Chapter 2

Who makes the diagnosis of dementia and how do you prepare for the assessment?

Serge Gauthier

Key points

- Primary care provides a more familiar, person-centred environment for the initial assessment.
- Referral to a specialist such as a geriatrician, neurologist, psychiatrist or neuropsychologist may be required for more complex cases of dementia.
- The online environment offers a wide range of resources for people seeking information about dementia although the quality of online resources varies greatly.
- To promote the benefits of the online environment while minimising harm, resources for dementia should be developed following established ethical guidelines.

This is a chapter of the *World Alzheimer Report 2021, Journey to a Diagnosis of Dementia* which can be accessed in full at: https://www.alzint.org/resource/world-alzheimer-report-2021/

General background

Whether it is you as a person with cognitive decline or a concerned family member or friend who initiates a search for diagnosis, the question is how to go about it. Most people these days go online using key search words such as 'memory, dementia or Alzheimer.' While there are websites with credible information, usually those hosted by Alzheimer or dementia organisations, specialist charities, or universities, there are some that feature questionable material or commercially oriented intentions. Some sites provide screening questions about the symptoms associated with dementia, while other sites include self-assessments tests. This type of search may be a good first step, but these sites are no substitute for an in-person clinical assessment by a healthcare professional.

Most countries encourage that initial visit be to your regular primary care physician. If you do not have one, a visit to a clinic with several primary care physicians may be advantageous; one may have an existing interest and experience in the diagnosis of dementia. Often, this is complemented with support by other healthcare professionals such as a nurse. They may take some preliminary patient history ahead of your visit, and/or complete some of the memory screening tests online or in person. Referral to a memory clinic or other specialised health professionals may be required after this preliminary assessment but is not always necessary.

Survey results

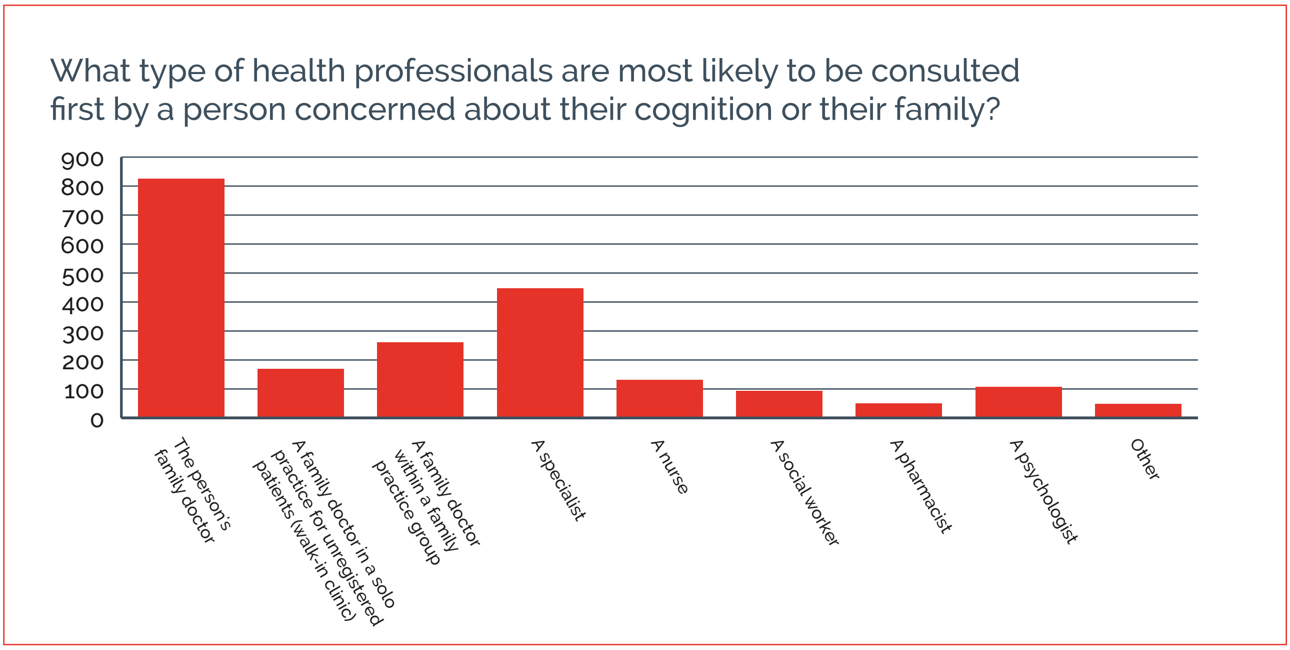

Chart 1. Clinician responses.

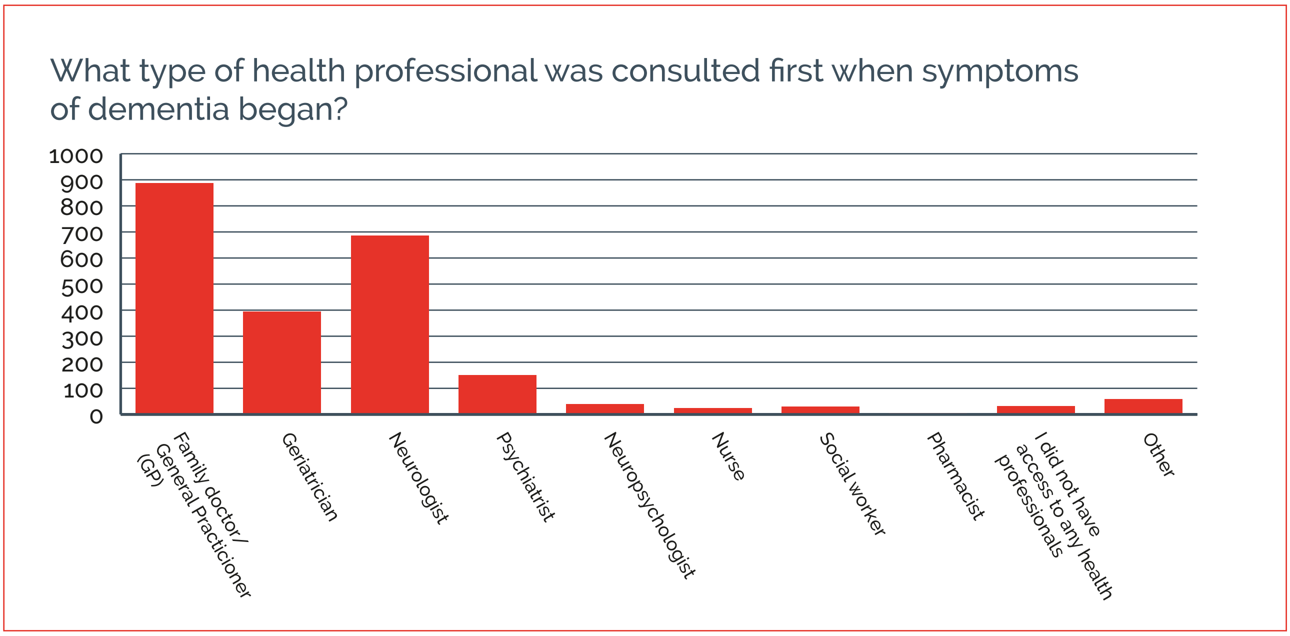

Chart 2. People with dementia and carer responses.

A total of 1,111 multidisciplinary clinicians responded to this survey and provided the anticipated response, namely that most people seeking a diagnostic opinion saw their family doctor as a first step (74%).

A total of 2,327 people with dementia and carers who completed the survey indicated that while most people saw their family doctor first (39%), specialists also played a major role in the diagnosis (neurologists, 29%; geriatricians, 17%; psychogeriatricians, 6%). Interestingly, many sought out information from the Internet before (29%), during (38%) and after (36%) the diagnostic assessment. The Alzheimer associations surveyed showed that access for all people in need of diagnostic assessment was only readily available in 36% countries represented. This was confirmed in the survey aimed at clinicians which identified the key limiting factors as being a lack of specialised tests, high costs, a lack of trained clinicians and fear of the diagnosis of dementia. The early warning signs of dementia are highlighted on nearly all Alzheimer associations websites (97%), specific information about diagnosis is given on 64% and updates about diagnosis on 42%.

Expert essay

21st century dementia care: the role of primary care

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Dementia is one of the costliest long-term illnesses to society, with 85% of costs related to family or social care (1), and is a significant contributor to loss of independence, disability and care home placement (2). Secondary care services have traditionally been the mainstay for the diagnosis and management of dementia. However, with increasing emphasis on timely diagnosis, to enable people with dementia and their family's earlier access to cost effective interventions to slow cognitive loss and improve quality of life, global policy has recommended primary care to have a greater role in both pre-diagnostic assessment and the long-term management of dementia (3). Such a policy shift has naturally occurred as 'market demand', our rapidly ageing populations and rising numbers of people living with dementia, outstrip healthcare resources, especially in lower- and middle-income countries (LMICs) where specialist services are often limited or even absent.

In Europe and the United Kingdom (UK), family physicians, or general practitioners (GPs) as they are also known, were hesitant about such a shift in care, largely due to concerns over lack of time and the appropriate knowledge and skills; however, this appears to be changing for the better (4). In 2017, a survey of 445 primary care providers across 25 European countries found the majority involved in dementia investigations and assessment. Notwithstanding there was considerable diversity in their responsibilities for post diagnosis care; such variation was explained through policy differences, for example the presence or absence of national dementia plans, and clinical practice, that is, the existence of clinical guidelines. This essay presents a case study from the UK, on the role and responsibilities of a primary care physician in dementia assessment and diagnosis, where national evidence-based, clinical guidelines have recently been critically reviewed and updated (5).

The role of primary care in dementia diagnosis: evidence-based clinical recommendations from the UK

Primary care and secondary care physicians play complementary roles in dementia diagnosis with updated, evidence-based guidance available to inform practice (5,6). Secondary care services have an important role in defining the dementia subtype, dealing with the management of more complex cases and stratifying which individuals with mild cognitive impairment are at greatest risk of developing a future dementia and most in need of follow up. In the UK, where primary care acts as the gatekeeper to other specialist healthcare services, the family physician/GP is usually the first point of contact for people experiencing cognitive difficulties, or their families who are worried their relatives may have dementia; they should have a low threshold for referring someone with suspicious symptoms for specialist assessment (7).

The role of primary care is to (7):

- Explore the patient's ideas and concerns around their symptoms.
- Exclude a potentially treatable illness or reversible cause of the possible dementia, for example drug-related, depression, vitamin B12 deficiency and thyroid disturbance (5).
- Refer more urgently for specialist assessment those with unusual symptoms (neurological, psychiatric, or behavioural changes) or those at significant risk (psychosocial issues, harm to self or others).
- Discuss and explain the possible investigations to be conducted in secondary care in order to reduce patient and family anxiety and uncertainty (8) and;
- Ensure individuals with mild cognitive impairment are followed up and, if their symptoms become more severe, refer for specialist assessment.

Primary care clinicians need to be aware of the diversity of presenting symptoms of a possible dementia illness ranging from the more usual memory loss and difficulty in finding words or making decisions to personality and/or mood changes. Changes in cognition and functioning are obviously influenced by a person's cultural and educational background. Increased frequency of patient visits to the family physician or local pharmacist, missed healthcare appointments or confusion over medication may also be warning signs (7). Family concern is of particular importance especially as an individual may compensate, or deny, their issues in the early stages.

In terms of reversible causes of cognitive decline, occasional lapses of memory are common as people get older, especially in the presence of stress, depression and acute physical illness. In such cases, the family physician is well placed to review the patient over the following months, after appropriate treatment has been given, before deciding on specialist referral (7). Evidence from large cohort studies has shown that certain drugs, those with high anticholinergic burden, can cause cognitive impairment, thus aggravating dementia or causing a false positive diagnosis: simple, validated tools, such as the Anticholinergic Cognitive Burden Scale, allow the family physician to identify potential medications to be stopped before referral to secondary care (6).

Initial assessment in primary care should include a careful history from both the person with dementia and their main carer, with particular emphasis on disturbance of cognitive function, activities of daily living and carer concerns. A physical examination should be undertaken to determine any focal neurological signs and exclude visual or auditory problems. Before referral to secondary care, the family physician should undertake baseline investigations (bloods tests and potentially a chest X-ray and ECG) and a brief cognitive assessment using tools such as: 10-point cognitive screener (10-CS); General Practitioner Assessment of Cognition (GPCOG); 6 item Cognitive Impairment Test (6CIT); Mini-Cog Assessment Instrument or Memory Impairment Screen (MIS) (5). The updated UK dementia guidelines found most brief cognitive assessment tools to be broadly similar in their properties and thus do not recommend one test above another. They equally found no evidence to justify the use in primary care of more time-consuming tests such as the MoCA or the MMSE, which also has copyright restrictions limiting its use in practice (5). It is important to note, however, that such tests have usually been developed in countries where English is the first language and may be unsuitable, and culturally inappropriate even when translated into the country's native language, for use in lower income countries (LICs) (9).

> **Primary care provides a familiar, person-centred environment for the individual with cognitive issues, and/or their families, to discuss their worries and concerns at both the pre diagnosis stage, where a potential dementia diagnosis may be sensitively raised, and post diagnosis to review how they are coping with the new diagnosis.**

Primary care provides a familiar, person-centred environment for the individual with cognitive issues, and/or their families, to discuss their worries and concerns at both the pre diagnosis stage, where a potential dementia diagnosis may be sensitively raised, and post diagnosis to review how they are coping with the new diagnosis. Healthcare professionals can be reluctant to speak openly and honestly about dementia, especially with the person concerned, with some reluctant to use the actual 'D' word. Although initially discussing the diagnosis may be distressing, evidence suggests most people prefer to know if they have dementia to access appropriate support and treatment and to plan ahead for the future. It also allows documentation of the person's family and informal support networks; the main family carer(s) of a person with dementia may also be patients of the family physician and require assessment and support (7).

In addition, with evidence demonstrating a preventative aspect to around 40% of dementias worldwide and the recent identification of 12 modifiable risk factors (10), primary healthcare affords an excellent opportunity for case finding. Case finding comprises proactively screening specific sub-groups who are at higher future risk of developing dementia (5); these include: people aged over 75 years; those with high vascular risk and past history of stroke disease and those with Parkinson's disease and learning disabilities. However, there is little evidence to date that case findings initiatives are cost effective and importantly do not cause more distress or harm to people than the benefits of earlier identification (5,7).

Unfortunately, even with the luxury of revised, evidence-based guidelines, dementia diagnostic rates in the UK, where there is a well-established, free to all, primary healthcare service, were still less than 70% prior to the corona virus pandemic. During 2020 and early 2021, these figures have fallen considerably due to national lockdowns and service disruption. Globally more considerable challenges exist. Currently over 60% of people with dementia live in LMICs, countries with the least capacity to cope with rising numbers of people with dementia due to a range of issues including: lack of public and professional awareness about dementia; culturally appropriate cognitive assessment tests, access to affordable primary care services and limited availability of specialist services and evidence-based therapies (3).

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Expert essay

Online resources about dementia: finding the balance between benefits and harms

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Internet use by older adults is growing worldwide. Although access inequalities persist (1), the 'digital divide' is narrowing between younger and older adults. The online environment offers a wide range of resources for older adults seeking information specifically about dementia. Dementia topics of interest include information about prevention and treatment, interactive self-assessments, and opportunities to connect with peers through social networks. However, the quality of information of these resources, and extent to which its presentation is based on an ethical foundation, vary greatly. The result is that those consulting online health information or engaging with interactive content regarding dementia may experience both benefits and harm. Critical evaluation of online dementia resources is vital to the promotion of individual and community well-being.

Online health information

A recent scoping review outlined the reported information needs of people living with dementia and their informal carers. Electronic sources, internet, mass media, and smartphones, were the preferred method of gathering information on the disease, patient care provision, healthcare services, and carer self-care (2). Information about stages of dementia, treatment options, prevention strategies, and caregiving considerations, among other topics, is available from websites of wide-ranging types of organisations such as advocacy, government, academic, and industry. These resources are typically freely accessible, easy to consume and share, and can help address the information needs of people at different stages of the dementia journey.

However, there are potential harms associated with online dementia information-seeking via websites. Accessibility can be challenging due to readability and demographics factors, such as disability and socioeconomic status (1,3). Website quality ranges from high to low, with substantive differences in content (4). Discerning credible, high-quality content can be difficult for non-experts, and this ambiguity is exploited by predatory or fraudulent sources (5). Conflicts of interest are not always immediately apparent or disclosed (4). Ease of information-sharing via websites and social media can perpetuate misinformation, which can undermine the relationship between people living with dementia and their healthcare providers. These issues stemming from an unregulated online environment are particularly troubling for vulnerable individuals, as some sites promote non-evidence-based treatments that may lead to financial loss or negative health outcomes (5,6).

Interactive content

Dementia information resources on the internet also exist in forms of dynamic multimedia, interactive assessment tools, and online communities. Benefits of interactive online spaces include up-to-date information presented in lay language, current or real-time opportunities to engage with services and research, and the ability to develop a network of peers to exchange information and advice. These benefits must be weighed against potential risks, which vary based on the affordances and context of the specific resource type.

Free online tests claiming to allow for the self-diagnosis of mild cognitive impairment, Alzheimer's disease, and unspecified dementias can be readily accessed (7). These tools may lead to feelings of empowerment or increased motivation to seek medical advice (7). However, expert analysis revealed that many of these online tests do not adhere to ethical standards regarding such matters as privacy, confidentiality or conflicts of interest and can provide clinically inaccurate results (7).

Social media is a popular platform for information exchange, where dementia experts and non-experts alike can interact in online networks (8). Online content creation platforms provide other methods of information presentation and incorporate social network elements for community-building. However, the lack of built-in verification methods for individual and organisational claims of expertise or legitimacy in the dementia field may contribute to the spread of misinformation or predatory content.

This is particularly true when individualised content curation creates information ‘bubbles’ that limit exposure to valid content sources.

Moving forward

To promote the benefits of the online environment while minimising harms to older adults, resources and tools for dementia should be developed following established ethical guidelines (9). Some researchers have proposed ethical strategies to adopt Internet and tech-based innovations in dementia and health research (9,10). One example in social media is Bender et al.’s principle-based framework to provide guidance on ethical issues that arise in health research recruitment (10). Although frameworks like this provide substantive clarity for online concerns like privacy, there remains a dearth of practical guidance for users in the social media space.

A principled approach to online dementia information may encourage the creation of higher quality resources, but that alone will not prevent the spread of misinformation or fraudulent claims. It is imperative that older Internet users become fully aware of its potential benefits and risks, and that they become able to make sound decisions about their information consumption, both from static resources such as health information sites, and from interactive resources such as social media. Health agencies and advocacy groups must take on the challenge of developing and promoting educational strategies to equip people living with dementia and their carers with the knowledge they require to safely navigate and use online resources about dementia.

Establishing beneficial standards for the development and implementation of online resources and for eHealth literacy programmes requires the engagement of members of the dementia community; particularly those with lived experience of dementia and their carers. Applying participatory design methods encourages action, critical reflection, and the empowerment of community members to collaboratively voice their needs and generate solutions (9). Patient-oriented research engages people with dementia as partners throughout the research process to identify priorities and strategies to improve health outcomes. Other methods for eliciting community knowledge and perspectives include public consultations, workshops for the co-creation of knowledge, qualitative and quantitative consensus-building, and creative visualisation such as digital storytelling and participatory video. Engagement of the broad dementia community will encourage the design of online resources that work best for members while acknowledging the rights and responsibilities of the individuals affected by this complex technology.

Only by taking a participatory approach to the development and evaluation of online resources, will we be able to create an online environment that ethically addresses the needs of the rapidly growing number of older people seeking knowledge and support resources regarding dementia.

Figure 1. Mind map of the factors affecting the reliability of online dementia information. The medium-sized boxes represent the major ethical factors. The smaller boxes are the aspects of each factor that can be used to assess the relevant risks and benefits.

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Conclusions

The Internet has become a wide-ranging source of information for people who have access to it. When first faced with concerns regarding their cognitive decline, most individuals, or their family and friends, will naturally search the Internet for information as it offers a wide range of material about the condition.

While there are many credible sites, especially those affiliated with universities or national dementia organisations, caution must be exercised as other websites may spread misinformation, fail to respect privacy policies, or have fraudulent intentions.

However, this online exploration does not, nor should it, replace an in-person assessment by a healthcare professional. The family physician is overwhelmingly the first point of contact for someone, or their family and friends, questioning changes to their cognitive condition, though consultation may also involve nurses and specialists.