

# People with dementia could be missing out on post-diagnosis care

September 26 2022

---



Credit: Unsplash/CC0 Public Domain

A new report has found that as many as 85% of people with dementia could be missing out on important post-diagnosis care.

Now world-leading [dementia](#) experts, including a team at Newcastle University, are calling for the condition's post-diagnosis care, treatment, and support, to be recognized as a human right.

Alzheimer's Disease International (ADI) has released the "World Alzheimer's Report 2022—Life after diagnosis: Navigating treatment, care and support," which was co-authored by McGill University.

The report focuses on the urgent need for significant improvements to essential post-diagnosis treatment, care and [support services](#) for more than 55 million people living with dementia across the globe. It also calls for robust plans to support the 139 million people forecast to have Alzheimer's Disease by 2050.

### **New approach needed**

Newcastle University experts contributed to the key global report with their Pridem program, which features as a research case study.

The Pridem program looked at how care and support was provided to people diagnosed with dementia in England. It found unacceptable, widespread inequalities in service provision with fragile and fragmented services often only funded in the first two years after diagnosis.

The program looked for examples of good practice and used this evidence to co-develop, with people with dementia, their families, and service providers, a primary care-led model of post-diagnostic dementia care which is now being tested in practice.

Professor Dame Louise Robinson, Regius Professor of Aging at Newcastle University, said: "Our research showed that even before COVID-19, people living with dementia were struggling to access care and support despite national clinical recommendations.

"We hope the approach we co-developed—basing a dementia nurse specialist in GP practices, who affords expert advice to both the families living with the illness and also the GPs and their teams providing general care, has the potential to transform and reduce existing inequalities."

Post-diagnosis dementia care, treatment and support refers to multiple interventions that can improve the [quality of life](#) for patients, including both pharmacological and non-pharmacological treatments, caregiving, access to healthcare, support for daily life activities, home adaptations, social inclusion and respite.

Paola Barbarino, ADI [chief executive officer](#), said, "We don't question whether people with cancer need treatment, so why is it that when people receive a dementia diagnosis, they're often not offered treatment or care?"

"Repeatedly, they're just told to get their end-of-life affairs in order. Coupled with improving diagnosis rates, post-diagnosis dementia care must be recognized as a human right.

"While dementia doesn't yet have a disease-modifying 'cure,' there is clear evidence that demonstrates that appropriate post-diagnosis treatment, care and support significantly improves the quality of lives of those living with this disease, allowing many to maintain independence for longer."

## **Quality of care**

It is estimated that up to 900,000 people in the U.K. have a form of dementia and deaths linked to the illness are rising year-on-year. The total cost of care for people with dementia in the U.K. is £34.7 billion.

Ms. Barbarino added, "Globally, clinicians are both under-educated on

dementia, and under-resourced to provide adequate post-diagnosis care for people living with dementia.

"It's up to governments to shore up their healthcare systems so that it's possible for health care professionals to provide quality care that people living with dementia desperately need."

Leading experts recommend governments should identify trained "navigators" to act as liaison for a newly diagnosed person with dementia, to enable them to connect and engage with the vital supports and services they need.

"The World Alzheimer's Report 2022—Life after diagnosis: Navigating treatment, care and support" can be viewed here:

<https://www.alzint.org/resource/world-alzheimer-report-2022/>

Provided by Newcastle University

Citation: People with dementia could be missing out on post-diagnosis care (2022, September 26) retrieved 1 January 2023 from <https://medicalxpress.com/news/2022-09-people-dementia-post-diagnosis.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.