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# Planning for the needs of people with dementia

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Provision for people with dementia requires a complex mix of different kinds of services, primarily concerned with maintenance and support rather than treatment. In principle, planning for their needs begins with assessment of the problems, a review of the resources available, and some attempt to match resources to need.

## Needs

Dementia is defined by Roth as

'a global deterioration of the individual's intellectual, emotional and conative faculties in a state of unimpaired consciousness'. (1)

The loss of intellectual faculties involves an inability to retain new information, and in consequence to absorb it. This does not necessarily affect an individual's capacity for self or household care, though it may affect aspects of household management, including the ability to handle money, shop or plan meals. The loss of conative faculties may affect both self and household care, as people become less able to maintain a routine, to distinguish day and night or to understand events around them. Emotions may become disturbed either directly, or as a consequence of the sufferer trying to make sense of their perception of 'something' being wrong. And mental impairments are frequently experienced with other impairments - including chronic physical illness, immobility and incontinence - which are compounded by the changes in mental state.

The consequences of dementia also affect social relationships; the condition is accompanied by growing isolation, and loss of stimulating contact. Often, the problems are exacerbated by other common changes experienced by elderly people, including the disruption in communication caused by sensory impairments, the limited ability to participate in social activities which results from physical impairments or financial constraints, and the disruption of relationships which follows retirement or bereavement.

No less important are the problems experienced by carers, who are often female kin, and not uncommonly themselves elderly. Gilleard argues that the ability of carers to cope depends on the kinds of problems which are experienced, and not on the perceived level of strain (2). The problems most often reported are an inability to dress unaided, restlessness, urinary incontinence; and, from the point of view of the carers themselves, embarrassment, anxiety, and a decreased social life. (3) Zarit et al, by contrast, find that the perceived burden of carers, and not the degree of infirmity, is the main factor determining whether carers place dementia sufferers in nursing care. (4) The commitment of carers may be challenged by particular events or states - sleep disturbance and faecal incontinence are particularly important in diminishing their ability to continue. (5) Jones also notes the importance of whether the burden of care falls on a single carer, rather than a number of people. (6)

The problems of people with dementia are multi-faceted. Levin et al. argue that the experience of people with dementia and their carers has to be understood in terms of a number of dimensions: practical, behavioural, interpersonal, and social. (7) The range of responses has to be no less wide.

## **Needs and services**

If people are 'in need', it is not simply because they have a problem, but because they are lacking something which will remedy that problem. (8) There are circumstances in which people with a degree of impairment have no identifiable 'needs' as a consequence: for example, some people with mild dementia continue to function normally in their own home. (9) But adverse factors include the presence of severe illness, or disruptive behaviour; physical complications; an excessive burden of care falling on only one relative; a shortage of money; and a lack of support from professionals. (6) Whether or not people are able to manage depends greatly on the resources they have available.

It is difficult to establish precisely what services people need; there is usually a range of possible options. For example, people who are socially isolated might have that isolation reduced in a number of ways: by introducing voluntary visitors (or even 'companions'); developing social activities outside the home, through lunch clubs or day centres; or by changing the home, which is commonly done through sheltered housing or residential care. People who need housework done might have it done through domestic assistance, but they might also have it done through substitute family care or residential care. Needs are often referred to as needs for services - like a need for housing, medical care, or domestic support. Strictly speaking, however, there is no such thing as a 'need' for a lunch club or a home help; rather, there are needs which services of this kind may be able to satisfy to a greater or lesser degree.

When trying to meet needs, people look for the response which is most appropriate, which is available, and which is feasible. "It is easy", a recent government paper comments critically, "to slip out of thinking 'what does this person need?' into 'what have we got that he/she could have?'" (10) But this is difficult to avoid in practice, because the definition of a 'need' is determined by the relationship between functional problems and possible responses. Some options - like 'very sheltered' housing, night sitting or elderly fostering - are not always available; others, like nursing care, may be well established but are not necessarily the most appropriate option. Equally, what the service agencies think of providing depends on what they can practically do; concepts of need within agencies are formed in the light of such constraints. (11)

## **Services and planning**

The current pattern of provision seems to be one in which the level of all services received remains fairly constant, irrespective of the severity of the dementia (12, 13) (Levin et al., by contrast, seem to find a general increase in some services as dementia is more serious, though this is not closely related to need (7)). There is a widespread mismatch between problems and services. Challis points to a number of problems associated with planning for the existing range of services: the growing numbers of elderly people requiring help exceed the resources of services to deal with them, needs and services often do not match, services are fragmented, and they are often uncoordinated at the level of the individual. (14)

The Griffiths report on community care (15) suggested that the process of allocation should be more dependent on a quasi-market; but given the pressures on services, people often have to choose what is available rather than what might be best suited for their needs. It is unclear that this kind of approach can resolve the kinds of problem we have described.

Service planners have to match the kinds of problem which are identified with the kinds of services which are available. To do this, they have to take into account the range of problems people experience, the available resources, the feasibility of introducing different kinds of option, and the perceived desirability of different options. For practical purposes, this requires information in a form which can be applied directly to the allocation of resources, and treated flexibly for the wide range of contingencies which it

is required to cover. We are in the process of developing an instrument which will make this possible. But this is only one stage of a complex process; many of the problems of finding resources, defining service priorities, and allocating provision for needs, will remain.

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## **Notes**

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