

Dementia is a progressive and fatal brain disease. Assessment and diagnosis largely take place in the primary health service. Should it be like that?

When the brain fails

At the time of writing, it is 105 years since Alois Alzheimer (1864–1915) presented for the first time the case history of the then recently deceased Auguste D (1850–1906). The woman had become ill in her 50s, and for several decades following Alzheimer's description, the condition «presenile dementia» was regarded as a rare disease that only afflicted fairly young people. In the 1960s and 1970s, however, it became clear that amyloid plaques also occur in the brains of elderly people with dementia. This insight was important for changing the general view of the condition. Until then, the fact that elderly people became «muddled» had been regarded as an unavoidable natural phenomenon. This conception is still well established, among other things through the erroneous term «senile» as a designation for persons suffering from dementia. Anyone who has experienced the development of dementia at close quarters will agree, however, that this is something more than a normal sign of old age; it is a progressive and fatal brain disease.

The myth of dementia as an unavoidable phenomenon of old age where intervention cannot help is unfortunately reflected in the manner in which the health service has elected to organize the assessment of the disease. Other equally serious diseases are evaluated in the specialist health service. When it comes to dementia, Norway is one of the few countries that have chosen to place the principal responsibility for assessment and diagnosis with the primary health service. There the task has to compete with all the other important responsibilities of the primary care doctors. The Norwegian government's «Dementia plan 2015» has certainly contributed to the establishment of dementia teams or coordinators by almost half of Norwegian municipalities. However, the goal when putting together the dementia teams is modest. There «ought to be a doctor associated with the dementia team», states the Directorate of Health – it sounds more like a pious wish than a minimum requirement (1). This despite the fact that the primary tasks of the dementia team are to be «assessment and follow-up of dementia» (1). The dementia assessment offered by the specialist health service is not consistent either, and in some places it appears to be almost non-existent (2). It is hardly surprising, then, that many busy primary care doctors feel alone with an assessment responsibility that is increasing in both complexity and volume.

A recent international meta-analysis and a new review article both document low precision in dementia diagnosis in the primary health service (3, 4). In Norway, only half of all those with dementia receive a diagnosis, and one survey found that a third of the dementia patients recently admitted to nursing homes had not received a dementia diagnosis (5). With the present organization of dementia assessment, there is thus considerable under-diagnosis. Does this matter to the individual dementia patient? Over the past 20 years great advances have been made in pathophysiological insights and in the use of pictorial diagnosis and biomarkers in clinical diagnosis. Unfortunately, the medicinal treatment is still ineffective, and a number of new drugs that seemed promising have recently yielded disappointing results in phase 3 studies (6). Nevertheless, early and correct diagnosis of dementia is important. The pathophysiological processes in Alzheimer's dementia begin several years before the disease becomes clinically evident, and an early treatment start is important. Many common drugs can cause atypical reactions and have a more unfavourable side-effect profile in dementia patients than in others. There are also potentially reversible causes of cognitive failure in a number of patients. Correct, early diagnosis is particularly important

for these. It has also been demonstrated that institutionalization of people living at home with dementia can be postponed by 18 months, on average, by giving training, advice and support to the family (7). Early diagnosis is therefore crucial. It also increases the possibility of the patients themselves being involved in taking important decisions, such as drawing up a will and choosing their subsequent care home.

It is estimated that the number of people with dementia in Norway will more than double over the next 40 years (8). A lot has been written about the enormous increase in the need for care services that will ensue. Considerably less has been written about the growing need for early, correct diagnosis. Assessment of dementia can be difficult, and makes increasing demands in terms of up to date medical knowledge and the use of specialized tests. The consequences of delayed or incorrect diagnosis can be substantial. Given the current capacity, it will not be possible to evaluate all patients with dementia symptoms within the relevant specialities of geriatrics, psychiatry and neurology. The new area of expertise – geriatric and nursing home medicine – will have to place emphasis on dementia knowledge, but is largely directed at patients in nursing homes. Assessment and diagnosis of dementia must take place before this stage of the disease. There is much to indicate that an early, multidisciplinary approach, with contributions from geriatrics, psychiatry and neurology, is the optimal solution (9). This means that we must centralize dementia assessment at regional or multi-municipal level to a far greater degree than today, with specialized assessment units as a national gold standard. Dementia will be one of the health service's greatest challenges in years to come. We therefore need dementia teams in all municipalities for early detection and subsequent follow-up, but we also need clearer, more ambitious standards for specialized, early assessment, such as we have for other progressive, fatal diseases.

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