

ndcan

National Dementia Carers
Action Network

Priorities & Focus Areas 2023-2024



activevoice@alzscot.org

Introduction

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group whose members all have experience of caring for someone with dementia. We are funded by Alzheimer Scotland and the Scottish Government and are the independent voice of dementia carers within Alzheimer Scotland.

We provide a platform and a greater voice to empower those who care for people with dementia to influence and inform dementia policy and carers policies and practice. We acknowledge that dementia carers are individuals with individual circumstances, experiences, culture and identity, and that these must inform and sit at the heart of how dementia policy and practice is developed.

For the year 2023 -2024, we have identified **5 key priorities** that will form the main focus of our campaigning work: These 5 priorities have been identified as:

- **Carer Support & Services**
- **Brain Health & Research**
- **Influence & Inform Carers Policy & Practice**
- **Dementia in Care Homes**
- **Dementia in Hospitals**

All 5 priorities, and indeed all our campaigning & awareness raising work, is enshrined in 2 overarching themes:

- **Human Rights-Based Approach** - People with dementia and their carers (family members and friends) have the same human rights as every other citizen. However, it is widely recognised that, in addition to the impact of the illness, they face cultural, social, and economic barriers to fulfilling these rights. We support the aims of the Dementia Charter to empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected.
- **Equality & Diversity** by creating an inclusive and welcoming environment. We promise to champion diversity and help build an inclusive and equitable culture for NDCAN members, and moreover for those living with dementia and their carers throughout Scotland and beyond.

Carer Support & Services

We will campaign at national and local level to ensure people living with dementia and their carers have access to the best possible support and services within their local community. This includes the implementation of robust and clear pathways for a timely diagnosis with structured support immediately after diagnosis and throughout the dementia journey. Our work for our Carer Support & Services priority will focus on:

- Continued support for the delivery of high-quality post diagnostic support that is individualised, extends past the one year commitment, and is available not only to those living with dementia, but their carers too.
- Advocating for timely health care checks through your local GP practice. These should be made available annually, at a minimum, and offered to carers as well as those they care for.
- Supporting the implementation of the '8 Pillar Model of Community Support' that sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness.
- Supporting the implementation of all elements of the Carers Scotland Act (2016) which aims to better support carers on a more consistent basis so that they can continue to care, if they so wish, in good health and to have a life alongside. This includes the right for all adult carers to be offered an adult carer support plan.
- Seeking proper support to address the financial impact of those caring. For example: carers who have had to give up work or reduced working hours because of their caring role; barriers to receiving Carers Allowance and campaigning for improved rate of Carers Allowance.
- Championing improved carer respite opportunities.
- Helping to ensure carers are recognised as EQUAL partners in care.
- Access to specific carers' counselling for those supporting a person with dementia.



Brain Health & Research

We see Brain Health & Research as an interwoven priority which encompasses the need to think ahead to benefit everyone affected by dementia and our future generations

- We will continue to support and promote the work of our colleagues at Brain Health Scotland as they embark on a long-term programme and a shift towards prevention and early diagnosis.
- Through our partnership with the Alzheimer Scotland Centre for Policy & Practice (ASCPP) at the University of West of Scotland (UWS), we will continue to contribute to research and support students both as advisors and co-researchers.
- In addition to maintaining and progressing our collaborative work with the ASCPP we will support other relevant research projects from across a range of disciplines which help deliver research throughout Scotland.
- We will continue to support the development of research ideas and help ensure the research carried out by students is appropriate and makes a meaningful difference.
- We will support 'Join Dementia Research' - a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone, with or without dementia, can register their interest in participating in dementia research and be matched to suitable studies.
- We will continue to support the work of the Scottish Dementia Research Consortium (SDRC), in particular the Alzheimer Scotland Student Research Program.



Influence & Inform Carers Policy & Practice

Our vision is to ensure that dementia policy and practice in Scotland respects the rights of carers, and that policy and practice is meaningfully informed by people with personal caring experience.

Our work over the years has brought about significant progress, however for most people the gap between policy and real-life experience remains too wide.

- We will continue to campaign for a better understanding of the individual circumstances of people living with dementia and their carers across Scotland, and for person-centred planning to underpin the wellbeing of everyone affected by dementia throughout the entire journey.
- We will support the implementation of delivery plans for the 4th National Dementia Strategy. We will campaign to ensure that specific targets, commitments, and funding are laid out in the proposed delivery plans, and we will strive to ensure that carers voices are listened to in every aspect of this work.
- We will campaign for the proposed National Care Service (NCS) to deliver positive transformational change to the approach to social care in Scotland. We will advocate for the voice of carers to influence the delivery of a NCS which best meets the needs of people affected by dementia in Scotland. We will also continue to campaign for action now to improve the lives of those living with dementia or caring for someone with dementia today.



Dementia in Care Homes

The COVID-19 pandemic highlighted and magnified long-standing issues with care homes and particularly for those affected by dementia. Evidence has exposed several overarching issues in relation to dementia care in care homes, therefore we will continue to campaign for positive change to ensure all care home residents who have dementia are provided with the good quality person centred care they deserve.

- The pandemic uncovered hugely challenging circumstances around visiting rights for residents and their loved ones, as well as for care home staff and colleagues. To this end, we will continue to support the full implementation of the 'Anne's Law' proposals to ensure that people who live in adult care homes have rights to see and spend time with the people who are important to them.
- We will champion the implementation of the Advanced Dementia Practice Model which sets out an integrated and comprehensive approach to providing care and support for people with advanced dementia and at end of life with dementia.
- We will continue to support Alzheimer Scotland's Fair Dementia Care Campaign which calls for an agreed definition of advanced dementia and seeks to address the inequalities faced by people living with advanced dementia in terms of access to health care, including equality of access to health and nursing care which is free at the point of delivery.
- We will continue to campaign for good practice in line with the National Care Standards which set out what people can expect from care services at all stages of their journey through a service: and the Standards of Care for Dementia which recognises that people with dementia often have great difficulty protecting their own rights.
- We will support workforce development to ensure that all care home staff who are working with people living with dementia, their families and carers have opportunities to achieve the appropriate knowledge and skills in their roles.
- We will support Alzheimer Scotland's Long-Term Care Commission which aims to agree national recommendations for the Scottish Government and other stakeholders to achieve a new, fairer, and more person-centred practice and funding model for the future of long-term care in Scotland.



Dementia in Hospitals

The unfamiliar environment of a hospital setting can trigger anxiety, confusion, and distress for someone living with dementia, and simultaneously, this has a detrimental impact on their carer.

We will advocate for a person-centred care approach to help alleviate some of the unfamiliar stress and to improve the overall experience and outcomes of hospital care for people with dementia - this includes the admission process, all the way through to a co-ordinated discharge, and ensuring carers are recognised as equal partners and their views are an important part of this process.

- We will continue to raise awareness of the negative impact a hospital admission can have on people affected by dementia, and we will champion positive change.
- We will support workforce development to ensure that all health and social care staff who are working with people living with dementia, their families and carers have opportunities to achieve the appropriate knowledge and skills in their roles.
- We will explore further opportunities to work with teams in acute, community and specialist dementia unit settings to improve hospital care for people with dementia. This includes our on-going collaborative work with Dementia Specialist Nurses and Dementia Champions.
- We will support the 'Transforming Specialist Dementia Hospital Care' report and proposals which seek to improve the experience and quality of support for those individuals requiring specialist dementia care.
- We will support the '10 Dementia Care Actions' created to support the implementation of commitments within the 3rd National Dementia Strategy which is supported by all the NHS territorial boards.
- We will promote the importance of gathering relevant information through the 'Getting to Know Me' form which details the personal history and care needs of a person living with dementia who is admitted to a hospital setting.



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Equality & Diversity
Rights