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(Dementia)
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Dementia: early diagnosis and intervention

ISSUES

Many people live with dementia without a diagnosis

Without a formal diagnosis PLWD may not have access to treatment, organised support and care; struggle alone; lack understanding and be confused by symptoms; fear nothing can be done; not access services that can enable them to live well.

ADI reports (2011) 90% remain undiagnosed; in any other branch of medicine a diagnosis rate of 50% would be scandalous.

We think we know the numbers/predictions in the future; for most people living at home there is a carer who does not access/accept support either without a diagnosis; under-estimate the long term effect of carer burden; they are a casualty of a lack of diagnosis,

Significant cost associated with process of diagnosis; poor integration between sectors.

Early diagnosis lifts disease out of shadows

Treats dementia as a chronic illness; explains behaviour and provide answers to issues and concerns; acknowledges long term impact; accumulates real data; opens communication; demystifies and reduces stigma.

There is some evidence that the currently available medications for dementia may be more beneficial if given early in the disease process; will help to maintain daily function and quality of life as well as stabilise cognitive decline in some people.

Many people with early stage dementia report initially feel ‘shattered’ by the diagnosis, but also say that they feel a sense of relief that the cause of their difficulties is identified, knowing the diagnosis can increase their sense of independence and enable an active role in planning for their future.

Symptoms of dementia can be caused by other diseases and conditions, some of which are treatable and reversible, including infections, depression, medication side-effects or nutritional deficiencies.

Ethical issues and professional responsibility around making a diagnosis – must include a referral to support service, follow-up appointment; should be early but also timely – balance benefits against risks; uncertainty of diagnosis – not simple test, differences in disease trajectory.

Diagnosis is not always seen as positive

Community stigma associated with the disease (based on ignorance & fear); provides a label and ‘classifies’ someone as ‘terminally ill’; is not always accompanied by education, services & ongoing support and many are left to soldier on alone; alliance with ‘ageing’ process is sometimes more acceptable for many.

STRATEGIES

Education and community awareness

Community knowledge and attitude – education not picked up if not seen as relevant; symptoms are insidious and can be ignored or diverted for long period of time; stigma associated with the disease –focus living with dementia while still in the community; fear associated with impact and progression – work, family, function, advanced stages and residential care; general fear and ignorance associated with 'brain' – last part of the body to really understand; tendency to 'laugh at' and downgrade significance of memory loss – not very funny for many people.

Health promotion - minimal evidence/support to demonstrate effectiveness of prevention strategies – mind-your-mind initiatives, neuroplasticity (best examples around stroke rehabilitation, brain injury recovery); effect of such activity hard to see (when compared to exercise, weight loss etc.); stuck where cancer was 10-15 years ago.

Health profession knowledge & understanding

First presentation usually to GP – most lack skills and time for investigation – significant education gap; also lack of psycho- geriatricians, geriatricians – waiting time is significant; many health professionals still have ambivalent attitudes towards diagnosis.

Need to develop expertise in others – e.g. Nurse Practitioners; Psychologists to there are other options to GP for initial investigation.

Limited knowledge, treatment & understanding steals precious time from families who need to plan for the future (financial, work, children's education, etc.).

Special needs groups

Strategies to support people with YOD to stay employed for longer (both for the person with YOD and for the employer); strengthening support services for people with YOD and their families – including psychological support for children (adolescence is a critical period – some children of people with YOD have witnessed their parent attempt suicide).

Emerging issue of alcohol + substance abuse-induced dementia, particularly among younger people

Special needs in Indigenous communities – different approaches to care of elders, lack of knowledge of symptoms, don't access limited resources

Policy

Need a national strategy for diagnosis, treatment, intervention and services; for community education & awareness; and for health professional education. Dementia needs to be seen as a chronic illness and receive same status as any other chronic illness. Focus is on what the person still has not what they have lost.

All service sectors – primary, acute, community and residential care, must have policy for diagnosis, treatment, management and education.

Funding for research must be available for the whole spectrum of the disease: while prevention, diagnosis and intervention are important and a cure would be wonderful, there will continue to be hundreds of thousands of people 'living' with the disease, part of families and communities, being cared for by unpaid carers; need funding for evaluation and innovation

We know that the majority of people in residential care have some significant memory loss; still need appropriate care, can still make a difference; education and appropriate intervention is important.