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Six Reasons Why the Early Diagnosis of Dementia Does not Occur

A recent survey with six European Countries reported that the delay between first onset of symptoms and diagnosis ranged from 10 months to three years. Clearly there is an issue here. Why is there such a delay in obtaining a diagnosis? I would like to suggest several reasons, each of which can be seen as a hurdle to be surmounted before the person with memory loss can obtain a diagnosis and a comprehensive plan of management.

1) Personal unawareness

The person or family is unaware that there are memory problems. Sometimes a lack of awareness is part of denial, an unconscious defense against admitting that there is something wrong. Sometimes it reflects insensitivity or ignorance.

The solution for helping people to overcome this barrier is to increase awareness about dementia and the significance of memory impairment.

2) Personal reluctance to seek help

The person or family may be aware that there is a memory problem but does not seek an assessment. This may be because of stigma or feelings of shame associated with dementia, ageing or mental illness. The person may be fearful that it is Alzheimer's disease or cancer, that he or she will be put into a home, or that nothing can be done. The person may be afraid that the consequences will be worse than the disease – shunned by family, dismissed from employment, unable to obtain health insurance, etc.

The solution for helping people pass to overcome this barrier is to reduce stigma in the community and dispel many of the myths surround dementia. Public awareness is key.

3) Dementia not diagnosed

There is solid research evidence that at least half the cases of people with memory loss presenting to their primary care physician or general practitioner do not receive a diagnosis. Commonly they are told it is just "old age". In fact dementia is not an inevitable part of ageing. But while 5 percent of the people over 65 and 20 percent of the people over 80 have dementia, 95 percent of the people over 65 and 80 percent of people over 80 do not! Over two thirds of people aged over 90 do not have dementia.

There are many causes of memory loss not all of which indicate a progressive degenerative condition. Depression, side effects from drugs, vitamin deficiencies, hormone imbalances are just a few of the potentially treatable causes of memory loss.

In our survey of Australian family carers, general practitioners were identified as the most helpful health professional but yet, paradoxically, were the recipient of most of the complaints about lack of diagnosis, lack of management and lack of information (Brodaty et al 1990). We then surveyed Australian general practitioners and found that they were not making a diagnosis because they did not have the knowledge, lacked the time, lacked suitable screening tools for checking memory, were uncertain how to manage the condition and generally lacked confidence (Brodaty et al 1994).

The solution to enable patients to overcome this barrier is more education and training for general practitioners.

4) Non referral

In many countries further management and treatment requires specialist confirmation of the diagnosis. It is prudent to obtain a specialist opinion, usually from a neurologist, geriatrician or psychogeriatrician, if symptoms are atypical, patients are young or the general practitioner is uncertain about the nature of the condition leading to the dementia symptoms. Referrals are often not made. Reasons include lack of awareness by the general practitioner, unavailability of specialist services or financial impediments to seeking specialist opinion.

As well as referral for diagnosis many patient require services. Systems of access to services vary but generally referral to a community nurse or social worker can set the process in train.

Referral to the local Alzheimer's Association is also important. In most countries there are community based self-health groups that provide information, counselling and support. To find your National Alzheimer's Association go to the website for Alzheimer Disease International, the World Federation of National Alzheimer's Association on www.alz.co.uk and follow the links.

The solution depends on the problem. It may require more education for general practitioners, improved relationships between GPs and specialists, better access to specialist services by use of telepsychiatry for rural or remote areas, attention to the financing of the health system by government, better linkage between GPs and paramedical and nursing staff and increased awareness about the Alzheimer's Association .

5) Lack of management plans

There are many reasons why diagnosis is important (see below) but it is only the first step. Patients and their families want to learn about strategies to deal with the dementia, how to manage the problems that are current or likely to occur and medication options.

The solution is education for patients, families and health practitioners about the availability of management possibilities.

6) Medication not prescribed

Reasons why doctors do not prescribe or patients do not take medication for dementia include lack of awareness by the doctor of the availability of drugs for Alzheimer's disease or lack of conviction of their efficacy. The costs of the drugs may be unaffordable by patients.

The solution includes education about the use of medication, advocacy for reimbursement for antidementia drugs.

Ten Reasons Why the Early Diagnosis Is Important

There has been some controversy about whether an early diagnosis is helpful. Some believe it will increase the anxiety of the patient and the family: if there is nothing that can be done what is the point in alarming people? Some consider that the provision of a diagnosis will decrease the quality of life of the patient and the family so it is better to live in ignorance. Let me dispel these myths and provide ten reasons why an early diagnosis is important.

1) Possibility of a reversible cause

There are many causes of memory loss apart from the progressive dementias. Infections, adverse reactions to drugs and depression may cause a picture similar to dementia. These can be treated effectively. Even if the diagnosis is dementia there are causes, which are potentially reversible, such as thyroid deficiency, vitamin B12 deficiency, calcium excess and some tumours. Admittedly the chances of finding one of these reversible causes are low but it is very easy to screen for them with a good history, clinical examination, blood tests and a CT scan of the brain. For one of these causes to be missed is a tragedy.

2) A relief!

Surprisingly many patients gain relief after diagnosis is given. "At last!" they exclaim, "now I can understand why I have been struggling so hard for the last few months". Patients have described it as trying to run through mud. They chastise themselves, feel guilty, and feel perplexed. The diagnosis gives the patient understanding of what is happening and the ability to start dealing with the problem rather than being puzzled and overwhelmed..

Families also gain relief from the diagnosis. Of course it is upsetting and a tragedy but they now too can understand what has been happening. The irritability, the family arguments, the disappointments now snap into clear focus. Formidable behaviours over months or even years become understandable. Planning for the future can begin.

3) Legal planning

Once a diagnosis is made it is prudent for the person with dementia to ensure his or her affairs are in order. There will come a time when the person will become legally incompetent, i.e. will not have sufficient mental capacity to make important decisions. It is wise to make provisions for this early in the course of the dementia by the appointment of an enduring (or durable) guardian and an enduring power of attorney. This provision is available in many countries and they enable persons with dementia to appoint someone, who is trusted, to make decisions as regards what treatment the person with dementia will have, where they will live and who will look after their financial affairs. In most jurisdictions, one or several people, jointly or individually, can be appointed to take on all or some of these functions.

It is also prudent for the principal caregiver, usually a spouse, to make similar provisions. Finally, both patient and spouse should examine their wills and make contingency plans in case the well partner predeceases the person with dementia. In other words if the well partner dies first and the condition of the person with dementia becomes more severe it would be better if another person is the executor of the estate.

4) Financial planning

The diagnosis of dementia has financial implications – lack of earning capacity, cost of medications and acute and long-term care. Options require consideration while the person with dementia can still participate meaningfully in discussions. In addition the importance of arranging an enduring power of attorney, i.e. a power of attorney that endures even if the person loses capacity has been mentioned.

5) Medical planning

The diagnosis of dementia should not overshadow other health problems. Indeed this is a very important reason why early diagnosis is important as patients may be neglecting their general health, e.g. they simply neglect to seek medical care or because they forget to take their medications such as antidiabetic or antihypertensive pills.

6) Life planning

Alzheimer's disease (and other dementias) is a diagnosis not a sentence. Life does not end when dementia is diagnosed. The clinician should be able to estimate, very approximately the diagnosis and the patient and the family may want to make life decisions based on this. The holiday abroad would best be done sooner because later there will be an increased risk of disorientation in a new environment. Similarly plans to downsize to a new home may best be organised sooner while the person with dementia can learn his or her way around the new environment.

7) Work

Patients with dementia, still employed, will need to consider whether it is wise and safe to continue doing so. It may be possible to continue in their normal occupation for some time, perhaps gradually relinquishing more cognitively demanding tasks, perhaps with adequate supervision. This is preferable to abruptly ceasing work, which will then cause double grief to the patient, i.e. the diagnosis plus the loss of role.

8) Driving

At some stage during the course of the dementia the patient will become unsafe to continue driving. In some countries it is mandatory to report a person as soon as the diagnosis of Alzheimer's disease (or any other dementia) is made. In other countries this is left to the clinician's judgment.

My own practice is to consider patients in three groups. Those that are clearly unsafe should stop driving immediately. This may be obvious from the family's history: has there been accident?, near misses?, traffic infringements? Is the patient becoming lost even on familiar routes? Have there been incidents where the patient forgets which side of the road to drive on, is unable to negotiate a round-about, or becomes disorientated while driving. Is there evidence of impaired visuo-spatial skills or of impulsivity and poor judgement.

There are those at the very early stages of diagnosis I warn them that there will come a time when they do have to give a driving and work towards this gradually. This comprises not driving long distances, not driving on strange routes, not driving at night, increasingly allowing their partner to take over the wheel. and limited drives to daytime and familiar routes.

For those in between I recommend an assessment at a specialist-driving centre. Neuropsychological tests or cognitive screens such as the MMSE correlate very poorly with the ability to drive and is only road assessments that can determine whether a person is safe. Usually the history from a family member is telling.

9) Relations with the family

The diagnosis of dementia inevitably means a readjustment of family dynamics. This can be done in a positive way so that both patient and family know what they are dealing with. Some of the tasks the patient previously did e.g. managing the bills or driving, may need to be transferred to another family member. This can be done in an open and constructive way that can be beneficial to everyone. Early diagnosis also means that the extended family can be drawn into the discussion to decide on how the family as a whole can work together to optimise the quality of life for both the patient and spouse.

10) Medication

The use of cholinesterase inhibitors for Alzheimer's disease has changed the face of dementia treatment. While they are neither cures nor disease modifiers, they are effective symptomatic treatments even if this effect is modest. There are data to suggest that earlier treatment is better and that people gain a greater advantage from beginning cholinesterase inhibitors as soon as a diagnosis is made. There may be slower cognitive decline and a delay in nursing home admission and death. However these data are based at least in part on open label studies and therefore not definitive. On the other hand, there appears to be nothing to lose by earlier treatment and there is no evidence that the effect wears off.

Summary

In summary there are many reasons why the diagnosis is missed and help is not given to the person with dementia and that person's family. A person must pass to overcome many barriers before they obtain optimal treatment and sometimes these barriers appear insurmountable, yet there are usually solutions that can be found. Ten reasons are provided why earlier diagnosis is better. The reasons given are based on clinical experience as, unfortunately, as yet there are no control studies to prove that earlier diagnosis does have these advantages.

References

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