible, but we know that this is seldom available to people living with dementia, and this must change.

Our key asks to protect the right to life:

- 1 **There must be an immediate end to the use of DNAR orders without people's knowledge, consent, or the involvement of powers of attorney. We join calls for an inquiry into this practice and the implementation of existing guidance for anticipatory care for people living with dementia.**
- 2 **Carer's health and wellbeing must be prioritised as highly as the person they care for. All carers should receive annual physical and mental health screenings through an Annual Carer's Consultation.**
- 3 **Frank's Law must be fully funded to guarantee access to social care when people living with dementia need it.**
- 4 **Self-Directed Support must be available early, and with genuine choice and control. There must be access to all 4 options for people living with dementia to empower them to live a full and active life doing things that are important to them.**

The right to freedom from discrimination



[Employers] should give you a chance to try. A probation period. It's direct discrimination against workers. [They] wouldn't be allowed to ask a working mum those questions."

Unpaid Carer of a person living with dementia



The inequity of care for people with dementia under 65 is unfair... [and breaches] their human rights. I paid privately for my husband's care while I waited for assessments, I know the costs personally and financially. If a person [is] taken into care under 65 there is no financial support from social care."

Unpaid Carer of a person living with dementia

People living with dementia and unpaid carers have reported experiencing discrimination across different areas of life whether due to the ongoing stigma against dementia; delays in accessing diagnosis; the lack of reasonable adjustments to enable them to continue working; or in accessing services that would enable them to lead a full and active life. It is not enough to simply have rights and legislation. There must be adequate mechanisms to enable redress if things go wrong.

Obtaining a dementia-diagnosis can be a lengthy and confusing process, particularly for those with early onset, but prompt and timely diagnosis is key to accessing various forms of support, including those that can help younger people living with dementia to continue working if they wish to. Having and retaining employment means so much more than simply keeping a job, it's about maintaining financial stability, independence, peer connection and social skills too.

Timely diagnosis can also enable carers to plan and prepare to ensure that they are not forced out of work by an unexpected crisis. Likewise, unpaid carers regularly face difficulties in retaining employment due to delays in access and entitlement to social care support as well as a lack of tailored support packages. Unpaid carers need clarity as to how quickly support will be put in place. The skills and experiences gained through caring should also be recognised whether they continue working or return to employment at a later date.

Our key asks to protect the right to freedom from discrimination

- 1 We join the Scottish Human Rights Taskforce and others to call for the UN Convention on the Rights of Disabled People to be incorporated into Scottish law.
- 2 We join Age Scotland's call for the creation of a Commissioner for Older People with special responsibilities for advancing and safeguarding the rights of people living with dementia.
- 3 We call on the Scottish Government to commit to systemic change to improve access to Self-Directed Support for people living with dementia.
- 4 We are calling for an improvement in the length of time it takes to achieve diagnosis, with additional support made available to people throughout this process. This in turn must be accompanied by a better understanding of early-onset dementia.
- 5 Unpaid carers should be provided with a detailed timescale in which a support package will be put in place for the person they care for. If the length of time exceeds the anticipated timescale, working carers should be entitled to access Scottish Carers' Assistance to compensate for any unpaid leave.
- 6 Ex-carers or unpaid carers returning to employment after a gap should be eligible for access to the National Transition Training Fund¹ entitling them to training in areas where growth is expected in the labour market.



¹ www.gov.scot/news/investing-in-skills-to-support-recovery

The right to education



Training 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."

Unpaid carer of a person living with dementia



Many people with young onset have partners who are working so it's very hard for them to get space to do training. We need someone independent who can help guide us through the process."

Unpaid carer of a person living with dementia

People affected by dementia are faced with navigating a confusing social care system and balancing risk, safety and independence without any formal training or independent advice. From our engagement activities, unpaid carers report varied experiences of either being offered no training, sparse training on subjects or times inappropriate to them, or being denied access to basic skills.

Unpaid carers are the family and friends of the person they support, making them well-placed to make person-centred recommendations which could improve their loved one's quality of life. We need to value unpaid carers as equal partners in care, and trust them to identify training that is at the right time for them and catered to their changing situation.

People living with dementia also highlighted a lack of information available that could help them manage their condition. Whilst prevention plays a part in brain health at a population level, a focus on prevention can feel blaming for those living with dementia, exacerbating the existing stigma. The people living with dementia we speak to believe that public health information which educates on how to live well with dementia should be prioritised. During our engagement, many people affected by dementia expressed that their most valuable learning about the condition came from peer support networks which promoted the informal sharing of information and advice.

A lack of dementia-specific information and specialist advocacy also impacts on the ability to navigate social care. Some may be unable to articulate their needs or desires or struggle to have their voices heard when organising formal support, and this needs to change.

Whilst improving Post-Diagnostic Support, access to services and outcomes for people living with dementia has been prioritised by successive National dementia Strategies, many of the unpaid carers and people living with dementia we speak to feel that the strategy has been too distant from their realities, and feel a lack of ownership over it's recommendations.

Our key asks to protect the right to education

- 1** 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.
- 2** As part of the development of the National Care Service, we urge the Scottish Government to fully fund and make it a legal requirement for free specialised-dementia independent advocacy support to be formally offered when accessing the National Care Service.
- 3** Improved funding should be made available for peer support for both unpaid carers and people living with dementia.
- 4** There should be a greater focus on living well with dementia in funded research. To enable people living with dementia to live well, public health messaging should be clear, non-stigmatising and based on improving holistic health and wellbeing.
- 5** We call for an independent evaluation of dementia strategies 1-3 and concurrent evaluation of strategy 4. This independent evaluation must include representation from people living with dementia and the unpaid carers of people living with dementia.



The right to freedom from inhuman and degrading treatment



In the last year of my husband's life he had over 130 different carers."

Former unpaid carer of a person living with dementia



All sense of control is taken out of your hands ... It's like sticking a pin in a balloon" ... [Care workers] can be there for 15 minutes and then walk out the door – [but] that starts your day ... It's not about any care, it's about the right care."

Unpaid carer of a person living with dementia



It's important to build relationships. Things are hard enough for people with Alzheimers and to put them with a stranger is just not feasible. They're just not getting treated fairly."

Professional working with people living with dementia



"If I manage to get someone in now, then that person over the next few years will ...get to know me as a person... as my illness progresses ... with dignity as well – that person won't worry so much about (this sounds a bit daft) but seeing me naked.... cos that's something that really concerns me, a stranger coming into my house and forcing me into the shower."

Person living with dementia

From our engagement with unpaid carers and people living with dementia it is clear that the current social care system does not provide person-centred care for people living with dementia. In some cases, care packages can exacerbate delicate situations leading to escalation and distress for the person living with dementia, and the unpaid carer left behind to pick up the pieces. There is no doubt that this amounts to inhuman and degrading treatment. We welcome the findings of the Feeley Review into Adult Social Care, and call for urgent implementation of its recommendations.

When you are reliant on receiving care you are in a vulnerable position and currently services for people living with dementia are under no obligation to prioritise regular carers. Having irregular carers who are not given the time to understand and get to know the service users amounts to inhuman treatment for the individual and inhibits meaningful relationships from being built. A lack of familiarity between paid carers and people living with dementia also adds to unpaid carer stress, and promotes an overreliance on unpaid carers.

Many unpaid carers already struggle to find time to meet basic needs such as bathroom breaks or uninterrupted sleep, and despite unpaid carers having a right to respite, it remains unachievable for most. Prior to the pandemic some unpaid carers were able to have peace of mind when their loved one attended day centres, or were able to find solace in community or peer networks.

Unfortunately, the pandemic has greatly impacted third sector, peer and community organisations and the future seems uncertain for some. Those organisations who have endured have been a lifeline for people living with dementia and unpaid carers and it is vital they are supported to continue delivering throughout Covid recovery.

Our key asks to protect the right to freedom from inhuman or degrading treatment

- 1 Procurement of services for people living with dementia through the National Care Service should prioritise services who demonstrate a commitment to building sustained and meaningful caring relationships between care staff and the people they care for.**
- 2 Unpaid carers have a right to respite and this should be enshrined in law. Carer's assessments should offer flexible and person-centred respite that enables a preventative approach.**
- 3 Social care must not be withdrawn in future emergencies. To increase availability of support we call for a commitment to expand recruitment and retention of the social care workforce.**
- 4 The Investing in Communities Fund² should be redeveloped to promote multi-year awards for community, peer-support and third sector organisations to ensure essential stability throughout covid recovery.**

² www.gov.scot/news/investing-in-skills-to-support-recovery

The right to home and family life



My children are young, the youngest 13 and the oldest 17, and I want them to live their lives. I don't want them hanging around the house, looking after me, that's not what they were put on this earth for."

Person living with dementia



I don't have any hobbies. I have nothing I do for me anymore and I hadn't noticed. It crept up on me by stealth ... Friendships have withered on the vine."

Unpaid carer of a person living with dementia



I'm his wife. No one ever asked me if I wanted to be a carer."

Unpaid carer of a person living with dementia



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

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. 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. But 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. People living with dementia deserve to live in accessible, adaptable and well-maintained housing at the heart of integrated and thriving intergenerational communities.

Early intervention is key to enabling people living with dementia to live at home for as long as possible. Housing officers are well placed to identify unmet need, 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.

The creation of a National Care service has many positives, but a major risk is the loss of links between local authority departments of housing and social care, without a formal mechanism to ensure that they continue to take place.

The way that houses are built and towns are planned is also often a major barrier to remaining connected to our neighbourhoods and communities. The location of care homes and sheltered accommodation may be on the outskirts of town, cut off from local amenities, and away from residential areas. Transport can often be poor, and as the pandemic has highlighted is often dependent on market demand rather than the needs of the community.

There is not enough housing to meet the demands of the population, but new-builds prioritise larger family homes that can be harder to adapt to our needs as we age, and prioritise space to park, over infrastructure such as shops and health facilities.

Finally, for many, a dementia diagnosis can have a huge impact on relationships within the home, with a shift in roles within the household. It should not be assumed that family members will want to or be able to take on the role of unpaid carer, and adequate alternatives should be made available to make the decision to care a genuine choice rather than due to a lack of alternatives.

Our Asks:

- 1 **We call for Housing to be represented on all Integrated Joint Boards, and on the new National Care Service.**
- 2 **We call for funding to support the roll out of the Care and Repair Dementia Enablement pilot projects³ to all local authorities across Scotland.**
- 3 **We support the recommendations on accessible housing contained in the Housing to 2040 strategy and urge all parties to commit to making them a reality.**
- 4 **Carers should be entitled to flexible, tailored and personalised post-diagnostic support to enable them to decide what is best for their circumstances, and to provide them with the skills they will need to care for themselves and their loved one.**
- 5 **A well-planned and integrated transport network is central to enabling independence as well as connections to friends and family. The Transport (Scotland) Act (2019) must be fully implemented to enable citizen involvement in planning local transport services**

³Blake Stevenson (2019) 'Evaluation of the Dementia Enablement Pilot Project' Life Changes Trust.
www.lifechangestrust.org.uk/publications/dementia-enablement-project-evaluation-report

How you can help

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

All the information and advice we provide is free and completely impartial and in helping people access their rights and entitlements, it can be life changing.

We are an ageing population and more people than ever are coming to us for support. You can help us be there for those that need us most.



Make a donation

No matter how small or large, donations make a massive difference and help us continue our important work.

- ▶ Call **03330 15 14 60**
- ▶ Visit **age.scot/donate**



Fundraise

Whether it is having a bake sale, running a marathon or knitting small hats for the Big Knit, there are so many ways to raise vital funds to support our work. To find out more, call **0333 323 2400** or visit **age.scot/fundraise**.



Leave us a gift in your Will

By choosing to leave us a gift in your Will, you can help Age Scotland to continue being there for vulnerable older people in the years to come. To find out more, call **0333 323 2400** or visit **age.scot/legacy**.

Let's keep in touch



Sign up to our newsletter

Our regular newsletters by email contain details of our campaigns, services and how you can support our work.

Sign up today by visiting **age.scot/roundup**



Follow us on social media

Our social media channels are a great way to keep up to date with our work and issues that affect older people.



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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 manifesto.

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