



**People with dementia  
in Northern Ireland  
have a Right to Know**

**Join our campaign**

Leading the fight  
against dementia

**Alzheimer's  
Society**

A right to diagnosis

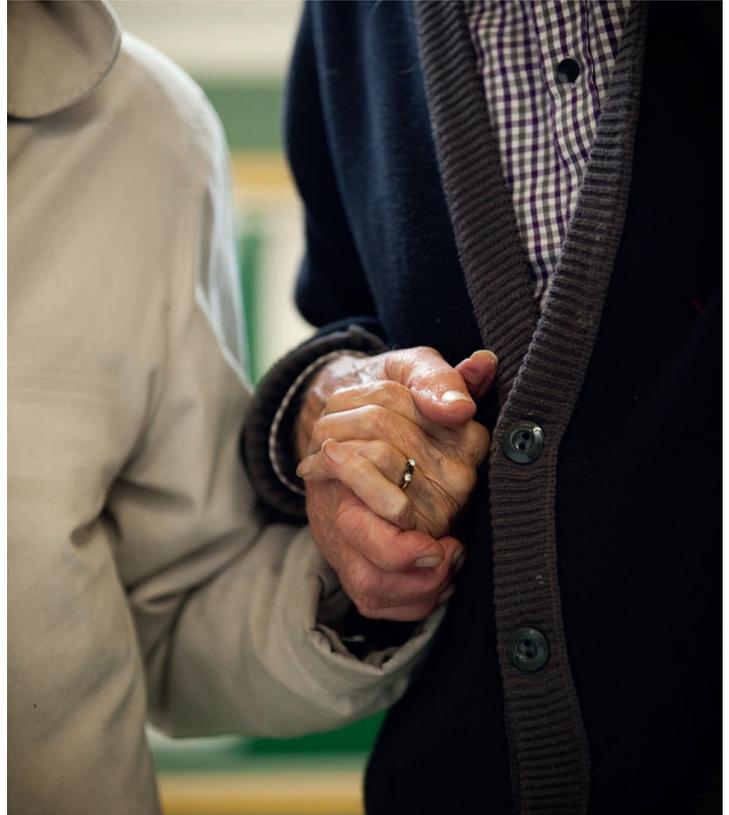
A right to support

**A right to know**

# People with dementia have a right to know

Without diagnosis or proper support, living with dementia can be isolating, frightening and exhausting.

- **7,000 people with dementia in Northern Ireland don't have a diagnosis.**
- **A quarter of people diagnosed receive no information or support.**
- **90% feel the support they receive is inadequate.**



# The Right to Know campaign

**We believe that everyone with dementia has a right to know about their condition.**

Getting a diagnosis is the first step to finding the information and support that helps people to understand dementia and to plan for the future.

Early diagnosis and support has benefits for the person with dementia, family carers and the health service. People with dementia also have a right to treatments that may ease some of their symptoms.

The right support means people aren't left to cope alone. Getting the right support early can keep people with dementia living well and avoids unnecessary hospital admissions.

But the reality is that in Northern Ireland this isn't happening for everyone.

Some GPs dismiss people's dementia symptoms as a natural part of ageing – while care home residents can be written off as not needing support for their dementia.

**We believe this is wrong and hope you will join our campaign for urgent change.**



# What we're campaigning for

We want Health and Social Care Trusts to do more to support people with dementia.

## **We want to see:**

- a diagnosis for everyone with dementia
- no longer than 12 weeks between first appointment with GP and diagnosis
- a Dementia Support Worker for everyone at the point of diagnosis.



# Dementia Support Workers

We're campaigning for everyone living with dementia to get a Dementia Support Worker at the point of diagnosis.

Access to a Dementia Support Worker makes a huge difference to the person with dementia and their family carers.



## **Dementia Support Workers can:**

- navigate local services so people get the best practical support and information
- act as a specialist point of contact between a person living with dementia and a wide range of health and social care professionals
- answer questions, offer advice and share ways to live well with dementia.

The service that Dementia Support Workers offer is vital but too few people are aware of it or only receive their support after months or years of coping alone.

**We believe this has to change.**



# Read how Dementia Support Workers change lives



**‘If only I’d known about you sooner!’**

## Providing specialist support

Dementia Support Worker Aisling Smith has seen the relief people with dementia and their carers feel when they realise help and support is out there.

‘I recently came across two cases where dementia had been diagnosed months ago but the people concerned received no information about it, or about services they might need to access,’ she says.

‘If only I had known about you sooner!’ is how they expressed their feelings of relief, tinged with regret.’

‘Getting sound information from a Dementia Support Worker at the point of diagnosis means a person knows where to go when they need support – they don’t have to cope alone.’

### Helping people stay well

Aisling finds it very satisfying when she hears how the information that Dementia Support Workers share helps relieve a carer’s stress so they can approach their caring role with renewed energy.

‘People want to know where they can get services or support that help the person with dementia to maintain and build social contacts, and keep them active, involved and well.’



**‘A Dementia Support Worker at diagnosis could have set about finding the necessary support.’**

## Making sure people are heard

In her role as a volunteer befriender Carol Hegarty met a woman in a care home who had reverted to speaking her native Irish – which caused a serious gap in communication between her and the care staff.

‘Staff were increasingly at a loss as to how to include the person in everyday social interaction so she felt involved,’ she says.

‘As a fluent Irish speaker I jumped at the chance to visit. We would spend the time looking at pictures of Donegal or chatting about her younger days. I could really see and sense that she was enjoying our time spent together.’

### Creating a connection

Carol also helped care home staff understand the woman’s needs.

‘I was able to explain what certain phrases meant, so that they could gain more insight into what the person with dementia was saying, which helped them communicate emotionally.’

Carol is glad of their time together. But she adds that the woman could have enjoyed a better quality of life if her needs had been identified and met earlier.

‘This is a classic case where a Dementia Support Worker at diagnosis could have anticipated this need and set about finding the necessary support.’



## Ending isolation

Having recognised the frustration expressed by a woman with dementia, Support Worker Danny Wilson was able to offer practical help to her and her family.

‘Recently I visited a client with dementia in her own home,’ Danny says.

‘Her family were concerned that their mother was becoming withdrawn and at times aggressive. It became clear to me that she was frustrated and becoming isolated.’

Danny suggested that she spend some time at an Alzheimer’s Society Dementia Café, where she could benefit from a relaxed, dementia-friendly environment.

Meanwhile, he referred her family to a carers’ support group where they could meet with people with similar experiences.’

**‘It became clear to me that the person with dementia was frustrated and becoming isolated.’**

### Better quality of life

Small changes over a period of months had a big impact on the entire family. At the café, a simple hand massage helped transform the woman’s mood.

‘She became calm and happy and even proceeded to give her daughter a hand massage and to express affection – which she hadn’t done for some months.’

‘At the end of the Dementia Café session the carer felt more confident that she could intervene to reduce agitation in her mother and to encourage more affectionate and less stressful engagement.’

‘The quality of life for the person with dementia and her family carers has definitely improved by these individual interventions and timely access to a range of services which meet some of their needs.’



**‘Most people are eager to talk and relieved to have the chance.’**

## Making sense of dementia

Dementia Support Worker Valerie Guthrie helps people cope with the impact of a new diagnosis and supports them as they plan for the future.

‘Sometimes the family is in shock and just take the written information home to read,’ she says.

‘But most people are quite eager to talk and are even relieved to have the chance. In some cases they’ve been living with the effects of dementia for some time. Getting a diagnosis makes sense of a lot of changes in the person, which they’ve been trying to cope with on their own.’

### Avoidable stress

Valerie is able to connect carers to activities in their area where they get to meet with people living with similar challenges. This means they have access to information and support and don’t feel so isolated.

She explains that many people don’t even know Dementia Support Workers exist.

‘One carer told me that the consultant who diagnosed her mother had been quite dismissive, didn’t explain things clearly to them and made no reference to Alzheimer’s Society as a potential source of support.’

‘The carer felt she should have been referred to a Dementia Support Worker at the time when her mother had been diagnosed rather than leaving it to chance and causing months of anxiety and avoidable stress.’



**‘The years of struggle had caused considerable stress which could have been avoided had they had a Dementia Support Worker.’**

# Giving carers the information they need

Providing access to a Dementia Support Worker at diagnosis means that carers don't have to cope alone. But in many cases, the help comes too late.

Dementia Support Worker James Erskine recently met a woman who is registered-blind whose mother has dementia. Together she and her partner cared for her mother at home for over eight years before she moved into a care home.

‘I was able to talk to them about dementia and its affect on the person, to reassure them that they had approached their caring role in a really positive and supportive way.’  
He says.

## Making access equal to all

‘However, the years of struggle had caused considerable stress which could have been avoided had they had a Dementia Support Worker who would have been able to supply information in audio format as well as Braille.’

James was able to supply the couple with these resources, but says this support could have come a lot earlier.

‘Had it been available from the outset and throughout the period when her mother had been living at home, it would have reduced and avoided stress and worry at the time and in the intervening years.’

# We need your help to make a difference

We believe everyone has the right to a diagnosis, plus the support they need to improve their quality of life and to plan for the future.

## The aim of the Right to Know campaign is to ensure:

- everyone with dementia gets a diagnosis
- no one waits longer than 12 weeks from first appointment with GP to diagnosis
- everyone has access to a Dementia Support Worker at the point of diagnosis.

**Help make this happen for over 7,000 people in Northern Ireland.**

## How you can help

If you are:

- **a member of the public** please sign up to be an online campaigner here: [alzheimers.org.uk/campaigner](https://alzheimers.org.uk/campaigner)
- **an elected representative** please write to the Minister for Health to ask how he intends to support the Right to Know campaign
- **a health and social care professional** find out more about how important it is to have a Dementia Support Worker at: [alzheimers.org.uk/DSWvideo](https://alzheimers.org.uk/DSWvideo)

Your support can help transform the lives of people with dementia and their family carers.

**#RightToKnow**



Leading the fight  
against dementia

**Alzheimer's  
Society**

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 135 local services in Northern Ireland.

We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

To find out more about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the Alzheimer's Society National Dementia Helpline on **0300 222 1122**

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Alzheimer's Society  
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