

What is dementia?

O que é demência?

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Dementia touches all of us. According to Alzheimer's Society¹ in the UK, one in two of us will be directly affected by dementia in our lifetime, either living with dementia ourselves or supporting someone who has the condition. A dementia diagnosis is life changing, progressively affecting the cognitive abilities that underpin everything we do. As the ageing demographic of developed countries and increased life expectancy in lower and middle-income countries result in growing numbers of people living with dementia worldwide, it is time to reconsider how we think about dementia.

Dementia is not a single entity, but a general term for over 100 constellations of symptoms that differ in their specific effects, especially in the early, mild-to-moderate stages. The brain changes underlying these effects are thought to develop gradually over decades. The effects themselves generally become evident in later life, although in a small proportion of people this occurs in mid-life. Our mental and physical abilities change continually across the lifespan, and we could think about dementia as an expression of this process, an extreme or accelerated version perhaps of age-related change that might happen to all of us if we lived long enough. In recent decades, though, the predominant paradigm has been one of disease. This has encouraged us to focus on understanding the underlying processes and how to modify, arrest or prevent them, and shed light on the contribution of lifestyle. These avenues of inquiry offer hope for the future, at least as regards some common types of dementia, but are less helpful for the many people already living with dementia, whose needs are not so much medical as social, or the many more who will go on to develop dementia in coming years.

With a long-term progressive condition for which there is no effective treatment and no cure, the challenge is how to support people to manage the condition and experience a good quality of life. This is not just a matter of dealing with symptoms. A good quality of life is closely linked to psychological well-being, which includes feeling positive about oneself, being able to deal with challenges, and having some hope for the future. Psychological well-being, in turn, reflects a person's experience and ability to function across many domains of life, such as physical fitness and health, social situation, social resources, relationships, and engagement in meaningful activity.²

Here, we can learn from thinking about disability. The definition of disability as arising where a physical or mental impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities is relevant for people with dementia and carries the expectation of a right to support. The World Health Organization (WHO) framework³ demonstrates that functioning is influenced not just by the cognitive effects of dementia and their secondary impacts such as loss of confidence, but also by the social and environmental context. People with dementia tell us that, when receiving a diagnosis, the one thing they are not offered is hope. This framework points to five ways in which we can offer much-needed hope for living with dementia:

1. Creating a social context where people with dementia are understood, accepted, and included, and have opportunities to support one another.

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2. Designing or adapting outdoor environments, indoor public spaces, and the technology we interface with in daily life to be cognitively as well as physically accessible.
3. Equipping people with dementia and their families to focus on strengths and retained abilities and develop strategies to manage or compensate for difficulties with everyday functioning. The Living with Dementia Toolkit⁴ is an example of a co-produced resource offering ideas and inspiration that has so far been accessed by users in 130 countries.
4. Supporting the family members, mostly women, who provide unpaid care. Worldwide, on average, family carers contribute 6 hours of unpaid care per person with dementia per day, with significant impacts on their own health, well-being, and quality of life.⁵
5. Developing and resourcing health and social care services and systems based on a reablement or rehabilitation philosophy to provide an integrated model of support for functioning from diagnosis to end-of-life with a holistic, personalised, strengths-based ethos. The WHO package of rehabilitation interventions for dementia⁶ is a comprehensive guide to which evidence-based interventions might be included and the skills and equipment needed to deliver them.

Whatever our understanding of dementia - whether we see it as a manifestation of ageing, as a disease, or as a disability - it is a condition people live with, often for many years, and our goal should be to support functioning and quality of life. People with dementia and family carers have an important role to play in advocating for and co-producing these changes. Working together will help to yield the changes needed to bring hope to everyone affected by dementia.

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