Living with dementia

LOIC HEMSI
M.R.C.P., F.R.C.Psych.

St George's Hospital Medical School, London SW17 0RE

Introduction

Dementia is a clinical syndrome (not a radiological or pathological appearance) of lasting deterioration of intellect and personality associated, by definition, with diffuse structural disease of the brain—demonstrated or presumed. The syndrome can occur at any age. However, before adulthood is reached development is still taking place and the cerebral disorder then manifests as mental handicap, and a blighted potential, rather than as decline from a level previously attained (Bicknell, 1982). Dementia can result from many different processes; the nature of these may itself influence the clinical picture.

Given the age structure of the population of this and other developed countries, old age is far away the commonest period of life in which dementia occurs. The two predominant pathological conditions are vascular disease, causing multi-infarct or vascular dementia, and cerebral atrophy with senile (Alzheimer's) plaques and neurofibrillary tangles, the basis for senile dementia—in which the blood vessels may be normal and are not in any event thought to be of major significance in the pathogenesis.

While dementia before the senium can present formidable problems and does differ in some respects from dementia in the elderly, the difference is not one of essence. Accordingly, for ease of exposition, this paper will confine itself to dementia in the elderly, the paradigm of the problem.

Dementia is common and seen in many settings. It affects not only the individuals with the condition, who in fact in many cases experience little or no distress themselves, but also those in their informal social network—family, friends and neighbours. It also has profound implications for members of formal helping networks, such as the National Health Service, Social Services departments, and voluntary and private bodies, and for social and economic policy. It regularly raises ethical problems. After years of neglect by academic circles, it is now the object of increasing research although much remains to be done (Lishman, 1977). It is a disabling syndrome, with at present no remedial treatment in the vast majority of cases. Once the diagnosis has been made it is often regarded by the medical profession as a 'social problem only' but in fact dementia requires the deployment of the efforts of several disciplines, and their collaboration, if the best at present possible is to be achieved.

In a broad sense, in our professional and sometimes in our personal lives, we all have 'to live with dementia'. As medical people we need knowledge from many sources and of several types, some of a traditional, disease-orientated nature, some not. The former includes epidemiology, neuropathology, neurochemistry, individual, family and group psychology and psychiatry (viewed as the assessment and management of people in psychological distress and with abnormal mental states, behaviour and reactions). The latter involves the assessment of risk in behaviour, the operation of the Social Services and Social Security systems, the administration of a service for a population as well as the provision of care for individuals in it, and the law in relation not only to mental health but to the financial protection of the mentally disordered. The skills required are mixed and some have hardly begun to be imparted in medical schools. They transcend disciplines. They call for the questioning of such accepted boundaries as community/hospital, consultant/general practitioner, and doctor/nurse/social worker. Even where such skills exist, their exercise can be frustrated by the resistance to change of established professional and administrative hierarchies.

It is not the aim of the present article to review current knowledge on the numerous aspects of dementia in the elderly. This has recently been done by the Royal College of Physicians (1981). Rather, the objective is to give a personal account, based upon clinical practice, of the experience of 'living with dementia'. In so doing, it is as well to make the point at the outset that only the person with dementia lives with the dementia itself: everyone else lives with a person who happens to have dementia, but many other characteristics also. It may be those traits, rather than the dementia, which cause problems to
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Intrinsic effects of brain damage

The brain damage itself causes a deterioration of general intellect, of a number of specific cerebral functions and of personality.

The higher general intellectual functions comprise such subtle activities as thinking, concept formation, logical reasoning, problem-solving, judgement, and insight. The range of normality is obviously wide, premorbid intelligence affects performance and its assessment and significant variation has to be judged, far more than is true for specific functions, by both quantitative and qualitative criteria. It is important not to mistake longstanding low intelligence (mild mental handicap) for deterioration (dementia). The former may present problems in old age for the first time, as supports are removed, for example by the death of a spouse whose activities masked the degree of social incompetence of the woman. Such 'pseudo-dementia' is not associated with brain disease and lacks the probability of further decline, often, although not always, implicit in the term dementia.

The specific functions are traditionally identifiable separately on clinical examination, although interdependent: memory, orientation, language, praxis, gnosia. They are tested qualitatively by clinical methods and there is a fairly clear operational notion of what constitutes abnormality in a test response.

It is not appropriate in this article to consider all such impairments but only certain aspects of some of them which are particularly relevant to the distress and behaviour of the patient and of others who are of particular significance. Whereas the mere presence of an abnormality may by itself be of great diagnostic import, it is only in so far as it impedes on the life of the people concerned that it is of significance in management (given a disease which is not remediable). So it is some of the practical implications which are examined further here.

Memory

It is commonplace and true to say that in dementia memory for recent events is affected earlier and to a greater extent than memory for remote events (Ribot's law). What this means in reality is that what is most impaired is the ability to learn: material long known already is retained comparatively well and it is new information which cannot be assimilated. Of course, as the disease progresses forgetting increases and thus established memories are eased also and the past wiped out. Confabulation is an extremely common association of amnesia in dementia.

The retention of established memories, coupled with the inability to learn and to integrate new experiences, explains much in the behaviour of the person with dementia. It explains the comparative
normality of behaviour in familiar surroundings (other things being equal), the absence of subjective distress in the patient at home and the tendency to continue old patterns of behaviour when they are no longer appropriate, such as getting ready to go to work long after retirement has taken place but the new fact of retirement has not been learnt. It explains the anxiety, and with it the restlessness and other manifestations of distress, on removal to unfamiliar places and in facing new people and situations. It explains the preservation of social behaviour long practised, and other behaviour patterns.

It follows that in a memory-disordered person very little can be predicted about how she will behave in a new environment. Equally, her performance in an unfamiliar setting, for example a hospital, is not a good guide as to how she will perform in her own home. Therein lies the fallacy in thinking of admitting such a patient for assessment—change the environment and you change the person even if not the disease and it is the person who is of concern, not her disease when that disease is itself untreatable.

Evidence is beginning to come to light that some patients with organic disorders of memory and orientation may be able to learn new material if the number of attempts is sufficiently large and the conditions right and that they may retain some of the information thus acquired, albeit for short periods only. This is the basis, for example, for Reality Orientation Training (Brook, Degun and Mather, 1975; Hanley, McGuire and Boyd, 1981). Amnesia in dementia may therefore be modifiable to some extent despite the brain damage. This fact, if such it is confirmed to be, may have implications in the future development of strategies for the care of such disabled people. For example, lost simple skills needed in daily living may be taught again to a degree sufficient to increase the patient’s independence; this would not only reduce the burden on others, but would also maintain a better quality of life and postpone the need for institutionalization.

Orientation

Disorientation in space can be regarded as in part an abnormality of learning and retention, that is, a memory-based disorder. There is impaired ability to assimilate, retain and use clues and cues. It is also a disorder of recognition, that is, a visual agnosia. It underlies the phenomenon of wandering: the patient loses her way, is unable to correct her mistake by using available information and continues to walk in search of familiar surroundings or even aimlessly. In enclosed but unfamiliar settings, for example a hospital ward, disorientation is one of the mechanisms operating in causing restlessness. Even in advanced dementia, topographical memory for long-trodden paths may be retained: for parts of the patient’s own home and for streets in her neighbourhood. Removal to strange places may not only induce or increase agitation but may also heighten substantially the risk of getting lost outside.

Disorientation in time, and the difficulties in accepting correction from others or to use cues to understand and rectify mistakes, is another major cause of abnormal behaviour in such patients.

Language function

Aphasic disorders are common in dementia: the areas for language are diseased, in common with others, as part of the diffuse brain damage. However, it is important to make the distinction between aphasia and dementia, whether it is aphasia in or with dementia, anterior (expressive) or posterior (receptive) aphasia, and to know of the psychological concomitants of, or reactions to, aphasia (Benson, 1973). Anterior aphasia is non-fluent with just a few words, pronounced badly with much effort and unmelodiously. Posterior aphasia is fluent with many words expressed easily and with good pronunciation but poor understanding. In the former, comprehension is good, insight preserved and distress marked. In the latter, understanding and insight are defective and the patient is not distressed but may be paranoid in the face of what she regards as unjustified intervention against her, such as attempts to investigate her or treat her in hospital.

The distinctions, detailed consideration of which is beyond the scope of this article, are needed not only for aetiological and therapeutic purposes (thus an isolated aphasia may be due to a remediable local lesion) but also to assist in the management.

Apraxia

This is the inability to carry out actions with no loss of motor and sensory neurological functions and no abnormality of the understanding of what is required. It is a disorder of parietal lobe function and interferes with most activities of daily living but most strikingly with dressing.

Agnosia

This refers to a disorder of object recognition by vision, hearing or touch and it too arises from parietal lobe disease. Agnosia accounts for much of the disorganized and incoherent behaviour seen in cases with substantial dementia; failure to recognize people, places, objects and their meanings removes most of the bases which inform ordinary conduct. It separates the patient from his long-known human contacts. It may, when the agnosia involves the
failing performance and irritability, with a hostile reaction to being tested and verbal or even physical aggression against the persistent interviewer or questioner. A catastrophic reaction may develop when the patient is placed under intolerable pressure. She may then become very anxious and agitated and break down completely into totally helpless, disorganized or aggressive and destructive behaviour.

Compensatory strategies. These may be adopted, particularly early on, with the keeping of diaries, the making of notes and the deliberate transfer of responsibilities to trusted people.

Suspicion. The patient may be suspicious of the actions of others, particularly of being 'put away', and may keep well-intentioned potential helpers at arm's length. This may lead to a frankly paranoid posture.

Regression. Occasionally, the patient may regress, becoming more dependent than her brain function warrants, incontinent, physically incapable, tending to stay in bed, or to fall about. These responses, when damaging, may all be alleviated by appropriate handling. Understanding, trust, tolerance, sympathy, firmness (on occasion), and time (always) are needed. Such an approach may make all the difference between an explosive situation and the restoration of calm. Much can be achieved not only by working directly with the patient but by counselling and advising those around her as to how to handle her.

Environmental influences upon the patient

It has been said earlier that there is an equilibrium between the patient and her environment, human and material. At its best, this results in a secure, contented and calm person who happens to have core disabilities of dementia. That adjustment can be broken by the actions of others. Distress and abnormal behaviour can be induced, possibly without necessity. This indeed is what would happen with any person subjected to strain beyond her ability to tolerate. The patient with dementia does not differ in kind in her reactions to stress from other psychiatric patients, or, indeed, from the general population. What is different is the drastically reduced threshold to stress and the excessive degree of reaction.

When a patient with dementia is overstressed, she may become anxious, depressed, irritable, aggressive, restless, regressed, paranoid, apathetic, unduly dependent and so on. In other words, she manifests the features described in the last section—but in response to external forces. Others may then behave in such a way, and take such steps, as themselves worsen the situation. This is not specific to dementia: it happens whenever people interact, whether they have diagno-
sable psychiatric disorders or not. The problem has been studied extensively in patients with schizophre-
nia. It has been shown in such patients that relapse is much more likely to occur if they live in a setting
where there is a high level of expressed emotion than in an emotionally neutral atmosphere.

The nature of these influences will be discussed in the next section, which deals with the reactions of
other persons to people with dementia.

The person with dementia and others

The overall prevalence of dementia in those aged 65 and over, is 6·2% but the condition is seen mostly
in the very old, 22% of the over-80s being affected (Bergmann, 1977).

The great majority of people with dementia live in
country households: Kay, Beamish and Roth (1964)
found in Newcastle-upon-Tyne that for every person
with dementia in an institution there were six living
at home. It is probable that such a distribution still
prevails, although no more recent survey in this
country has been published. At the same time,
institutions also have large numbers of old people
with dementia in them, permanently, or temporarily
or relatively temporarily. These include homes for
the elderly, geriatric hospital beds, psychiatric hospi-
tal beds or short-stay beds of most departments in
general hospitals. Large numbers of people therefore
are faced with the problems posed by dementia. Such
people can be thought of as being in social networks
connected with the person with dementia, informal
networks, as in the case of family, neighbours and
friends, or formal networks as in the case of staff of
agencies whose specific jobs are to provide help to
the disabled.

People in those networks all have feelings and
opinions about the care of the person with dementia.
For the psychiatrist, one of the rewarding aspects is
the elucidation and the handling of these and of the
management issues which arise around the (relatively
uncomplaining) patient, now to be discussed. First
the informal and then formal networks will be
considered.

Informal social network

This consists of the nuclear and the extended
family, of neighbours and friends. It usually com-
prises a relatively small group of people, with constant
or frequent direct contact, long-standing
bonds and relationships (whether satisfactory, unsatis-
factory or mixed) and prolonged, albeit voluntary,
commitment. Such people tend to be more available
for unpredicted events than employed staff, more
familiar with the problem and not bound by the
professionalization, institutionalization and demar-
cation of roles. They do, however, lack skill and
knowledge of what is possible and available to the
patient and to themselves in caring for her. Their
problems in living with the person with dementia can
now be examined. Much of what follows applies not
only to the patient’s family but also to her friends and
neighbours.

By the time she reaches old age a woman will have
formed such relationships as will largely determine
how her family and others will approach her needs
when she becomes disabled and dependent. Obvi-
ously, the better and the closer the bonds the more
help can be expected—geography, personality and
circumstances permitting. But dementia within a
family is usually a disaster and a prolonged distress
for its members, even if, through the fortunate loss of
insight, not subjectively experienced as such by the
patient herself. Naturally, reactions vary but certain
types can readily be identified (Hemsi, 1982).

Anxiety occurs most frequently. There is fear of
what the dementia will produce in the patient and of
its implications for others. Much of it is perfectly
realistic but some may be caused by ignorance of
what help is available and by a feeling of isolation in
coping with the problems, a feeling which should
become less and less justified as services are created
to help such patients and their families. Relatives are
anxious about risks—of self-neglect, wandering,
accidental fires and explosions, of undetected falls, of
inadequate diet, and of mishandling money and
property. Such anxiety may lead to an attitude of
undue protectiveness and restriction of the patient,
for the best of motives but with the consequence of
inducing distress in the patient and often frustration
in somebody who has no grasp of the problem and
this itself may cause the patient to become aggressive.

Depression and guilt afflict families and may lead to
a vicious circle, as inability of the relatives to cope may
well worsen the patient’s behaviour by her becoming
irritable, restless or aggressive and this itself then
increases the burden on the family. In many ways
there is a pattern of mourning—for the ‘dead’ healthy
person—and of readjustment to a new person.

Rejection and hostility may be the reaction but are
uncommon as an unalloyed pattern. Much more
frequently they are part of an ambivalent attitude to
the patient—rejection followed by guilt followed by
expiation and overcompensation. Hostility usually
betokens a poor earlier relationship, the presence of
pulls on the individual from sources other than the
patient herself or else a very chronic and unrelieved
burden. Rejection is more likely where relationships
have long been bad.

Occasionally there is denial by relatives, of the
dementia and its problems, or at any rate of its
severity. Sometimes this is associated with a mis-
placed sense of shame that the old person can have so
deteriorated, or with sublimation, for example by a
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with signs of disease, it is the members of the informal network who are in practice the 'patients' and they may well have to be those who are given the most 'treatment' by psychological and social means. It is here that professional helpers come in.

Professional networks of help—assessment, treatment and management in dementia

When a patient who may have dementia, or, much more commonly, someone else connected with her, seeks help from a professional worker, there is often unnecessary difficulty in obtaining it. There are many reasons and this is not the place to consider them all. However, one set of factors is especially relevant, namely the indifference or even the hostility with which the elderly in general, and those with dementia in particular, tend to be viewed by staff in the health and social services. That attitude in turn stems partly from uncertainty as to what should be done, what can be done and who is to do it. Training rightly emphasizes the individual patient or client as the focus of intervention but as a result it is possible in this group to overlook the fact that a modified approach is required. Much work, much productive and rewarding work, is necessary for others than the designated patient, in order indirectly to help the patient, or at least to prevent unnecessary distress being caused to her.

The clinical and administrative aspects of dementia have been dealt with in detail elsewhere (Hemsi, 1982). Here only the essentials will be described: as patients with dementia are seen in so many places, not only in the wards of general hospitals, it is important that the principles of their assessment, treatment and management be understood well beyond the specialist orbit.

Assessment

Assessment must be firstly of the patient and secondly, and at least as important, of those around the patient. It is best done at the patient's home, if this is possible.

The problem must be elicited in ordinary language from the patient (who may see none) and from the others who are relevant. Perceptions of what the difficulties are may vary considerably from informant to informant. Behaviour patterns should be described in detail and an account of the patient's activities over a 24-hour period obtained. This will not only identify the general nature of the disability and the differential diagnosis but will also pinpoint the particular features which are really troublesome, name the people who move around the patient (the anatomy of her social network) and show the nature of their interactions with, attitudes to, and worries about the patient and one another (the psychology of the social network). This history of the present illness is then supplemented by a full biographical psychiatric history and examination of the patient's physical and mental state. This assessment will provide initial answers, which may well have to be expanded or modified later, to the following questions. (a) Who is the problem? For example, is it the patient and her illness or is it the attitude of another person who has particular views of what the patient should be like,
and what is good for her. (b) Is the patient suffering from a psychiatric disorder? If she is, what is its nature: functional or organic? If organic, is it acute (and potentially treatable) or chronic? If chronic is it focal, such as a simple memory disorder, a disorder of language, an isolated change of personality (indicative possibly of a localized lesion such as a tumour or a haematoma), or generalized (and likely in an old person to be due to a diffuse degenerative process)? (c) What further investigations (if any) are needed to clarify the nature of the disease process and what further enquiries are necessary in order to understand the psychodynamics within and around the patient? (d) What are the objectives, respectively for the patient and for others? How are they to be attained, and by whom?

These points are embodied in the formulation following the assessment. Such a formulation summarizes the history and the examination, sets out the problem, considers the factors leading up to it, determines what treatment might be given and plans care for the patient and the others who are relevant. The formulation also sets a priority for the case in the light of the needs of other cases and of the total resources available.

Treatment

For practical purposes, the drug treatment of patients with dementia is symptomatic only (Reisberg, Ferris and Gershon, 1981) and then largely for symptoms such as agitation, insomnia and depression, which are not core symptoms.

Psychological approaches intended to modify particular abnormalities, such as incontinence and disorientation, are now being actively explored (Miller, 1977) and Reality Orientation Therapy is widely applied, especially in institutional settings. How far these methods are effective, and how much they improve the patient's well-being when effective, is still uncertain and a matter for continuing research. That they do help staff morale, by removing some of the sense of impotence in the face of dementia, is very likely. They are therefore to be encouraged. However, until the pathological processes leading to dementia can be reversed or arrested, it is not to be expected that such techniques will have a dramatic impact upon patients.

In the view of the author, this is not as serious a problem to patients as may appear at first sight, and dementia is not as hopeless a therapeutic challenge as it seems, once one thinks through what the objectives are for the patient, on the one hand, and for others on the other hand. It is then that it becomes clear that much can be done to improve the quality of life of the patients, to avoid influences which make matters worse for the patient and to help others around her to come to terms with the illness. In this way, they are more likely to be willing to continue to support an old person who may be very disabled and yet whose suffering and distress may subjectively be slight or even non-existent. Management in these cases means support, for the patient and for the others involved, and the construction of systems of support, more difficult and more satisfying than may immediately be obvious, is the task of professional staff.

Management in dementia

The patient's interests should be paramount ethically. A common error is to identify with normal people around the patient, thus seeing the problem only through their eyes and running the risk of neglecting or even harming the patient (usually by pressing prematurely for institutionalization) in the course of furthering the interests of others. This can all too easily be done under the guise of helping the patient because there may be no clear view of what the objectives for the patient should be.

The objectives for the patient

These are to relieve distress when present; to avoid so far as possible the causation of distress; to provide the basic necessities of life, namely shelter, food and fluids, warmth, cleanliness, drugs for certain physical diseases, safety and money to buy these. Standards to be aimed for are reasonable standards and not perfection.

As has been stated already, most patients with dementia are not subjectively distressed and the first objective is therefore usually attained with little or no difficulty. It is harder to avoid inducing distress and this can easily result from overconcern about the lowered standards and the increased risks inherent in the patient's condition.

The objectives for those supporting the patient

Because the patient is dependent upon others for her physical survival, the objectives for those others also have to be considered and their needs met so far as possible. These are: to help reduce their physical fatigue and their emotional distress; to provide factual information; to provide practical assistance; to provide partial relief by day care for the patient and by intermittent admission; to have support available in an emergency; in due course to provide permanent residential or in-patient care.

To fulfil these objectives, it is necessary to construct two support systems, one for the patient and the other for everyone else concerned with her or upon whom she impinges. Detailed planning and coordination between agencies and between individual workers is crucial to success, including the agreement
of roles. In this process, probably the most important single component is the counselling of the patient's supporters and the handling of the psychodynamics around the patient (Hemsi, 1982). An integral part of the function of the specialist is to support less experienced other professionals to deal with their own anxieties and other feelings, often similar in type and degree to those in the patient's informal social network. At the end of the day, what is needed is to provide the essentials for the patient and to enable others to live with anxiety, risk and imperfection, because the alternative is usually worse for the patient or else impossible!

Conclusion

As the number of the very old increases, so will the prevalence of dementia in the population rise. Most people affected will continue to live outside institutions, partly because there are not enough institutional places and staff for them all, partly because many will not go into institutions and partly because institutions so often remain dehumanizing and inferior to life in a personal home. And so, specialist teams are likely to spend more and more time outside hospitals, working with patients and their families and with the general practitioner and social services teams in the community. An appreciation of the issues by other hospital staff is needed if the scale of the problem is ever to command its proper share and deployment of resources to ease the distress not so much of the elderly with dementia but of the middle-aged and young who live with or near them!

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L. Hemsi

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