



2 BY 2050
MILLION
PEOPLE
IN THE UK WILL
BE LIVING WITH
DEMENTIA²



FRONT_{OF}MIND

Across the UK, people living with dementia and their carers are facing unfair and unacceptable challenges in accessing the support and care they need – an issue exacerbated by the COVID-19 pandemic. This not only has significant personal cost, but is damaging to the NHS, economy, and wider society.

Dementia is already the leading cause of death in the UK, and in contrast to other chronic conditions – such as heart disease and respiratory disease – continues to see increasing mortality rates.¹ This will only rise further as the number of people living with dementia in the UK is projected to increase by 146% by 2050, from 850,000 to two million.²

Without action to better recognise and meet the needs of people living with dementia – and the 700,000 family and friends who already provide unpaid care to them – the UK stands wholly unprepared to meet the growing demand that this will place on the NHS, social care, and society as a whole.

Seeing the scale of this challenge, Roche and tide – together in dementia everyday – are raising awareness of the issues faced by people with dementia and their carers, and are calling for action to be taken to provide the recognition and support they need.

We are calling on you to support this campaign and help give people with dementia, and their carers, the recognition and support they deserve.

TOGETHER
IN DEMENTIA
EVERY DAY

2 UP TO
YEARS
BEFORE A
PATIENT SEEKS
ADVICE FROM
THEIR GP⁶

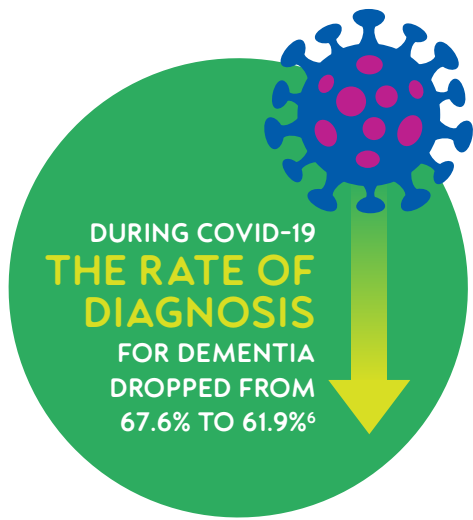
34 UP TO
WEEKS
WAITING FOR
MEMORY
ASSESSMENT
SERVICES⁷

WHAT CHALLENGES DO PEOPLE LIVING WITH DEMENTIA EXPERIENCE?

Currently, **1 in every 14** of those aged 65 years and over is living with dementia³ – the most common cause of which is Alzheimer's disease, affecting **over 520,000** people in the UK.⁴ But, despite this significant – and accelerating – number, many people with dementia are struggling to access basic care and support.

NICE guidelines state that those with dementia should have access to a timely and accurate diagnosis, to enable them to access treatment quickly and plan for the future.⁵ In reality, this remains out of reach for many people with suspected dementia symptoms:

- On average, it takes **2 years** from first signs of symptoms before a patient seeks advice from their GP, before a further **6 to 12 weeks** to be referred to a specialist⁶
- Although the majority of people are referred to memory assessment services (MAS), even prior to the pandemic, there was wide variation in access to these services – with some patients waiting as long as **34 weeks**⁷



- During COVID-19, the diagnosis rate for dementia in those aged over 65 dropped from **67.6%** in February 2020⁷ to **61.9%** in May 2021.⁸ From this, we can estimate that nearly **270,000** people with dementia over the age of 65 do not have a diagnosis⁹

Without a confirmed, accurate diagnosis of dementia, people living with dementia will struggle to access medical and social interventions that could ease their symptoms, and ultimately, delay the progression of disease. This also means that their carers are denied access to support and benefits.

This is further complicated by the fact that there is **no standardised dementia pathway** in the UK, creating unfair variation in access to care.

WHAT ABOUT THEIR CARERS?

For many people living with dementia, unpaid carers – usually spouses or children and, in 60-70% of cases, women¹⁰ – provide the bulk of care, and are relied upon heavily by the health and care system.¹¹ Currently however, carers are not sufficiently recognised, supported, or included in policymaking, both in the NHS and society more broadly. This means that many unpaid carers are unable to find the support they need, despite the considerable strain that caring can cause:

- Over **60%** of carers report that caring has caused them to feel stress. Set against this, only **35%** feel they have enough encouragement and support, and only **23%** report having as much control of their daily life as they would like¹²
- During the pandemic, the number of carers reporting they did not have the breaks they needed to look after their own physical and mental health increased from **44%** to **72%**¹¹
- Unpaid carers are **twice as likely** to suffer from ill-health because of their caring role,¹¹ with over **20%** reporting that they developed their own health conditions as a result of caring, and a further **20%** seeing an existing condition deteriorate¹²

The financial distress of caring can cause additional anxiety for many unpaid carers. While many carers are retired, **23%** are not in paid work due to their caring responsibilities. For younger carers, this can be particularly damaging: **the majority of unpaid carers under 65 years old** report experiencing 'a lot' of financial difficulties.¹²




WHAT IS THE WIDER IMPACT ON THE ECONOMY?

The economic impact of dementia and unpaid care is multi-faceted and far-reaching:

- Dementia costs over **£34 billion** per annum across the UK – including over **£4.9 billion** to the NHS – and could rise to over **£80 billion** by 2040¹³
- Unpaid care accounts for **40%** of these costs, at a current value of **£13.9 billion**¹³
- In 2014, unpaid care for dementia was estimated to cost English businesses **£1.6 billion**¹⁴ – this is likely to have increased as the impact of dementia has grown

WHAT CAN BE DONE?


The forthcoming strategy for people with dementia and their carers, promised in the recent Social Care White Paper,¹⁵ provides a timely opportunity to reframe our attitudes towards dementia and unpaid care. People living with dementia and their carers must be properly recognised and supported. The profound personal and societal costs associated with unpaid care cannot continue this way. It is crucial that the strategy takes steps to:




Facilitate the development of **clear, evidence-based pathways** that enable equitable access to diagnosis, treatment, and care for those with suspected and confirmed dementia



Enhance **national leadership and accountability** for dementia, that better recognises dementia as a disability, with medical as well as care needs



Recognise **unpaid carers as a critical part** of the health and care system, and ensure that the right data is collected to better understand the impact of unpaid care, and what carers need in their caring role



Ensure that **unpaid carers get the support** they need to look after their own health and stay in work, continuing to play their essential role as caregivers while contributing to the economy



Include the **voices of people living with dementia and their carers** in service design, delivery and change, particularly as Integrated Care Systems (ICSs) in England take on a greater role in building services around the needs of their local populations

CASE STUDY¹⁶

The Sandwell dementia pathway brings together all parts of the system – including people with dementia and their carers – in an integrated and clear pathway that provides a wide range of holistic support.

With Dementia Navigators and Community Dementia Advisers providing support throughout the pathway, from initial symptoms, to diagnosis, to long-term care, people with dementia and their carers are offered advice and information, sign posting, peer support, and training for carers and people with memory concerns.

As a result, people with dementia and their carers report decreased anxiety, greater confidence in self-management, and an improved ability to plan ahead.



HOW CAN YOU HELP?

You can help amplify our campaign by:

- **Tabling Parliamentary Questions** exploring how the Government intends to better support people with dementia and their carers, now and in the future.
- **Write to the Secretary of State for Health and Social Care** to highlight the challenges currently faced by people with dementia and their carers, and calling for an improved approach to supporting them.
- **Write to your local health and care system leaders** to understand what actions are being taken to better build services around the voices and needs of people with dementia and their carers.
- **Join tide's network** to help us to continue to grow and amplify the voice of carers in policymaking across the UK

The campaign would welcome the opportunity to support you in any action you choose to take.

Roche

tide™

FRONT_{OF}MIND

To discuss the issues raised in this briefing further, or if you have any questions, please contact:

Samantha Bolam
Chief Officer, tide
samantha@tidecarers.org.uk

Conn O'Neill
Public Affairs Partner, Roche
conn.oneill@roche.com

Front of Mind is a joint campaign by Roche and tide (together in dementia everyday), calling for people with dementia and their carers to receive the recognition - and support - they deserve.

Roche is a pioneer in pharmaceuticals and diagnostics, focused on advancing science to improve people's lives. Roche is committed to rising to the global challenge of Alzheimer's disease through innovation and collaboration.

tide is a national involvement network for carers and former carers of people with dementia. tide believes that carers have the experience and knowledge to improve health and social care, research, and policy development throughout the UK.

REFERENCES **1** Alzheimer's Research UK Dementia Statistics Hub, [Deaths due to dementia](https://www.dementiastatistics.org/statistics/deaths-due-to-dementia/), accessed January 2022 **2** Alzheimer's Research UK Dementia Statistics Hub, [Prevalence projections in the UK](https://www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk/), accessed January 2022 **3** Alzheimer's Research UK Dementia Statistics Hub, [Numbers of people in the UK](https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk/), accessed January 2022 **4** Alzheimer's Society, [Alzheimer's disease](https://www.alzheimers.org.uk/about-dementia/types-dementia/alzheimers-disease), accessed January 2022 **5** NICE, [Dementia: Quality Standard](https://www.nice.org.uk/guidance/qs184/resources/dementia-pdf-75545721373381), June 2019, accessed January 2022 **6** Roche, Data on file **7** NHS Digital, [Recorded dementia diagnoses - February 2020](https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/february-2020), March 2020, accessed January 2022 **8** NHS Digital, [Recorded dementia diagnoses - June 2021](https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/june-2021), July 2021, accessed January 2022 **9** Roche, Data on file **10** Alzheimer's Research UK Dementia Statistics Hub, [Impact on carers](https://www.dementiastatistics.org/statistics/impact-on-carers/), accessed January 2022 **11** Carers UK, [Carers UK briefing: Health and Care Bill](https://www.carersuk.org/for-professionals/policy/policy-library/carers-uk-briefing-on-health-and-care-bill-july-2021), July 2021, Accessed January 2022 **12** NHS Digital, [Personal Social Services Survey of Adult Carers in England \(SACE\), 2018-19](https://files.digital.nhs.uk/88/F04948/PSS_SACE_Report_2018-19.pdf), June 2019, accessed January 2022 **13** London School of Economics and Political Science, [Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040](https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/carer-support#:~:text=The%20Care%20Act%20now%20require), November 2019, accessed January 2022 **14** Alzheimer's Society, [Alzheimer's Society's view on carer support](https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/carer-support#:~:text=The%20Care%20Act%20now%20require), accessed January 2022 **15** Department of Health and Social Care, [People at the Heart of Care: Adult Social Care Reform White Paper](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037594/people-at-the-heart-of-care_asc-form-accessible.pdf), December 2021, accessed January 2022 **16** Sandwell Dementia Pathway, [The Story...](https://www.sandwell.gov.uk/~/media/Sandwell%20Council/Assets/2022/04/16/Sandwell%20Dementia%20Pathway.pdf) Data on file, accessed January 2022

Date of preparation: April 2022 | Roche Material Number: M-GB-00006916

© 2022 Roche Products Limited. All rights reserved.

Roche Products Limited, Hexagon Place, 6 Falcon Way, Shire Park, Welwyn Garden City, AL7 1TW, United Kingdom