

107

DEMENTIA



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CONTENTS

	<i>Page</i>
Chapter	
1. Introduction	5
2. The epidemiology of dementia	12
3. The clinical picture	19
4. Treatment and therapy	27
5. The organisation of services	32
6. Questions of cost and value	46
7. Prospects for the 1990's	58
References	68
Appendix – The causes of dementia	75

1 INTRODUCTION

Dementia is a condition whose causes are poorly understood, which can not be cured and for which current treatments of symptoms have at best marginal effects. Dementia affects a significant proportion of the population of elderly people in developed countries, and it is estimated that over half a million people in the UK have it. There are thus important implications for the health and social care resources required to support them.

The term dementia refers to a constellation of signs and symptoms reflecting global impairment of higher intellectual functions. It involves progressive deterioration of the brain, the principal causes of which are Alzheimer's disease, strokes and alcoholism. That is, dementia refers to a cluster of disease processes. In its most severe forms it involves massive atrophy of the brain, with consequent deterioration of mental and physical functioning. Often, however, dementia does not progress beyond a mild form even though someone may have it for several years.

Dementia has always been thought of as an age-related condition, and has almost certainly become more prevalent as the numbers of elderly people have increased. It is, though, distinct from ageing, which is not an illness: the popular association of old age and senility is erroneous. Indeed, the identification of dementia associated with AIDS and HIV infections may come to change the general perception of dementia as a disease of old age. Dementia is an important component of more general changes both in the UK and other developed countries, where changes in the structure of populations suggest that financing health care, social care and pensions will pose serious challenges in the first quarter of the next century (OECD, 1988).

Yet this should not be taken to imply that we can only despair: informal care and statutory services can between them ensure that people with dementia have the highest quality of life possible, within the constraints imposed by their condition. A major task for service providers, from all sectors, is to ensure that people with dementia and their carers receive support appropriate to their needs. Current evidence, both from the UK and elsewhere, suggests that this is the exception rather than the rule.

The hope for ameliorating the effects of dementia still lies in the future. Researchers are beginning to unravel its causes, and this is an important step towards developing effective treatments. In particular, the origins of Alzheimer's disease, the most common cause of dementia, are under intensive investigation. This review discusses the evidence and arguments about dementia, and looks at the current developments in research and in service provision which will shape

the experiences of people with dementia in the future. In contrast with most earlier reviews, it seeks to bring together two topics that are normally discussed separately, namely the organisation of health and social services and the impact of pharmaceuticals. It seems very probable that their interaction will have a major impact on people with dementia during the 1990's.

The emergence of dementia

Alzheimer's disease and the other causes of dementia have undoubtedly been around for a long time, but it is only relatively recently that both Alzheimer's disease and dementia have attracted widespread attention in the media and the general population. In an important sense, dementia is a new condition, both for society in general and for medicine in particular.

The present understanding of dementia as a clinical condition has developed over the course of this century. Three main themes can be traced. First, dementia is now distinguished from a range of other organic and functional disorders. In the nineteenth century several clinical classification systems were developed, with dementia named as a distinct mental disorder. However, the uses of the term included conditions that we recognise today as schizophrenia (*dementia praecox*) and paranoia. By the turn of this century, dementia was defined more precisely and more closely to its present definition. It was due to brain disease, among whose causes were Alzheimer's disease and arteriosclerosis, popularly referred to as 'hardening of the arteries' (Mahendra, 1984).

The second theme concerns the link between dementia and Alzheimer's disease. Until the 1970's most clinicians and researchers thought that the two were quite distinct, with the onset of Alzheimer's generally before the age of 65, and dementia after 65. A principal reason for this was that arteriosclerosis was widely assumed to be the primary cause of dementia. It was only the landmark studies in Newcastle in the 1960's which showed both that arteriosclerosis had been greatly overestimated as a cause of dementia, and that the half or more of all people dying with dementia showed the neuropathological characteristics of Alzheimer's disease (Tomlinson et al, 1970). These and other studies gradually led to widespread acceptance that Alzheimer's and dementia were linked. So although the clinical link was made at the beginning of the century, it is only recently that the research evidence has established it beyond doubt. (In fact, it now appears that there may indeed be biochemically distinct forms of Alzheimer's, but the difference between them is more complex than originally thought, and any age-related cut-off may be later than 65 years of age.)

6 Third, the relationship between dementia and normal processes of

ageing has been radically rethought. Again, it is only remarkably recently that the assumption of 'senility' being an inevitable consequence of old age has been successfully challenged, and even now the association appears to remain in the minds of sections of the population at large. In fact, even the fittest elderly people experience a decline in some functions, and post-mortem studies of the brain often show signs of degeneration. But these changes may have only minor effects on people during their lives, and they are quite distinct from the disease processes and effects on people with dementia.

Given that dementia has been classified as a distinct clinical condition for so long, it is perhaps surprising that wider recognition of its importance has come so late. But the perception that it was of little consequence dogged progress, and was shared by many policy makers and researchers alike. This was especially true in the United States:

'The whole story on neuro-chemistry of Alzheimer's disease could have been unravelled 12 or 15 years before 1976 when the first papers came out detailing the specific chemical deficit. That work could have actually been done in the early sixties but it wasn't, because who cared about Alzheimer's disease then. ... It was really the application of existing technology to a new problem that was the result of increased interest in the disease'. (P. Davies quoted in Fox, 1989).

Once the link was made, though, it was realised that far from being marginal, dementia was a major cause of morbidity and disability among older people in developed countries, affecting 2-3 per cent of the population over 65 years of age.

More generally, the rise in the proportion of older people in the population attracted the attention of governments who were paying benefits to them and providing their health and social services. Initially these increases were most marked in parts of Europe, and as a result much of the early research into the social and clinical dimensions of dementia were undertaken in Britain and Scandinavia. This, together with the emergence of groups articulating their needs and demands – both in Europe and elsewhere – has raised their political profile. Fox (1989) identifies a series of coalitions between lobbying groups, concerned governments and researchers which has fuelled progress on a number of fronts over the last ten or fifteen years. As we progress into the 1990's, the situation is changing rapidly on some fronts, particularly in understanding the causes of dementia, but less so on others, most obviously with regard to government policies which take account of the special problems dementia poses.

What is dementia?

Dementia is one of the class of conditions with multiple causes, which

presents in many different ways. Much of the difficulty in describing dementia in the past was due to the absence of definitive tests for its presence during life: it could only be shown post-mortem, (although it now appears that these difficulties may have been overstated).

The Royal College of Physicians (1982) gave the following definition:

‘Dementia is the acquired global impairment of higher cortical functions including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills, all aspects of language and communication and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often progressive though not necessarily irreversible’.

Dementia can involve massive changes in cognition and behaviour, but in people who are conscious and often able to hold conversations. In most cases, particularly in Alzheimer’s disease, onset is slow and takes months and years to develop. Some people never progress beyond a relatively mild form of dementia. In other people onset can be very rapid, from normality one week to severe dementia the next, where memory and other functions are grossly impaired. The presentation of dementia can be highly variable, particularly in the degree of confusion or memory loss, and some but by no means all demented people are aggressive in their behaviour. But in all cases the clearest indication of dementia is marked memory loss, particularly of recent events.

Described from the point of view of the person with dementia, its principal characteristics include (King’s Fund, 1986):

- **Memory.** The fadeout time of current memory become faster, so that it is difficult to hold material in the mind. Concentration is therefore affected and becomes poor. Inappropriate memories of long ago may appear as current events.
- **Orientation.** Ability to recall ‘where and when it is’ increasingly dominates existence. The clues as to who other people are become increasingly difficult to recall.
- **Dysphasia.** Inability to recognise or name objects, including everyday objects such as pens and watches.
- **Grasp.** Greater difficulty is experienced in teasing out what is going on and what is being said. This is particularly so if events move too fast, with little repetition to aid memory, or if a whole series of concepts are rapidly introduced.
- **Communication.** On top of the stresses described above, there is a restricted power of communication, so that even if something is available in memory it is not expressed.

- **Depression.** The stress of the failing mental mechanisms may cause normal reactions such as anxiety or depression. Sometimes the reaction may become severe enough to cause serious agitation or even misinterpretations, delusions and hallucinations.
- **Confusional states.** Physical illness frequently occurs during the course of dementia and gives rise to greater temporary mental disturbance. Drugs and social and environmental changes may have similar effects.
- **Neurological states.** Some people with dementia may experience paralysis or abnormal body movements.

Dementia is distinguished from other conditions by the global nature of its effects: people have several of the above problems rather than any one. In addition to those listed, the massive changes in the brain can cause physical problems, notably with urinary and faecal incontinence and with mobility. It is easy to dwell on the negative aspects of dementia for those who have it, but it should be stressed that many appear to observers to be quite happy in themselves. If someone is aware that dementia is progressing, as can happen, then that knowledge may be extremely difficult to cope with. But once someone is demented, the lack of awareness of the singularity of the condition gives protection from worrying too much about the things that concern the rest of us.

Dementia can look rather different to others. Most people with dementia live in their own homes and are cared for by relatives or friends. The great majority of them want to do the caring, but the relentless nature of caring can cause them stress and illness. The progressive nature of dementia means that satisfaction can not be gained from any improvements made by the person cared for. Dementia is also very much about those who do the caring.

Some authors have questioned whether there is in fact any critical distinction between dementia and the processes of normal ageing. It is now generally agreed that dementia is distinct from normal ageing, but many signs and symptoms – and also pathological changes – are best conceived as being on a continuum from healthy old age to severe dementia. The two main arguments in support of this view are that there are many older people who remain cognitively intact, and show no obvious deterioration in intellect; and that the condition is also found in people in their fifties. Recently it has become clear that people with AIDS and HIV can have dementia, which dramatically emphasises the distinction between dementia and ageing processes. Services are currently geared to older people, and the needs of this mostly young group represent a new challenge.

The development of understanding of the different causes and

effects of dementia has led to the use of a variety of terms to describe it. Throughout, the terms listed here will be used, unless reference to a specific paper requires a different term to ensure precision. It should be stressed that there is elasticity, and in some cases disagreement, over the use of these terms: but we have to start somewhere.

Confusion. A general term for people who may be forgetful or disorientated: there is no presumption that confusion is associated with dementia. The term is often used by professionals working in the community, where the fact of someone having dementia or another condition has little or no effect on the services provided.

Dementia, demented. A constellation of signs and symptoms, as outlined in the definition above. It is used mainly in the clinical context, in the absence of pathological evidence confirming the presence of disease: it is a syndrome rather than a diagnosed condition.

Many authors distinguish between mild, moderate and severe dementia. The terms are useful in research, but are perhaps less useful as precise descriptors in normal clinical practice.

AIDS Dementia Complex. With the rise in the numbers of people with AIDS and HIV, it has become apparent that many of them exhibit dementia-like signs and symptoms.

Reversible dementia. Some authors refer to a class of dementias which can be reversed, including vitamin B₁₂ deficiency and hypothyroidism: treatment of the cause removes the dementia (Byrne, 1987). Similarly, alcohol-related dementia may be reversible through abstinence. Other authors hold that dementia is essentially irreversible, so that these conditions are inappropriately named.

There are also a number of rarer diseases which some class as dementias. These include Huntington's Chorea, Creutzfeldt-Jacob disease and Gerstmann-Straussler Syndrome. Some people with Parkinson's disease also have dementia: this is a particularly important example of the general phenomenon of coincidence of dementia with other conditions.

The list omits a number of commonly used terms, including pre-senile and senile dementia, and senile dementia of the Alzheimer type (SDAT). These terms are not used here, not because they have no value but to avoid confusion through use of different terms with overlapping meanings. Conversely, it has also become increasingly clear that many forms of dementia are closely related pathologically, and so several distinctions formerly made are now felt to be of limited use.

Structure of the review

The next six chapters review the current status and future prospects for research and service provision for people with dementia. Chapter 2 examines the evidence on the prevalence and incidence of dementia, which suggests that precise estimates are difficult to arrive at, but that the numbers involved are large. Chapter 3 briefly presents the clinical picture presented by dementia, and Chapter 4 the pharmaceutical and other therapeutic strategies currently available. (An appendix reviews progress in understanding the causes of dementia). At this point the focus moves away from clinical issues. Chapter 5 considers the organisation of services for people with dementia, and discusses the role of informal carers. Then Chapter 6 reviews evidence on the cost and value of care for people with dementia. Finally, Chapter 7 looks at the major developments and policy issues which are likely to determine the experiences of people with dementia and their carers in the 1990's.

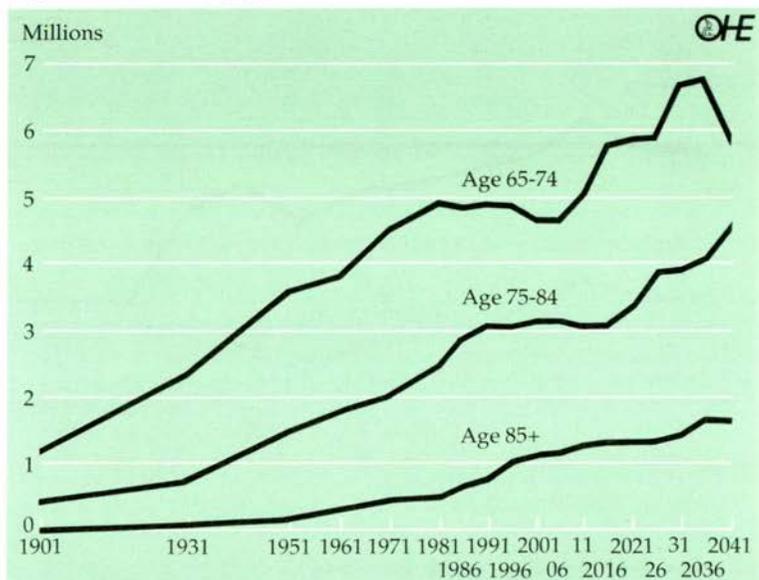
2 THE EPIDEMIOLOGY OF DEMENTIA

Measurement of the numbers of people who have dementia has proved difficult, and analysis of data requires care. Estimates and projections of the total numbers of elderly people in the population are given in Figure 2.1. While the number of people over the age of 65 is projected to fall slightly over the next decade, the numbers of those aged 85 years and over will continue to grow rapidly (Figures 2.2 and 2.3). Figures suggest that the number of people with dementia has been increasing over the last two decades, and this trend will continue at least for the remainder of the century. Early next century the numbers of people over the age of 65 will again climb, leading to additional pressures on health and social services (OECD, 1988; Gillion, 1991).

Figure 2.1 Population changes 1989-2011, England

	1989	2001	2011	1989-2011 % change
Total population (thousands) aged:				
All ages	47,689.4	49,539.3	50,481.3	
65-69	2,478.4	2,100.6	2,468.7	-0.4
70-74	1,721.9	1,901.4	1,909.8	+10.9
75-79	1,574.0	1,614.4	1,518.5	+3.5
80-84	1,036.2	1,113.1	1,152.9	+11.3
85+	712.0	998.7	1,136.8	+59.7
Estimated number (thousands) of people aged 65+ who are:				
Living alone*	2710	2675	-	
Unable to get in/ out of bed unaided*	160	168	-	
*In the community.				

Figure 2.2 Elderly population of Great Britain



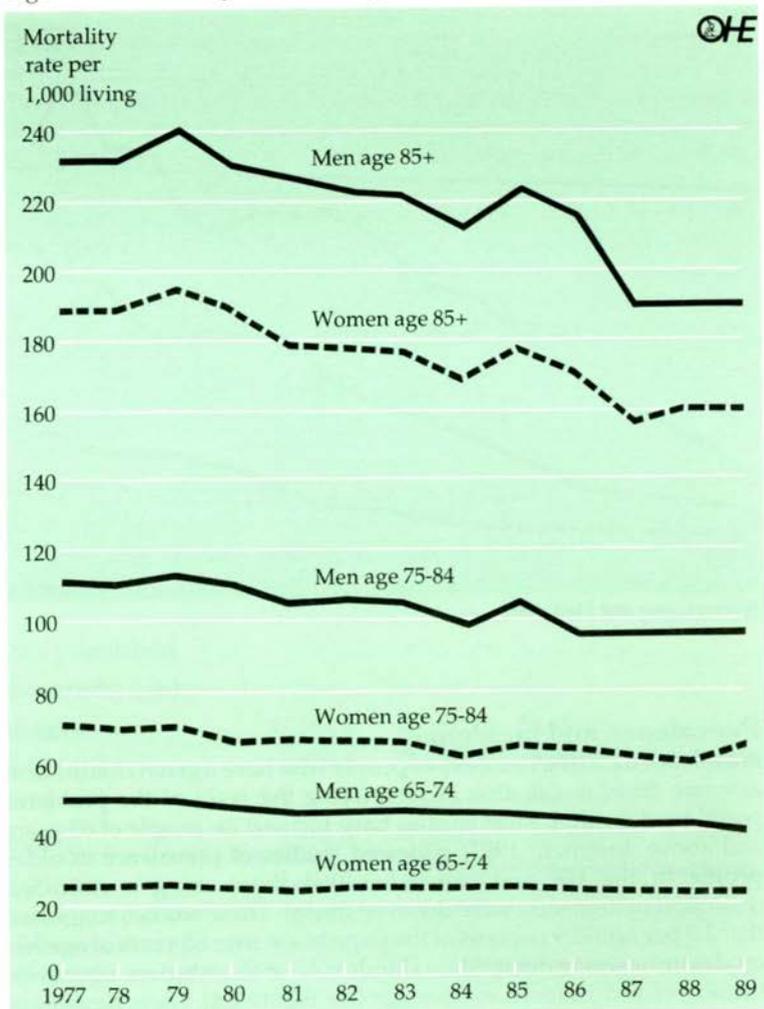
Source: Laing and Hall, 1991

Prevalence and incidence

Prevalence data (the numbers of people who have a given condition at any one time) is valuable in identifying the scale of the problems posed by dementia. Most studies have focused on people of 65 years and above. Ineichen (1987) reviewed studies of prevalence in older people in the UK and concluded that those using a restricted definition of dementia were the most useful. These studies suggested that 2.8 per cent-2.9 per cent of the population over 65 years of age has moderate or severe dementia; a simple rule-of-thumb gives figures for those over and under 75 years of age (see Figure 2.4). These figures are broadly confirmed by a more recent study (O'Connor et al, 1989), which found rates of 5.3 per cent for moderate/severe dementia and 5.2 per cent for mild dementia in a population aged 75 years and over (Figure 2.5). These results are, though, lower than those derived from 22 pooled studies from several countries (Jorm et al, 1987: Figure 2.6), and those presented in a WHO report (1986).

Figures from studies using broader definitions of dementia range from 2.5 per cent to 24.6 per cent: such figures emphasise the difficulties of measurement of prevalence, particularly when mild

Figure 2.3 Mortality rates for England and Wales, 1977-89



Source: OPCS

Figure 2.4 Ineichen's rule-of-thumb for the prevalence of dementia

<i>Age (years)</i>	<i>Prevalence (%)</i>
65-74	1
75 and over	10

Source: Ineichen, 1987

Figure 2.5 Sample severity rating criteria for research projects

Mild dementia

Difficulty in recalling recent information: limited or patchy disorientation to time and place; impaired problem solving, reasoning and the capacity to manage usual activities; diminished clarity of speech; defective knowledge of names of prominent figures; social facade and emotional responsiveness may be well retained but cognitive deficit present on testing.

Moderate dementia

Severely impaired reasoning, problem solving and recall of recent events. Disorientated in time and place. Language unclear but not to a marked degree. Unable to manage housework, shopping, finances independently. Needs help with dressing and other self-care; may be occasionally incontinent. Testing reveals advanced deficits.

Severe dementia

Incapable of recall, reasoning and self-care. Almost invariably incontinent, apathetic and inert. Totally incapable of independent existence.

Source: O'Connor et al, 1989

Figure 2.6 Age-specific prevalence of dementia: pooled data from 22 studies

<i>Age (years)</i>	<i>Prevalence (%)</i>
60-64	0.7
65-69	1.4
70-74	2.8
75-79	5.6
80-84	10.5
85-89	20.8
90-95	38.6

Source: Jorm et al, 1987

dementia is included. Indeed, mild dementia is perhaps best viewed as being on a continuum between normal ageing and more severe dementia, and identification of appropriate cut-off points is problematic. The sources of the differences in results can be explained in part by differences in cut-off points for positive identification, and in the nature of the sample populations. But explanation of the origin of some differences remains elusive (Black et al, 1990), and this suggests a need for rigorously applied interviews and diagnostic criteria across studies (Henderson, 1986). There appear not to be any significant differences between sexes, although there are differences between regions within countries (Jorm, 1990).

To date there have not been any systematic studies which include people with Aids Dementia Complex (ADC). Clearly, any study would involve sampling of very different populations to those discussed here. Anecdotally, it appears that between ten and fifteen percent of people with HIV and AIDS may exhibit the signs and symptoms of ADC. Over the next few years the numbers of people in this group may grow significantly, so that population estimates for dementia in people under 65 years – and under 25 – can be expected to increase.

Incidence rates (that is, the numbers of people becoming demented over a specified period of time) also vary between studies. Incidence studies are important theoretically for understanding the effects of dementia on survival, in estimating lifetime risks of dementia, and the risk of dementia in relatives of demented people (that is, where genetic factors are involved, as in many cases of Alzheimer's disease). But relatively few studies have been undertaken and at present our understanding of incidence is poor (Jorm, 1990). Some (eg. Mortimer, 1983) suggest that rates may rise until around 75 years of age and then level off. Others (eg. Aronson et al, 1991) found that incidence continued to increase with increasing age at least until the age of 85: they reported an overall incidence rate for all age groups of 3.4 per 100 per year in an eight year period.

If anything, successive studies have increased the uncertainty about the prevalence and incidence of dementia, with the most recent increasing the ranges of figures reported. At the very least, this indicates the need for comprehensive, systematic assessment in future studies, ideally using common instruments for assessment and monitoring.

Other measures

The effect of dementia on life expectancy is also uncertain. Dementia appears to be associated with reduced life expectancy, but the relationship is not clear cut: this occurs for a number of reasons, including difficulties of measuring survival after the onset of

dementia, and because life expectancy for the whole population has been increasing, so masking the effects of the condition. Maule et al (1984) found increased mortality, but Christie (1985) analysed data from longitudinal studies and found that survival time appears to be lengthening. Moreover, it may be that the setting affects mortality: for example people in institutional care may live longer than those who stay at home (Nygaard and Laake, 1990).

Finally, some other figures offer insights into the scale and pattern of the potential demand for services. At least four fifths of confused

Figure 2.7 Prevalence (%) of dementia, locomotor problems and incontinence (population = 1202)

<i>Factor present</i>	<i>Prevalence % (number)</i>
Dementia, locomotor problems, and incontinence	1.7 (20)
Dementia and incontinence	0.2 (2)
Locomotor problems and incontinence	6.7 (80)
Dementia and locomotor problems	1.7 (20)
Dementia alone	0.4 (5)
Locomotor problems alone	30.8 (370)
Incontinence alone	3.7 (45)
Any of the above	45.1 (542)

Source: McGrother et al, 1991

Figure 2.8 Behavioural disturbance and mood disorders in Alzheimer's disease

	<i>Number</i>	<i>Percentage</i>
	<i>(sample total = 178)</i>	
Urinary incontinence (n=174)	83	47.7
Aggression	35	19.7
Wandering	35	18.5
Depression (n=174; observed by rater)	41	23.5

Sources: Burns et al, 1990a, 1990b

elderly people live in their own homes. Figure 2.1 gives estimates for (all elderly) people living on their own: as we shall see in Chapter 5, this is an important risk factor for demented people entering institutional care. And the numbers of people available as carers, who play a crucial role in the lives of dementing people, which has been increasing over recent decades, appears set to decrease (Green, 1988). Already, some one in four confused people have no close relative or helpful neighbour (Levin et al, 1983).

It may also be the case that the prevalence of the important problems experienced by people with dementia are useful predictors of future demands for resources. Many people with dementia have urinary incontinence (Campbell et al, 1985; McGrother et al, 1990), although the majority of incontinent people are not demented (Figure 2.7). These findings were broadly confirmed in a study by Burns et al (1990a, 1990b) of people with Alzheimer's disease: they also noted the numbers of people with a range of other problems (Figure 2.8). Figures such as these may be just as important as those for the prevalence of dementia if new symptomatic treatments become available.

3 THE CLINICAL PICTURE

As people progress into their later years they experience declines in certain functions, such as reaction time and hearing. The popular image of elderly people appears to be based on the perception that these and other changes are the norm: being old is about functional deterioration and illness. In the minds of many people old age is still equated with mental deterioration, often labelled as senility. In fact, many elderly people remain healthy and active, and make few demands on statutory services. It is often only in the last few years of life that significant numbers of elderly people become vulnerable to diseases which are associated with high morbidity or mortality. It is at this time too that most chronic conditions, including dementia, become more severe for many people.

The causes of dementia remain obscure. As with other chronic degenerative diseases such as rheumatoid arthritis and many types of cancer the research literature provides a bewildering variety of clues, which are gradually coming together to form a coherent story of cause and effect. There are several hypotheses about the causes of dementia, each of which is currently being investigated. What does seem to be certain is that there are a number of immediate causes, which involve damage to a number of areas of the brain. The most important area is the cerebral cortex, which controls higher mental functions including memory and consciousness. In the most severe forms of dementia, damage can be very extensive and many areas of the brain atrophy. However, to what extent the various causes act through similar pathways leading to the characteristic pathology and clinical presentation of dementia is not yet clear. These issues are discussed further in the Appendix.

Normal processes of ageing

Although elderly people do consume a disproportionate amount of the health care budget, many remain in good health well into their eighties and nineties, and require little health or social service assistance. This suggests considerable variability in health status within the elderly population.

Nevertheless, research suggests that there are physiological and psychological changes associated with ageing. These changes provide a benchmark against which 'abnormal' functional and organic changes can be assessed (Schneider and Rowe, 1990). Relatively few individuals follow the pattern of age changes predicted from averages based on measurements made on different subjects. Because of the large range in the performance of most physiological variables of people of the same chronological age, it appears that age alone is a poor predictor of performance. As a result, variability in the clinical

manifestation of an illness may be due to: variability in the underlying physiological changes; the other diseases that the individual has accumulated over time; the pattern of response to illness and the interaction with health care professionals that are characteristic of the individual; his or her social circumstances; and the varying degrees of severity of pathophysiological processes.

Among the physiological processes associated with ageing that are reasonably well understood, are:

- increasing physical frailty, associated for example with increasing brittleness of bones and osteoarthritis;
- deterioration of eyesight, due to clouding of the cornea and distension of the lens;
- increasing hearing loss, particularly at high frequencies;
- incontinence.

As a result of these and other processes, most elderly people do eventually come into contact with health and social services. Any assessment has to take account of the following (Gurland and Wilder, 1984):

- many elderly people have more than one health or social problem;
- the assessment of any one problem often involves its distinction from other problems that may resemble it (eg. the separation of depression from dementia). This calls for adequate specification not only of the features of the targeted problem but also of those problems with overlapping features;
- the origin of one problem may be best understood by reference also to concomitant problems. Interactions between problem areas are particularly likely to occur with advancing age;
- the prognosis of the targeted problem may vary with associated problems (eg. the chronicity of depression in elderly individuals varies with the presence of physical illness);
- the appropriate treatments will depend upon the combination of problems encountered and may require on-going monitoring of all problems in order to prioritize treatments and later to make adjustments of treatment;
- judgements of progress must take into account the possibility that one problem may get better while another gets worse. The treatment that improves one problem may aggravate another;
- the consequences of deterioration in one problem area may be most evident in the emergence of another problem (eg. intellectual deterioration manifesting as functional impairment).

The problems that elderly people experience are the same as adults', but they tend more often to occur in combination. As a result, elderly people are often prescribed many drugs and treatments, and these can also complicate the process of identifying dementia.

Dementia and depression

While the relationship between normal ageing and dementia is very important in terms of the conceptualisation of disease processes, in practice the challenge is to identify conditions accurately so that appropriate treatments – if available – can be provided. Dementia can occur alongside many other problems; depression is one of the most important and is presented here as an example. Depressive illnesses in elderly people appear to be strongly associated with disruptive and stressful events in their personal lives. Events such as bereavement, the moving away of children and close friends, physical illness (particularly cancer and heart disease), and a variety of psychological stresses.

There are four ways in which depression and dementia can interact (although as with many other aspects of dementia not all would agree with this list):

1. Awareness of one's deteriorating condition is maintained, and the individual knows something is seriously wrong. This knowledge triggers the depression. The resulting depression is non-psychotic. This occurs particularly in association with vascular dementia.
2. There is a simple coincidence of depressive illness and dementia.
3. The depression is so severe it interferes with cognition. It appears initially to be similar to dementia, but is not. Later on, the dementia develops and overshadows the depression. In the early stages, there is no evidence of atrophy brain scans, and brain chemistry suggests depression. In order to distinguish the two in the individual, one has to rely on patient history, eg presence or absence of depression in early life, or family history of depression.
4. A person has a serious depression and no initial cognitive loss. But cortical atrophy follows the depression, so that the dementia syndrome emerges from the depression. The link is presently associational rather than causal. It particularly affects men. It is often a person's first ever depression, and very severe: disturbances of perception and interpretation occur, as often do guilt, delusions, and a sense of unworthiness. This is a psychotic depression.

Groups 1 and 2 are fairly common, groups 3 and 4 much less so. As with dementia, people with depression may be found in all types of settings, and receive widely varying assistance and support in the community.

Clinical assessment and diagnosis of dementia

In spite of the fact that the signs and symptoms of dementia can be so marked, it was pointed out in Chapter 1 that its nature and time course are highly variable, and diagnosis can be problematic. Studies carried out in Newcastle upon Tyne in the 1960's included post mortem brain examinations which showed the massive deterioration associated with dementia. Since that work, researchers have sought methods for arriving at accurate diagnoses during life. Some, particularly in north America, favour the use of high technology to aid diagnosis. Radiological investigations have been used to demonstrate anatomical and physiological changes in the brain, and CT scans are routinely used. But in the UK the approach depends more on the use of examination and interview, rather than extensive investigation.

Indeed, the reliability of any instrument used may depend in large part on where an assessment is done. For people living in their own homes, it is important to assess them there, rather than in a GP surgery or other environment. Scores generally go down for any test administered outside the home, running the risk of finding people to be less able to cope than they really are. This risk may be especially marked where people have been admitted to acute hospital wards, or any environment when there has been a crisis at home.

Instruments used for the assessment of people with cognitive impairment, including dementia, have been comprehensively reviewed elsewhere (Bowling, 1991; Jorm, 1990). Given the nature of the people being assessed, it is not surprising that brief instruments have proved to be most reliable and useful: all instruments have supporters and detractors, but some appear to be more generally accepted than others. The most widely used is the Mini-Mental State Examination (MMSE; Folstein et al, 1975). For general functional abilities the Barthel Index (Mahoney and Barthel, 1965) is widely used.

For the diagnosis of dementia, the most widely used instruments are:

- Geriatric Mental State (GMS; Copeland et al, 1976), from which a computerised algorithm for standardising the diagnostic process was developed (AGECAT; Copeland et al, 1986);
- Comprehensive Assessment and Referral Evaluation (CARE), which has shorter versions including SHORT-CARE (Gurland et al, 1984) which covers only dementia, depression and disability;
- Cambridge Mental Disorders of the Elderly Examination (CAMDEX; Roth et al, 1986).

These are used in epidemiological research, and not generally in normal clinical practice.

Finally, there are aids to diagnosis which are not currently widely used in clinical practice, but offer means of increasing the reliability of diagnosis. For Alzheimer's disease, the National Institute of Neurolo-

Figure 3.1 NINCDS-ADRDA criteria for clinical diagnosis of Alzheimer's disease

1. The criteria for the clinical diagnosis of probable Alzheimer's disease include:
 - dementia established by clinical examination and documented by the Mini-Mental Test, Blessed Dementia Scale, or some similar examination, and confirmed by neuropsychological tests;
 - deficits in two or more areas of cognition;
 - progressive worsening of memory and other cognitive functions;
 - no disturbance of consciousness;
 - onset between ages 40 and 90, most often after age 65; and
 - absence of systemic disorders or other brain diseases that in and of themselves could account for the progressive deficits in memory and cognition.
2. The diagnosis of probable Alzheimer's disease is supported by:
 - progressive deterioration of specific cognitive functions such as language (aphasia), motor skills (apraxia), and perception (agnosia);
 - impaired activities of daily living and altered patterns of behaviour;
 - family history of similar disorders particularly if confirmed neuropathologically; and laboratory tests of:
 - normal lumbar puncture as evaluated by standard techniques;
 - normal pattern of non-specific changes in EEG, such as increased slow-wave activity, and;
 - evidence of cerebral atrophy on CT with progression documented by serial observation.
3. Other clinical features consistent with the diagnosis of probable Alzheimer's disease, after exclusion of causes of dementia other than Alzheimer's disease, include:
 - plateaus in the course of progression of the illness;
 - associated symptoms of depression, insomnia, incontinence, delusion, illusions, hallucinations, catastrophic verbal, emotional, or physical outbursts, sexual disorders, and weight loss;
 - other neurological abnormalities in some patients, especially with more advanced disease and including motor signs such as increased muscle tone, myoclonus, or gait disorder;
 - seizures in advanced disease; and
 - CT normal for age.
4. Features that make the diagnosis of probable Alzheimer's disease uncertain or unlikely include:
 - sudden, apoplectic onset;
 - focal neurological findings such as hemiparesis, sensory loss, visual field deficits, and co-ordination early in the course of the illness; and
 - seizures or gait disturbances at the onset or very early in the course of the illness.

Figure 3.1 *continued*

5. Clinical diagnosis of possible Alzheimer's disease:
 - may be made on the basis of the dementia syndrome, in the absence of other neurological, psychiatric, or systemic disorders sufficient to cause dementia, and in the presence of variations in the onset, in the presentation, or in the clinical course;
 - may be made in the presence of a second systemic or brain disorder sufficient to produce dementia, which is not considered to be the cause of the dementia; and
 - should be used in research studies when a single, gradually progressive severe cognitive deficit is identified in the absence of other identifiable cause.
6. Criteria for diagnosis of *definite* Alzheimer's disease are:
 - the clinical criteria for probable Alzheimer's disease and histopathological evidence obtained from a biopsy or autopsy.
7. Classification of Alzheimer's disease for research purposes should specify features that may differentiate subtypes of the disorder, such as:
 - familial occurrence;
 - onset before age of 65;
 - presence of trisomy-21; and
 - coexistence of other relevant conditions such as Parkinson's disease.

Source: McKhann et al, 1984.

gical and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) in the USA have developed diagnostic criteria (McKhann et al, 1984; Figure 3.1). Burns et al (1990c) have studied elderly psychiatric patients and compared the results of using the NINCDS/ADRDS criteria with post-mortem brain examination. They found that it correctly predicted probable Alzheimer's disease in 88 per cent of patients, and possible Alzheimer's in 78 per cent. These results tell us the sensitivity of the instrument - that is, its ability to predict the number of true positive cases - but not the specificity, or number of false negatives that would have resulted had non-Alzheimer's patients been included in the study. Nevertheless, the results compare favourably with most diagnostic instruments, and suggest that Alzheimer's disease may not be as difficult to diagnose as generally thought.

Diagnostic criteria have also been developed for vascular dementia, and for dementia in general (American Psychiatric Association, 1987). It should be noted, though, that the criteria for these other causes of dementia have not been so extensively investigated, reflecting perhaps the greater research interest in Alzheimer's disease.

Risk factors for dementia

Risk factors for Alzheimer's disease and for vascular dementia have been the subject of much research over the last decade. They are important because they may provide evidence for developing strategies for prevention or delay of onset of dementia.

Figure 3.2 summarises risk factors for Alzheimer's disease. Only old age, family history and Down's syndrome are confirmed: clearly, more research is needed to establish the other important risk factors (Jorm, 1990; Van Duijn et al, 1991). The situation is similar for vascular dementia: conclusive evidence is limited, and age and identifiable stroke seem the only probable risk factors. It does seem, however, that the risk factors for vascular dementia are similar to those for stroke: they include old age, familial disposition to stroke, and diabetes

Figure 3.2 Summary of the current state of knowledge about risk factors for Alzheimer's disease

<i>Status</i>	<i>Factor</i>
Confirmed risk factors	Old age Family history of dementia Down's syndrome
Possible risk factors	Many ulnar loops Head trauma Family history of Down's syndrome
Needing further investigation	Sex Race and nationality Family history of haematological malignancies Handedness Advanced maternal age Advanced paternal age Reduced fertility Solvent exposure Use of vibratory tools Encephalitis and meningitis Heart disease Kidney disease Sleep apnoea Phenacetin abuse Alcohol consumption Physical inactivity Malnutrition Aluminium in drinking water Antiperspirant use
Unlikely risk factors	Birth order Animal exposures Travel in South Pacific Thyroid disease Diabetes Herpes infection Stomach ulcers Arthritis Allergies Operations General anaesthetics Antacid use Smoking Tea and coffee consumption Aluminium cooking utensils Eating raw meat or animal brains

Source: Jorm, 1990

mellitus. Other factors which are currently less well documented include cigarette smoking, alcohol consumption and a history of depression (Jorm, 1990).

In summary, research offers a variety of tantalising clues for the design of therapeutic strategies for dementia. Some may be based on enhanced understanding of the role of genes in familial Alzheimer's disease, but a third or more may depend on understanding of other mechanisms. To date, few have been explored in any detail: hopefully the 1990's will see the development of effective treatments based on our enhanced understanding of disease processes.

4 TREATMENT AND THERAPY

Dementia is a condition for which there are at present no effective treatments. In spite of this, it is worth briefly reviewing the treatments that have been evaluated, and considering possible future strategies for treatment and prevention of dementia. This chapter considers both pharmaceutical and non-pharmaceutical approaches.

Pharmaceuticals

Dementia presents a picture of major chemical and pathological change (Selkoe, 1991). In principle drugs can offer the possibility of prevention or treatment, in a condition where even modest gains would be greatly welcomed. But progress has been very limited, and the literature consists mainly of reports of failures. Yet the scale of the research and development effort currently under way is massive, with dozens of pharmaceutical companies around the world active in the field (Moran, 1991). Given the scale of the effort, it would be very surprising indeed if several new drugs were not licensed during this decade.

While some clinicians do prescribe drugs for treatment of dementia many do not, on the grounds that none has been demonstrated to be effective (Byrne and Arie, 1990). Some of the reasons for the absence of treatments are directly related to our lack of understanding of underlying disease processes, and of problems of isolating effects when there is coincidence of other illnesses. These problems have been compounded by poor research designs in many instances where drug effects have been investigated (Jarvik et al, 1990; Levy, 1990): problems include poorly defined end-points and small numbers of patients.

Here, drug treatments are reviewed in brief, in order to indicate the range of treatments used to date rather than consider the pros and cons of each one. In general:

- studies have been focused on Alzheimer's disease, somewhat at the expense of other dementias;
- strategies have been directed to correcting neurotransmitter deficits, and deficits in the neurotransmitter acetylcholine have been targeted in more reports than have other neurotransmitters.

The rationale for this concentration appears to have been that dementia might be like Parkinson's disease, where a single neurotransmitter system is clearly implicated. As time has gone on, however, this analogy has become less convincing. Dementia has such widespread anatomical and biochemical effects that one might wonder whether any single drug, targeted at ameliorating symptoms, can be expected have much of an effect.

The list of treatment strategies in Figure 4.1 is by no means

Figure 4.1 Examples of pharmacological strategies used in the treatment of dementia

Each section in this list refers to a different chemical transmitter system within the brain (1-6), or to drugs which might have a more general effect on brain functioning (7-9).

1. Cholinergic system
 - acetylcholine precursors, eg. choline, lecithin
 - anticholinesterases, eg. physostigmine, THA
 - cholinergic agonists
 2. Dopaminergic system
 - dopaminergic blockers, eg. chlorpromazine, haloperidol
 - dopaminergic agonists
 3. Noradrenergic system
 - studies of monoamine oxidase inhibitors and propranolol
 4. Serotonin
 - potentiation of serotonin transmission, eg. tryptophan plus trazodone
 5. Gamma aminobutyric acid (GABA)
 - sedatives active at GABAergic synapses are largely contraindicated in dementia, with the possible exception of chlormethiazole
 6. Peptides
 - vasopressin
 - adrenocorticotrophic hormone (ACTH)
 - opiate antagonists
 7. Antihypertensives
 - possible effects on cerebral blood flow
 8. Drugs with a range of possible effects
 - eg. co-dergocrine (Hydergine)
 9. Aluminium chelation (eg. Crapper et al, 1991)
-

exhaustive. In the great majority of cases, there have been no beneficial effects, or positive changes have been offset by important side-effects. It is also worth noting that other developments may be significant in the longer term: for example, chemical markers for Alzheimer's disease (Ghanbari Hossein et al, 1990).

Drugs for the rarer forms of dementia have been little studied. There are reports of use of amantadine for Creutzfeldt-Jacob Disease, and of zidovudine for Aids Dementia Complex. But these both await systematic studies.

The only pharmaceuticals which at least have a reasonable body of evidence showing positive effects are:

- physostigmine improves memory – but only a minority of people with Alzheimer's disease benefit, and there are unpleasant peripheral side effects;

- propranolol ameliorates aggressive behaviour – although proper studies are awaited;
- co-dergocrine (Hydergine) improves memory and behaviour – but studies are difficult to interpret. It may be that its effects are general ones on mood rather than direct ones on cognition.

The start of the 1990's was marked by renewed controversy about THA (Tacrine). Earlier studies reporting positive effects had been criticised on methodological grounds, and others had found no benefits. Attempts have been made to obtain approval from the US Food and Drug Administration, so far without success (Moran, 1991). Tacrine has been described as a cognition enhancer, and it may be that some of the first drugs to reach the market will be the so-called memory enhancers (or nootropics). They, like Tacrine, may be expected to raise a series of heated arguments about symptomatic treatment of dementia.

Although most of the drugs used in Alzheimer's disease and other forms of dementia have been intended to ameliorate neurotransmitter losses, there are a variety of plausible mechanisms for the onset of dementia (see Appendix), which suggest that there are in turn a number of therapeutic strategies which merit investigation:

1. prevent loss or restore 'normal' levels of neurotransmitters in the brain;
2. reduce risk factors eg. risk of stroke, aluminium accumulation;
3. intervene in the gene-protein sequence to delay or prevent abnormal processes (eg. plaque deposition), perhaps by influencing gene regulation;
4. intervene in other ways to reduce deposition of plaques eg. prevent deposition of beta-amyloid near blood vessels;
5. for the rarer dementias, investigate the role of prions and intervene in prion infection pathways;
6. develop strategies based on understanding of the causes of Aids Dementia Complex.

Broadly, the strategies are of two types. One is treatment of symptoms, and includes the treatments investigated to date. The other is to intervene in the processes that cause dementia, and so delay or even prevent onset. Each might in principle lead to improvement in the quality of life of individuals and their informal carers, and to reductions in the resources required to support them. Delay or prevention would probably yield the greatest benefits to individuals, but it appears that effective pharmaceuticals will be more difficult to develop. Most of the strategies listed have not yet been investigated to any significant extent, and many are hypothetical rather than real options at present. Nevertheless, progress in molecular biology may render the hypothetical real, and open up possibilities which presently seem outlandish.

Non-pharmaceutical approaches

Although dementia has an organic basis, it may nevertheless be possible to ameliorate the deterioration in some functions by providing appropriate environments or specific therapies. People with dementia are sensitive, perhaps exceptionally sensitive, to the environments they live in. The most striking evidence of this is the stepwise deterioration that occurs when they move into institutional care. People are often able to indicate, either verbally or through their behaviour, their dissatisfaction with the new environment. This, together with the belief that appropriate interventions can usefully help to maintain functional abilities, has led to the development of therapeutic approaches.

Reality orientation (RO) therapy has two main forms, 24-hour orientation and RO group sessions, with the latter typically consisting of thirty minute sessions two or more times each week. 24-hour orientation is intended to be a continuous process, where the strategy is to take every opportunity to improve orientation, whether through clocks and other physical signs or in conversation. Group sessions usually use visual or auditory aids to discussion of current events or of significant past events. Neither form of RO has been systematically evaluated, and evidence remains inconclusive. On the one hand, evidence for positive effects is limited, and is restricted to learning of specific tasks taught. Improved orientation does not spill over into general behaviour, and effects may be short-lived. On the other, both forms of RO may be valuable as part of an overall approach to the care of dementing people.

Reminiscence is also used, and formalised by some into reminiscence therapy where aids such as photographs or music are used to stimulate discussion of past events. Whether viewed as an enjoyable recreation or as a therapy, its value lies in reviving coherent memories of the past which reinforce a sense of identity, and in distinguishing past and present. Not all memories are positive, of course, and reminiscence requires sensitivity in dealing with emotions that may surface. As with RO, reminiscence has been little studied, but the view of many professionals is that it can be rewarding for people with dementia (eg Jacques, 1988).

The role of informal carers in the lives of people with dementia will be considered in more detail in the next chapter. One strategy for supporting them, and so enabling them to care for someone, is to provide written information to them. Charities produce a great deal of practical guidance, and at least some of this seems to be helpful (Toner, 1987).

Valuing people

In the absence of clear evidence of the benefits of pharmaceuticals or of therapies, attention properly focuses on the more general qualities of the environments in which people with dementia live. Given their often heightened sensitivity, one strategy is therefore to provide care in a familiar environment: this underpins the argument that most people with dementia should remain in their own homes for as long as possible, and should certainly have to move home as seldom as possible. Even more important is the quality of the care provided. Where relatives and friends are involved in caring, there is anecdotal evidence that keeping peoples' minds and bodies as active as possible slows the rate of decline. Carers can, over long periods, help people retain awareness of the present and evoke memories of the past, encourage them to move around, and retain their dignity through good dressing and toileting.

The belief that the efforts of informal carers can enhance quality of life can also inform the approach taken by people providing services, both in the community and in institutions. One important formulation of such views is the concept of normalisation. Proposed originally for services for people with mental handicaps, it has since been adopted for other groups. At its simplest, normalisation is concerned with valuing people positively, and providing services according to norms used for the population in general. As a general approach, normalisation clearly has a great deal to commend it, not least because it draws attention to the fact that people with dementia are among the least valued in society, and the provision of services may reflect this low valuation.

The concept of normalisation has been developed by a number of authors, notably the King's Fund (1986), who have produced practical guidance on the delivery of services. It could be argued that normalisation runs into difficulties when examined closely, particularly with respect to the norms to be achieved. Should they be those that apply to everyone else, even if these are poor? Or is the objective the best possible service? These criticisms are important, but at present miss the point that the general objectives of normalisation are desirable and often not achieved.

In summary, it is clear that the attitudes and values of carers and service providers are important determinants of the experiences of people with dementia, just as those of our friends and colleagues affect us. Within a positive overall approach, specific techniques such as reminiscence may be valuable.

5 THE ORGANISATION OF SERVICES

There are wide variations between countries in the organisation and delivery of services to elderly people. For example, some have integrated health and social care at local authority level; and countries such as the Netherlands and Denmark view institutional care as a positive option for some people, in contrast to others such as Italy and Spain which strongly favour community-based care (Defever, 1991). All, though, see community-based living as the preferred option for most elderly people. And most already have or are moving towards a mixed economy of care, with combinations of public, private and voluntary provision of services. There is little evidence available about the options available to people with dementia in many countries, but in general it seems that most live in the community, and also comprise a significant proportion of those living in institutions.

This chapter discusses the services available to people who have dementia and their carers in the UK, where the stated policies of successive governments have favoured community-based care, but there remains a significant supply of institutional accommodation. In the UK and elsewhere the crucial role of informal carers is increasingly recognised, and services being designed to support them in their caring role. The more general, and fundamental, policy changes which will influence service delivery in years to come are discussed in Chapter 7.

Carers

The term carer is a broad one. Many people with dementia are cared for by relatives: in practice this usually means women, either wives, sisters or daughters (Finch and Groves, 1980). As life expectancy grows, there are more cases of elderly people whose children have dementia: it is quite possible for an 85 or 90 year old person to have a son or daughter who has dementia. People may live in their own homes, move into the relative's home, or live nearby. In some cases people are cared for by friends or more distant relatives: often this involves the carer and cared for living in their own homes, with carers making frequent visits.

Following a review of carers for all kinds of people with illness or disability, the Social Services Committee (1990) concluded that:

'For too long carers have been the unrecognised partners in our welfare system. Their services have been taken for granted. They have been regarded as a resource, but not as people with their own needs. With the greater dependence to be placed by Government upon care in the community it is time to bring the carers into the mainstream ... and give them the recognition which they deserve. That recognition will inevitably cost money, but it is long overdue'.

Indeed, the recognition of the importance of informal care probably stems from increasing awareness of its major contribution to the economy, and in particular the costs of providing other forms of care when it is not available. This is reflected in a growing research literature (eg. Glendinning, 1992).

Informal carers play a vital role in the lives of people with dementia, and in almost all cases want to do so, even though the mental and physical burden can be considerable and they are themselves usually elderly. Where they are close relatives, they may see their role as a simple extension of their relationship to the demented person. Many services seek not only to care directly for individuals, but also to care for the carers and so relieve the burden on them. This is consistent with UK government policies geared to maintaining people in their own homes. But by no means all elderly people have someone who can care for them: about one in three people over 75 years of age have no close relative; and almost half live on their own. Figures for people who have dementia are broadly in line, with one study finding that some three out of four lived with others or had a helpful relative nearby (Levin et al, 1983): so one in four did not. And even where there is a carer, it is often the case that the person cares alone, since there are no other relatives. So caring often falls on individuals, who do not have their own informal support network.

The challenge of dementia

The major signs and symptoms of dementia were described earlier. From the point of view of those caring for people with dementia, there are a number of problems that have to be coped with. Levin et al (1983) found that carers faced problems in four main areas:

- **Practical** – giving the elderly person regular help with household and personal care, for example, getting their relatives up, washed and dressed, toileting them, making sure they ate, putting them to bed.
- **Behaviour of the elderly person** – for example, incontinence, repetitive questions, aggression, wandering, unsafe acts, night disturbance.
- **Inter-personal** – for example, sadness at the change in their relatives, losing their tempers with them and tension in their households.
- **Social** – for example, restrictions on getting out, seeing family and friends, having a holiday, going out to work.

This categorisation was confirmed in a more recent study (O'Connor et al, 1990). The list emphasises that dementia poses problems which are at least as much social as medical. The relentless nature of caregiving, where timescales are measured in years and there is little respite, means that formal support could help with practical tasks, advice on behavioural problems and providing

periods of respite from caring.

As Twigg et al (1990) point out, there is uncertainty about the role of carers in relation to some services: sometimes it appears that services help carers to support people in ways that take account of carer's needs, but at other times there must be concern that carers are simply being exploited. Twigg et al do, though, point to services which are wholly or partially focused on carers. These include:

- help with personal and domestic care (although households where there is a carer tend to be selected against for social services);
- medical services, particularly district nursing (though help with personal care tasks is typically available only intermittently);
- respite care in hospitals, residential homes or day centres;
- sitting services, where a helper substitutes for the carer. Most schemes are organised by the voluntary sector, and tend to be day rather than night services;
- carer support groups of various kinds including self-help groups or groups organised by professionals.

These services have seldom been subjected to rigorous evaluation in terms of their impact on carers, although such evidence as is available suggests that each is effective, or could be effective if appropriately organised. And in the single most comprehensive study of carers, Levin et al (1983) found that the home help and respite care services were particularly highly valued.

There have been several attempts to enhance carers' skills in coping, using techniques such as meditation, counselling and training in stress management (eg. Levine et al, 1983; Brodaty and Gresham, 1989). Results suggest that such interventions can be successful in reducing the psychological burden on carers, although in most studies outcomes for carers and cared for were not rigorously evaluated. There is no evidence that this kind of support can or should substitute for practical forms of support from outside: rather, they can be a useful adjunct to them.

Health services

By their nature, health services tend to be provided for people with dementia rather than their informal carers. These are not provided in isolation, but as part of those for the generality of people who are elderly or have mental health problems. In most cases the first point of contact with health services is the general practitioner (GP).

A study of seven practices in Cambridge (O'Connor et al, 1988) asked GPs to rate all of their patients as definitely not demented, possibly demented or definitely demented. Their ratings were compared with the results of independent assessments. The GPs correctly identified 58 per cent of all cases and 65 per cent of people with moderate or severe dementia. 22 per cent of patients who were

not demented, but suffering from functional psychiatric disorders (notably depression) were incorrectly rated as possibly or definitely demented. Similar results were found by Iliffe et al (1991), and Macdonald (1986) also found that GPs underestimated the numbers of people with depression in their practices. This suggests that GPs miss many dementing people (thus reducing the probability that they receive medical or other services appropriate to their needs), and have difficulty in distinguishing between organic and functional problems.

In the O'Connor et al study community nurses were also asked to rate their (smaller number of) patients. They correctly identified 86 per cent of all cases and 96 per cent of people with moderate or severe dementia. They did, though, misclassify more patients as demented who had a functional psychiatric problem than did GPs. O'Connor and colleagues point out that community nurses may have an important part to play in identifying cases, alerting GPs and supporting families.

If people continue to live at home they may be referred on to one or more other services. One study found that GPs referred almost half of patients identified as confused to district nurses, and a third each to psychiatrists and social workers (Levin et al, 1989). The study also found that many GPs 'miss' dementia, and that where referrals do occur they tend to be on medical rather than social grounds. Within the NHS, referrals can be to:

- district nurses, who can provide a range of practical services. This typically includes bathing (though this is less common than it once was), medical procedures such as changing dressings and giving advice to carers. In some areas they provide 'twilight nursing' services for people with intensive care needs. Nursing auxiliaries may offer similar support;
- psychiatrists, who in many areas are now based in community units and are increasingly interested in social as well as narrower health issues;
- consultants in the care of the elderly, who are generally based in hospitals;
- community psychiatric nurses, who are trained in dealing with mental health problems and so are in a position to advise carers;
- to therapists, chiropodists or other professional for other health problems.

Each of these groups can help people with dementia in practical ways, or in the case of consultants arrange for support to be provided. (Indeed, consultants are often involved mainly at times of crisis). By and large, however, the problem is not the kind of support that is received, but rather that there is not enough of it. This is most obviously the case for district nurses (Sinclair and Williams, 1990),

who may visit only weekly or fortnightly: the kind of practical assistance they provide would be more effective if available more often. People with dementia are typically in contact with services, but do not receive large enough 'packages' of care.

People may also need to enter hospital for treatment, which may or may not be related to their dementia. Whatever the reason for admission, it seems that entering hospital can act as a one-way door for people with dementia. Even though someone may have been coping at home before admission, hospital doctors may judge that discharge back home is too risky for them: the consequence is that people may be admitted instead to residential care or to a long-stay hospital bed. In contrast, rationing of long-stay beds has, anecdotally at least, had a knock-back effect on acute hospital admissions. Some consultants may be reluctant to admit people in case they can not be discharged and block a bed: and so even though they would be admitted if not confused, they may have to remain at home.

The number of available long-stay hospital beds has been declining, but they are still the final destination for many people with dementia. Rationing of the remaining beds has been effected in many places through policies that only 'acutely ill' people should be admitted. In this context a stay in hospital may be measured in weeks and months, but in many cases the intention is that people be discharged back into the community.

As time goes on, it seems that admission of people to long-term hospital care will become less frequent. Given the fact that such care has attracted widespread criticism, and poor conditions have provided an important spur to community care policies, this should not be a cause for lament. But it raises the question of where people with major health care needs will now go, if domiciliary care is not deemed a feasible option.

In the meantime, the contingent nature of the pathways via which people enter institutional care emphasises the uncertainty of the process, and the fact that people may well not end up in environments which suit their needs. It may also be a matter of chance whether someone sees a psychiatrist or a consultant in the care of the elderly – although the relevant Royal Colleges have developed ground rules to guide local practice and promote appropriate treatment and referral. (It is interesting to note that in the more 'competitive' environment in the US and Canada, psychiatrists, consultants in the care of the elderly and neurologists all actively seek out people with dementia. But there seems to be no immediate prospect of the same occurring here).

Finally, it must be asked how far dementia is a medical condition, given the current lack of effective treatments. There seems to be a good case for community nursing input, but we have seen that many of the problems that can be addressed are essentially practical in

nature. It might be expected, therefore, that social services might play a greater role in service provision.

Social Services

The key individual in the delivery of social services is the social worker, who acts as co-ordinator of services. In general it is the social worker's decision that a service should be provided. In their own homes, people may be supported by:

- home helps and home carers, who may help with a range of domestic tasks;
- meals on wheels (these may also be provided by voluntary services);
- incontinence laundry service (this may be provided by health authorities in some areas).

Outside the home, there is:

- day care, which may be provided in a day centre, a residential care home or by a voluntary organisation (eg. Age Concern);
- other forms of respite care, where someone stays in a local authority residential care home (or in hospital), often for a fortnight at a time.

Domiciliary services are valued by those who receive them, but as with health services there are not enough available. Some services are available in most areas but effectively rationed, for example home help time. Other services, notably incontinence laundry, are not available in all areas. Day care is also valued, but there is controversy about the value of other forms of respite care, with some questioning its value (Rai et al, 1986; Melzer, 1990) and others supporting it (Pearson, 1988; Selley and Campbell, 1989). In addition to the listed services, additional support is available in some areas through sitters (who are often retired home helps); and social workers may have the option of purchasing private home care services.

As one might expect for a disease whose presentation varies so greatly, the patterns of service delivery also vary. This variation is due not only to need, but also to:

- local availability of services, and the attitudes and behaviour of those providing them;
- flexibility, which is the exception rather than the rule, so that services are unable to respond to immediate, unplanned needs;
- awareness of services. Carers seem often to be unaware that respite care and other services are available.

This means that peoples' experiences of services will vary depending on where they live. For the UK as a whole, the task now is to reduce the variation in standards, through systematic improvement in the level and organisation of services.

The overall picture is a patchwork of health and social support services, which are appreciated but not available in sufficient

quantities. It is very often the case that confused people are in contact with at least one service (Levin et al, 1983), but that those who most need services do not receive them. Dementia is thus a condition to which the inverse care law often applies (Tudor Hart, 1971). That is, the quantity and quality of care received is inversely proportional to need. Resources are often shifted towards people with relatively minor problems at the expense of those in greatest need.

Statutory services are enhanced in some areas by the voluntary sector: care attendants and sitting schemes are typically available through voluntary organisations. Indeed, it is the voluntary sector that has provided some of the most innovative support schemes.

Collaboration and Innovation

One of the obstacles to the delivery of appropriate services is the historical division between health and social services. There have been many exhortations by governments to both sides to collaborate, but apparently little heed has been taken in many places (Parker, 1990). To set against this, though, there are now many local examples of collaboration based on multi-disciplinary teams. Such teams take different forms in different places, but for the purposes of illustration the Community Team for Mental Health in the Elderly in Lewisham in south London comprises:

- social worker;
- occupational therapist;
- community psychiatric nurse;
- community-based psychiatrist;
- psychologist.

People may be referred to the service, often by GPs, or it may be contacted directly by relatives or friends. Each member of the team undertakes assessment and may co-ordinate care; and there is open referral within the team if necessary. The attraction of such teams for people with dementia and carers is clear enough: they enhance the probability of coming into contact with services they need, and of those services being properly co-ordinated.

Elsewhere, there are schemes which are GP-based (eg. in Bradford), and which formally involve voluntary organisations (Alzheimers Disease Society in Cleveland).

The White Paper, 'Caring for People' endorses a different approach to the organisation of services, based on the Kent Community Care Project (Challis and Davies, 1986) and since taken up elsewhere. This is care management, where an individual is nominated as the principal support worker, holds a budget and allocates it on behalf of those in his or her care. The nominated person may be anyone from health or social services. Another characteristic of the Kent model is the home care assistant, someone in the local community who is paid

to undertake any of a range of tasks. They can be effective in supporting many elderly people. The endorsement of the approach suggests that it is the model of choice for the 1990's.

An outstanding problem often left even by the best of these services is practical support in the evenings, at night and at weekends. That is, it could be said that many people already have care managers or are in contact with multi-disciplinary teams, but do not receive the quantity of support they need. The nature of the support required is straightforward, consisting for example of sitters who support carers by giving them 'time off' during the day or at night, or intensive practical support when a problem arises. Such support does exist in some places, where people from any sector may have initiated it, but it remains very much the exception rather than the rule.

Residential and Nursing Homes

People who have dementia will always require alternatives to living in their own homes: some really can not be supported properly at home, and carers may themselves become ill or die. One option already noted is long-stay hospital care. The NHS has also experimented with nursing home care (Donaldson and Bond, 1991), which is intended for people who require a significant amount of health care: such homes remain few in number. The bulk of nursing homes are in the private sector, where provision grew enormously in the 1980's fuelled by social security subsidies. In fact the private sector offers a range of accommodation, from residential (primarily non-health) to nursing homes. Some people who live in these homes are demented, but usually because they have become so after admission (admission itself does not affect the onset of dementia). And some homes have clauses in contracts which exclude people with dementia. It is rare for people who are already dementing to be admitted, and the numbers in private homes are relatively small.

Accordingly, the major institutional alternative to hospital is local authority residential care. Originally intended for use by people with few health care needs, these have come in recent years to be filled with people with a range of chronic illnesses (Gosney et al, 1991). As with private homes, admission policies often specifically exclude people with dementia, but residents may become demented once admitted. Yet local authorities have increasingly been under pressure to find places, with increasing numbers of people with dementia on the one hand and an effective freeze on building new homes on the other. Many have responded by designating particular homes or parts of homes for people with dementia.

The shortcomings of residential care have been comprehensively discussed elsewhere (eg. Booth, 1985; Peace et al, 1982): they include lack of attention to people's emotional needs evidenced through loss

of privacy and dignity, loss of self-determination, and so on. Others have argued that such analyses overstate the problem (Elkan and Kelly, 1990), but the fact remains that for many people residential care is a poor substitute for life at home. Consumer evidence for this view comes both from people in residential care (Peace et al, 1982) and people still living in their own homes (Salvage et al, 1989).

As with domiciliary services, there have been a number of innovative residential schemes for people with dementia, typically motivated by the desire to overcome perceived problems with hospital and residential care (Norman, 1987). There are examples of buildings designed for people with severe dementia, who have their own rooms with en suite washing facilities; people are encouraged to perform as many normal daily activities for themselves as they can. There are also a number of very sheltered housing schemes, sometimes described as 'Part two-and-a-half'. These are similar to sheltered housing, but with more intensive services available. Tinker (1991) found that they are highly valued by some groups of people, for whom they can be an attractive alternative to living at home.

These innovative schemes increase the options available even for some severely demented people. Some have developed through the work of single authorities, but others depend on novel financing arrangements, such as a building being owned by one body (say a Housing Association) and run by another (a health authority or social services department). As the number of different schemes grows, and traditional provision is under pressure, dementia is fast becoming a housing issue. It is simply unclear how local authority housing departments - and others - can or will respond to the challenge of housing people with dementia.

AIDS Dementia Complex

All services for people with dementia are currently designed for older adults. Given the particular nature of AIDS and HIV infections, they are not appropriate for people with AIDS Dementia Complex (ADC). Even if only one in ten people with AIDS or HIV has ADC, then there will be important service consequences. To date, AIDS/HIV services cope poorly with ADC. The London Lighthouse offers two or three weeks respite care to some people, but this is exceptional; elsewhere, there is little practical help available. The provision of adequate services to people with ADC is, it appears, a task for the future.

Questions of risk and uncertainty

One of the themes informing the preceding discussion is the perception of risk and uncertainty associated with dementia. For example, innovative projects may seek to maintain people at home in spite of the possibility of 'things' going wrong, or seek to maximise

their quality of life within institutions by doing things others would regard as too risky. The decision is a responsible and calculated one, but emphasises that many professionals make risk estimates in arriving at decisions. Indeed, a major question concerns who takes decisions: the dementing person, carer or professional.

Two related but distinct decisions are of interest particular here. The first concerns people putting themselves 'at risk' of injury through their own actions, either at home or in a more institutional setting. There is very little quantitative evidence of professionals' estimates of risk, but qualitative evidence suggests that:

- people who have dementia and are living at home are deemed to be at risk of such things as leaving gas cookers on, and failing to look after themselves by eating or washing properly;
- staff in more institutional settings are risk averse, and so do not allow people to carry out 'risky' tasks such as preparing simple meals.

A distinguishing feature of some innovative projects is that they set out to encourage activities that others regard as risky. Hence some community professionals support demented people living by themselves, and institutions such as the Domuses encourage the performance of simple self-care tasks that are not countenanced elsewhere. What the consequences are of such risk taking or aversion is not known. Indeed, the lack of knowledge about the consequences of different types and levels of support suggests that risk estimates may be driven in part by uncertainty about outcomes. It would be interesting to know the actual risks of problems occurring, as compared with the risks faced by elderly people in general.

This raises the issue of rights to services. In recent years the notion that people with dementia and their carers, along with other vulnerable groups have rights to services has gained ground, notably among some psychiatrists and social services professionals. This can be viewed as a response to perceptions of poor services in the past, and as a move to guarantee adequate services in an environment where there are ever increasing pressures on resources (see Figure 5.1). This could be interpreted as an attempt to transfer decision-making back from professionals to individuals and their carers, although some would question how far this has actually succeeded.

Dementia poses the further problem of the need for advocacy for people who can not easily articulate their own needs. It is not difficult to imagine that there may be conflicts in ensuring the rights of both individuals and their carers. This issue is important and complex, and the reader is referred to Dworkin (1986) and Buchanan and Brock (1986) for detailed discussion.

The second decision concerns admission to institutional care.

Figure 5.1 Kent Social Services Department: extract from 'A guide to the good care of elderly people living at home'

This guide sets out the standards for care which Kent County Council expects to be maintained by the providers of services for elderly people living at home. It is intended to serve as a statement of those standards for all who are involved in caring, including elderly people themselves, their family and friends.

The service principles are as follows:

- To regard elderly people as individuals, tailoring the service to their needs. The purpose of providing particular services to elderly people should be clearly stated, regularly reviewed, and should be developed in co-operation with elderly people and their carers, wherever possible.
- To see, wherever possible, to enable people to live in their own homes, if that is their wish, or failing that, to provide as homely an alternative as possible close to their home area. This means that services should be locally based and related closely to the cultural norms of individual communities.
- To ensure that elderly people can live in settings which have the minimum of restrictions on their movement and activities. This implies accepting a degree of risk sometimes over their physical safety in order to ensure their general wellbeing.
- To ensure that all services adapt to the changing needs and wishes of elderly people and their carers.
- To ensure that all agencies involved in the care of elderly people work together to meet statutory requirements and the needs of the county's elderly population, in the most cost effective way. This requires flexibility of attitude and an open-minded approach to service provision, with the best interests of elderly people being foremost.

It is important when organising the providing services to operate within a framework of elderly people's rights as follows:

- the right to exercise religious and political expression without fear or hindrance;
 - the right to the protection of themselves and their property through the law;
 - the right of freedom of speech and self-expression;
 - the right of equal access to the full range of community facilities for leisure, education, housing and transport;
 - the right to exercise some reasonable control over services that may affect themselves or their community;
 - the right to live out their chosen lifestyle. This right should only be removed by the use of legal powers under the most exceptional circumstances;
 - the right of protection from serious harm and exploitation;
 - the right to full information about the range of services available from all agencies;
 - the right to personal privacy in residential care;
 - the right to have their social, emotional, religious, dietary, cultural and political needs accepted and respected wherever they may live, including residential care;
 - the right to exercise control and choice in a residential setting, even if this means allowing risks to be taken;
 - the right to make an active contribution to community life even if living in residential care;
 - the right of access to an advocate who is able to represent them on an impartial basis.
-

Community care policies assume that in general people prefer to remain in their own homes rather than enter an institution – or at least enjoy the comforts of home. This has been shown to be correct for elderly people in general (Sinclair, 1990), and is consistent with the preferences of carers for those they care for (Levin et al, 1983). There are difficulties in asking people with dementia about their preferences, but one study suggests that they too prefer to remain at home (National Consumer Council, 1990). Nevertheless, many people are admitted to residential care, and have:

- high cognitive impairment;
- significant behavioural or interpersonal problems;
- no informal carer;
- carers who were in favour of residential care (typically because they felt that they could not go on themselves, rather than seeing it as a positive choice);
- carers in poor physical health, particularly with heart conditions;
- packages of services which did not include respite care for carers;

(Levin et al, 1983; Sinclair et al, 1988; Sinclair, 1988). Identification of these factors facilitates prediction of the risk of admission. In many cases, there is a crisis, a breakdown in support, with the carer falling ill (perhaps unrelated to the stresses of caring) or needed services not being provided.

In the US, the risk of admission to long-term nursing home care has been investigated (Morris 1988; Shapiro and Tate, 1988; Weissert and Cready, 1989). These studies found similar risk factors to the UK studies, and in addition identified poverty, bed availability and being white as determinants of institutional care. These three factors may to some extent reflect the different financial environment in the US (poverty may lead to qualification for Medicare or Medicaid funding), but may also be suggestive of factors important in some areas in the UK. Williams (1990) notes the particular problems faced by elderly people from ethnic minorities in gaining access to appropriate services in the UK, although it is not known if this extends to institutional care.

Risk factors for admission to acute hospitals are not so easily identified, not least because admission may not be directly related to dementia, but to another acute or chronic condition. And factors which influence admission to long-term hospital care now that places are declining are little researched. Data in these areas would be useful. Both for residential and hospital care, it is clear that there are often considerable uncertainties surrounding decisions, and immediate crises often overshadowing longer term considerations. As noted earlier, it seems that people may be propelled down new service pathways, with the momentum of 'the system' taking over. The context of the decision affects the outcome. The decision to enter an

institution may also reflect uncertainty about the nature and appropriateness of the available options. It may be that GPs, social workers and others over- or underestimate the extent to which people can cope at home, or are unaware of the long-term consequences for someone entering institutional care.

The nature of the influence of professionals on the decision to enter an institution remains unclear. It is known that there are significant variations in the way that doctors practice and in their outcomes for a range of acute medical conditions (Wennberg, 1987), and also in decisions about referrals and admission to hospitals (Coulter et al, 1990) so that it would not be surprising if those involved in decisions about people with dementia also varied. In fact, there is no evidence of the influence of professionals' value judgements on the fate of people with dementia: it would be interesting to know to what extent their attitudes, training or other factors influenced their advice.

For purposes of discussion one can identify two broad groups, risk takers and risk avoiders, with one important illustration of the difference between them being their attitudes towards institutionalisation. Risk takers typically seek to maintain dementing people in their own homes as long as possible, even if they exhibit risk factors for admission to an institution such as living on their own. Risk avoiders tend to recommend admission to institutional care earlier, on the grounds that people are safer and better cared for there. These two positions might be held for any number of reasons, but the important point is that both groups see themselves as acting responsibly and yet practice in ways which have different consequences for people who have dementia.

An important task for professionals is to maximise the numbers of people appropriately admitted, and minimise the numbers of people unnecessarily admitted. For some people it is possible to plan admission, undertake health and social worker assessments, and time admission: clear guidelines on assessment are available (Neill, 1989). But often, the shortage of places locally means that people can not be admitted when professionals judge it appropriate. In this circumstance, there is little alternative but to wait until a crisis – perhaps the carer falling ill – occurs. People may then be admitted to hospital or residential care as emergencies. Thus breakdown of community-based services precipitates admission.

There have been few studies of inappropriate moves to institutional care. There are reports of high levels of cognitive and physical impairment, which might suggest that they are rare. But Sinclair et al (1986) found that over half of elderly people may be inappropriately admitted, and admission could have been prevented by action either at the point of application or at an earlier point in time. And Butler et al (1983) concluded that a significant minority of people in their study

of sheltered housing would have been just as happy in well designed ordinary housing.

Researchers in the United States have been developing decision analytic models of the decision to enter an institution. This approach is attractive because it offers the possibility of combining data on patterns of admission with actual outcomes (eg. life expectancy or quality of life) or with peoples' preferences for each option. Greene (1987) advocates the construction of simple decision trees for investigation of the effectiveness of alternative options. Hopefully future research will provide us with the data to use such models.

6 QUESTIONS OF COST AND VALUE

That dementia has a major economic impact both on society as a whole and on individuals and their families would seem to be beyond dispute. But what are the scale and nature of this impact? What is the relationship between resources provided and effects on dementing people and their carers? Such questions are important to those people currently charged with allocating resources, and those lobbying for resources on behalf of people with dementia. They will also be crucial in the evaluation of any new treatment or of innovative ways of delivering services.

Impact on the national economy

The impact of dementia on society as a whole can in principle be deduced from the costs of the services that are provided, and the costs falling on people with dementia and their carers (see Figure 6.1). The costs over and above those delivered to the generality of elderly people represent the additional cost to society of dementia.

It was emphasised in Chapter 3 that care is needed in identifying relevant populations, so as to arrive at useful estimates of the prevalence of dementia. Inevitably, the prevalence estimates used have a direct effect on estimates of costs. In the US, for example, published studies relate only to Alzheimer's disease, and the estimates are very different, reflecting a number of different assumptions made in their calculation (Figure 6.2). In the UK, prevalence data has not been used to estimate costs, although the fact that the numbers of people with dementia are large is suggestive of the order of costs involved.

On the basis of the evidence presented in Chapter 5, two points can be made about any estimate that might be made. First, the typical underprovision of services means that any estimates made using current levels of resources will underestimate the potential resources needed, perhaps by a wide margin. Second, there may be significant differences between sectors in the resources potentially required for people with dementia. Much of the international debate has focused on health care costs, but UK studies point to the importance of personal and social services costs. Taken together, these points suggest a high degree of uncertainty about the potential impact of dementia on national economies.

Taking health care costs first, it is possible to imagine two broad scenarios of the future for health care of elderly people (Fries, 1989: see Figure 6.3). One involves extension of life expectancy and the provision of health services and treatments which alleviate symptoms. Since treatment does not affect the age of onset of the disease, the implication is that morbidity accumulates over a longer

Figure 6.1 Direct and indirect costs

One approach to estimating the economic impact of dementia is to calculate each of the direct and indirect costs of treatment and care.

Direct costs are those for which payment is made, either by individuals or by other parties on their behalf. These include:

- medical care, both in the community and in hospitals;
- social care, which may be provided by statutory or voluntary services;
- accommodation costs, whether at home or in institutional care;
- other costs, including travel.

Indirect costs are those for which no payment is made. These include:

- foregone earnings of individuals and their carers;
- other costs associated with disability and premature death of the individual, eg, activities foregone;
- the emotional stress on carers.

There are two methods which are commonly used to value indirect costs in monetary terms. One is the human capital approach, which focuses upon lifetime losses in earnings or productivity contingent upon the disease. This captures economic losses, but does not attempt to measure other types of loss. This may be of limited usefulness in mainly retired populations. The other approach is willingness-to-pay, where the indirect costs of a disease are the amounts of money people would be willing to pay to reduce the probability of death or disability from that disease. This method can in principle obtain broader valuations than the human capital approach, but is difficult to implement.

It is not always necessary to express costs in monetary terms. A third method may be particularly relevant to dementia, which might best be termed the 'willingness-to-participate' approach (Lubeck and Yelin, 1988). Rather than deriving monetary valuations, the method asks a battery of questions to elicit ratings (on a 1 to 5 scale) which value the importance of daily activities, and of foregoing those activities. The authors argue that they have developed a simple survey method which reliably captures changes in activities and the value individuals place on those activities.

The overriding point about indirect costs is that it is difficult to arrive at reliable estimates, perhaps particularly so for people with dementia. But such estimates are important, since for people with chronic diseases the impact of lost abilities may be greater than the costs due to direct expenditure on medical care.

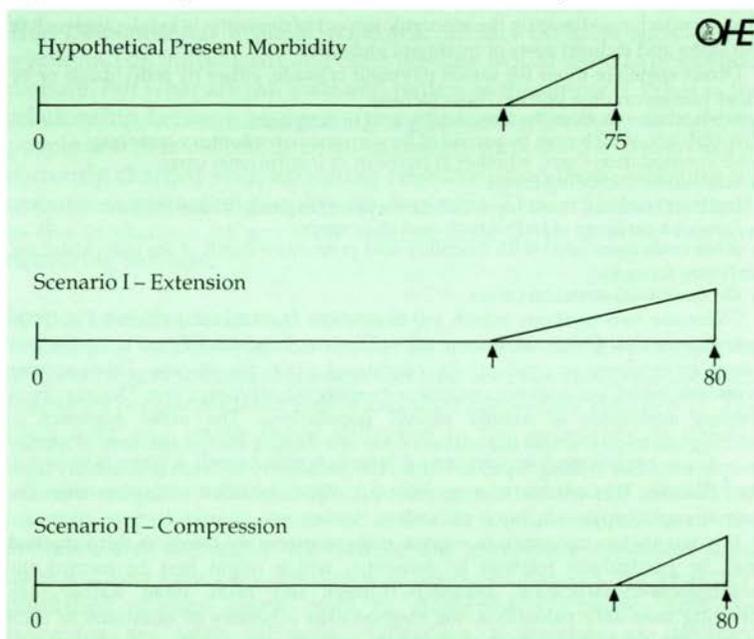
Figure 6.2 Studies of prevalence and costs of Alzheimer's disease in the USA

<i>Study</i>	<i>Prevalence (millions)</i>	<i>Total marginal cost⁽¹⁾ (\$ billions)</i>
Hay and Ernst (1987)	1.50	32
Huang, Cartwright and Hu (1988)	3.66	88

(1) Present value of total net costs of formal and informal care in 1985.

The Hay and Ernst estimate is for people first diagnosed as having Alzheimer's disease in 1983. Huang et al estimated the costs for all people in the USA with Alzheimer's disease in 1985. Neither study investigated what tasks informal carers actually performed, nor included informal care costs for people living in institutions.

Figure 6.3 Compression or extension of morbidity



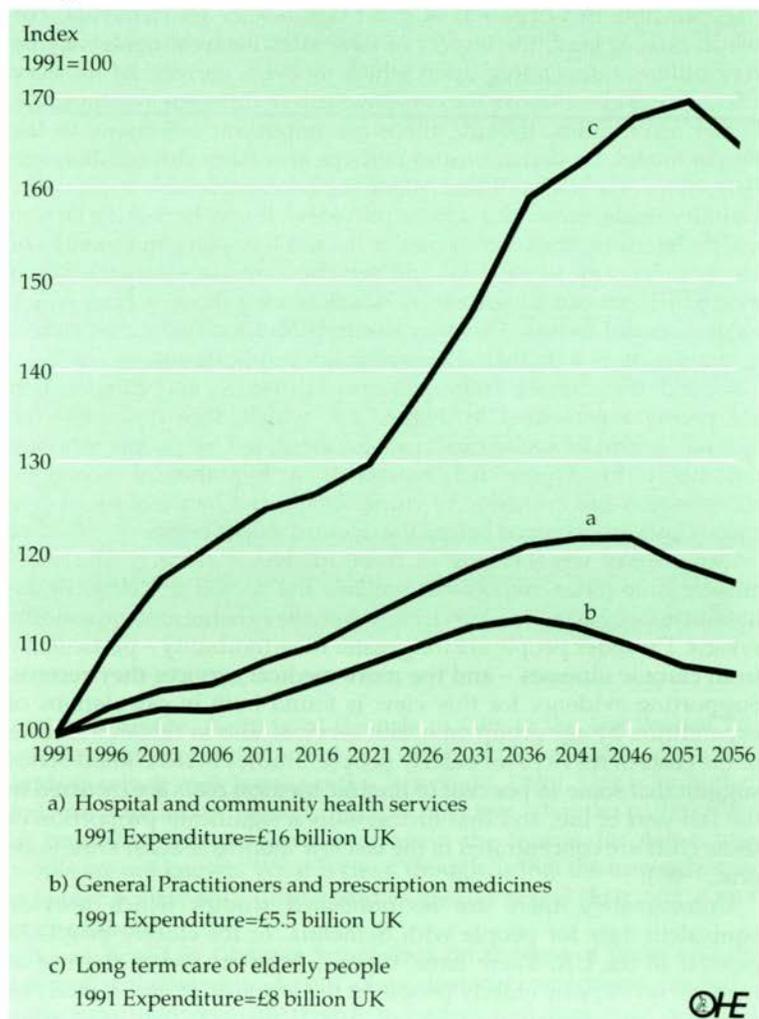
Source: Fries, 1989

period and the total costs may be greater than before. Life expectancy is increased at the cost of increased morbidity.

In the second scenario life expectancy again increases, but the onset of chronic illness is prevented or delayed, so that the period for which people have significant morbidity is shortened. If it is assumed that life expectancy is unaffected by whatever treatment is administered, then morbidity is 'compressed' into a shorter period. Fries posits an equivalent compression of costs, so that the economic consequences of the two models may be radically different.

For elderly people in general, it is a matter of debate as to which of these views most nearly approximates to reality, or whether reality lies somewhere in between. Policy makers in the UK (Figure 6.4) and elsewhere (Verbrugge, 1986) take the first view, and expect the demand for health services to increase over this decade and into the next century. Arguments for the second view are put forward by Fries (1989), and there does appear to be evidence to support him (eg. Johnson et al, 1990). If he is correct, then there should not be significant

Figure 6.4 Resources required to keep pace with demographic change in sex, 1991 = 100



future additional demands for health services compared to the present.

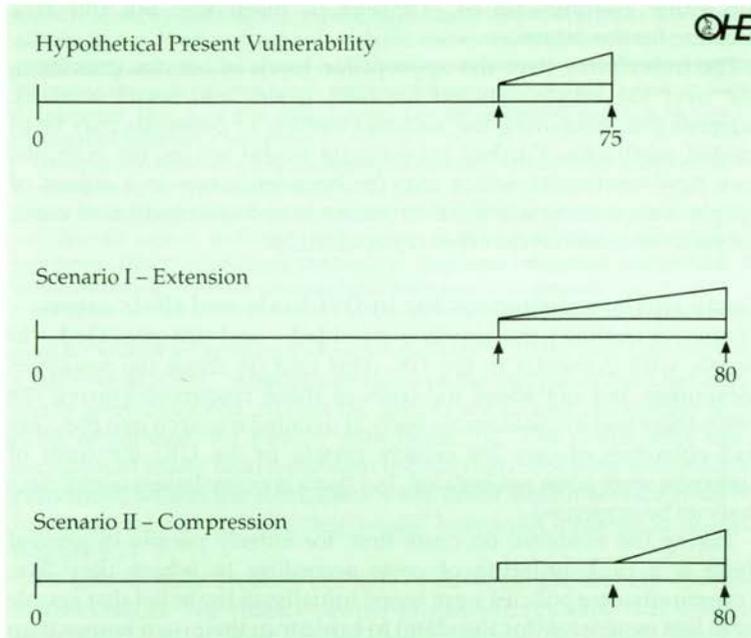
In principle this debate is of great significance for dementia. For health care, at least, the impact of new, effective treatments may be very different depending upon which model is correct. At the very least, it focuses minds on the consequences of different assumptions. To set against this, though, there are important objections to the simple model, for dementia and perhaps also other chronic diseases. First, dementia is a condition which incurs considerable *social* costs, for individuals, carers and service providers. It may be that the factors which determine the costs of care in the last few years and months of life are in large measure social, and that these are more important than morbidity. One can imagine scenarios mirroring those of Fries which focus on social factors. This may similarly imply economic extension or compression, with their different policy implications.

Second, the *economic* consequences of extension and compression are poorly represented by Figure 6.3, which does not show the 'normal' health or social care costs accumulated by people who are reasonably fit. Figure 6.5 represents a hypothetical economic compression and extension of vulnerability, and hence of social care costs. Costs are incurred before the upward slopes begin.

Can we say whether any of these models is correct? The short answer is no: Fries' hypothesis remains the subject of debate in the literature (see Haan et al, 1991). However, the existing evidence merits review. The older people are the greater their morbidity – particularly from chronic illnesses – and the more medical services they receive. Supporting evidence for this view is found both in calculations of expenditure by age group on health services, and in research studies of the costs of services for elderly people. Studies in the United States suggest that some 18 per cent of lifetime medical costs are incurred in the last year of life, and that furthermore a significant proportion of these costs are concentrated in the last few months (Fuchs, 1984; Roos et al, 1987).

Unfortunately, there are no published studies which provide equivalent data for people with dementia, or for elderly people in general in the UK. There have, though, been studies of the use of medical services by elderly people in the last year of life. A study of hospital care (Henderson et al, 1991) showed that the mean cumulative time they spent in hospital did not change appreciably between 1976 and 1985. (People who died at 85 years of age or over were less likely to be admitted than those aged 65-84 years, but the older group spent longer in hospital once admitted). The gain in life expectancy over the period was about one year from the age of 65: this gain was made without any substantial increase in time spent in hospital. Another study (Cartwright, 1991) confirms this general

Figure 6.5 **Compression or extension of vulnerability: economic consequences**



pattern of usage. A study of the role of GPs in the last year of life revealed that people had an average of around ten contacts, about two thirds of which were home visits (Cartwright, 1990). This is far higher than the population average, but it is not clear what the patterns are for immediately prior years, and again the figures for dementing people are not known. What is clear, though, is that the upward slope in Figure 6.3 are real: future studies should reveal their origin and angle of ascent.

It was noted in Chapter 3 that data on the age of onset and on survival with dementia do not allow clear-cut conclusions about the relationship between them. If it is correct that incidence peaks at around 75 years of age, then it may be that age of onset is more closely tied to chronological age than to age of death. But if incidence simply increases with age, then the relationship between onset and death may be closer. There is not currently enough data available to judge which of the scenarios described above is the more accurate for people with dementia, and so the questions of economic consequences for the UK as a whole, and for local service delivery, remain open. It would be

particularly interesting to know the financial consequences of differing community care policies (or degree of success with them) and either compression or extension of morbidity: but this is a question for the future.

The uncertainty over the appropriate levels of service provision, and over the future demand for both health and social services, suggests that estimating the 'national burden' of dementia may be of limited usefulness. Further, no estimate would tell us, for example, how new treatments which may be beneficial only to a subset of people with dementia will affect the scale and distribution of costs. For this, we must turn to other types of study.

Costs and consequences for individuals and their carers

Chapter 5 outlined the services provided - and not provided - to people with dementia in the UK. This told us about the resources committed, but not about the costs of those resources. During the 1980's there was a considerable body of detailed research into the costs and outcomes of care for elderly people in the UK: the costs of dementia were often not isolated, but there is nevertheless useful data that can be presented.

Taking the evidence on costs first, for elderly people in general there is a rank ordering of costs according to where they live. Community care policies were based initially on the belief that people were less expensive (for the state) to care for in their own homes than in any institutional setting, and there is evidence to support this view. One study found that hospital provision was most expensive, followed by residential care, with community-based care being least expensive (Wright et al, 1981). Generally, private residential care is less expensive than care in local authority homes (Judge and Sinclair, 1986). And an evaluation of very sheltered housing found that it was more expensive than typical community-based services (though also more highly valued), but less expensive than some innovative domiciliary schemes (Tinker, 1991). It should be stressed though that for each setting costs vary from place to place within the UK, so that (for example) the costs of home-based care can at times approach or exceed those of residential care. It is also unclear how structural changes in the provision of community services, and increased supply of private residential and nursing home places has affected the relative costs of each sector in recent years. And the basis for calculation of costs is different in different studies (Figure 6.6).

Second, evidence from the Kent and Darlington projects (described in Chapter 5) show that confused people are provided with more resources than elderly people in general, both because they receive higher levels of support in their own homes and because they are at

Figure 6.6 Which figures should we believe?

The studies reported here use different costing methods. Ideally studies should identify all direct and indirect costs falling on individuals. In practice it is often the case that some direct costs are not available, and estimation of indirect costs can be problematic, as noted in Figure 6.1. Within any one sector these difficulties may not be important, if it can be shown that any missing costs would not affect overall judgements: that is, if the *relative* costs can be estimated and can be used to distinguish between alternatives.

Comparison between sectors is more problematic. The facilities provided in, say, a private and a local authority residential home may be different, making it difficult to calculate costs on a common basis. It thus becomes necessary to attempt to calculate all inputs, including such factors as the capital and running costs of buildings. This requires large studies, but they have been done and provide the most convincing evidence on costs for elderly people in general.

greater risk of admission to residential care (Challis and Davies, 1986; Challis et al, 1991). Almost one third of the people in the Darlington study were confused, so that the results are at least suggestive of the costs of services for people with dementia. The community-based service had lower total costs than the alternative of long-stay hospital provision; within the total, there were lower health service costs but higher social service costs than would have been incurred in hospital (Figure 6.7).

Of course, costs are only one side of the equation, and effectiveness is also critical. For elderly people in general, it seems that schemes such as those in Kent and Darlington can be highly effective, particularly in the context of offering an alternative to residential care. However, dementia remains a challenge to care management, and Challis and Davies make it clear that much of the potential for improving the effectiveness of services in other locations has yet to be realised.

The findings of Levin et al (1989) may be particularly important here. They also pointed to the additional resources required by people with dementia, but suggested that relatively small 'packages' appropriately directed could be highly effective. These need not be focused on particular problems, but help by supporting the carer in caregiving. Care managers may be instrumental in organising such support, but they could in principle be provided within different organisational frameworks.

Third, since the thrust of government policy is that people should remain in their own homes as long as possible, and most people with dementia live at home, the costs of maintaining them there are of considerable interest. The Home Support Project (Askham and Thompson, 1990) suggested that specially designed support for dementing people at home can be cheaper than hospital care and (usually also) residential care. The Home Support Project appears to

**Figure 6.7 Costs of caring for confused elderly people:
Darlington study**

	<i>Project cases</i>		<i>Control cases</i>	
	<i>Over 6 months</i> £	<i>Per week alive</i> £	<i>Over 6 months</i> £	<i>Per week alive</i> £
Community Care Project	2850	143	–	–
Other SSD (revenue net cost)	30	1	115	4
Other NHS (5% capital allowance)				
1. DMH base	870	51	9838	398
2. Geriatric base	659	39	6205	251
Total agency costs				
1. DMH base	3750	195	9953	402
2. Geriatric base	3539	183	6320	255
Total social opportunity cost				
1. DMH base	4977	254	10493	424
2. Geriatric base	4766	242	6859	277

1. Long-stay hospital costs at Darlington Memorial Hospital (DMH) level.
2. Long-stay hospital costs at geriatric hospital level.

1986-87 prices

Source: Challis et al, 1991

be more cost-effective than residential or hospital care, but the figures provided only allow this to be a tentative conclusion. Additional evidence about innovative services comes from a study in Canada which suggests that schemes designed to support carers can be cost-effective (Drummond et al, 1991). Conversely, an innovative scheme for elderly mentally infirm people and their carers proved to be almost three times more costly than services which would otherwise be provided (Donaldson and Gregson, 1989; Donaldson et al, 1988), although it did result in avoidance of admission to institutional care.

An important theme emerging from these studies is that it is the psychic and physical burden of caring which often necessitate the more visible financial costs of respite care, and in some cases long-term institutional care. Given that these costs can be high, it is important to know what these costs are. Traditionally, governments have viewed informal care as a free good, a position which appears to be unaltered by the new community care proposals where support will be provided to unpaid carers, organised by care managers. Some commentators argue that informal care should be explicitly valued, and carers ensured a basic income (perhaps through income supplements) so that they have a measure of control over decisions

about what support they receive: they can be more active consumers (Jordan, 1990). The Social Services Committee (1990) recommended that the Government should set three long-term objectives to improve public support for carers. These were:

- improved income maintenance;
- improved opportunities to combine work with caring, and;
- improved availability of domestic and nursing services.

Whatever the merits of such arguments, they point to the fact that valuation has a political dimension. The growing concern reflected in the Social Services Committee's report has been reflected in the commissioning of research into the costs of informal care, for elderly and other people. Wright (1991) and Netten and Beecham (forthcoming) point to the real theoretical and practical problems in valuing the contribution of the informal sector. Nevertheless, data will become available which indicates costs associated with dementia. And Glendinning (1991) provides qualitative evidence on costs, as illustrated by these quotes:

'I had got down to washing on a Monday and a Thursday for the children...but now I wash bedding every day, and an extra load of clothing every two days.' (Ms Johnson, married woman, whose mother had dementia)

'I've never actually sat down and costed it. It's just Mum and I said I would take her.' (Ms Grey, married woman, whose mother had dementia)

A rather different approach, which seeks to value the contribution of carers, comes in a study of people with Alzheimer's disease in California (Rice et al, 1991). The study used what is often described as the 'insurance approach', which seeks to place a value on all inputs by carers. (This kind of study is sometimes used to estimate potential changes in the costs of insurance for people with dementia, eg. Manton and Tolley, 1991.) This is at variance with the other studies reported here, which focus on the additional costs of dementia, rather than the total costs of caring.

Two samples were used, one drawn from people living in the community and the other from people living in nursing homes. The study found that:

- the total financial costs were almost the same for the two groups, at around \$47000 per person (1990 price);
- the distribution of costs differed significantly between the two groups. For example, informal care comprising almost three quarters of the costs for people living in the community, compared to 12 per cent of costs for those in institutions (Figure 6.8);
- for both groups, around three fifths of the care costs were met by individuals and their families.

Figure 6.8 Total cost of care per person (\$US) with Alzheimer's disease by type of care and location of residence, 1990. Study undertaken in San Francisco Bay area.

Type of Care	Location of Residence			
	At home		Institutionalised	
	Amount	Per cent	Amount	Per cent
Formal Care				
Hospital care	1,646	3.5	496	1.0
Physician visits	460	1.0	632	1.0
Medicines	231	0.5	371	0.8
Nursing home care	62	0.1	38,980	81.9
Social services	9,580	20.4	35	0.1
Other	586	1.2	1,535	3.2
Sub-total	12,565	26.7	42,049	88.4
Informal Care				
Caregivers	34,517	73.3	4,478	9.4
Volunteers	-	-	1,064	2.2
Sub-total	34,517	73.3	5,542	11.6
TOTAL	47,083	100.0	47,591	100.0

Source: Rice et al, 1991

The effectiveness of the services provided - in terms of avoidance of institutionalisation, say - was not studied, so that the appropriateness or otherwise of the resources used is not known. Clearly, the figures can not be used to make inferences about the costs of care in the UK, but in spite of using different methods they do confirm the overall pattern of findings: total costs may not vary greatly between settings, but costs falling on different agencies may vary greatly depending on the setting.

Residential care

Chapter 5 emphasised the importance of the decision to enter an institution. There have been major shifts in provision of institutional places over the last decade, which presumably imply shifts for people who have dementia. The most dramatic of these occurred following decisions in the early 1980's to allow the use of social security Board and Lodging payments to subsidise private residential accommodation costs. This led to a massive increase in private residential care facilities. This has occurred along with reductions in the numbers of long-stay hospital beds, and a virtual freeze on the expansion of local authority residential places.

available on the relative costs of residential care for elderly people, both within and between sectors. They found that within-sector variations were large, but cited data which suggested that if one looked only at direct costs to residents then private homes were most expensive, followed by voluntary and then local authority homes. But they caution that cross-sector comparisons are based on fairly crude averages, and do not include factors such as facilities provided or the mix of residents (or indeed evidence of outcomes for residents). If one takes a broader view of costs, then the rank order is reversed. Once again, cost data for the subset of dementing people is not available, so that it is not possible to state the financial consequences of each residential care option for them. More recently, the costs of NHS nursing home care have been studied (Donaldson and Bond, 1991), with the results suggesting that they are comparable with hospital care. They appear to be more costly than private sector nursing homes, although the latter cater for a less disabled (less expensive) mix of residents.

Underprovision

In summary, there is far less evidence on costs and effectiveness of services for individuals with dementia than that for elderly people in general. Cost data are based on small samples, and deal mainly with innovative schemes rather than 'typical' services. Nevertheless, combined with the information on resources from Chapter 5 it is clear that people who are confused or demented and their carers are a relatively expensive group, many of whom require intensive support and often are not receiving the support they require. This obvious gap between need and provision will have to be quantified in order for the potential future impact of dementia on individuals and local services to be calculated.

In the future there is the probability raised by the NHS and Community Care Act that local authority residential homes will decline in numbers and more long-stay hospitals close, with places perhaps being displaced into the private or voluntary sectors, and even more people living in their own homes. It is too early to say with any certainty how these changes will affect the options available to people with dementia or the costs of those options: but these are important issues, to which we now turn.

7 PROSPECTS FOR THE 1990'S

Over the last few years there has been growing awareness of the social and economic impact of dementia, and perhaps particularly of Alzheimer's disease. The crucial contribution of informal carers is more widely recognised. But most government policies do not differentiate dementia from the experiences of older people. This chapter discusses some of the main policy issues influencing the experiences of people with dementia: some of these are shared with other groups, and others are particular to people with dementia. Discussion of these experiences generally focuses on the organisation of services. It is argued here that the arrival of new pharmaceuticals may also exert considerable influence on the pattern of services for people with dementia and their carers.

Government policies in the 1980's

By implication, government policies throughout the 1980's for people who were confused and demented included:

1. their status as a 'priority' group for receipt of health and social services;
2. the general assumption that they should remain in their own homes for as long as possible, where they would be looked after by friends and relatives;
3. the costs associated with disability were increasingly borne by individuals;
4. reduction of the numbers of long-stay hospital beds, and an effective freeze on places in local authority run residential homes;
5. a publicly subsidised increase in private residential care.

The broad desire for 'care in the community' embodied in these and other policies came under increasing strain (Parker, 1990). One problem was that the numbers of people available to do the caring was not sufficient to the task. Another was that support services were often inadequate. As noted in Chapter 5, Levin et al (1989) found that the amount of formal help available was often inversely proportional to the severity of need. Other problems included the increase in private residential care, which tended to undermine the thrust of stated policies, and continuing difficulties in achieving the necessary coordination between services.

The gulf between the stated intentions and the reality of community care was highlighted in a number of reports, notably in reports by the Audit Commission (1985; 1986). This set the government on the path to reform, through Sir Roy Griffiths' report on community care (1988) and the acceptance and inclusion of many (but not all) of its recommendations in the NHS and Community Care Act 1990.

Other developed countries face broadly similar problems in

designing and implementing social policies for elderly people, and hence those with dementia. Comparison across national borders is difficult, not least because there are major structural differences in the organisation of services. But many countries have (Illsley and Jamieson, 1990; Kelman, 1990):

- developed community-based care policies, and experienced difficulties in implementing and maintaining them;
- difficulties in closing the gap between need and provision of services;
- in particular, found it difficult to co-ordinate services provided by different agencies.

Many countries in western Europe are implementing reforms of their health and social services, in many cases in an attempt to contain costs and promote more rational allocation of resources. On the face of it, there seems likely to be convergence in the organisation of service delivery, and so lessons from any one country will increasingly have relevance to others.

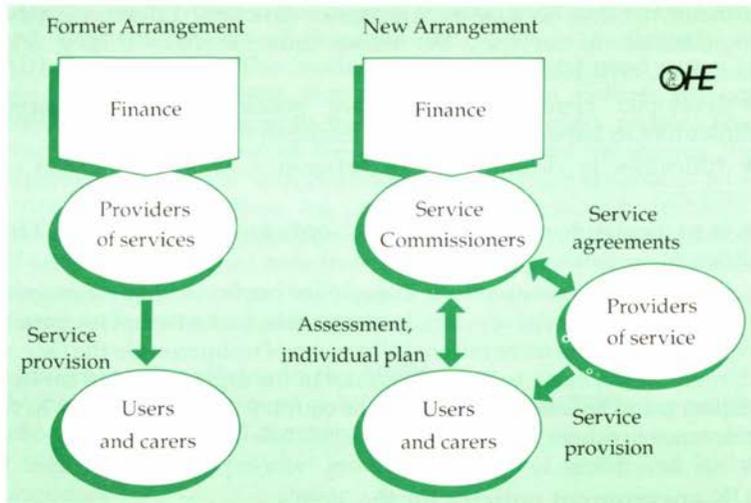
UK government policies for the 1990's

It is a fact that many professionals show little interest in people with dementia: the situation is improving, but dementia remains a Cinderella condition. As a result it may only be through careful design of policies, with appropriate incentives built in, that positive change is effected in the short and medium terms. The new policies embodied in the NHS and Community Care Act seek to make explicit the incentives to improve the efficiency and effectiveness of health and social services. They address some of the reported problems, principally through reform of financing arrangements and separation of the purchase and provision of services, whereby available resources will – it is hoped – be better targeted.

The new community care policies concern themselves principally with general mechanisms for financing and delivery of care, rather than with details for particular groups. The key structural change is the separation of the purchase and provision of services (Figure 7.1). Within the NHS, District Health Authorities (DHAs) are now purchasers (and hence co-ordinators) of services, and one of their principal tasks is to assess the health need of their local populations (Figure 7.2). Increasing numbers of GP practices hold their own budgets and so have a dual role, as both purchasers and providers of services. Services are provided principally by GPs, hospitals and community health services. They may also be provided by the private or voluntary sectors.

Local authorities are currently implementing arrangements similar to those in the NHS, where local authorities will purchase non-health services, and others provide them. Again, these other providers

Figure 7.1 The changing funding arrangements



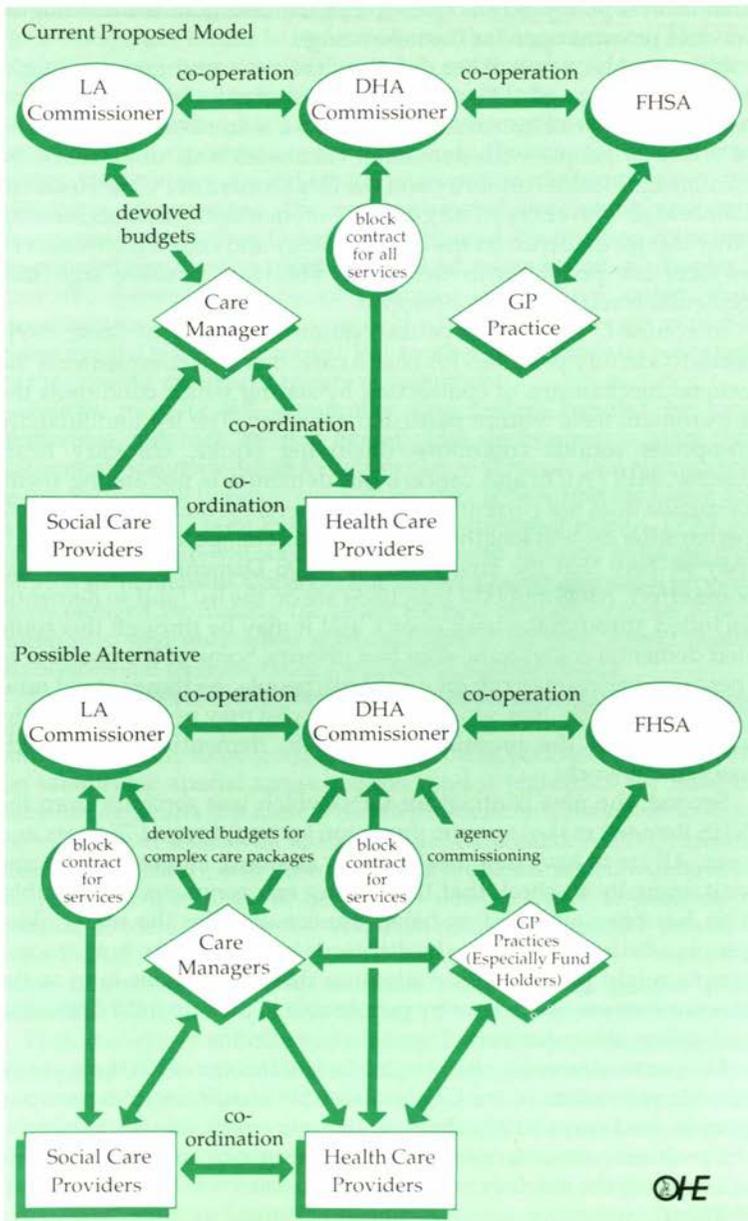
Source: Audit Commission, 1992

might include private and voluntary organisations as well as social services departments. Local authorities may continue to provide some services directly, but the government has made it clear that this will not be encouraged. In allocating resources local authorities are charged with taking into account not only needs but also preferences of those who receive services.

An important potential weakness of the new arrangements is that providers will practice adverse selection: that is, they may select only those patients or clients who are 'desirable' on grounds of cost or convenience. Since dementia can be a high cost condition and many doctors and social workers remain uninterested in it, people with dementia may be selected against. This is not to say that services will necessarily deteriorate – they were poor enough before the Review – but that existing weaknesses may not be rectified.

In general, there does not seem to be anything inherent in the purchaser-provider split or many of the other new arrangements which will change the services that people with dementia receive. Some argue that services will become fragmented, but the Department of Health is at least promoting better co-ordination between providers, particularly between community-based and hospital care. Services for people with dementia have always been

Figure 7.2 Integrated commissioning through care management



Source: Audit Commission, 1992

poorly co-ordinated, with any exceptions due to local initiative rather than central policy. So the question of the effects of contracting on services remains open for the time being.

Nevertheless, some of the details of the new arrangements might encourage change. First, the Department of Health has commissioned work on assessing needs for a number of groups, one of which is people with dementia. (The work was undertaken by Cambridge Health Authority and the Department of Public Health at Cambridge University.) The guidance on dementia assesses, among other things, evidence on the epidemiology and cost-effectiveness of services for people with dementia. This is a positive sign that dementia is recognised as a priority.

In contrast, The Health of the Nation (Secretary of State, 1991) seeks to identify priorities for health care: that is, it complements the general mechanisms of contracting by stating which conditions the government feels require particular attention. The list undoubtedly comprises serious conditions (including stroke, coronary heart disease, HIV/AIDS and cancer), but dementia is not among them. Dementia does not currently fulfil the criteria for inclusion in this list: perhaps the list will lengthen or the criteria change at a future date. It may be here that the emergence of AIDS Dementia Complex has some effect. AIDS and HIV infections are on the list (and so dementia included 'through the back door'), and it may be through this route that dementia comes to be seen as a priority. Some of the glamour of these conditions may rub off on elderly people. As things stand now, though, it is a pity that omission from this list may negate some of the advantages of the prominence given to dementia in the needs assessment work.

Second, the new contract for GPs (which was separate from the NHS Review) makes specific provision for people aged 75 years and over. All are to have their health needs assessed, and receive a home visit annually to check that their living environments are suitable. This has been criticised as being unnecessary for the many older people who have little or no health needs in a given year, but for some people might prompt closer attention than hitherto, as long as the assessments are carried out by people able to pick up mild dementia, and differentiate dementia from other conditions.

Of course, dementia often begins before the age of 75: there are no specific provisions in the GPs contract for identifying this group of people. And surprisingly, there is no requirement for GPs to address the problems of carers, even though this might be at least as valuable as assessing the needs of a dementing person.

Third, care management has been endorsed as a mechanism for organising community-based services, where identified individuals

take responsibility for service delivery. While care management might be something that many people with dementia receive already, the arrangement is now to be formalised. The Department of Health's Social Services Inspectorate (1991) has published guidance on care management and assessment. This may prove to be a positive change, since there are individuals in the system who can be approached and even lobbied for more resources. It remains to be seen, though, to what extent client views are taken into account in decisions about the allocation of resources. The mechanisms of purchasing and care management will need to be integrated, and establishing roles and responsibilities may be problematic. And it was noted in Chapter 5 that the problem is one of quantity of services rather than organisation – care management will have to help increase available resources if it is to be successful. Put another way, dementia poses one of the greatest challenges to care management.

Fourth, most of the community care budget handled by local authorities will not be ring-fenced. The government argues that authorities' statutory duties to deliver care will ensure that appropriate sums are spent. However, since April 1991 a new Specific Grant for Mental Illness has been in operation (Department of Health, 1990). Its objective is to improve services for this group through ensuring that more is spent on them. Collaboration between health and social services is encouraged by making the Grant payable through regional health authorities, and only when plans are agreed by both district health authorities and their matching social services departments.

There has been considerable confusion as to whether the Grant includes people with dementia. This serves as an example of the difficulties likely to be faced in implementing policies which depend on identifying special target groups. And it highlights the issue of whether dementia is a mental health problem: this issue will have to be resolved, at least as far as financing is concerned. AIDS Dementia Complex, similarly, will pose boundary problems which will have to be resolved. It remains to be seen to what extent it is possible in practice to identify potential recipients of Grant-supported services: we are after all starting from a low base. But at least the Grant may offer a positive incentive to identify and assess people with dementia.

Fifth, the reform of financing mechanisms is designed to remove the existing perverse incentives, notably for admission to private residential care. People will be encouraged to stay in their own homes wherever possible. It has already been noted that people are already selected against by many private residential and nursing homes. With the numbers of long-stay hospital beds also set to decline, the probability of institutional care being available when it is ultimately needed seems set to diminish. It may be that this situation can only be

addressed through financial incentives to providers of such care.

This raises a large, and so far little discussed issue, relating to housing policy for people with dementia. The focus of policies on service provision is surely correct, but this may obscure a growing housing problem. Simply, if institutional care is declining at a time when the numbers of people with dementia are rising, then where will they live? This lacuna in policy making warrants early attention.

Finally, none of these policy changes obviously addresses the problems posed by the increases in the numbers of people with dementia, outlined in Chapter 2. The rate of increase during this decade will impose greater strains on already inadequate services. There is no obvious mechanism for managing the increase in demand: it is greatly to be hoped that adequate forward planning takes place at local level.

Dementia poses a major challenge to the designers of health and social policies. They share with other groups the need for better targeting of services, and also demonstrably require an absolute increase in provision and flexibility in their delivery. If GPs, social workers and others have the will, then they can use the new system to increase and improve services. However, there are no obvious mechanisms which will inevitably lead to improvements, and in the case of residential care some which may actually reduce the availability of options. The general lack of clear relationships between new policies and effects on the ground makes prediction difficult, but gives cause for concern to those who know that dementia is unlikely to become a priority – unless people have incentives to make it one. Not for the first time, a great deal will depend on the amount of money available to provide services, and the mechanisms of its allocation.

Impact of a new pharmaceutical

Announcements and reports about new pharmaceuticals for the treatment of dementia have been made before, and so far led to disappointment. During this decade, though, new drugs will become available. These are most likely to be for symptomatic treatment, but there is a chance that some will be designed to arrest the progress of disease. Suppose for a moment that some are highly effective in alleviating symptoms, but costly. One possibility is that there is no change in services but there are significant improvements in quality of life: or that the burden on carers and the quantity of services required is reduced. If this were the case patterns of service delivery would not change. It seems rather more likely, though, that there will be changes consequent on doctors being able to provide treatment: a scenario of the future might involve substantial change in both the nature and pattern of services.

with GPs in general taking more interest, and being more likely to attempt to diagnose it, or at least to investigate the particular symptoms which a new drug ameliorates. It will be important for them to have instruments which distinguish dementia from other conditions. Similarly, hospital doctors would be more likely to examine people and order pathology or radiology tests which aid diagnosis. The costs of medical care might thus be expected to increase: and this poses the question of where extra resources will come from, or more likely what will be given up in order to pay for a new treatment. This emphasises the need to educate doctors both in the basic facts about dementia and in how to identify appropriate people for treatments, if inappropriate prescription is to be avoided: as we have seen already, GPs 'miss' dementia in many cases.

It may also be that care managers supporting significant numbers of people with dementia find they provide a different level and mix of services: clearly, the scale of any effect would be related to the nature of effects of new drugs, and it is not possible to quantify any possible changes. It is worth noting in passing, though, that the effectiveness of any drug would in practice be less if adequate services were not being provided in the first place: it might narrow the gap between need and provision, rather than reduce the need for existing levels of support. Again, total costs of services would go up rather than down.

Similarly, there might be changes in institutional care. Quite what changes is hard to predict, but one example would be that people with dementia become easier and cheaper to care for and so looked on more favourably for admission. Alternatively, it may be easier to help them live in their own homes for longer. Another possibility would be that people could be admitted for longer periods of 'respite care', in the knowledge that they could go home at a later date. This would be important in such instances as acute illness in a carer. Evidence from the USA that admission rates increased following the limiting of drugs available for elderly people is suggestive of the kind of shifting that might occur (Soumerai et al, 1991).

All of this implies that there might be significant shifting of services – and hence costs – between sectors. This will remain in the realm of speculation for some time to come, but does indicate the relationship between breakthroughs in treatment, service delivery and government policies. It also emphasises the unpredictability of the future costs of services. It might be the availability of a new drug which provides the incentives for professionals to make dementia a priority.

Even if amelioration of symptoms is significant, the availability of new drugs will pose practical dilemmas for people who purchase and provide services. They will need to make trade offs between drugs and services. It is also quite possible, of course, that some of the drugs

that become available will be of limited effectiveness. If costs are high this will raise serious ethical issues about their administration. There may be some very difficult decisions ahead.

Conclusions

The next few years will witness major changes in UK government policy, in understanding of the causes of dementia and probably also in the pharmaceutical treatments available. It remains to be seen to what extent these actually change the experiences of people with dementia and their carers. Positive change seems presently to depend most on local initiatives – that is, on attitudes. This may well remain true whatever else happens in the future.

In the short term, there is enormous scope for improvement. As the new community care policies are implemented, their impact – or lack of impact – on individuals and carers should be closely monitored. At best people will be involved in determining what services they receive, and these will be improved in quantity, targeting and flexibility. At worst, dementia will remain on the margins and service options will be reduced. Either way, dementia poses a serious challenge to the success of the new arrangements, and as so often much will depend on the amounts of money committed to implementation. But money alone may not solve the problems of adverse selection and of ensuring that resources are channelled to those who are best able to provide support. Confusion as to whether the Specific Grant for Mental Illness includes dementia is illustrative of the tendency of dementia to fall between the gaps in service provision. It does seem that specific incentives may be required to ensure that available monies are allocated more nearly according to need.

The difficulties that GPs and other community-based professionals experience with dementia indicates a need for education in identifying it, and in the availability and effectiveness of services. Without such education, attempts to break the inverse care law may founder. So, if new policies are to succeed they need to be bolstered by practical interventions.

The agenda for research into the causes of dementia has been highlighted in earlier chapters. Progress made in the last few years suggests that understanding will develop rapidly during the 1990's. As this research continues, there is time to investigate the epidemiological and economic aspects of the disease. Resolution of uncertainties about prevalence and incidence will provide a solid platform for the assessment of effects of new treatments on survival and quality of life. Data on the costs and effectiveness (and utility) of care and treatment will establish a basis for comparison of successive innovations, whether they be packages of care or pharmaceuticals.

The emergence of pharmaceuticals with clear but limited effectiveness would pose serious political and ethical questions, as the debate over Tacrine has already demonstrated. The pressure to prescribe a drug that helps even a little would have to be balanced against its (probable high) expense. Somewhere over the horizon lies the prospect of combinations of care and pharmaceuticals which make dementia a condition which has relatively limited effects on individuals and those who care for them. But these hopes for the future are not an excuse for inaction in the present.

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APPENDIX

The Causes of Dementia

Research into the causes of dementia has intensified in recent years, and a picture is beginning to form of its anatomical and chemical basis. This Appendix briefly discusses progress in piecing the picture together: it is selective, and makes no attempt to reflect the very many avenues currently being explored.

Vascular dementia

Given that the association has been made for the whole of this century, and was once thought to be the major cause of dementia, it might be expected that the mechanism whereby cerebrovascular disease causes dementia would be well understood. In fact this is far from the case, and if anything questions about the role of vascular disease are increasing. It is clearly the case that cerebrovascular disease and dementia can occur independently of one another, and arteriosclerosis does not itself appear to be a cause of dementia. Indeed, one of the most important changes in our understanding of vascular dementia is that it is not caused by vascular disease but by one or more strokes (hence the often-used term multi-infarct dementia). It appears that strokes can result in a clinical picture of dementia, and may do so through one or more mechanisms (Figure

Figure A.1 Mechanisms of dementia related to stroke

1. **Location** of cerebral injury, with involvement of specific regions important for higher cerebral functions, especially:
 - association areas of the posterior cerebrum;
 - areas surrounding the posterior cerebral;
 - distal field territory from carotid occlusive disease, including the superior frontal and parietal regions.
2. **Volume** of cerebral injury, with infarct size reaching a critical threshold overcoming the brain's compensatory capacities.
3. **Number** of cerebral injuries, with multiple small (or large), deep (or superficial) infarcts having:
 - additive effects;
 - multiplicative effects, as in 'multi-infarct dementia';
 - location-specific effects.
4. **Co-occurrence** of vascular dementia and Alzheimer's disease (AD):
 - additive effects, eg. stroke deficits superimposed on AD, adding to baseline changes;
 - multiplicative effects, eg. stroke interacts with AD, aggravating mild AD or unmasking preclinical AD;
 - amyloid angiopathy associated with AD leads to multiple small infarcts.

Source: adapted from Tatemichi, 1990

A.1). Often, these strokes are small and highly localised, and not detectable through clinical examination: they are only revealed in high resolution radiological images such as computed tomography (CT) or magnetic resonance imaging (MRI).

Somewhat surprisingly, there have been very few studies investigating such questions as whether or not dementia actually follows a stroke, or whether a stroke accelerates a decline that has already begun. And there is disagreement as to whether 'dementia' that improves as a person recovers from a stroke is a 'real' dementia, or whether the term should be reserved for those cases where it progresses. Nevertheless, epidemiological evidence suggests that the risk factors for vascular dementia are similar to those for stroke, and it is generally accepted that stroke can cause dementia (Tatemichi, 1990). About a third of dementias are due to vascular causes. The clinical presentation of dementia is very similar – many would say often indistinguishable – from that of Alzheimer's disease, with an over time.

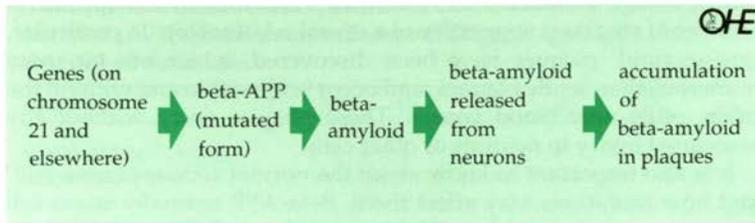
Alzheimer's Disease

In contrast to vascular dementia, awareness of the importance of Alzheimer's disease as a cause of dementia has increased greatly in the last fifteen or twenty years. It accounts for over half of all people with dementia, and has been far more intensively studied than other forms of dementia. It appears to have multiple possible causes: it is inherited in some families, and also occurs sporadically (that is, due to individual or environmental factors) with no obvious genetic component.

The two major pathological changes associated with the disease were observed by Alois Alzheimer himself. The first are *senile plaques*, which consist of altered axons and dendrites of neurons surrounding an extracellular mass of thin filaments. These extracellular deposits are termed amyloid; the principal constituents of amyloid filaments are proteins, which are folded in characteristic beta-pleated sheets (Figure A.2). Senile plaques evolve slowly over periods of years, and in their mature state contain two types of altered glial cell: microglia (which are usually scavenging cells) in the centre and reactive astrocytes (often found in injured areas of the brain). Second, there are *neurofibrillary tangles* which are dense bundles of abnormal fibres in the cytoplasm of neurons. These are composed of a modified form of a normally-occurring protein called tau. In its most severe form, the brain is ravaged by these changes, and is significantly smaller than that of a normally functioning person of the same age.

The role of genes and their associated proteins in familial Alzheimer's disease has for some time appealed to researchers as a route to understanding the sequence of events leading to the

Figure A.2 Sequence of events in formation of senile plaques



characteristic chemical and pathological changes. Intensive research in the late eighties and at the start of the 1990's has for the first time raised the possibility of tracing a link from a specific biochemical event to the brain changes characteristic of Alzheimer's disease.

One of the possible sequences of events leading to the formation of beta-amyloid in Alzheimer's disease is now being unravelled. First, the gene sequence which codes beta-amyloid is on chromosome 21. (Interestingly, people with Down's syndrome are born with an extra copy of chromosome 21 and typically have beta-amyloid deposits early in life). As is often the case in the production of proteins, a long sequence of amino acids is formed which is then chopped up to create one or more active proteins. The longer sequence is called the beta-amyloid precursor protein (beta-APP), variously reported as having 695 or 770 amino acids. Beta-amyloid is a fragment of beta-APP some 40 amino acids long.

It has been established that in some families Alzheimer's is associated with abnormal processing of beta-APP. Research has shown that all members of a family with Alzheimer's had a mutation in beta-APP – a change of amino acid from valine to isoleucine (Chartier-Harlin et al, 1991; Goate et al, 1991). They and others have now found other families with mutations in beta-APP. It may thus be that the mutation leads to the abnormal deposition in Alzheimer's disease, without any other abnormal event occurring.

While the APP gene may be a gene for Alzheimer's, it appears not to be the only one. A group at the University of Washington in Seattle, and more recently the Familial Alzheimer's Disease Collaborative Study Group in the USA have shown that in the families they studied the gene could not be on chromosome 21, and must be elsewhere in the genome. Thus even the hereditary form of Alzheimer's is a heterogeneous disease. It is now clear that familial Alzheimer's disease is associated not only with the gene for beta-APP, but can apparently be caused by many different genetic defects on different chromosomes. Given the massive changes that occur in Alzheimer's, this is perhaps not surprising.

The next issue is whether beta-amyloid deposition is a cause – rather than a product – of Alzheimer's disease. Evidence from a number of studies is suggestive of a causal relationship. In particular, 'pre-amyloid' plaques have been discovered, which are far more numerous than senile plaques, and occur both within and without the brain, often near blood vessels. These plaques occur without any associated injury to neurons or other cells.

It is also important to know about the normal actions of beta-APP and how mutations may affect them. Beta-APP normally spans cell membranes, and may be an inhibitory molecule which regulates the actions of proteases (protein-cleaving enzymes). The region containing the beta-amyloid molecule is embedded in the cell membrane, so that abnormal processing must somehow lead to the release of the protein from the membrane.

It must be stressed, though, that there are a number of questions outstanding, not least concerning the precise sequence of events in the deposition of senile plaques, and whether environmental factors exert their effects via this mechanism or have some as yet unknown action. The development of strains of mice which might be used as models promises advances in these areas (Quon et al, 1991; Wirak et al, 1991), as long as remaining technical problems can be overcome (Kawabata et al, 1992).

Studies of the role of genes and proteins in families with Alzheimer's disease is clearly very important, but it should not be forgotten that many people have Alzheimer's where there is no obvious genetic component, and the cause of the disease in these cases is still unknown. It thus remains important to study the anatomical and biochemical aspects of Alzheimer's, and to understand the risk factors for the disease. Much of the effort to date in developing treatments has been focused upon the major reductions in the neurotransmitter acetylcholine and its associated enzymes. But in Alzheimer's disease (and some other types of dementia) there are significant reductions in the levels of several neurotransmitters (Figure A.3). These deficits occur in many parts of the brain but are localised in particular areas, notably the cortex. Again, it is not clear how the anatomical and neurotransmitter changes are related, save that one would expect gross anatomical changes to affect neurotransmitter levels significantly.

Alcohol-related dementia

Alcohol-related dementia is the third cause of dementia identified in most studies. Some 10 per cent of alcoholics exhibit dementia-like symptoms, and prevalence increases with age. Alcohol has a chronic toxic effect, and people have to drink heavily for 15-20 years before exhibiting symptoms: dementia develops insidiously and steadily,

Figure A.3 Neurotransmitter changes in Alzheimer's disease (AD), Huntington's disease (HC), alcoholic dementia (Alc), vascular dementia (VD), Parkinson's disease (PD), and ageing in the absence of dementia

<i>Transmitter</i>	<i>AD</i>	<i>Alc</i>	<i>VD</i>	<i>HC</i>	<i>PD</i>	<i>Ageing</i>
Acetylcholine – choline acetyl transferase	↓ ↓ ↓	↓	→	↓	↓	↓
Acetylcholine – acetylcholinesterase	↓ ↓	↓	→	↓		→
Dopamine	↓	↓		↓	↓	↓
Noradrenaline	↓	↓	→		↓	↓
Gamma amino butyric acid	↓	↓		↓		↓
Serotonin	↓ ↓			↑	↓ ↓	→
Corticotrophin-releasing factor	↓ ↓				↓	
Neuropeptide Y				↑		
Somatostatin	↓					→
Substance P				↓		
Glutamate	↓					→

Key: ↑ increase, ↓ decrease, → no change

Source: Whalley, 1989

associated with cerebral atrophy (American Psychiatric Association, 1987).

The presentation of this form of dementia is complicated by the general effects of alcohol and the typical coincidence of malnutrition. These may mask the dementia, and make it difficult to establish whether or not particular people are treatable. It is also possible that, as with vascular dementia, alcohol-related dementia may not be strictly irreversible, since abstinence may lead to arrest or reversal of decline.

Environmental factors

The possibility that toxic substances in the environment might cause dementia has long been suspected. Attention has focused particularly on aluminium as a cause of Alzheimer's disease, although a variety of other substances have been investigated. Evidence for a role for

aluminium includes: the presence of high concentrations of aluminosilicates in the cores of senile plaques (Edwardson et al, 1988); and accumulation of aluminium in neurofibrillary tangles. What is not clear, however, is whether aluminium is a cause or a consequence of these processes: if it is a cause then treatments preventing its accumulation might be effective, but if a consequence then treatments may not affect the dementia. And it should be pointed out that not all authors accept a role for aluminium (Whalley, 1989).

One of the major puzzles about aluminium is how it gets into the brain and is then concentrated within plaques and tangles. The gastrointestinal tract (ie. ingestion) and nasal pathways have been proposed, but the uptake of significant quantities by this route seems unlikely. As with so many aspects of dementia, then, the possible role of aluminium is tantalising and elusive.

AIDS Dementia Complex

The devastating effects of AIDS and continuing spread throughout the world have prompted a massive research effort into understanding its causes and developing treatments. One of the most common and important sources of morbidity in infection with human immunodeficiency virus type 1 (HIV-1) is Aids Dementia Complex (ADC). Indeed, it appears that ADC is due not to any secondary infections but to the effects of HIV-1, and further that the severity of ADC reflects the extent of HIV-1 infection.

The prevalence of ADC is not clear, but estimates suggest that about one in ten of people with AIDS-related complex may have mild abnormalities consistent with ADC; later, a slightly higher percentage of people may exhibit mild to severe ADC.

The biological basis of ADC is as yet poorly understood, and hence it is difficult to draw up possible therapeutic strategies. ADC is likely to be important for (at least) two reasons: first, it is potentially a good indicator of underlying HIV-1 infection, and could be used as an index of therapeutic efficacy of AIDS drugs; and second, it may provide important clues about causes and effects of dementia. The ways in which a virus may cause dementia promise to illuminate the mechanisms whereby external agents exert their effects.

Prions: life, but not as we know it

What is the link between scrapie, BSE (bovine spongiform encephalopathy) and dementia? The answer is a surprising one: it now seems that all can be caused by proteins, which are transmissible and inheritable. Evidence increasingly supports the view that prions (proteinaceous infectious agents) cause these conditions, and furthermore evidence for involvement of DNA or RNA in the infective process (as one would expect conventionally) is lacking. This

goes against all previous understanding of disease processes, and points to prions being a novel form of life (Harrison and Roberts, 1991), but has come increasingly to be accepted.

The most persuasive evidence for the existence of prions, which have yet to be isolated and characterised, comes from studies of scrapie in sheep and BSE in cattle. It has become increasingly clear that two rare forms of dementia, Creutzfeld-Jacob disease (CJD) and Gerstmann-Straussler syndrome (GSS) are also prion diseases (Palmer et al, 1991). (Both are closely related to Alzheimer's disease pathologically and clinically, although it appears that their chemistry differs somewhat, for instance in the nature and sites of deposition of senile plaques).

Piecing together the evidence from different species, a general picture is emerging. The key points are that:

- prions are encoded by normal cellular genes;
- prion production is thus a normal event in healthy brains;
- gene mutations have been found which may be a cause of abnormal (pathological) prion production in both CJD and GSS;
- it nevertheless also remains probable that CJD and GSS are acquired by infection.

Alzheimer's disease is not infectious, and so seems unlikely to be a prion disease, at least in the way that CJD and GSS are. But there are interesting parallels in their pathologies, including the deposition of beta-pleated amyloid conformations and possible neuron-to-neuron spread, suggesting that a pathological and biochemical classification of the dementias might now be possible.

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