

Chapter 1

What is dementia, why make a diagnosis and what are the current roadblocks?

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Key points

- The term dementia is used to describe a group of symptoms affecting thinking, mood and behaviour severe enough to interfere with daily life.
- Most countries encourage individuals to visit their primary care physician (family doctor) as a first step towards a diagnosis of dementia.
- A significant roadblock to obtaining a diagnosis is a lack of knowledge and awareness about the disease by the general public.



What is dementia?

The term 'dementia', otherwise known as 'major neurocognitive disorder', is not one specific disease but rather a group of symptoms that happen because of a disease. It impacts memory, behaviour, thinking and social abilities severely enough to interfere with one's activities of daily living and social autonomy. While Alzheimer's disease is the most common cause of dementia in people over the age of 65, it is not the only one. Most people over the age of 80 have more than one cause to account for their dementia, such as small strokes or Parkinson's disease. In this report, we discuss differential diagnostic issues once the presence of dementia has been established by a clinical assessment supported by appropriate laboratory tests and brain imaging.

Many of the diseases that cause dementia exhibit similar symptoms, including memory loss, disorientation, confrontational behaviour, language problems, and a variety of physical issues altering vision and mobility. For each disease, and each person affected, these symptoms can present in different ways.

Alzheimer's disease: The distinguishing feature of Alzheimer's disease is the presence of beta-amyloid and tau proteins that build up in the brain to the point that they obstruct normal cognitive functions. This usually manifests

with changes in memory, abstract thinking, judgement, behaviour, mood and emotions, and ultimately interferes with physical control over the body.

Vascular dementia: This is the second most common form of dementia. It occurs when the brain is deprived of vital nutrients and oxygen from the blood flowing through the brain. This can happen after one stroke in a strategic brain area, or a series of small strokes. Other factors that can contribute to the development of vascular dementia include a history of heart attack, irregular or unusually rapid heartbeat (atrial fibrillation), hardened arteries that restrict blood flow (atherosclerosis), high blood pressure, diabetes, high cholesterol, obesity and smoking.

Dementia with Lewy bodies: This type of dementia combines the cognitive impairments of Alzheimer's disease with the diminished motor skills associated with Parkinson's disease. This can make diagnosis especially challenging. Dementia with Lewy bodies is characterised by the presence of alpha-synuclein proteins that form clusters in brain cells. These invasive structures then interfere with normal brain functioning. While also encompassing the more common symptoms of dementia, dementia with Lewy bodies is differentiated by recurring visual hallucinations, fluctuations in attention

and alertness, and declining cognitive abilities such as problem solving, and increased visuospatial problems that make it difficult to interpret what is seen. Individuals with dementia with Lewy bodies may have more nocturnal sleep disturbance than people with Alzheimer's disease.

Frontotemporal dementia: The frontal and temporal cortexes atrophy (shrink) as neurons in those parts of the brain die. Early signs of frontotemporal dementia usually include changes in speech, personality, behaviour, impulse control, and coordination. Frontotemporal dementia tends to occur at a younger age.

Young-onset dementia: This rare form of dementia, accounting for approximately 3% of cases, may be caused by any of the above-described diseases, be it Alzheimer's disease, vascular, Lewy bodies or frontotemporal dementia. The only difference is that it occurs in people under

the age of 65. In many cases, there is a delay in obtaining an accurate diagnosis as dementia is often overlooked as a possibility in a younger person.

Although this report's primary focus is dementia, we can, in some circumstances, diagnose conditions such as Alzheimer's disease in its pre-dementia symptomatic stage, designated as mild cognitive impairment (MCI) and mild behaviour impairment (MBI) due to Alzheimer's disease or prodromal Alzheimer's disease. This diagnosis does however require laboratory-measured biomarkers. These are not yet available for use in a primary care setting. This report provides an update about the current science and research relating to these biomarkers and Alzheimer's Disease International will be monitoring their validity and use in the future. It should be noted that mild cognitive impairment may be reversible or non-progressive over time and may be the best opportunity for secondary prevention against dementia.

Seeking a diagnosis for cognitive complaints

There are many reasons one might encourage a loved one family member to consult a healthcare professional for a cognitive assessment. Perhaps there is a family history of dementia, or awareness that a friend or relative seems 'off' – they are uncharacteristically forgetful, anxious, or depressed. It is often difficult for many family and informal carers to convince someone they care about to seek medical advice. Some people deny having a problem with their cognition for various reasons. Changes in the brain associated with dementia can interfere with the ability to recognise differences in memory and/or behaviour, as well as in the ability to perform daily tasks (the medical term for this is anosognosia). 'Why bother getting a diagnosis of dementia if there is no cure, and they will take my driver's licence away?' is a common belief. Fear of losing control of one's independence once a disease is officially diagnosed may also be a concern.

Although a progressive decline in memory regarding recent events is one the most common symptoms of dementia, there may be other types of early warning signs such as searching for words, errors with directions, not recognising familiar faces, hesitation in making decisions and a significant change in mood and behaviour. There are often psychological symptoms associated with cognitive decline, such as anxiety, social withdrawal, irritability, and depressive feelings. They can be part of the disease process but may also be adverse reactions to what is happening. Since there are many reversible or controllable causes of cognitive decline, it is very important to seek medical attention and obtain a proper assessment.

The diagnostic journey for a person with cognitive complaints may differ around the world; however, most countries encourage individuals to visit their primary care physician (family doctor) as a first step. In many cases, they will be assisted by a nurse who may record some medical history ahead of the visit, and/or administer some of the memory screening tests over the phone, by email or in person. For those individuals who do not have a primary care physician, it is recommended that they visit a public healthcare clinic with multiple primary care doctors or other healthcare professionals who may have the expertise to perform the assessment and diagnosis of dementia.

It is important to the diagnostic process that any information about the signs and symptoms of concern from the person experiencing cognitive complaints, or from their family and friends, be shared with the healthcare professional. Some screening scales have been developed to get a general measure of their cognitive abilities; the score is then compared to that of an average person in the same age group and level of education. These scales are often repeated at each subsequent visit to assess whether the person is improving, stable or declining. The initial cognitive tests will focus on the warning signs of dementia, such as problems with language, disorientation, misplacing items and other signs highlighted by ADI as part of global awareness raising. See Figure 1 for information about warning signs of dementia.

Other scales have been designed to assess more specific difficulties with speech production (such as naming words from a letter) or understanding, writing, reading or identifying faces or objects. These scales usually require a separate assessment by a healthcare professional who has been specially trained to administer these tests.

While a healthcare professional may be able to confirm evidence of cognitive and functional decline, it is rarely feasible to give an accurate diagnosis of dementia and its causes after only one visit based solely on medical history and basic cognitive testing. Where possible, the complete diagnostic process will include a series of additional tests, such as basic blood tests and brain scans, and occasionally, brain scans using radioactive substances and/or a lumbar puncture to measure proteins in the cerebrospinal fluid. These tests, combined with accumulating information gained from observing the progression of signs and symptoms, lead to a diagnosis of the cause of the dementia – such as Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia or mixed dementia (attributed to more than one cause).

Making an accurate and timely diagnosis is the first step in a long process that can last years. Support for the person living with dementia as well as their family and friends is crucial. Physicians have a role to play in assisting people with dementia and their carers to navigate this journey. From the moment an individual is diagnosed, early intervention of a multidisciplinary team of healthcare professionals, along with legal advice, can have a positive effect on care. This report brings together leaders in the global medical community to provide the latest information regarding the diagnosis of dementia. The aim is multi-pronged: to provide an arena where knowledge and research is shared, to facilitate dementia understanding for the person living with cognitive decline, as well as their family members and friends who may act as carers, and finally, to influence policymakers who can advocate for continued support for the advancement of research, science and innovative strategies.

10 warning signs of dementia

If these signs are new, they may be a sign of dementia.
Dementia is not a normal part of ageing.
Speak to your doctor or contact your dementia and Alzheimer association.

www.alzint.org

Alzheimer's Disease International
The global voice on dementia

Figure 1. ADI 10 warning signs of dementia.ⁱ

ⁱ ADI 10 warning signs of dementia infographic is available to download at <https://www.alzint.org/resource/warning-signs-of-dementia-infographic/>

Roadblocks to a timely diagnosis

Never before has there been so much attention focused on Alzheimer's disease and/or dementia-related illnesses. According to the World Health Organizationⁱⁱ (2020), Alzheimer's disease and other dementias are the seventh leading cause of death and there are more than 55 million people worldwide who have been diagnosed, with countless others unaccounted for due to lack of awareness about the signs and symptoms of the disease, cultural or geographical biases, inaccessible resources and lack of trained professionals.

As our population ages, Alzheimer's disease, as well as other forms of dementia and major neurocognitive disorders, are on the rise. Dementia affects people of every gender, culture, ethnicity, religion, citizenship, sexual orientation and ability. While the number of people being diagnosed with dementia increases, so does the number of people finding themselves in the role of carer without the knowledge or training to manage the condition and properly care for the person living with dementia.

One of the most significant roadblocks to obtaining a diagnosis of dementia is a lack of knowledge and awareness about the disease by the general public. Despite the increased media attention over the past several years, including being featured in several compelling Hollywood movies, very few countries have public awareness campaigns that provide information about the signs and symptoms of the condition. As a result, progressive cognitive decline and/or changes in behaviour are often thought to be associated with normal ageing or depression or mistaken for other mental illnesses.

Once the symptoms progress to the point that medical intervention is needed, the person with dementia and their carer who are seeking a diagnosis may well be confronted with several obstacles. These include limited access to healthcare due to confusion about which healthcare professional to consult; remote geographical locations; transportation restrictions and language barriers. It may also be because of a shortage of specialised healthcare care experts and accompanying diagnostic tools; an absence of health insurance coverage; or a lack of access to free public healthcare and/or limited finances.

Depending on the type and nature of the symptoms, some people assume that a psychiatrist is required while others make an appointment with a family doctor. Stigma and negative stereotypes associated with dementia prevent many individuals, families and carers from seeking the help and support they need.

As the survey results suggest, the most significant roadblock regarding dementia care management after diagnosis is the absence of a 'Prescription of Care' (a term used by the McGill University Dementia Education Program) for what may lie ahead. A dementia diagnosis often leaves the individual and their family carers devoid of information, specifically about how it may progress, and how to manage its related everyday challenges. Other than prescribing an initial round of medication which may or may not help symptoms, the medical community does not always provide crucial educational material, nor does it refer to support services in the community.

ⁱⁱ For WHO dementia-related information please see https://www.who.int/health-topics/dementia#tab-tab_1

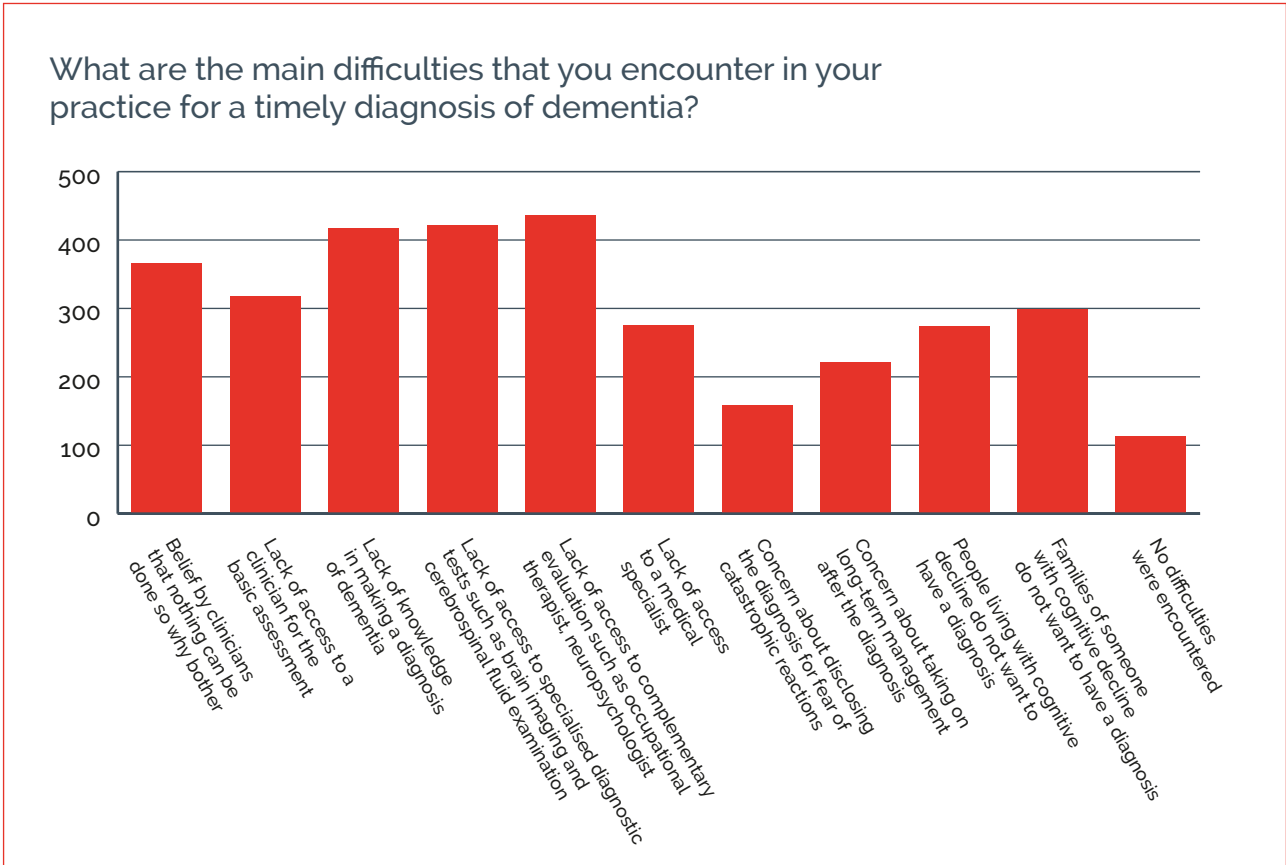


Chart 1. Clinician responses (multiple answers selected).

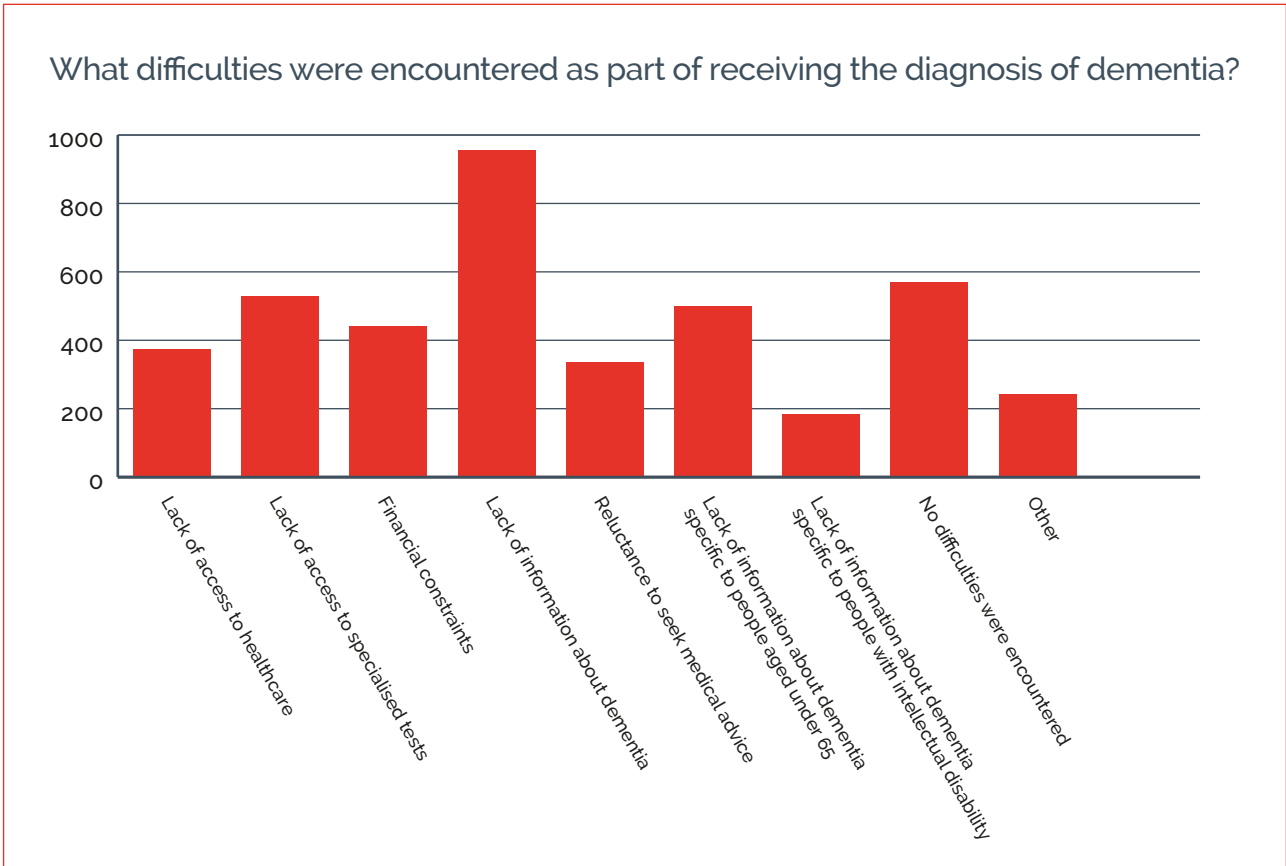


Chart 2. People with dementia and carer responses (multiple answers selected).

Conclusions

The journey through a diagnosis of dementia is a complex one. It is a multiple step process that begins by understanding the early signs and symptoms of an illness that is still plagued by an overall lack of social awareness. A shift in focus is needed, one that makes research, education, advocacy, and most importantly, universal access to an informed and knowledgeable healthcare system a priority. From there, it is a matter of creating a support system that prioritises the needs of the person living with dementia alongside the needs of their carer.

There is still much to learn and do about dementia and a united front is needed – one that reduces stigma, that increases awareness and that heralds change and scientific advances. ADI calls for governments to lead the way in providing a standardised and ethical online assessment option. Aligning a dementia-centric approach on all fronts is paramount.