

# The New Deal on Dementia

# Alzheimer's Society's strategy 2017–2022

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# The New Deal on Dementia

Alzheimer's Society leads the fight against dementia across England, Wales and Northern Ireland and has made great advances through our previous strategy *Delivering on Dementia* (2012 - 2017). In the next five years, we need to go further so that people affected by dementia get the care, support, and hope for the future they deserve.

This document is for our volunteers and employees, and those close to us, so you can play a crucial role in delivering the New Deal on Dementia. As we move into our new strategy, I look forward to your participation in taking our ambition into a changed world for people affected by dementia.

Jeremy Hughes CBE  
CEO

Dementia can devastate lives. For someone with the condition, as well as their family and friends, dementia means the plans you made, and the future you thought you had, will not be so.

**Our vision is simple: a world without dementia.**

We know that moment will come. Until that day, we will create a society where those affected by dementia are supported and able to live without prejudice. Today, too many people with dementia struggle. They can't access information, help and support. Everyday things people take for granted become difficult.

But dementia won't win. We make no apologies for the scale of our ambition. We will see the day when dementia is no more. Until then, we will work relentlessly for a cure - getting closer every day.

**Our mission is to transform the landscape of dementia forever.** Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.

**People with dementia must have a new deal. Now is the moment.**



## Our values

Our values capture the essence of who we are. The behaviours we each demonstrate every day are how we bring our values to life. They underpin our new brand, and support us to work together to deliver our strategy.


Committed to creating a world without dementia,

**We get it:** we are trusted experts, informed and inspired by people affected by dementia

**We are united:** together we achieve more

**We will do it:** we demand and deliver lasting change.

**We  
get it**



Elaine,  
living with  
dementia,  
East Sussex,  
England

**We are  
united**



We will lead and inspire the growing dementia movement that will transform society. We will be the rallying point for everyone who wants change, and will challenge those who do not want to change. Together, we will create a society where people with dementia are included. Together, we will beat dementia. We will only be able to do all that if we are united.

Abdus,  
living with  
dementia,  
London,  
England



Today, the news that you have dementia can leave you in the loneliest of places. The road ahead looks frightening. Getting a diagnosis, and then the health and care support you need, is rarely straightforward.

When you leave the doctor's surgery and step back into your community, you should step back into a society that includes you. A society where your family, friends, neighbours and strangers understand dementia. Where you know that, however hard the road ahead, you do not walk it alone. You should be part of workplaces and communities where people with dementia and family carers are supported, not afraid to speak out and ask for help. Today, that is not the case but, together, we can change this.



**We will  
do it**

James,  
living with  
dementia,  
Cardiff,  
Wales

# 1979

The creation of the  
Alzheimer's Disease Society

# 98

Members at the first annual  
general meeting in  
September 1980

# 10,000

Volunteers and Dementia  
Friends Champions

# 90,000

Campaigners

# 1.8 million

Dementia Friends

In 1979, two people with extensive experience of caring for loved ones with dementia discussed the pressing need to raise awareness and improve the quality of care, support and information for people with dementia and carers. This led to the creation of the Alzheimer's Disease Society. At the first annual general meeting in September 1980, 98 members and supporters attended.

A lot has changed since then; including in 1999 our name. Over the last five years, we have brought dementia out of the shadows. We are supported by more than 10,000 volunteers, 10,000 Dementia Friends Champions, 90,000 campaigners and over 1.8 million Dementia Friends. We work in partnership, not just with individuals but organisations big and small, and from all sectors of society and the economy. Everything we do builds on our previous years of achievement.

This work is our launchpad for the next five years. Our ambition may look daunting, but change is possible. Dementia will not win.



# Change is possible



# Our promise

To a person living with dementia today, and to the 1 million people who will develop dementia between now and 2022, we make a promise.



Our promise  
You are not alone

# You are not alone

We will be available to every person who receives a diagnosis, who needs us. We want everyone affected by dementia to know that, whatever you are going through, wherever you are, whoever you are, you can turn to Alzheimer's Society for support, information and advice.

**Our promise**  
We can change today

We will change the conversation on dementia. We will bring dementia rights into the mainstream and make sure people with dementia are treated as an equal member of society. We want everyone to know that, in your community, by campaigning, giving your time or your money, you can join us to make change happen.



# We can change today

Our promise  
We will change tomorrow

# We will change tomorrow

We will lead dementia research, building connections between researchers, funders and policymakers nationally and internationally. We will fund research that will: find the answers that help us understand dementia better; prevent or slow its development; and find a cure. At the same time, we will use research to better support everyone living with dementia today.





# How we will work with people with dementia

We will stand with people affected by dementia, from pre-diagnosis to end of life. This begins with listening to people with dementia and their carers and putting them at the heart of how we make decisions. Only then can we deliver our strategy.

We commit to working in partnership with people affected by dementia, making sure they are involved in setting our priorities and the approach we take, from board level to operations on the ground.

## We will do this by:

- holding the biggest ever consultation with people affected by dementia to shape a new 'National Dementia Declaration'. This will set out the rights of people living with dementia as equal members of society. We will develop meaningful and lasting opportunities to involve people affected by dementia locally and nationally, building on our ground-breaking, consultative panels
- listen to people affected by dementia and gather evidence to better understand people's experiences at every stage of dementia and make the case for change
- supporting people with dementia to have a choice and voice in their local communities, through actively supporting inclusion in local decision making
- making sure people with dementia and carers are included in the workplace, positioning Alzheimer's Society as a leader in employment and volunteering practice.
- ensure the voice of people affected by dementia is heard in the health and social care system.

**How we will  
work with people  
with dementia**



'My grandmother has mixed dementia and I want to do all I can to help find a cure and raise awareness of this terrible disease.'  
Hanna, Media Assistant, Cardiff, Wales

**Inspiring  
each other**

We want people with dementia,  
their family, friends and carers,  
to know that they are not alone.

# Pillar one

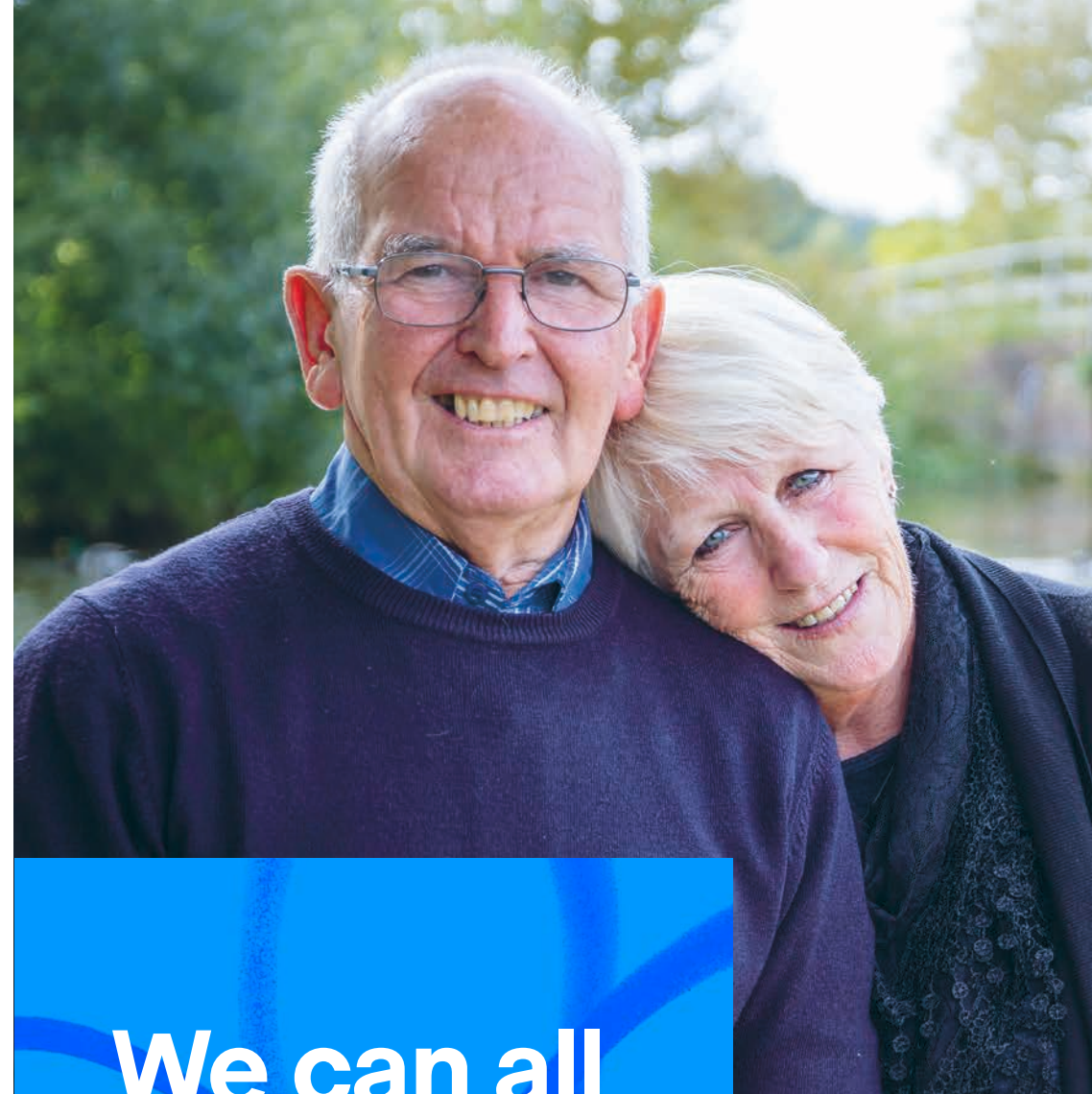
# The new deal on support



## We will:

- help join up the health and social care system for people affected by dementia by providing information and support online, on the phone and face-to-face. We'll also provide more specialist advice and help for people who need the most support
- support people with dementia to live better by linking them up with volunteers who can help them to take an active part in their community. The volunteer will not only support the person with dementia to do an activity but help secure change around them by building dementia friendly communities
- work in partnership with health and social care organisations, businesses and others who want training and professional guidance on how to better support and include people affected by dementia.

Pillar one  
The new deal  
on support



We can all  
make a  
difference

'We had support and help from Alzheimer's Society with Bryan's cousin and my mum. We felt we wanted to give something back.'

Ruth and Bryan,  
Volunteers, Salisbury,  
England

## To deliver this, we will:

- have simple, universally accessible, support for everyone affected by dementia. A trained adviser will be the trusted, reliable link to everything Alzheimer's Society can offer for someone affected by dementia. Through our signposting, training and coordination, they will be able to access wider health, housing and care services

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## An online hub will support, advise and help people manage their condition.

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- develop an online interactive hub for people affected by dementia to go to for information, support and advice and to help them manage their condition. They will be able to download information into a personalised online wallet, chat online with trained employees and volunteers, and search for local services to manage their condition. With an expanded knowledge team, we will make sure we are consistently providing the latest, high quality support and advice

- expand the work of our helpline so that anyone affected by dementia can speak to an advisor for support and advice. This will provide dedicated support for people who are often marginalised, vulnerable, or have specific needs. Our trained people will give advice on the phone, online or face-to-face, depending on what those who need help prefer
- harness the efforts of volunteers to help people with dementia. Our Side by Side service will help people with dementia to get out to do the things they love. It will link them with people in their community who want to provide support. The volunteer will support the person with dementia to do an activity and also help build dementia friendly communities. We will make sure people living with dementia in every part of the country can access support from Side by Side
- lead others to improved care and support. By working with others, we will deliver training and consultancy to key staff across the health and social care sectors. Better trained and supported staff will provide improved care and make sure more people affected by dementia receive the support and treatment they deserve
- continue to ensure people benefit from community support, such as Singing for the Brain, helping to build dementia friendly communities.

**Pillar one  
The new deal  
on support**

**Our ambition, by 2022, is to reach out to everyone from the time of diagnosis to offer help, and deliver a universally accessible support and advice service.**

**Pillar one  
The new deal  
on support**



# Pillar two

## The new deal on society

We want everyone affected by dementia to know that we are making change happen nationally and locally, galvanising all those who want to achieve change and joining them in the dementia movement.

## We will:

- use our reach, trusted expertise and insight to influence decision makers, organisations and communities. We will help create an integrated, person-centred health and social care system that better meets the needs of people with dementia and those who care for them
- make sure having dementia does not mean you are treated unequally. At every stage of the dementia journey, from pre-diagnosis to end of life, the health and social care system will uphold the rights of people affected by dementia and support and accept them
- support people living with dementia to be part of their community, wherever and however they are living. We'll do this by building Dementia Friendly Communities that are shaped by people affected by dementia. We will support all who want to take social action to change the community around them

- make sure people live in neighbourhoods and communities where their friends and neighbours understand dementia and support people living with it. We will do this by inspiring people to become Dementia Friends. We will galvanise and lead a dementia movement to change the public conversation on the condition. This will bring the rights of people affected by dementia into the mainstream so that they are treated as equal members of society

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**Through Dementia Friends, we will galvanise and lead a dementia movement to change the public conversation on the condition.**

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- encourage and support those who want to join us, using their generous offer of time, talent and money, in the most effective way possible
- share our expertise and experience, helping others around the world to transform their communities to better support people affected by dementia.

**Pillar two  
The new deal  
on society**

## To deliver this, we will:

- transform the way we gather evidence on people's experiences of dementia. We will commission longitudinal studies and bespoke research and use information, insight and data from our services and partnerships, including our online information and support service. We will lead a review of the National Dementia Declaration, setting out a new ambitious charter that captures the wishes and aspirations of people affected by dementia. We will also launch a new State of the Nation series of reports that articulate the experiences of people affected by dementia
- maintain and enhance our leadership position in the health and social care sectors. We will use evidence and analysis of the need for change to do this, and involve people living with dementia in defining their right to be an equal member of society. We will influence decision makers nationally and locally, making sure we are able to respond to the evolving health and social care sectors across the nations we work in.

Pillar two  
**The new deal  
on society**



'I realised I couldn't do everything, but I could do something!  
Be positive - set goals and we can change things!  
Una, Volunteer  
Lisburn, Northern  
Ireland

**Together  
we can  
change  
society**



## To deliver this, we will:

- develop an approach to campaigning that supports people to drive change through their own initiative and activity, locally and nationally We will have a greater international presence, articulating and defending the rights of people affected by dementia

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**The aim of our Dementia Friendly Communities programme is to make sure as many people with dementia as possible live in communities that support them.**

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- make sure as many communities as possible are dementia friendly. We will extend the reach of our Dementia Friendly Communities programme. This will involve businesses, the health and social care sector, local government, the voluntary sector, faith and community groups and others. The aim is to make sure as many people with dementia as possible live in communities that support them

**Pillar two  
The new deal  
on society**

- use the power of our reach to mobilise people who want to achieve change in their community. We will inspire the biggest ever health and social care movement, recruiting a minimum of 4 million Dementia Friends. We will help them change their local communities, so that those living with dementia know that in every neighbourhood, there are people who understand dementia and are ready to help

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**We will help change local communities, so that those living with dementia know that in every neighbourhood, there are people who understand dementia and are ready to help.**

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- underpin our work through national brand awareness campaigns to make sure people affected by dementia know they are not alone and can turn to Alzheimer's Society for help and support. We will shift public awareness and understanding of dementia, identify and fight fear.

**Our ambition, by 2022, is to change the conversation on dementia. More people in 2022 living with dementia will say they live in communities that support them. We will have increased public awareness and understanding of dementia, ending the stigma associated with the condition today.**

**Pillar two  
The new deal  
on society**



# Pillar three

# The new deal on research

We want everyone affected by dementia to know that our researchers are leading the way. They are finding answers that will make sure we better understand dementia, how to prevent it, improve care today and, ultimately, find a cure.



## We will:

- help people with dementia live better through investing more money in all areas of dementia research, including biomedical, prevention, assistive technology and care research. We will influence our partners and others to do the same
- make sure our investment has maximum impact and help join up the research landscape, linking researchers across the UK with those based internationally
- underpin everything we do with evidence. We will develop evidence-based interventions that improve the quality of life of people affected by dementia, establishing ourselves as a national leader in this area
- put the knowledge and experiences of people affected by dementia at the heart of the research agenda

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## We will develop evidence-based interventions that improve the quality of life for people affected by dementia.

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- lead the way in making sure people with dementia are involved in developing the UK and international research agenda
- make sure research is put into practice so it improves lives as quickly as possible.

**Pillar three  
The new deal  
on research**

## To deliver this, we will:

- establish eight centres of excellence by making focused investments in specific research topics that are high priority for people affected by dementia
- use seed funding to drive innovation in dementia research. We will grow new areas of research
- shape the UK Dementia Research Institute. As a founding charity partner of the institute, we have a clear remit to ensure its scope includes biomedical, care, technology and public health research. We will also make sure the voice and experience of people affected by dementia inform all aspects of the institute
- work across the research community to support collaboration and develop a cohesive structure for dementia research. This will involve helping develop virtual and real communities of research interest and practice. It will bring together researchers from across disciplines, institutions and countries with people affected by dementia, policy makers, service providers and funders. They will share knowledge, develop ideas and work together to address significant challenges in dementia research.

**Pillar three  
The new deal  
on research**

## To deliver this, we will:

- involve people affected by dementia in research, through the Research Network Volunteer programme. They will help in all areas of research, from setting priorities to considering proposals

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## **We will push boundaries of best practice in care and support.**

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- be national leaders on evidence and evaluation, pushing boundaries of best practice in care and support, including in our services and everything we do. We will develop demonstrator sites that we will deliver ourselves or encourage other providers to adopt – building evaluation in at every stage
- continue to play a leadership role in attracting and retaining the very best talent in dementia research. We will build and support the next generation of researchers through our Dementia Research Leaders programme.

**Our ambition by 2022 is to have made our biggest ever investment in dementia prevention, care and cure research. This will transform the landscape of dementia research, here and abroad.**

Pillar three  
The new deal  
on research

# Making it happen

Our people – volunteers, employees, and our supporters – will make the commitments we make in this strategy possible. We will support these people to deliver the change we need to make, maximising our impact.



## To do this, we will:

- raise more money than ever before to ensure more people with dementia can live better. Our mission demands that, by 2022, we raise at least £137 million from donors each year. But we will not just be charity leaders in fundraising innovation, we will raise funds in a way that builds public trust in what charities do and how they do it. We will make sure all those who support us are always thanked and have a good experience – because, without them, we couldn't do what we do
- make sure that everyone who wants to support us, including volunteers and campaigners, can do so alongside those who want to change their community, for example, by becoming Dementia Friends
- work as one organisation, using the skills of our volunteers and employees. We will attract the best people to join us because we offer a workplace that is fulfilling and rewarding. We will have a world-class commitment to volunteers that supports volunteers to play a significant role in shaping our tomorrow.

**Making  
it happen**



**Creating  
a world  
without  
dementia**

'If my involvement can help even a few people to have a better experience then I am happy.'

Suzie, Dementia Support Worker, London, England

## To do this, we will:

- use digital technologies, from apps to online platforms, to significantly increase our reach. We will build a new digital platform and use social media to accelerate the growth of the dementia movement. We will underpin this work by improving our data insight and creating personal user experiences for supporters, researchers and people who use our services

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## We will give staff and volunteers the tools needed to work more efficiently.

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- support remote and online working for employees and volunteers through technology, giving them the tools they need to work more efficiently
- support working environments that fulfil the needs of the organisation and help us to deliver our commitments in the most cost-effective way.

**Making  
it happen**



'There is more to me than the diagnosis of Alzheimer's. There is me.'  
Alison, living with dementia, Surrey, England

**United  
against  
dementia**

# Bringing it all together: our brand

For someone with dementia wondering where to turn for help, to someone in the community thinking about where to volunteer. Or a person considering where to look for a new job, and all those wanting to donate to tackle dementia. How we are seen and heard is vital. Our brand is key to this.

Brand communicates clearly and succinctly who we are and what we stand for. It sets an expectation, which we need to deliver on. But it is more than that. Our brand is our DNA. And it sets the tone for how we think, act and communicate.

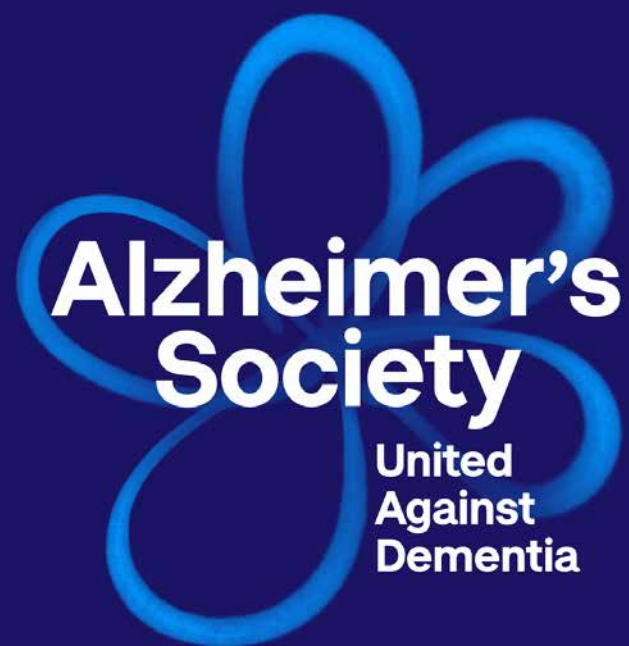


Our new brand supports our strategy. This includes a new strapline which encapsulates who we are and what we will do: **United Against Dementia**. We will make sure that our identity, culture, values and brand are expressed in all of our communications, and all that we do. With a punchy, defined message, we will present a brand people can connect with, find relevant and feel inspired by.

**We will** build mass communications campaigns, with one core message, across different platforms, encouraging people to join a conversation on dementia.

**We will** raise awareness of dementia, and of Alzheimer's Society, reinforcing our position as the rallying point of a dementia movement. One that is reaching new people in creative ways and making sure more people know who we are and what we do.

**We will** make our communications relevant, reaching people in new and innovative ways. We won't wait for people to come to us – we need to bring people into the dementia movement. From festivals to corporate boardrooms, faith groups to health centres, we'll find innovative ways to reach people with our communications.



**Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.**

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operates in England,  
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