

# DEMENTIA IN OLD AGE



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## **Office of Health Economics**

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- To collect data from other countries.
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## Introduction

Dementia – that is, irreversible and usually progressive destruction of the brain in old age, the causes of which have yet to be identified – is arguably the most significant single problem currently facing the health services. Ten per cent of the population aged 65 years and over (more than 700,000 people) are affected by the condition(s) and of these about half exhibit symptoms of a severe degree. The characteristic clinical features are usually associated with a loss of and structural changes in certain brain cells and include failing memory, intellectual deterioration and behavioural disturbance. The speed and extent of this disintegration of personality vary considerably but for the more severely affected the outcome is almost invariably a shortened life expectancy and a steadily diminishing capacity to undertake simple everyday tasks culminating eventually in an inability to survive without considerable assistance.

The absence so far of specific preventive or curative therapy for dementia implies that the care of affected individuals is based on wide ranging support from relatives and the health and social services. Most people suffering from dementia either live alone or are looked after by their families and friends: for every one in long-term institutional residence, five are cared for at home. However, the nature and extent of the problems encountered by affected individuals and by families who undertake responsibility for the care of their demented relatives have only recently attracted attention and it is clear that in many cases insufficient assistance and guidance is being received.

In the institutional sector care is provided in psychiatric and geriatric hospitals, local authority homes, private nursing establishments and even on acute hospital wards. But long-standing inequalities in service provision and resource constraints have, in the face of increasing demands from an ageing population for institutional care, given rise to pressures on domiciliary services, or families providing support and throughout health care provision as a whole.

Furthermore, demographic trends and age specific prevalence rates suggest that the dementia problem will become more acute throughout the remaining years of the present century. For example, the number of persons aged 80 years or over, among whom the prevalence of dementia reaches its peak with more than one person in five being affected, will expand by over half a million between 1977 and 1995 to 1.76 million in England and Wales. The growth of this particularly dependent community group will, against a background of social change which may diminish the possibilities of family support and likely shortfalls in

service provision, result in an intensification of the pressures already evident in the care of the elderly demented.

This paper describes the nature of the condition(s), the pattern of occurrence and the current and projected problems in the provision of health and social services for the elderly demented. It also attempts an assessment of the economic and social implications of dementia in old age. Finally, it examines the present state of knowledge about the causes of dementia and the barriers to further scientific advance both in this area and in the development of effective medical intervention.

## The classification of dementia

Throughout history the use of the term dementia to describe certain clinical manifestations of psychiatric disturbance experienced in old age has given rise to much confusion. The word appears to have been first used by Aretaeus (*circa* AD 150), the physician of Cappadocia, although its evolution and its differentiation, if any, from normal senescence are not clear (Alexander 1972). It was not until the publication of Esquirol's *Traité des Maladies Mentales* in 1838 that a comprehensive description of the psychiatric deviations associated with senile dementia was established. Even then, however, '*démence sénile*' emerged as a vague and over-inclusive concept comprising a miscellany of senile disorders.

Advances in neuropathology towards the end of the nineteenth century enabled Kraepelin (1912) to incorporate in his model classificatory system clinically viable differentiations between cases of arteriosclerotic dementia, senile dementia and Alzheimer's disease (a form of dementia occurring earlier in life). Interest in the psychiatric disorders of old age continued to develop and in 1955 Roth published a paper in which he postulated that a large proportion of psychiatric illness experienced by the elderly could be subdivided into five diagnostic categories. One of these was senile psychosis which was identified by a history of gradual and progressive failure in general efficiency in everyday life dominated by changes in the intellect, memory and personality, occurring in the absence of any evidence of specific aetiological factors such as neoplasm, chronic intoxication, infection or cerebral infarction caused by cerebrovascular disease. Another was arteriosclerotic dementia which was characterised by similar clinical manifestations but associated with focal indications of cerebrovascular disease and a fluctuating disease process. (The remaining three diagnoses were affective psychosis, late paraphrenia and acute confusion.) More recent classifications have focused specifically

on the concept of dementia with subdivisions based on a variety of criteria such as aetiological considerations or neurological signs.

The problems of terminology stem largely from the confused use of the word dementia to describe on the one hand a particular pattern of behaviour and, on the other, to define a specific pathological entity. In the former case, dementia, denoting a clinical state comprised of failing memory and a loss of other intellectual functions, may be caused by traumatic injury, intoxications and a diverse range of physical illness including infectious diseases, neoplasms, metabolic upset and certain deficiency states. Indeed, Hodkinson (1975) has emphasised that psychiatric disturbance of this nature may be regarded as one of the main indicators of acute illness in elderly people, often replacing such symptoms as pyrexia, rapid pulse or pain which typically herald acute illness in younger persons. Many of these conditions such as acute respiratory and urinary infections can, however, be effectively treated and hence the manifestations of dementia are reversible. In such cases confusion or delirium, often prefixed by the word acute, may be more appropriate descriptions of the temporary disruption to the patient's mental health.

On a pathological basis dementia may be seen as chronic organic brain disease which results in structural changes in and the destruction of neurones, giving rise, in the initial stages at least, to clinical manifestations resembling those which characterise acute confusional states. The essential distinction between the two, however, is that the damage to the brain is irreversible and often progressive. The fundamental causes of this condition remain unclear. Indeed, to a certain extent this diagnosis is a 'rag-bag' category, left over when more precise aetiological factors are not present. Nevertheless, research has shown that there are several distinct disease processes, revealed in part by the course the illness takes and its clinical associations but more decisively by the pathological changes observed in the brain at autopsy. These irreversible forms of cerebral degeneration with onset invariably in old age are the subject of this paper.

## The nature of dementia

Irreversible dementia in old age is of two major types, senile and arteriosclerotic. In the latter there is a degeneration of brain substance associated with softenings due to infarction and an impaired blood supply. (While arteriosclerotic changes are certainly present in vascular dementia, the critical lesions are the many small infarcts and for this reason the term 'multi-infarct dementia')

(Hachinski *et al*, 1974) is increasingly being used to describe this condition.) The damage, which may range from scattered micro infarctions, perhaps with multiple small areas of cystic degeneration, to the massive destruction of tissue that can result from the occlusion of a major cerebral artery, is unevenly distributed throughout the brain, giving rise to fluctuations and inconsistency in clinical presentation. It is thus possible for some affected individuals to suffer severe dementia with little physical involvement while others experiencing a major stroke show no signs of intellectual impairment.

The course of multi-infarct dementia is typically by a series of 'little strokes' – episodes of confusion sometimes associated with minor neurological signs (slurring of speech, weakness down one side of the body, or in a single limb) due to sudden inadequacy of the cerebral circulation as happens, for example, when a vessel becomes completely blocked. The network of arteries to the brain is extensive, and after a few days or weeks the circulation may be restored. This may then be followed by clinical improvement or even full recovery, until the next episode, which may take place quite soon, within weeks or months, or may be delayed for more than a year. Eventually, however, after a succession of such bouts there is progressively less recovery – confusion and personality changes become more apparent often accompanied by increasing emotional lability – until, by a process of 'stepwise' deterioration, profound dementia develops.

The more frequently diagnosed form of irreversible dementia is generally referred to as senile dementia.<sup>1</sup> It is characterised by degeneration of the parenchymatous tissue of the brain (the rate of which may be determined genetically) which, if progressive, produces a steady deterioration in mental function and in the capacity for self-care. Post mortem investigations have shown that many nerve cells disappear, some develop grossly thickened fibrils and vast numbers of minute 'plaques' of degenerating tissue become scattered through the grey matter and particularly the cortex of the brain.<sup>2</sup>

1 The available evidence suggests that in a group of elderly demented patients sufficiently ill to require hospital treatment the proportion showing senile dementia alone varies between 20 per cent (Robertson and Mason Brown 1953), 40 per cent (Newton 1948) and 50 per cent (Tomlinson *et al* 1970). About 20 per cent show signs of cerebral softening and other changes due to vascular disease (Tomlinson *et al* 1970). Not all cases of dementia are of course clear cut: it has been estimated that approximately 20 per cent of patients experience senile and atherosclerotic brain damage simultaneously (Pitt 1974).

2 It should be noted that a suspicion of dementia based on post mortem findings has not always been upheld by investigation of the patient's medical history. Nevertheless, as a generalisation, 'the more severe the cerebral atrophy the more likely it is that a person has been demented' (Corsellis 1977).

A selective impairment of memory for recent events is often the most conspicuous defect in the early stages of senile dementia while recall of the distant past may well be preserved. With further deterioration, however, memory for recent experience becomes a void and for the past it is restricted to a few muddled recollections.

Intellectual deterioration is also experienced and may be reflected in an inability to generate or grasp ideas, to apply experience to new situations or to discern the significant from the trivial. Affected individuals may misunderstand the actions of those caring for them and this may be reflected in a variety of responses such as a desire to escape from the immediate environment. Episodes of wandering away from home, frequently occurring at night, impose considerable strain on relatives and constitute one of the major reasons for referral to specialist care.

Personality changes, perhaps reflecting a loss of 'normal' inhibition, may include tactlessness, apathy and irritability. In some instances, such developments may represent an understandable response to a progressively restricted ability to perform everyday tasks. In general, however, affected individuals become increasingly unaware of both their predicament and their unusual behaviour.

In severe cases, the condition advances to a stage where there is loss of almost all intellectual faculties, with extreme incoherence and irrationality. Mutism, unresponsiveness and incontinence may supplement the clinical picture and at a late stage secondary physical deterioration may also take place. Febrile illness or metabolic upset may induce coma. Finally, the patient becomes almost totally bedfast with death resulting from pneumonia or some other intercurrent infection. The whole degenerative process may evolve over a period of months or years, usually the latter.

## Epidemiology

Although epidemiological studies have yielded important prevalence data which in turn may serve as crude guidelines for establishing appropriate levels of health and social care provision they have as yet facilitated little insight into the identity of those factors which may or may not have aetiological significance in dementia. In part this stems from the fact that most studies of relevance have necessarily focussed attention at the 'generic level' of cerebral degeneration because lack of knowledge has inhibited the disaggregation of component disease entities within dementia. Furthermore, comparisons of the findings of investigations carried out by different workers may be difficult because of both funda-

mental and minor variations in survey definitions, population variables and methodology.

Perhaps the major drawback, however, centres on the question of sample size. In order to identify a broad spectrum of dementia, including those early and borderline cases which may not always present for medical assessment, a community sample would be necessary. But a randomly chosen sample of elderly community residents is likely to yield less than 10 per cent of subjects who will be of interest in this context. Thus a community screening procedure will be required to define index cases and a large sampling frame will be needed, say between 5,000 and 10,000 elderly subjects, in order to obtain sufficient cases for further study and differentiation into clinical subgroups. Financial constraints and the organisational difficulties of multidisciplinary research pose major obstacles for an investigation on this scale (Bergmann 1977).

### Prevalence

The most frequently quoted estimates of prevalence are those obtained by Kay and his colleagues in their 1960 Newcastle Study (Kay *et al* 1964). The principal objective of this investigation was to establish the prevalence of all and specific forms of mental illness in the general aged population and to ascertain the proportions receiving treatment or care in institutions and at home. Their findings suggested that approximately 10 per cent of the population aged 65 years or more experience dementia of either the senile or arteriosclerotic type and that in half of these cases, that is 5 per cent, the condition is severe (Table 1). Other surveys (Table 2), undertaken in a variety of cultural settings, have yielded prevalence figures which though showing variation are more remarkable for their constancy (Bermann 1977).

**Table 1** *Prevalence of dementia (Newcastle upon Tyne 1960)*

|  | <i>Institutional cases<br/>per 1,000<br/>aged 65 and over</i> | <i>Home cases<br/>per 1,000<br/>aged 65 and over</i> | <i>Total prevalence<br/>per 1,000<br/>aged 65 and over</i> |
|--|---|--|--|
| Senile and<br>arteriosclerotic                         | 6.8   | 38.8   | 45.6 ± 11.0  |
| Other severe brain<br>syndromes                        | 0.8   | 9.7  | 10.5 ± 5.0   |
| Mild brain syndromes<br>(mild mental<br>deterioration) | 5.3   | 51.8   | 57.1 ± 12.6  |

Source Kay *et al* 1964.



**Table 2** *The prevalence of the main psychiatric syndromes of old age, according to various authors*

|   | Percentages                         |                                    |  |   |                                      |                                     |                                       |      |
|---|-------------------------------------|------------------------------------|--|---|--------------------------------------|-------------------------------------|---------------------------------------|------|
|   | Sheldon<br>(1948)<br>(N=369)<br>65+ | Bremer<br>(1951)<br>(N=119)<br>60+ | Essen-Møller<br>(1956)<br>(N=443)<br>60+ | Gruenberg<br>(1961)<br>(N=1,592)<br>65+ | Primrose<br>(1962)<br>(N=222)<br>65+ | Nielsen<br>(1963)<br>(N=978)<br>65+ | Kay et al<br>(1964)<br>(N=297)<br>65+ |      |
| Senile and arteriosclerotic psychoses                     | 3.9                                 | 2.5                                | 5.0                                      | —                                       | 3.6                                  | } 4.5                               | 3.1                                   | 4.6  |
| Other organic syndromes                                   | —                                   | —                                  | —  | —                                       | 0.9                                  |                                     | —                                     | 1.0  |
| Major functional disorders                                | —                                   | 4.2*                               | 1.1                                      | —                                       | 1.4                                  | 3.7*                                | 2.4                                   |      |
| Psychoses, all forms                                      | 3.9                                 | 6.7                                | 6.1                                      | 6.8                                     | 5.9                                  | 6.8                                 | 8.0                                   |      |
| 'Mild mental deterioration'                               | 11.7                                | —                                  | 10.8                                     | —                                       | —                                    | 15.4                                | 5.7                                   |      |
| Neuroses and allied disorders (moderate/<br>severe forms) | 9.4                                 | } 12.6                             | 5.0                                      | } 12.0                                  | } 12.6                               | } 8.7                               | } 12.5                                | 8.9  |
| Character disorders                                       | 3.2                                 |                                    | 12.6                                     |   |                                      |                                     |                                       | 10.6 |

\*Includes 'constitutional' and 'psychogenic' psychoses.

Source Kay et al 1964.

A further survey in 1964 by the same group (Kay *et al* 1970) made possible new estimates of prevalence among those living at home. By combining this sample with the relevant elements of the one undertaken in 1960 and excluding from both those cases in which the diagnosis was not considered to be firm they derived age specific rates for senile and multi-infarct dementia together. Table 3 shows that prevalence increases steadily with age until 80 years and over when it accelerates to 22 per cent.<sup>3</sup> It is also clear that the rates for males and females do not differ significantly confirming that the apparently higher prevalence among females is a reflection of the more favourable survival they experience in old age.<sup>4</sup>

On the basis of the overall prevalence rate of 10 per cent among the population aged 65 years and over shown in Table 1 it may be estimated that perhaps 715,000 elderly people are affected to varying degrees by irreversible dementia in England and Wales (1977 figures).<sup>5</sup> A population growth in this section of the community of 1.75 per cent is projected over the period to the beginning of the next century so that by 2001 the numbers of elderly demented may have risen marginally, *ceteris paribus*, to about 727,000.

A comparison of two points in time separated by almost one-quarter of a century is of course misleading. Firstly, it disguises the changes occurring during the intervening years. Thus official projections suggest that in 1990 the elderly population aged 65 years or more will reach a peak of almost 7.6 million. In conjunction with prevalence data this growth implies that the numbers of demented will increase steadily (with the exception of the period 1981-85) by about 45,000 (6.3 per cent) between 1977 and 1990.

Secondly, such a comparison obscures the implications of variations in age specific dementia prevalence rates and the differential rates of population growth within the elderly section of the community (Figure 1, Table 4). Focusing for example on the population aged 80 years or over, amongst whom the pre-

3 The reduced overall prevalence shown in Table 3 reflects the omission of some of the dubious or mild cases of dementia as well as those affected individuals resident in institutions. It should be emphasised that the data were derived from studies undertaken in the first half of the 1960s and that as the elderly population ages this overall rate will shift upwards.

4 Age related differences that do exist may reflect a tendency for multi-infarct dementia to affect males at younger ages and for females to be affected by the parenchymatous form of dementia at relatively older ages.

5 This is in stark contrast to certified dementia mortality (ICD 290.0) patterns. In 1976 in England and Wales only 1,176 deaths (75 per cent of which were females) were attributed to this cause, equivalent to just 0.26 per cent of all deaths among those aged 65 years or more.

**Table 3** Prevalence of chronic brain syndromes by age and sex, Newcastle upon Tyne, 1960 and 1964 samples

| Age   | Both sexes |     |                | Males |      | Females |      |
|-------|------------|-----|----------------|-------|------|---------|------|
|       | N          | CBS | % $\pm$ S.E.   | N     | %    | N       | %    |
| 65-69 | 253        | 6   | 2.3 $\pm$ 0.9  | 110   | 3.6  | 143     | 1.4  |
| 70-74 | 243        | 7   | 2.8 $\pm$ 1.1  | 91    | 3.3  | 152     | 2.6  |
| 75-79 | 144        | 8   | 5.5 $\pm$ 1.9  | 51    | 5.9  | 93      | 5.4  |
| 80+   | 118        | 26  | 22.0 $\pm$ 3.8 | 39    | 20.5 | 79      | 22.8 |
| Total | 758        | 47  | 6.2 $\pm$ 0.9  | 291   | 6.2  | 467     | 6.2  |

Source Kay et al 1970.

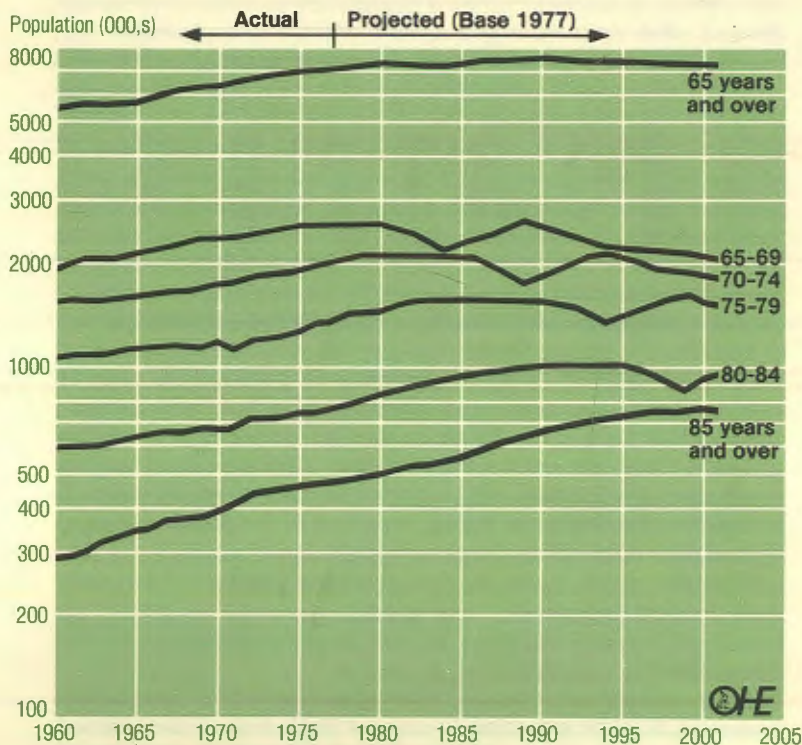
valence of 'definite' dementia exceeds 20 per cent, it may be estimated that the number of affected individuals will increase between 1977 and 2001 by more than 41 per cent to a total of 388,000. Over the same period of time, 'definite' cases among those aged 65-69 years are projected to fall by 17 per cent. It is therefore the change in the age structure of the population aged 65 and over rather than the growth in the latter's overall size that will be the major factor in the increasing burden of dementia over the next 20 years.

### Prognosis

Estimates of life expectancy following a diagnosis of irreversible dementia may be expected to show a high degree of variation depending on the stage of brain degeneration at assessment, the severity and, more speculatively in the present state of knowledge, the nature of the disease process or processes involved. Nevertheless, the effect of senile dementia in a variety of settings seems to be remarkably constant: increased mortality has been found in both hospital and community samples. In 1955 Roth published a paper showing that approximately 60 per cent of those entering hospital for dementia had died within 6 months of admission and that by the end of two years this figure had risen to 80 per cent.

In a study with follow-up lasting for more than 20 years or until death Kay (1962) found that the mean expectation of life of patients with dementia was 2.6 years for males and 2.3 years for females (all patients who had been traced were dead before the follow-up period had ended). In the group without dementia the mean period survived at the end of follow-up was 8.7 years for males and 10.9 years for females and 17 patients were still alive. The comparison of patients with dementia against actuarial estimates of life expectancy showed a highly significant

**Figure 1** Actual and projected elderly population, England and Wales, 1960-2001, thousands



Source Office of Population Censuses and Surveys.

diminution of life expectancy, demented females having only 25 per cent of the life expectancy of comparable unaffected people and males 34 per cent.

Follow-up of the combined Newcastle community surveys (Kay *et al* 1970) which generated the age specific prevalence rates shown in Table 3 indicated that 74 per cent of the 47 individuals initially diagnosed as suffering from 'definite' dementia had died within two to four years (Table 5). This contrasted with a figure of 26 per cent for age and sex matched normal controls. A community survey by Gilmore (1975) which identified 28 cases of dementia with follow-up 3 years later obtained approximately similar results (Table 6).

The longitudinal follow-up of the two Newcastle samples also provided an opportunity of examining the development of

**Table 4** *The elderly as a percentage of the total population, 1901-2001*

| <i>Year.</i> | <i>65-74 years</i> | <i>75-84 years</i> | <i>85 years and over</i> | <i>65 years and over</i> |
|--------------|--------------------|--------------------|--------------------------|--------------------------|
| 1901 (UK)    | 3.3                | 1.2                | 0.2                      | 4.7                      |
| 1911 (UK)    | 3.9                | 1.3                | 0.2                      | 5.3                      |
| 1931 (UK)    | 5.3                | 1.8                | 0.2                      | 7.4                      |
| 1951 (E & W) | 7.4                | 3.1                | 0.5                      | 11.0                     |
| 1961 (E & W) | 7.6                | 3.6                | 0.7                      | 11.9                     |
| 1971 (E & W) | 8.6                | 3.9                | 0.9                      | 13.3                     |
| 1977 (E & W) | 9.2                | 4.3                | 1.0                      | 14.5                     |

Projections based on 1977 data

|              |     |     |     |      |
|--------------|-----|-----|-----|------|
| 1981 (E & W) | 9.3 | 4.8 | 1.0 | 15.1 |
| 1991 (E & W) | 8.7 | 5.1 | 1.4 | 15.2 |
| 2001 (E & W) | 7.8 | 5.0 | 1.5 | 14.3 |

*Source* Annual Abstract of Statistics, various years.

**Table 5** *Mortality during follow-up of the 1960 and 1964 Newcastle (age and sex matched) samples*

| <i>Sample</i> | <i>Follow-up period</i> | <i>Normal controls</i> |              | <i>CBS</i>  |              |
|---------------|-------------------------|------------------------|--------------|-------------|--------------|
|               |                         | <i>Dead</i>            | <i>Alive</i> | <i>Dead</i> | <i>Alive</i> |
| 1960          | 4 years                 | 7                      | 14           | 17          | 4            |
| 1964          | 2-3 years               | 12                     | 40           | 18          | 8            |
| Total         | 2-4 years               | 19                     | 54           | 35          | 12           |

*Source* Kay et al 1970.

**Table 6** *Outcome of subjects with organic brain syndrome three years after initial examination*

| <i>Degree of brain failure</i> | <i>Unchanged</i> | <i>Died</i> | <i>Hospitalised</i> | <i>Other</i> | <i>Total no. of cases</i> |
|--------------------------------|------------------|-------------|---------------------|--------------|---------------------------|
| Mild                           | 2                | 9           | 1                   |              | 12                        |
| Moderate                       | 3                | 5           | 4                   | 1            | 13                        |
| Severe                         | 1                | 2           |                     |              | 3                         |

*Source* Gilmore 1975.

the condition in borderline cases<sup>6</sup> (Bergmann *et al* 1971). Focusing on those with a suspicion of having early senile dementia produced a group of 20 individuals of whom 19 were traced at follow-up (Table 7). These subjects fell into one of three groups showing development of dementia at follow-up, no change or improvement. The health of more than one-third of the individuals in the traced sample was such that the initial diagnosis of organic cerebral impairment was unlikely. Social class analysis, psychiatric interview and memory and information testing indicated that dementia appears to be most readily misdiagnosed in those subjects in whom low social class, incoherence and low intelligence are found together.

It is not clear whether survival has improved over time. Analysis by Gruenberg and Hagnell (1978) of the Lundby population in southern Sweden found that until about 1949 the duration of senile dementia was on average less than 3 years, whereas after 1949 the illness lasted much longer. Figure 2 indicates that the general population survival curve for the decade after 1947 paralleled almost exactly that for the decade following 1957, although the latter showed a slight improvement in expectation. In contrast, follow-up of cases of senile dementia present in 1947 and 1957 revealed a remarkable extension of life among those traced from the latter year. This improvement may be attributed to postponement of death from intercurrent infections, particularly pneumonia. Certainly the phenomenon is not unique to senile dementia: it has, for example, been well documented in Down's syndrome. It is nevertheless surprising to

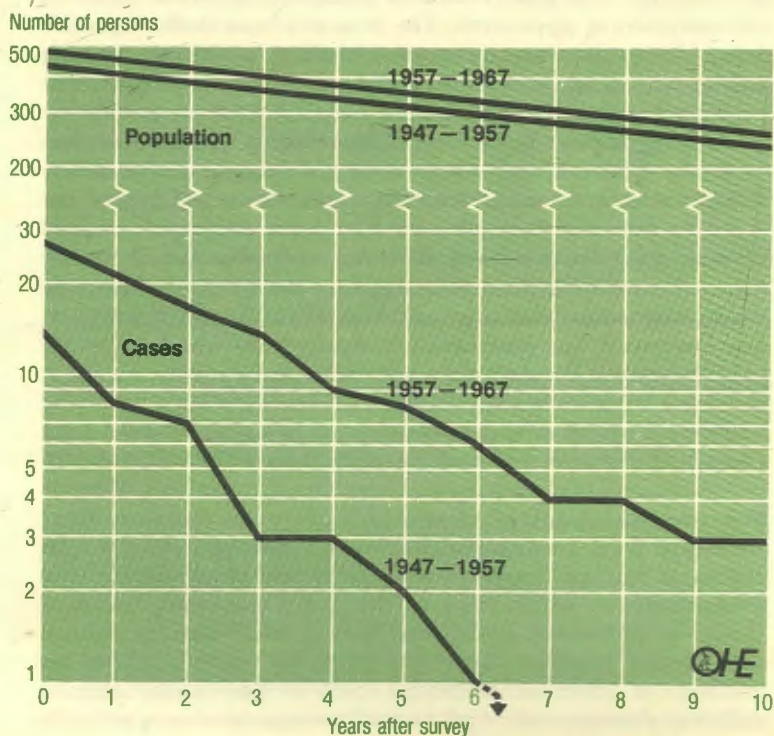
**Table 7** *Condition of suspected chronic brain failure group at follow-up (Newcastle samples)*

|                    |        | <i>Dead</i> | <i>Alive</i> | <i>Total</i> | <i>Per cent</i> |
|--------------------|--------|-------------|--------------|--------------|-----------------|
| Demented           | Male   | 1 } 3       | 2 } 3        | 6            | 30.0            |
|                    | Female | 2 } 3       | 1 } 3        |              |                 |
| Unchanged          | Male   | 2 } 3       | 3 } 3        | 6            | 30.0            |
|                    | Female | 1 } 3       | 0 } 3        |              |                 |
| Normal             | Male   | 0 } 0       | 2 } 7        | 7            | 35.0            |
|                    | Female | 0 } 0       | 5 } 7        |              |                 |
| Total at follow-up |        |             |              | 19           | 95.0            |
| Not traced         |        |             |              | 1            | 5.0             |
| Total              |        |             |              | 20           | 100.0           |

*Source* Bergmann *et al* 1971.

6 Surveys suggest prevalence rates between 2.6 and 15 per cent for borderline and mild states of senile dementia (Bergmann 1977a).

**Figure 2** Survivorship of general population and of cases of senile dementia over two decades. Data are from Lundby, Sweden, 1947-57 and 1957-67



Source Gruenberg and Hagnell (1978).

be able to demonstrate such a substantial increase in illness duration based on a population of this small size; other factors, including consistency in definitions, severity and timing of diagnosis, may also need to be taken into account. Unfortunately, there is no other body of data currently in existence with which valid comparisons could be drawn.

Furthermore, hospital samples analysed by Bergmann (1977a) have failed to evince evidence of improvement in survival. He found, as Roth had done, that around half of his female dementia patients had died within 6 months of admission. He suggested that hospital admission may therefore represent a critical stage in the brain disease beyond which little can be done to prolong survival.

## Genetics

Kallman (1951) found that if one of a pair of non-identical twins developed senile dementia, the risk for the other twin suffering the condition was 8 per cent. For genetically identical twins the risk increased to 43 per cent. The most extensive study of genetic factors in senile dementia was undertaken by Larsson and his colleagues (1963). They examined the records of two Stockholm psychiatric hospitals over a period extending from before the Second World War up to 1950. This revealed 377 definite cases of senile dementia according to Roth's (1955) classification. Relatives were traced from parish registers and 2,675 of the 3,426 family members so identified were subjected to field investigation. It was found that the morbidity risk for senile dementia was more than four times greater for the relatives of demented persons than for members of unaffected families. It was concluded that this increased risk reflected the influence of genetic factors. The authors were unable to be conclusive about the mode of inheritance but they favoured a process involving a single autosomal dominant gene. Other workers, however, have postulated a recessive or multifactorial mode of inheritance.

## Further epidemiological research

In many ways the epidemiological knowledge gained so far represents the basic foundations for the second phase of systematic investigation in which clues to the many remaining questions should be uncovered as the condition or conditions are defined with greater precision. Little is known, for example, about the incidence of dementia. A ten year study by Kay (1962) afforded sufficient data to suggest an annual average incidence of senile psychosis of 2 per cent after corrections for death but it is not possible to make any judgement on incidence patterns over time because of the lack of comparability between the few surveys that have so far been undertaken. Yet knowledge in this area is crucial to the planning of future services for the elderly demented. It has been suggested that the onset of dementia may now be occurring at later ages and that quite a small change of this kind could radically alter calculations concerning the proportion of high dependency in the elderly population (Godber 1979).<sup>7</sup> There is therefore a need for a new epidemiological study on a population sample to confirm or revise the findings of the Newcastle samples which were first surveyed almost 20 years ago.

Detailed information about age specific incidence profiles might hint at the existence of more than one disease process and would be useful in other contexts. For example, Tomlinson and

<sup>7</sup> Such calculations could be further confused by unpredictable improvements in life expectancy obviously not reflected in current population projections.



Kitchener (1972) found that the prevalence of the condition identified at autopsy as senile brain disease levelled off during the ninth decade of life. This could mean that the age specific annual incidence of the condition also levels off in this older age group. If this were the case, it would have important implications for research: individuals who had passed through the age of highest risk would have little chance of developing the condition and could serve as controls (Gruenberg 1978).

An important negative epidemiological finding is that no evidence has emerged implicating environmental influences such as isolation and poor social conditions. These factors are found in association with senile dementia but appear to be a consequence of the condition rather than having an aetiological bearing on it. In general, however, epidemiology has so far shed little light on the potential causes of dementia. Some studies, for example, have suggested that B<sub>12</sub> or folic acid deficiency may make an important aetiological contribution but disappointing results have emerged wherever populations of hospital patients with senile dementia have been investigated for this deficiency. Solving this type of question, that is the relationship between organic brain disease and scientific findings in the fields of biochemistry and immunological study, will rest on representative sampling, early diagnosis and appropriate control groups and is likely to become an important objective of future epidemiological investigation.

## The management of dementia

The inability to intervene pharmacologically or surgically to halt or reverse the insidious process of brain destruction in dementia means that care provision principally involves social and material support for affected individuals and their families. In this respect the term management, implying accurate diagnosis, the combined efforts of the psychiatrist, geriatrician, social worker and members of the primary health care team as well as the availability of facilities for day care and for 'respite' and long-term admission to institutional accommodation, is more appropriate than treatment (BMJ 1977). The role of medicines for example is, in the present state of knowledge, limited mainly to the relief of symptoms such as restlessness, although this is not to deny drug therapy a potentially important role in the correction of the biochemical and related abnormalities found in dementia in the future. This section will therefore examine the adequacy and appropriateness of current and projected health and social service provision for the demented and the likely impact of demographic trends over the remaining years of the century.

### Official guidelines

In the present decade policy documents have established the care of elderly persons as a major priority in health and personal social services provision (DHSS 1976, 1977). Furthermore, old age has recently been the subject of a discussion document (DHSS 1978a) and, at the time of publication, it was proposed that this should be followed by a Government White Paper. The general aim of policy is to help the elderly maintain independent lives in their own homes for as long as possible and to support those who care for them. The main emphasis is therefore on the development of domiciliary services and on the promotion of a more active approach towards the treatment of the elderly in hospital. It is, however, also stressed that it is important to provide hospital and residential care for old people unable to live independently in the community and to improve hospital facilities for early diagnosis, intensive treatment and rehabilitation.

Official guidance concerning the care of elderly persons with dementia (DHSS 1972, 1975) reflects the basic philosophy outlined above. It is considered that these individuals may be subdivided into three broad categories:

- i those with mild dementia but not suffering from other significant physical disease or illness.
- ii those with severe dementia but not suffering from other significant physical disease or illness.
- iii those with dementia, whether mild or severe, and also suffering from other significant physical disease or illness.

The first of these groups is by far the largest and includes those who are mildly confused and may have a tendency to wander but, though occasionally restless, over-active, noisy or aggressive, do not need continuous nursing care. Their condition may be associated with certain physical disorders such as some degree of incontinence. Given appropriate care and support, particularly at night, they can be looked after satisfactorily at home or in residential homes. Attendance at a day hospital or local authority day centre may also be a useful means of keeping the individual's needs under review and enabling him or her to continue to live at home.

Investigations undertaken in Newcastle during the 1960s indicated that the vast majority of elderly persons suffering from dementia were to be found living at home rather than in long-term residential or inpatient care; for every affected individual in institutional accommodation there were five in the community. On this basis it may be estimated that in England and Wales there are probably about 600,000 elderly people suffering from varying degrees of dementia living at home (1977 data).

Focusing on cases of 'definite' dementia in the community, application of the age-specific prevalence rates shown in Table 3 reduces this number from 600,000 to approximately 463,000. Projections based on the population in 1977 indicate that the latter total will have risen to 576,000 by 1995. These individuals do not constitute a homogeneous group, either in terms of severity of impairment or availability of family support, both of which may become modified over time. Nevertheless, it is clear that the burden of care will intensify in the remaining years of the twentieth century because all of the net change between 1977 and 1995 will be accounted for by the increase in the numbers aged 80 years or more.<sup>8</sup>

### **Determinants of survival in the community**

In 1978 Bergmann and his colleagues published a paper which attempted to identify those patients with dementia who were most likely to survive in the community and the factors which differentiated them from other individuals with the same condition whose viability in this setting was considered doubtful. Their research was based on 83 consecutive first admissions<sup>9</sup> to the acute assessment unit in a day hospital. Each patient was subjected to a rigorous multidisciplinary assessment, the results of which were re-evaluated after 3 months, and then followed up 12 months later.

It was clearly demonstrated that community resident day patients with dementia are a vulnerable group, about 70 per cent had died or were in institutional care before the end of the 12 month follow-up period (Table 8). Undoubtedly the most important factor which affected the patient's viability in the community was family support. Nearly 46 per cent of those living with children were still at home at the end of the twelve months. Patients living with just an elderly spouse were more vulnerable while those who lived alone were considered to be at greatest risk.

Demographic trends and social change do not, however, generate an optimistic outlook for the care of the elderly demented in the community. In England and Wales in 1931, there were more than 10 people aged 45-64 years for each person aged 75 and over. By 1951 the ratio had dropped to seven to one. Today

8 Those aged 80 years or more made up 59 per cent of the definitely demented elderly population in the community in 1977; this proportion will have reached 67 per cent by 1995.

9 Within this total the following diagnoses were recorded: senile dementia 51 per cent, arteriosclerotic dementia 34 per cent, presenile dementia 10 per cent and confusional states 5 per cent.

**Table 8** *Fate of community residents with dementia 12 months after initial assessment*

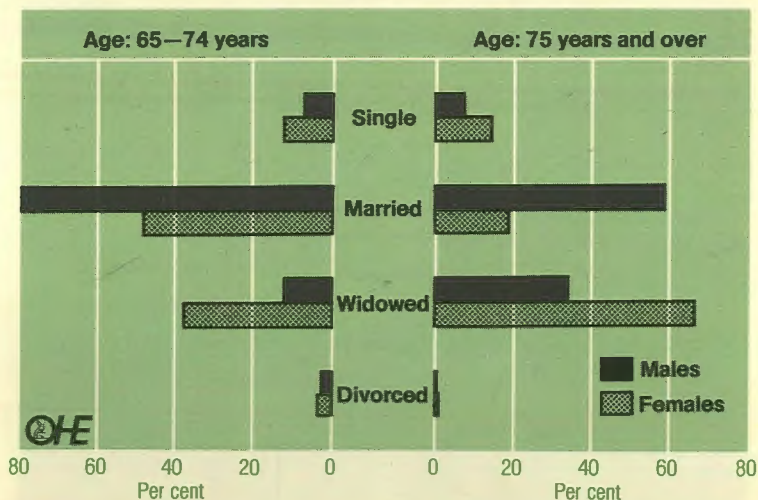
|                                |                           | <i>Initial domestic situation</i> |                    |                      |              |
|--------------------------------|---------------------------|-----------------------------------|--------------------|----------------------|--------------|
|                                |                           | <i>Living alone</i>               | <i>With spouse</i> | <i>With children</i> | <i>Total</i> |
| Outcome at 12 months follow-up | Resident in the community | 5 (19)                            | 5 (29)             | 11 (46)              | 21 (30)      |
|                                | In residential care       | 8 (30)                            | 0 (0)              | 3 (13)               | 11 (16)      |
|                                | In hospital               | 5 (18)                            | 5 (28)             | 4 (17)               | 14 (20)      |
|                                | Dead                      | 9 (33)                            | 8 (44)             | 6 (25)               | 23 (33)      |
| Total                          |                           | 27 (100)                          | 18 (100)           | 24 (100)             | 69 (100)     |

*Notes* 1 Percentages in brackets  
 2 12 patients originally in institutions  
 3 2 patients not traced

*Source* Bergmann *et al* 1978.

it is just over four to one, and by 1991 it will be little more than three to one. An estimated 25 per cent of those aged 65 and over have no children to assist them in times of need. Furthermore, provisional mid-year figures for 1977 suggest that in England and Wales among the population aged 65-74 years 20 per cent of males and 52 per cent of females were either single, widowed or divorced and that these proportions rose to 41 and 81 per cent respectively for those aged 75 years or more (Figure 3). Finally, data from the recent OPCS survey *The Elderly at Home* (Hunt 1978)

**Figure 3** *Marital condition of males and females aged 65-74 years and 75 years and over, England and Wales, 1977*



Source Annual Abstract of Statistics, 1979 Edition.

**Table 9** *The percentage of elderly people living alone, England, 1976*

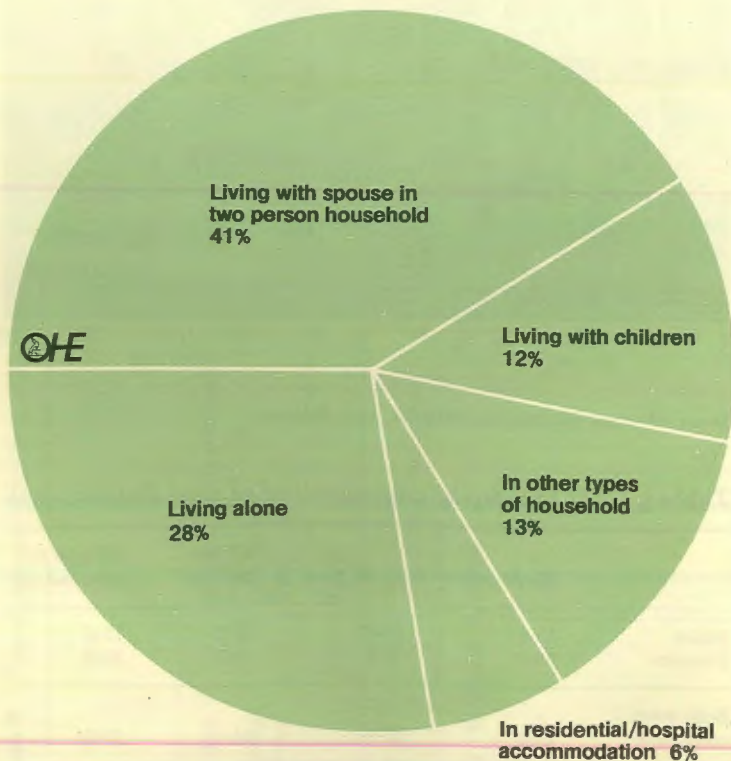
|                     | 65-74 years | 75-84 years | 85 years and over | All aged 65 years and over |
|---------------------|-------------|-------------|-------------------|----------------------------|
| Males               | 13.6        | 19.8        | 27.3              | 15.6                       |
| Females             | 33.6        | 47.1        | 50.0              | 38.8                       |
| Both sexes combined | 25.0        | 37.4        | 44.0              | 29.6                       |

Source Hunt 1978.

indicates that 69 per cent of the elderly population in England in 1976 lived alone or in a two person household with their spouse (Figure 4) and that the percentage of one person households rises sharply with increasing age (Table 9).

Even where there are children to care for their parents in old age changes in society may tend to make it increasingly difficult for families to assume this supportive role. The greater mobility of young adults in search of employment and regional depopulation due to industrial decline has in some instances left, and will leave in the future, elderly people isolated in traditional family neighbourhoods where previous generations had lived and worked. Continuing improvements in full and part time employment opportunities for females may mean that fewer women can devote as much time as may be necessary to care for a demented parent or parent-in-law at home. Better standards of living and expecta-

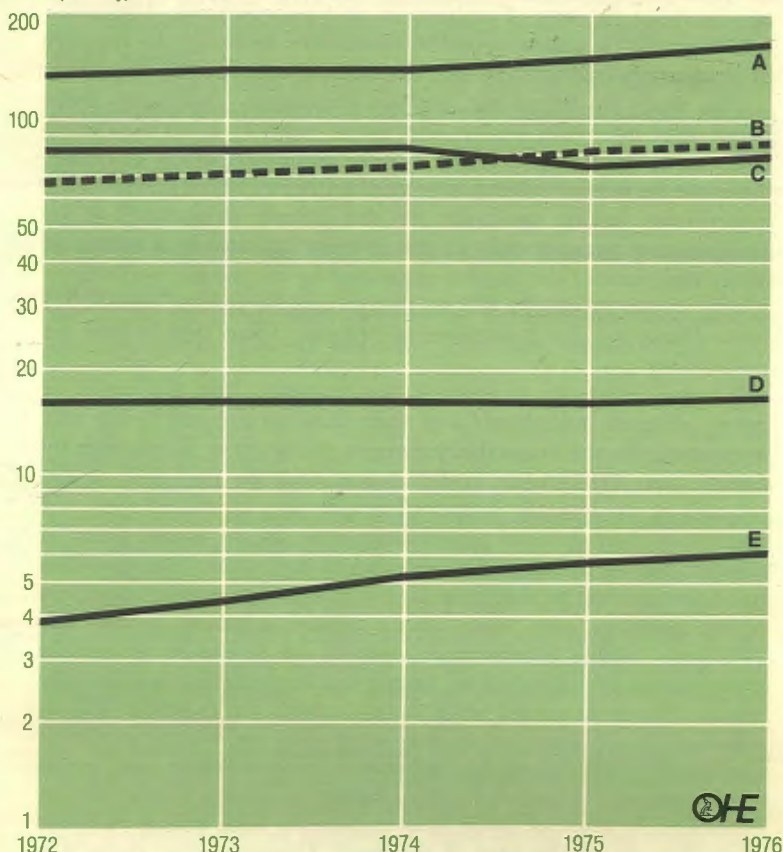
**Figure 4** *Who the elderly live with, England, 1976*



Source Hunt 1978.

**Figure 5** *Health and Social Services provision for the elderly, England, 1972-76*

Rates (see key)



**KEY**

**A. District nursing**

Cases attended of persons aged 65 and over (1.13 million in 1976) per 1,000 aged 65+.

**B. Home helps**

Cases attended of persons aged 65 and over (570,400 in 1976) per 1,000 aged 65+.

**C. Health visitors**

Cases attended of persons aged 65 and over (531,000 in 1976) per 1,000 aged 65+.

**D. Residential care**

Persons aged 65 and over in accommodation provided by or on behalf of local authorities (115,111 in 1976) per 1,000 aged 65+.

**E. Meals service**

Meals provided (40.5 million in 1976) per individual aged 65+.

Source Health and Personal Social Services Statistics, 1977.

tions of further improvements do not accord with caring for a persistently disturbed relative. Furthermore, it may increasingly be the case that the children of the very old are themselves at or approaching the age of retirement and experiencing difficulties which would be compounded to intolerable levels by the support of another individual who can do little to help him or herself.

The study by Bergmann and his colleagues (1978) also indicated that adequate health and social support is an important element in the survival of the elderly demented living at home. Thus the increasing provision of local authority social services and community health resources for the elderly (Figure 5) is an encouraging sign not only in this context but also as a means of absorbing some of the burden generated by the ageing population which would otherwise fall on institutions furnishing residential care. However, for a number of reasons, these trends may be misleading.

There is evidence to suggest, for example, that the needs of many affected individuals and their families are not being met adequately by the domiciliary services. A survey in Edinburgh by Stokoe and Williamson (1964) found that 80 per cent of the severely or moderately demented people they identified were not known to their general practitioner who, as an initial point of contact, has an important role to play in their care. This situation has been fostered by a general lack of knowledge among members of the primary care team about mental infirmity in old age (Williams 1978). Furthermore, within the workload of certain professionals the elderly may simply not be regarded as a priority group. As far as social work is concerned, for example, this is reflected in the observation that work with the elderly is almost exclusively undertaken by untrained social workers and social work assistants (Stevenson 1978). Similarly, health visitors devote considerably more of their time to families with young children than they do to the care of the aged. Consequently, there is a large hidden morbidity among the elderly which remains 'silent' until a crisis occurs.

It is also apparent that current levels of provision fall short of those recommended by the DHSS (Table 10) and there is evidence that such deficiencies may impinge more severely on the demented than on other groups. A survey by Foster and her colleagues (1976) found that in a randomly selected sample of 477 people aged 65 years and over living at home, 12 per cent were receiving domiciliary services from the local authority and a further 20 per cent were considered to require them (Table 11). Within the sample 27 people were diagnosed as suffering from chronic brain degeneration. Twelve (48 per cent) of the latter were in receipt of services and this was a higher proportion than in any other sub-



group. Despite this a further 9 (36 per cent) of the subjects with dementia were considered at risk and were recommended for domiciliary services. Moreover, for all the recipients except one, additional services were recommended, whereas fewer than 50 per cent of the non-dementia recipients were thought to require extra support.

The trends shown in Figure 5 also disguise the distribution of domiciliary services within the elderly population and do not indicate whether this represents the most effective allocation of resources. Bergmann and his team (1978) found that before their initial referral to day hospital, significantly fewer patients living with relatives (37 per cent) received local authority support than patients on their own (75 per cent). Following full assessment some of those in the former group were recommended for additional social work support (21 per cent) and local authority day centre care (21 per cent). However, assessment of those living alone suggested that the provision of further domiciliary services would have little value and in 61 per cent of these cases it was considered that admission to residential care was the preferable alternative. The authors concluded that there appears to be a strong case for focusing social work support, day centre care and other resources on those elderly demented patients who are cared for by their families.

Bergmann's analysis therefore suggests that the elderly demented living in the community may be separated into two broad groups – family supported patients and those living alone – and that a different approach to care is required in each case. Regarding the former, the principal objective is to prevent the family becoming overburdened and perhaps rejecting interest in, as well as the responsibility for, the patient's care. This implies a need to alleviate problem symptoms (for example restlessness at night), to provide a range of services extending from practical help such as laundry or night sitting to the much more elusive, but no less important, opportunities for the relief of feelings of despair, anger and guilt and to remove the patient temporarily when he or she is an added burden (for example, during acute confusional exacerbations or at times of family crisis or illness) or simply to give the family respite from the constancy of caring for the individual.

Day care in particular is an important element of the services for the elderly demented whose families provide the equivalent of nursing care at other times.<sup>10</sup> In this context the emphasis is on

<sup>10</sup> This means of support is, however, unlikely to be effective for all demented people. Many affected individuals react poorly to being moved from place to place and easily become confused (Arie 1973). For others transport difficulties may inhibit the use of day care.

**Table 10** *Provision of services used mainly by the elderly, England, 1976-77*

| <i>Service</i>   | <i>Official guideline</i>   | <i>Out-turn<br/>1976/77</i>               | <i>Illustrative<br/>projection<br/>1981/82</i> | <i>Percentage of<br/>cases involving<br/>those aged 65<br/>and over</i> |
|--|---|---|--|---|
| Health visitors  | 0.33 staff (WTE)<br>per 1,000 total<br>population                 | 0.15                                      | 0.21   | 13.7 (1976)   |
| District nursing                                       | 0.40 staff (WTE)<br>per 1,000 total<br>population                 | 0.26                                      | 0.35   | 40.6 (1976)   |
| Local authority<br>residential care for<br>the elderly | 25 places available<br>for every 1,000<br>aged 65+                | 18.6                                      | 18.7   | 100   |
| Home help  | 12.0 staff (WTE)<br>per 1,000 aged<br>65 years and over           | 6.3                                       | 7.5  | 87.4 (1976)   |
| Meals  | 200 meals per<br>week per 1,000<br>population aged<br>65 and over | 118                                       | 139  | Almost all  |
| Social work  | —   | 0.46 staff<br>(WTE) per<br>1,000 aged 65+ | 0.51   | Unknown   |

|   |   |        |        |  |
|---|---|--------|--------|--|
| Local authority day care for the elderly      | 3.0-4.0 places available for every 1,000 aged 65+ | 3.1    | 3.3    | 100  |
| Geriatric inpatients                          | 10 beds available for every 1,000 aged 65+        | 8.4    | 8.2    | 100  |
| Non-psychiatric day patients                  | 2.7 places available for every 1,000 aged 65+     | 1.3    | 1.4    | Unknown  |
| Mental illness inpatients                     | 0.5 beds available per 1,000 population           | } 2.1  | } 1.7  | In 1975 48 per cent of inpatients were aged 65 years or over |
| Elderly severely mentally infirm inpatients   | 2.5-3.0 beds available for every 1,000 aged 65+   |        |        |  |
| Mental illness day patients                   | 0.65 places per 1,000 population                  | } 0.32 | } 0.40 |  |
| Elderly severely mentally infirm day patients | 2.0-3.0 places per 1,000 aged 65+                 |        |        |  |

Source HPSS, 1978; DHSS 1978; Mental Health Enquiry 1978.

**Table 11** *The percentage of elderly people receiving (R) and needing (N) domiciliary services as reported in various surveys*

|                                | Home help |         | District nurse |     | Meals   |     | Health visitor |      |
|--------------------------------|-----------|---------|----------------|-----|---------|-----|----------------|------|
|                                | R         | N       | R              | N   | R       | N   | R              | N    |
| Williamson <i>et al</i> (1964) | —         | —       | 1.0            | 2.5 | —       | —   | 2.5            | 38.0 |
| Harris (1968)                  | 3.9-7.4   | 3.5-7.1 | 1.2-4.0        | —   | 0.4-1.0 | —   | 1.5-4.0        | —    |
| Townsend and Wedderburn (1965) | 4.4       | 5.7     | —              | —   | 1.0     | 5.9 | —              | —    |
| Gruer (1975)                   | 1.0-4.0   | 11.3    | 7.7            | —   | 1.0-4.0 | —   | —              | —    |
| Foster <i>et al</i> (1976)     | 6.5       | 6.5     | 2.1            | 3.8 | 1.2     | 6.3 | 4.4            | 20.3 |

Source Foster *et al* 1976.

day hospitals rather than on local authority day centres where activities are predominantly designed to meet the need for social care. The former cater for the treatment needs of individual patients, aiming to improve health and as far as possible to overcome disability.<sup>11</sup> It is intended that day hospitals should function as an alternative to inpatient care, serving to postpone or avoid admission to, or expedite discharge from, the latter. Recent evidence suggests, however, that their role may assume unintended characteristics. Green and Timburg (1979) for example found that their day hospital (serving part of the Western District of the greater Glasgow Health Board), in the event of the increasing numbers suffering from dementia and the shortage of beds and other supportive facilities, has been used to provide short-term support until beds become available on long-stay wards.

### Local authority residential care

The DHSS recommendation for the care of people suffering from dementia for whom domiciliary support is not feasible (generally those without families to look after them) but whose condition

<sup>11</sup> Day hospital facilities are to be available at least five days a week and places for the demented are included within the levels of provision for mental illness shown in Table 10. Some inpatients suffering from severe dementia may also benefit from attendance at day hospitals. The latter are to be located close to the inpatient accommodation with 2 to 3 places per 1,000 aged 65 years and over. This ratio also includes provision for demented persons who are not inpatients.

does not warrant admission to hospital, is that places should continue to be made available by local authorities in old people's homes under Part III of the National Assistance Act.<sup>12, 13</sup> However, it is difficult to assess accurately the magnitude of the demented population in such homes because estimates show considerable variation and are difficult to reconcile with one another. To some extent such inconsistencies may be real in the sense that surveys undertaken at different points in time will reflect developments in official policy concerning institutional care and the associated provision of alternative care facilities. More important, however, are discrepancies in regional service provision and in the criteria used to judge the severity of the condition. Consequently the following data provide only approximate orders of magnitude.

Jefferys (1978) has estimated that for every two elderly severely confused patients in psychiatric hospitals there are a further four in residential homes. On this basis it may be calculated that the affected population in residential care in England and Wales totals 40,000, a figure which appears to be reasonably consistent with the lower limit of Arie's (1973a) estimate that between one-third and one-half of individuals in such institutions are appreciably demented. Further, it represents one-third of the elderly demented population in institutional care<sup>14</sup>, a proportion confirmed, at the local level at least, by Pasker and her colleagues' survey (1976) in north-east Essex.

Provision for the demented in local authority homes is to be accommodated within the overall guideline of 25 places per 1,000 elderly. However, figures for 1976/77 indicate that, nationally, only three-quarters of this target has so far been achieved. 'The legacy of the erratic munificence of past benefactors and municipal provision' (Jeffreys 1976) and variations in social, economic and demographic factors imply that deviations from the norm may be magnified to an even greater extent at certain local

12 In practice it is the severity of behaviour disturbance rather than of dementia itself which constitutes the major criteria in determining whether residential care is appropriate to the needs of particular individuals (Godber 1979a). Jolley (1979) has suggested that with a more intensive medical and nursing input Part III residential homes offer perhaps the most suitable environment for the care of the majority of demented persons unable to live at home irrespective of whether their sufferings are physical or mental.

13 Voluntary and private homes also provide residential care for the elderly but because of inadequate staff numbers and expertise, admission policies tend to favour more able individuals. A joint study of voluntary homes by NCCOP and Age Concern (1977) found that 58 per cent of the homes felt unable to care for the mentally confused.

14 Estimated at 120,000 on the basis that 1 in 6 of all elderly demented are cared for in institutional accommodation.

levels.<sup>15</sup> Such shortfalls (nationally estimated at more than 40,000 places), in view of the expanding size of the elderly population and the pressures imposed upon families and other institutions providing care, have in the meantime encouraged the authorities to place more emphasis on the development of day care, community support groups and sheltered housing to satisfy unmet needs.

Demographic changes have also generated pressures within residential homes. At the same time as the number of elderly in care has risen (Table 12) concern has been mounting at the disproportionate increase in the workload generated by the 'ageing' of the residents. Since 1966 the number of persons aged 85 and over has increased by 50 per cent and is currently approaching the 50,000 mark. Extrapolations from data provided by the eighth report of the Health Service Expenditure Subcommittee indicate that in 1976 in local authority owned old people's homes, 18 per cent were aged 65-74 years, 44 per cent were in the 75-84 age group and 38 per cent were 85 years or older. The percentages in 1970 were 20, 45 and 35 respectively. The problems inherent in these developments have been enhanced by an increasing tendency for these homes to undertake, albeit reluctantly, the care of more individuals with greater degrees of impairment than in the past (Clarke *et al* 1979).

A survey by Wilkin and his colleagues (1978) which assessed the behavioural characteristics of residents in 7 local authority homes for the elderly, in 2 long-stay geriatric hospital wards and in one psychogeriatric ward in 1976 and 1977 in south Manchester found that much of the burden of increased mental and physical impairment among old people in long-term institutional care was being absorbed in social services residential care. The number of relatively able residents in the homes decreased, while the number of moderately and severely impaired increased in 1977. At the same time, the long-stay hospital wards contained fewer severely impaired patients in 1977 than in 1976, giving some bed space to those with smaller degrees of impairment.

There remains of course a range of able and disabled persons within individual homes but the increasing proportion of more dependent residents has not been matched by corresponding improvements in staffing levels, training programmes, and physical amenities. Consequently, it is feared that if the develop-

15 On a more optimistic note there has been a general improvement in the standards of residential care. Small purpose-built homes for example have increasingly replaced the workhouses which had their origins in the Poor Law era. In 1959 nearly half the residents were in large homes with an average of over 150 residents, but, in 1975, 80 per cent of residents were in homes which averaged only forty-three residents.

**Table 12** *The elderly in residential care, England, 1970-76*

|      | <i>Persons aged 65 and over in accommodation provided by or on behalf of local authorities<sup>1</sup></i> | <i>Persons in registered voluntary homes<sup>3</sup></i> |                                     | <i>Persons in registered private homes<sup>3</sup></i> |                                     |
|------|--|--|-------------------------------------|--|-------------------------------------|
|      |  | <i>Elderly and disabled aged 65+</i>                     | <i>Mentally disordered aged 65+</i> | <i>Elderly and disabled aged 65+</i>                   | <i>Mentally disordered aged 65+</i> |
| 1976 | 115,111  | 23,788 <sup>2</sup>                                      | 222 <sup>2</sup>                    | 21,320 <sup>2</sup>                                    | 317 <sup>2</sup>                    |
| 1975 | 109,743  | 22,454   | 207                                 | 18,759   | 259                                 |
| 1974 | 107,186  | 22,708   | 264                                 | 18,926   | 192                                 |
| 1973 | 105,517  | 23,418   | 314                                 | 19,750   | 127                                 |
| 1972 | 102,857  | 23,887   | 261                                 | 18,820   | 164                                 |
| 1971 |  |  |                                     |  |                                     |
| 1970 | 99,659   | 23,262   | 244                                 | 18,090   | 146                                 |

*Notes* Figures relate to 31 December prior to 1972 and 31 March thereafter.

<sup>1</sup> Accommodation provided under Sections 21(1) (a) and 26(1) (a) of the National Assistance Act 1948 excluding temporary residents.

<sup>2</sup> Figures for 1976 are for registered and unregistered homes.

<sup>3</sup> Provision within the terms of Sections 37-40 of the National Assistance Act 1948 for Homes for the Old and Disabled; Sections 19-21 of the Mental Health Act 1959 for Homes for the Mentally Disordered.

*Source* Health and Personal Social Service Statistics 1977.

ments observed between 1976-1977 continue, then the many advantages that residential homes offer as alternatives to long-stay hospital wards are in danger of being compromised. The general problem, which is especially pertinent with regard to dementia, is to determine the point at which infirmity warrants admission to residential homes and at which it is severe enough to be beyond the scope of this type of care. Unfortunately, in practice, rational judgements may be pre-empted by the pressures of the day-to-day interaction between the demand for care and the availability of resources.

### **The nature of residential care**

Experience of caring for the elderly demented in residential accommodation has resulted in the development of two different forms of management, that of integration in which affected persons and the rational live together and that of segregation where special homes or parts of already existing homes are made available specifically for the mentally confused. In an attempt to discover whether there was justification for the existence of special homes and what the effects both on the demented and the other residents and staff might be, Meacher (1972) undertook a survey of three homes in each category. He found that non-conforming behaviour, expressed in a variety of ways such as undressing in public and an uninhibited use of obscene language, was one of the major problems posed by the demented. On the whole however, it appeared that few residents in the integrated homes complained of the presence of demented patients, indeed other things unrelated to confusion, such as gossiping, caused them more distress and there was a degree of sympathy for the mentally infirm.

Perhaps one of the most significant of Meacher's findings was the existence of some manifestation of confused behaviour in at least 16 per cent of patients in normal homes and in only 58 per cent of those in 'separatist' homes. In other words more than two-fifths of the residents in the special homes were not considered to be confused. He found that these premises were used also for the accommodation of those who might be less socially acceptable in ordinary residential homes and for other individuals admitted under crisis circumstances when the need to find accommodation quickly meant that little regard was paid to the distinctions between confusion and non-confusion.

Meacher thus argued against 'separatist' homes as there may be a tendency for them to become a general dumping ground for 'difficult' or unwanted persons, rather than on evidence that they are intrinsically undesirable. Furthermore, many commentators consider that it is to the benefit of the elderly demented to be



cared for in an environment which includes individuals with a range of abilities and disabilities. On the other hand elderly confused people may settle more easily into specialist homes where provision can be made for their particular requirements.

As an alternative to both types of residential home some observers have suggested that, with early identification of individuals at risk and appropriate supportive services, sheltered housing could play an important role in providing accommodation for the elderly demented. Godber (1977) for example has proposed that a campus comprising a spectrum of units from the virtually unsupervised purpose-built old person's flat or bungalow to a nucleus of flats in which the residents could be supported to a point at which they require quite a degree of supervision and care would help to improve the quality of life for many of the individuals concerned. Consequently, he has suggested that the departments of housing, in cooperation with the hospital and social services, have an important part to play in the provision of facilities for the elderly and thus for the demented in the future.<sup>16</sup>

Much of the debate at present is based on anecdote, subjective opinion or generally untested assumptions and often reflects individual experiences with facilities which show substantial variation in both quantity and quality throughout the country. Careful analysis of those types of residential care (and their access to back-up health and social services) which appear to be particularly successful in satisfying the needs of their elderly clients is therefore required if plans for the future are to be based on knowledge rather than prejudice. However, it would be unrealistic to suppose that there is one superior form of residential care for all elderly mentally infirm people (MIND 1979).

### **Psychiatric hospitals**

Persons suffering severe dementia without any other significant physical disease or illness may require continuous nursing supervision which can only be provided on a hospital inpatient basis. Persistent incontinence without treatable cause may be a principal factor determining this requirement. Access to the wide range of diagnostic and treatment facilities available only in general hospitals may be required initially for assessment but is not normally needed subsequently for longer term care. The DHSS therefore recommends that these patients may most appropriately be accommodated in relatively small hospitals serving local

<sup>16</sup> Whilst the total number of sheltered housing units is unknown, in recent years about one-quarter of the local authorities' housing programme has involved this type of accommodation (DHSS 1979).

communities where numbers can be kept manageable and where the interest of friends, relatives and local communities can be more easily maintained.<sup>17</sup> Responsibility for admission would rest with the psychiatrist to whom patients will have been referred for assessment and who will it is hoped be a psychiatrist with a special interest in the psychiatry of old age. Day to day medical care may be given by local general practitioners working at the community hospital.

It is anticipated that at any one time bed provision for the elderly severely mentally infirm is required on a scale of 2.5–3.0 beds per 1,000 aged 65 and over. This is currently equivalent to an average inpatient population in England and Wales of nearly 20,000 (1977 data). Most of these patients are still accommodated in the old mental illness hospitals and units where, according to figures for 1975, they represent an estimated 21 per cent of all inpatients and 43 per cent of those aged 65 years or more.

The Mental Health Enquiry (England 1975) also indicated that in the same year there were 4,796 *first* admissions (70 per cent of which were females) to psychiatric hospitals for senile and presenile dementia among those aged 65 or more. This diagnostic category represented 31 per cent of all first time admissions in this age group. *All* admissions among the elderly for dementia totalled 8,809 (71 per cent females), equivalent to 23 per cent of admissions for all diagnoses.<sup>18</sup>

The 5,034 discharges of persons with senile or presenile dementia from mental illness hospitals and units accounted for only 3 per cent of the total in 1975 and 60 per cent of these had been inpatients for periods of less than 2 months. Conversely, dementia deaths in hospital represented 36 per cent of the total and substantially greater proportions – approaching 50 per cent – among those with durations of stay of between 6 months and 3 years (Figure 6).

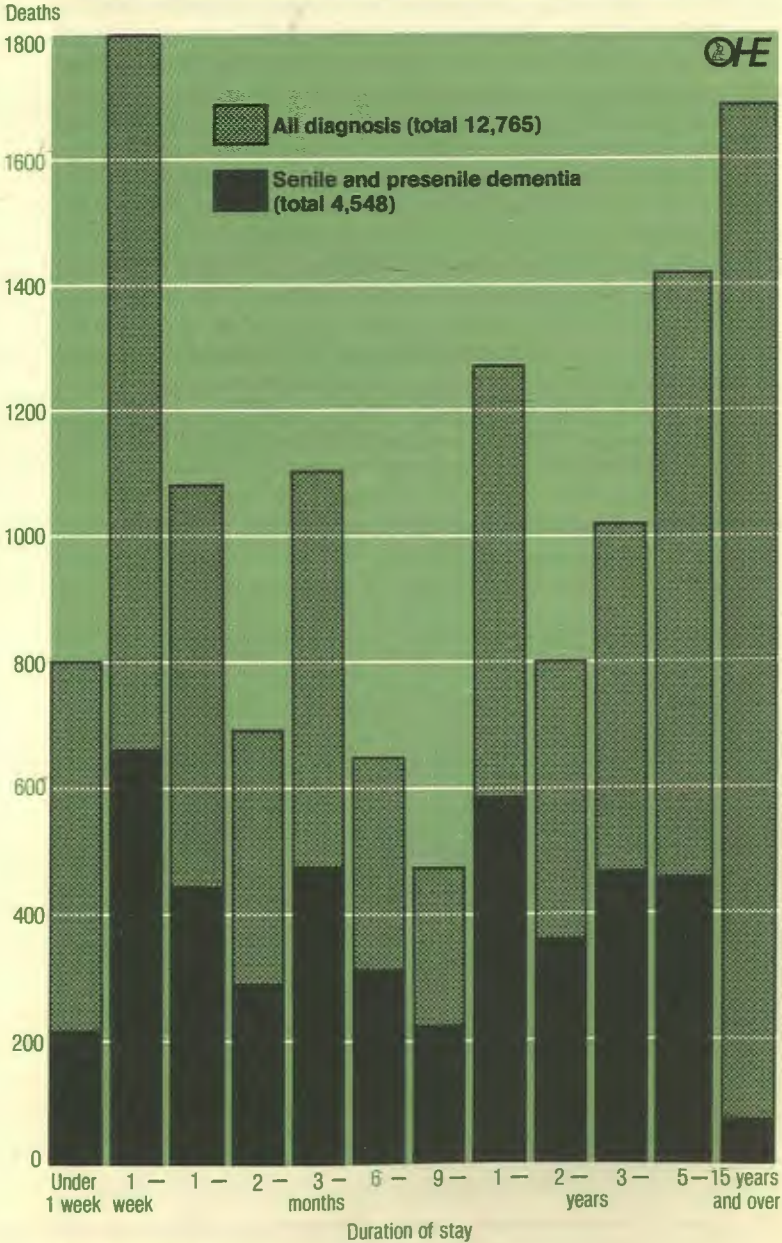
### Recent Trends

Focusing on the population aged 65 years or more, the data show that all and first admission rates to mental illness hospitals for all

17 A community hospital is a local hospital which: provides services for patients living locally who do not need full specialist facilities of a DGH; does not form part of a DGH complex; provides services for patients under the care of general medical practitioners as well as patients under the care of hospital consultants; is not confined to one specialty; and, where appropriate and practicable, provides, among other services, rehabilitation and continuing care of elderly patients, including the elderly severely mentally infirm.

18 In 1975, 80 per cent of admissions for senile and presenile dementia were to mental illness hospitals compared to 69 per cent for all diagnostic categories together; 14 per cent were to units in general hospitals compared to 27 per cent and 6 per cent were to units in geriatric hospitals compared to 3 per cent.

**Figure 6** Deaths in mental illness hospitals and units by duration of stay, all diagnoses and senile and presenile dementia, England, 1975

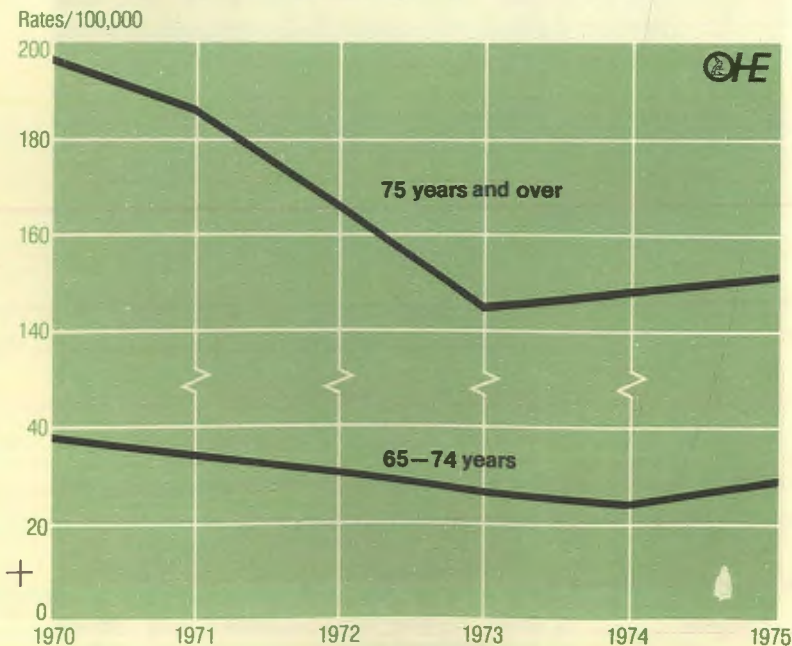


Source Mental Health Enquiry 1978.

diagnostic categories together fell by one and thirteen per cent respectively over the period 1970-75 in England. The rates specifically for senile and presenile dementia together altered more spectacularly: all admissions rates fell by 15 per cent and those for first time events by 24 per cent (Figure 7). (The percentage changes would have been considerably greater had 1970 been compared with 1974. Whether the reversal of trend shown by 1975 data will continue remains to be seen.)

A combination of factors may be responsible for this trend which, in view of the increasing size of the elderly population, may appear surprising. Expansion of the community health and local authority social services may have enabled more demented old people to be cared for adequately at home (Figure 5). However, while this growth might be expected to have improved the circumstances of the elderly able to look after themselves at home or those relying on family support and even to have reduced the total number of days of care in hospital, it is unlikely significantly to have diminished the number ultimately deteriorating to the

**Figure 7** *First-admission rates for patients with diagnosis of senile or presenile dementia, England, 1970-75*



Source Mental Health Enquiry, various years.

point at which they require the continuous nursing supervision and care available in psychiatric hospitals and units.

The expansion of residential care and particularly of homes for the elderly mentally confused may possibly have contributed to the fall over these years— though in the latter half of the 1960s when growth was even more rapid there was no evidence of a corresponding abatement in the flow of demented old people in psychiatric hospitals. Since 1970 there may also have been some shift to geriatric care of patients who normally would have been admitted to psychiatric units but, in the absence of appropriate data, this hypothesis is difficult to test. Other explanations, reflecting individual experience, have attributed the decline in admissions to falls in the overall number of psychiatric beds available (Todd 1978) and to an effective reduction in capacity to admit resulting from increased lengths of stay (Pullen 1978).

An alternative hypothesis, proposed by Shulman and Arie (1978), suggests that recent trends are a reflection of the increasing reluctance of psychiatrists to admit new elderly demented patients to their hospitals. The time when the trend changed— 1969–70— coincided with the beginning of reports of 'scandals' in institutional care. The publication in 1969 of the Ely Hospitals report and soon after, that on Whittingham Hospital, were followed by an unprecedented scrutiny of long-stay or residential care. The visits of the Health (formerly Hospital) Advisory Service to all psychiatric units during this time drew attention to overcrowding, shortages of staff and resources, and consistently encouraged further reductions in bed numbers. As a result of these developments psychiatrists have become increasingly concerned about both overcrowding, with its consequences for the quality of life of both patients and staff, and personal criticism in the face of the ever-present danger of incidents and scandals so that they may be less willing to admit elderly patients, especially those who are unlikely to leave hospital. If this is the case, Shulman and Arie argue, then a consequence of the general improvement of the internal environment of psychiatric hospitals that has taken place during this period may have included greater hardship for old people and their families at home.

### **Adequacy of psychiatric inpatient provision**

The non-availability of reliable data means that it is not possible to determine whether official guidelines are being achieved at either national or regional levels.<sup>19</sup> More fundamentally, however, Jolley (1977, 1978) has criticised the adequacy of the proposed

<sup>19</sup> At the 1971 census of mental illness hospitals a substantial degree of regional inequality was found; 6 of the 14 English regions fell below the suggested level of 2.5–3.0 beds per 1,000 elderly and only two exceeded it.

norm on two main grounds. First, he has pointed out that this ration was derived from the census estimate of beds occupied by the demented in mental hospitals in 1971 and although it provides reassurance that there will be no reduction of beds for these patients, it does not take account of the significance of future demographic patterns. A norm based on the number of people aged 65 and over is not in itself sensitive to the prevalence of dementia, which is most common among very old people. Projections show that the number of people aged 75 and over will increase much more rapidly than those over 65, and that the former will continue to increase after the latter have 'levelled off'. Guidelines based on the over 65s could thus be quite inappropriate to the pattern of need deriving from the main users of services, the very old.

The second criticism is that the norm fails to take account of the extent to which care is provided (sometimes inappropriately) for the demented by geriatric hospitals and residential homes. Jolley's survey in south Manchester in November 1975 found that 21 beds were provided for elderly demented patients by psychiatric hospitals while local geriatric hospitals contained 59 patients whose sole disability was severe dementia. In old people's homes approximately 10 per cent of the residents were found to be severely demented. It may be argued that where there are active geriatric facilities the elderly need fewer psychiatric services. However, in terms of bed availability region by region there is no consistently raised geriatric provision in areas where few beds in psychiatric hospitals are available to demented patients (crudely indicated in Table 13). Furthermore, the argument ignores the official tripartite division of dementia and the role of different institutions in fulfilling care requirements.

Jolley considers that if the number of beds for these patients remains the same as that formerly provided just by the psychiatric service then it will not be possible to maintain the level of services as the size of the demented population increases. Consequently he believes it essential that 'the 1971 survey of inpatients be repeated and extended to include not only psychiatric hospitals but also geriatric hospitals and to be truly comprehensive it should include Part III accommodation as well'.

It has also been emphasised that the number of beds *in use* can be a very misleading guide to the numbers of beds *needed* (Jolley and Arie 1976). The latter is of course influenced by questions concerning the quality and type of service desired. A low number of beds might well be sufficient for an effective crisis service, or even for a long-stay care service, while not giving opportunities for elective admission, early treatment, relief for relatives, or for investigation.

| Area          | Geriatrics   |                     | Mental illness                                    |                     |
|---------------|--|---------------------|---|---------------------|
|               | Average daily available beds per 1,000 population aged 65 and over | Ranking high to low | Average daily available beds per 1,000 population | Ranking low to high |
| England       | 8.3  | —                   | 2.1   | —                   |
| Northern      | 9.2  | 3                   | 2.1   | 9                   |
| Yorkshire     | 10.4   | 1                   | 2.3   | 11                  |
| Trent         | 8.2  | 9                   | 1.7   | 2                   |
| East Anglia   | 8.8  | 5                   | 1.8   | 4                   |
| NW Thames     | 7.0  | 13                  | 2.7   | 12                  |
| NE Thames     | 8.6  | 7                   | 2.0   | 7                   |
| SE Thames     | 7.3  | 11                  | 2.2   | 10                  |
| SW Thames     | 6.7  | 14                  | 3.1   | 14                  |
| Wessex        | 8.8  | 5                   | 1.8   | 4                   |
| Oxford        | 8.1  | 10                  | 1.3   | 1                   |
| South Western | 7.2  | 12                  | 2.0   | 7                   |
| West Midlands | 9.5  | 2                   | 1.8   | 4                   |
| Mersey        | 9.2  | 3                   | 2.8   | 13                  |
| North Western | 8.4  | 8                   | 1.7   | 2                   |

Source Health and Personal Social Service Statistics, 1977.

1 Provisional data.

### Non-psychiatric hospitals

The combination of dementia, whether mild or severe, and significant physical disease or illness is one which is frequently found in old age.<sup>20</sup> When affected individuals require hospital inpatient treatment it is proposed that they should be accommodated in geriatric beds and provision for this demand is included in the officially recommended planning ratio for geriatric services

<sup>20</sup> Mezey *et al* (1968) found psychiatric disorders of varying severity in 30 per cent of patients in a geriatric unit in their North London Study. This compared with 63 per cent in Belfast (Kidd 1962a) and over 58 per cent in Newcastle (Kay, Beamish and Roth 1962). In the psychiatric unit they found that 52 per cent of patients were suffering from a physical illness or disability. The corresponding figures were 47 per cent in Belfast (Kidd 1962a) 28 per cent in Newcastle (Kay *et al* 1962) and 33 per cent in Brighton (Herbert and Jacobson 1966).

of 10 beds per 1,000 population aged 65 and over.<sup>21</sup> Occasionally, because of behavioural problems such patients may have to be transferred, possibly temporarily, to accommodation supervised by the psychiatrist. The question of transfer to psychiatric care also arises for patients who have been successfully treated for their physical condition but in whom a severe degree of dementia becomes apparent. For the majority of patients discharge back to the community or perhaps to residential care should be possible once appropriate arrangements have been made with relatives, the general practitioner and local authority social services departments.

Estimating the numbers of elderly demented in non-psychiatric hospital care poses many problems. Traditional measures are of limited value: the Hospital Inpatient Enquiry (HIRE), for example, does not primarily aim to identify mental disorders even when they are one of the fundamental reasons for admission.<sup>22</sup> Furthermore, in general hospitals frequently no note is made of the presence of mental disorder when a patient is admitted with, say, a fractured femur or congestive cardiac failure. Nevertheless, a survey of 100 elderly patients admitted to an acute medical unit in a general hospital (Bergmann and Eastham 1974) found that 7 per cent of those screened were demented.<sup>23</sup> Although it is not possible to measure this area of 'overlap' at a national level, the growing proportion of hospital beds occupied by the elderly (Table 14) increases the likelihood that more rather than fewer inpatients will show signs of dementia.

Jefferys (1978) has estimated that for every two severely confused persons in psychiatric inpatient care there are a further three in geriatric hospitals. This ratio generates a figure of approximately 30,000 for England and Wales which is equivalent

21 Provisional data for England indicate that in 1976 8.3 geriatric beds were available per 1,000 aged 65 and over. It is recommended that 50 per cent of geriatric beds should be sited in general hospitals where there is already access to the full range of diagnostic and therapeutic facilities and that the remaining beds should be situated in smaller local hospitals nearer to the patient's home. The development of day hospitals is also encouraged, and a norm of two day places per 1,000 elderly population has been recommended.

22 This is reflected in the HIRE estimate that there were just 5,717 discharges and deaths for senile and presenile dementia in 1974.

23 The demented patients ascertained in this study were demonstrably less impaired intellectually and behaviourally than patients receiving long-term care (Blessed *et al* 1968) and less socially disadvantaged as a result of their dementia than the community residents described in the Newcastle series. The authors suggested therefore that the acute medical ward may represent an opportunity for early assessment of such patients and appears to provide a good platform on which to initiate support to the patient and more especially the relatives.



**Table 14** *Percentage of average number of (non-psychiatric) hospital beds in daily use occupied by those aged 65-74 years and 75 years and over, by selected departments, England and Wales*

|                   |       | 1968 | 1970 | 1973 | 1976 |
|-------------------|-------|------|------|------|------|
| All departments   | 65-74 | 17.5 | 17.6 | 18.6 | 19.2 |
|                   | 75+   | 25.5 | 26.3 | 30.1 | 33.9 |
| General medicine  | 65-74 | 23.9 | 25.4 | 27.3 | 28.2 |
|                   | 75+   | 19.9 | 20.6 | 21.6 | 23.4 |
| Diseases of chest | 65-74 | 21.6 | 24.2 | 28.0 | 29.4 |
|                   | 75+   | 14.8 | 13.9 | 16.0 | 20.1 |
| Geriatrics        | 65-74 | 23.9 | 21.7 | 21.9 | 20.5 |
|                   | 75+   | 64.7 | 66.5 | 69.8 | 75.3 |
| General surgery   | 65-74 | 19.2 | 20.9 | 21.9 | 23.7 |
|                   | 75+   | 13.7 | 14.3 | 16.4 | 18.5 |

*Source* Hospital Inpatient Enquiry, various years.

to 30 per cent of the 99,835 non-psychiatric hospital beds occupied daily by those aged 65 years or more in 1976 (HIFE 1979).<sup>24</sup> This figure is also consistent with Pasker's (1976) observation in north-east Essex that geriatric services provided 28 per cent of institutional psychogeriatric care. It appears that the demented may therefore constitute a sizeable element of the geriatric inpatient population. The proportions of long-stay residents, of those awaiting discharge either to their homes or to other forms of residential care and of those admitted primarily for the treatment of physical disorders are, however, unknown.

### **Psychogeriatric assessment units (PGAU)**

The extent to which psychogeriatric patients are 'misplaced' within the institutional care sector and the implications this may have for their well-being were established as issues of major importance in the early 1960s. In a study of groups of elderly people admitted to psychiatric and geriatric units in Belfast, Kidd (1962) contended that 24 per cent of patients in the former and 34 per cent in the latter could be classified as either definitely or probably misplaced according to his criteria. Furthermore, at follow-up he claimed to show that individuals regarded as misplaced experienced a higher mortality rate and longer stays in both hospitals than those who had been correctly placed.

<sup>24</sup> 51,243 of these beds were in geriatric departments and 79 per cent of these were used by persons aged 75 years and over with a mean stay of 86 days.

Subsequent studies failed to replicate these findings. Mezey, Hodkinson and Evans (1968), in two densely populated boroughs in north London identified a much smaller degree of misplacement: 14.6 per cent and 8.3 per cent in the psychiatric and geriatric units respectively. Langley and Simpson (1970) working in the West Country obtained similar results. In addition, neither groups, nor Copeland and his colleagues in Camberwell (1975) could confirm the adverse effects of misplacement on prognosis.

There is also evidence of 'misplacement' of people of greater independence and of those with excessive disability in local authority homes – that is, residents who do not need the degree of support offered by such homes and others whose requirements are beyond the scope of this type of care (Gilleard and Pattie 1977). Coleman (1975) has quoted studies which suggest a misplacement rate of between 20 and 60 per cent of residents considered to need a less dependent regime, for example, sheltered housing or community support. On the other hand social services departments have noted an increase in the age and dependency of elderly people coming into their care during the last decade (DHSS 1977a). Pattie and Gilleard (1978) have suggested that the problem arises, in part, as a result of the absence of detailed criteria for admission, an observation supported by recent research by Brocklehurst and his colleagues (1978): after screening 100 old people at the time of their acceptance for admission to residential care they recommended that 12 would have been more appropriately cared for at home and a further 5 would have been better off in long-term psychogeriatric care.

The misplacement of elderly persons suffering psychiatric disorder may also stem from inadequate investigation of individual patient needs. In view of deficiencies of this nature and the involvement of both geriatricians and psychiatrists in the care of such patients, the DHSS (1970, 1975) has consistently advocated the establishment and use of joint psychogeriatric assessment units and the latter now constitute an important cornerstone of official policy concerned with psychogeriatric care. It is recommended that the units should contain 10–20 beds for every 250,000 general population and that they are best located in the geriatric department at the general hospital<sup>25</sup> where a full range of appropriate medical and nursing skills, together with diagnostic and treatment facilities are available to the patient from the time of admission. Patients would normally remain in the assessment unit for not more than about 4 weeks, those needing further

25 As geriatric and psychiatric departments become provided in general hospitals in close proximity to each other the need for a discrete joint assessment beds is likely to diminish.

treatment being transferred to the geriatric or psychiatric wards as appropriate.<sup>26</sup>

The PGAU has a particularly valuable role in promoting collaboration between geriatric and psychiatric services in the care of the elderly mentally infirm especially where facilities exist in separate localities (Arie 1979). It may also serve as a centre to give joint psychiatric and medical training to nurses and doctors involved in all aspects of the care for the elderly. Furthermore, it functions as a sorting station for patients who are likely to require long-term care in mental hospital beds and for those with both dementia and major physical disability who might ultimately reach long-stay geriatric beds. For individuals who do not require continuous nursing attention full assessment and rehabilitation may pave the way to residential care or even forestall it. The PGAU may also provide a means of satisfying demand for short periods of hospital care arising, for example, from transient deterioration in the dementing condition or from the development of a crisis in the patient's domestic environment.

However, the PGAU is not to be seen as a panacea for the psychogeriatric problem (Godber 1978). Criticisms have, for example, included the fact that it may be disadvantageous for the elderly patient to be admitted to one place and later to be transferred to another, just as he or she has settled down. The availability of assessment beds may also discourage adequate pre-admission domiciliary assessment, which has been shown to be particularly important in determining appropriate strategies for the management of demented patients (Arie and Dunn 1973). But perhaps a more fundamental problem concerns the ability of these units to function in the designated way.

The increasing size of the demented population will necessitate a rapid turnover of patients in the PGAUs but it is this area that they are particularly vulnerable. Apart from the normal problems of negotiating patients' discharge to their own homes or to residential accommodation the PGAU also has to place a significant proportion of its patients in long-stay geriatric and psychiatric beds. If there is a hold-up in the transfer of patients to the geriatric area the unit may increasingly take on the characteristics of a long-stay geriatric ward. The equivalent pattern may occur when the blockage is in the psychiatric part of the service and even more seriously when there is a blockage in both. Furthermore, delays in the transfer system may mean that

<sup>26</sup> Robinson (1977) has suggested that the recommended maximum period of bed occupancy in the PGAU may be insufficient and that in many cases six weeks is the minimum consistent with safety and good therapy.

urgent cases which would have been admitted to the PEAU may have to be diverted as 'social admissions' to acute medical or psychiatric beds, generating the type of misplacement the PEAU is designed to avoid in the first place.

The effectiveness of the PEAU is thus highly dependent upon an adequate level of resources in, as well as the efficient functioning of, those areas of the health and social services which provide care for the elderly demented. Currently, however, there is evidence of widespread deficiencies and it seems likely that these may become still greater as the size of the elderly population increases. Against this general background there has increasingly been a tendency to reconsider the concept of the PEAU with attention focusing on the principles and methods of some of the most successful services caring for the elderly mentally infirm, many of which do not employ formal units of this nature (Jefferys 1979).

## Economic and social costs

The cost in 1976-77 of the Health and Personal Social Services (HSS) Budget in England was capital £477 million and current (or revenue) £5,608 million, making a total of £6,085 million at November 1976 prices. The estimated capital and revenue costs of the services used mainly by the elderly and physically handicapped (officially identified as those services marked by an asterisk in Table 15 in addition to chiropody, aids and adaptations and services for the disabled) were £61 million and £735 million respectively. Together the latter represent 13.1 per cent of total HSS expenditure in England.

This proportion, however, relates only to those services used *mainly* by the elderly; the latter are of course major consumers of most of the other health services. For example, 48 per cent of mental illness hospital inpatients are aged 65 years or more, 38 per cent of the average number of acute beds used daily (1976 data) are occupied by patients over 65 years of age (Hansard 1979), and almost 20 per cent of the general practice workload, measured in terms of consultations, is generated by the elderly (OPCS 1974). Consequently, it has been estimated that some 35 per cent of HSS expenditure is attributable to the treatment and care of the over-65s and 20 per cent to the over-75s (Owen 1976). On this basis, expenditure per head stood at £131 in 1976-77 for the population as a whole, £320 for individuals aged 65 years and over and £507 for the over-75s.

The scope for identifying that part of the expenditure on the elderly which stems specifically from dementia is severely limited

by a lack of knowledge about levels of service usage and the accounting problems in apportioning the costs of caring for individuals suffering from more than one illness. Indeed, only the cost of maintaining the demented in psychiatric hospitals and residential homes can be calculated with any degree of confidence: applying officially determined out-turn costs to the inpatient populations derived earlier in this paper indicates approximate expenditures of £85 million and £53 million respectively in 1976-77.

Unfortunately, it is not possible to estimate the cost of caring for the demented in geriatric hospitals because the size of the relevant population is unclear and the facilities provided in this sector do not constitute a homogeneous entity. Thus 30 per cent of geriatric beds and 50 per cent of cases are in acute (types 1, 2 and 3) hospitals compared with 42 per cent of beds and 26 per cent of cases in type 19 (eg, geriatric) hospitals (DHSS 1978). The average cost per day - all inpatients - in a type 1-3 hospital in 1975-76 was £26 compared with £12 in a type 19 hospital.<sup>27</sup>

Nevertheless, if it is assumed that one-quarter of the resources consumed by elderly patients (Table 15) can be associated with dementia then combining the resulting sum with the cost of psychiatric inpatient and local authority residential care it may be estimated that this condition involved an expenditure in excess of £300 million in 1976-77. This figure represents of course only a crude order of magnitude which, if anything, is likely to understate the true level of cost because no account is taken of other hospital expenditure, the use of drugs and the economic burdens experienced by caring relatives.

### **The economics of domiciliary care**

For about 20 years the Department of Health and Social Security has been advising, on both social and economic grounds, that whenever possible domiciliary care is to be preferred to custodial alternatives for the elderly sick. Consequently, official statements of policy have repeatedly placed emphasis on the development of domiciliary services. However, the economic issues are by no means straightforward and as the following analyses make clear the outcome of costing exercises in this field are highly sensitive to the nature of the input data.

Wager's (1972) cost benefit examination of the resource costs

<sup>27</sup> This does not mean that the daily costs of all beds in types 1, 2 and 3 hospitals are the same - long-stay patients use expensive diagnostic and therapeutic services far less than short-stay. However, it would require a detailed analysis beyond the scope of the present paper to derive a more accurate picture of the usage and costs of these services.

**Table 15** *The cost of services used mainly by the elderly, England, 1976-77 (November 1976 prices), £ millions*

| <i>Service</i>   | <i>Out-turn cost 1976-77</i> |                | <i>Illustrative projection 1981-82</i> |                | <i>Estimated amount of total 1976-77 cost due to elderly</i> |
|--|------------------------------|----------------|--|----------------|--|
|  | <i>Revenue</i>               | <i>Capital</i> | <i>Revenue</i>                         | <i>Capital</i> |  |
| Health visitors  | 47                           | —              | 63                                     | —              | 6.4  |
| District nursing*  | 81                           | —              | 108                                    | —              | 32.9   |
| Local authority residential care for the elderly and disabled* | 170                          | 20             | 188                                    | 9              | 174.8  |
| Home help*   | 105                          | —              | 131                                    | —              | 91.8   |
| Meals*   | 12                           | —              | 15                                     | —              | Almost all   |
| Social work  | 107                          | —              | 119                                    | —              | Unknown  |
| Local authority day care for the elderly and disabled*         | 23                           | 5              | 26                                     | —              | 16.8   |
| Geriatric inpatients and outpatients*                          | 263                          | 35             | 310                                    | 36             | Not 100 per cent as units for younger disabled are included  |
| Non-psychiatric day patients*                                  | 15                           | —              | 18                                     | —              | Unknown  |
| Mental illness inpatients and outpatients                      | 393                          | 24             | 426                                    | 32             | 200  |
| Psychiatric day patients                                       | 16                           | —              | 20                                     | —              | Unknown  |
| Family practitioner services                                   | 1,019                        | —              | 1,144                                  | 1              | 198  |

\*See text

Source DHSS 1978.

of domiciliary and residential care led to the conclusion that for those living in sheltered housing or lower value 'normal' housing there was, on average, a margin of between £3 and £4 per week to be taken up by domiciliary services before the expense of domiciliary care became equated with the cost of residential care. In higher value housing the margin was smaller or negative, consequently domiciliary care failed to offer any resource saving for the community over residential care and was in some cases substantially more expensive.

More recently, an investigation by Opit (1977) into the costs of domiciliary support for 139 elderly sick patients receiving home nursing services has further helped to dispel the notion that the former is universally a cheap alternative to institutional care. The study calculated the direct costs of care, for example, nursing, home help, meals, laundry services and the provision of aids and equipment, according to diagnostic category and patient activity state.<sup>28</sup> In order to facilitate comparison with the expenditures involved in institutional care, account was also taken of indirect costs: pension, benefit and attendance payments, which are reduced or abolished on admission to an institution, were designated positive elements in the overall cost of domiciliary care. It was then shown that services for a patient receiving weekly four hours' visiting, four hours of home help and two meals cost the equivalent of the non-medical resources given to a person in a residential home and about two-thirds of those available to individuals in an established geriatric inpatient unit. Opit also suggested that if the work created by his sample of patients represented half of the total nursing load of the administrative district in which the study was undertaken, then 5 and 10 per cent of all patients would cost more to support at home than in hospital and residential care respectively.

The contribution made by families and friends to the support of elderly individuals at home is an important consideration in the economics of domiciliary care. Yet the difficulties in deriving a representative monetary value for the goods and services provided have resulted in the exclusion of this potentially substantial indirect cost from many analyses. An exception, however, is Rickard's (1979) paper in which he also took capital costs into account. A sample of chronic sick patients was divided into quartiles according to the number of nursing visits received. The

<sup>28</sup> There were 25 patients in the dementia diagnostic category. Four were classified as bedfast (10 per cent of this activity grouping), 15 as partial self-care (23 per cent) and 6 as self-care (17 per cent). In each activity grouping the direct costs of care for dementia exceeded the average, by 36 per cent, 11 per cent and 43 per cent respectively.

use of services by the fourth quartile, comprising patients on the borderline between domiciliary and long-term hospital care, was recorded and a cost schedule drawn up. Data from the Family Expenditure Survey was used to provide estimates of daily household costs.

The private expense to families of domiciliary care – job opportunities foregone, leisure sacrificed, changes in the pattern of family life, strain and anxiety – are not readily quantifiable in money terms. The only guide to the value placed on such voluntary labour by central decision-makers is the constant attendance allowance paid to a member of the family who is obliged to provide continuous support to a sick person. Rickard used this 'transfer' cost to define the lower limit of the value of family support and earnings foregone, measured by average weekly wage levels, as the upper limit.

The inclusion of capital values in comparisons of the costs of domiciliary and other forms of care is relevant if it is the case that when a person is admitted to long term care, the house or rooms he or she would otherwise have been occupying are released for alternative use. The higher value shown in Table 16 represents the example of a person previously living alone in a house which is then sold or relet whilst the lower value denotes a situation in which transfer to institutional care of a family supported individual releases a room for use by other members of the family, even though no financial transaction takes place.

Table 16 shows the resulting range of costs of domiciliary care for both the observed level of services and for more intensive support involving daily nursing visits. It is clear that substantial variations in the total cost of care are determined by different assumptions concerning society's valuation of family support and the extent to which hospitalisation releases housing for alternative use rather than by alterations in the level of provision of NHS resources.

Domiciliary care is cheaper than a local authority home when a person lives with a family and when no cost is included for family support. The position is reversed, however, for a person living either alone in a house of high capital value or with a family one of whose members is then unable to go out to work. Long-stay hospital care is more expensive under all options but it might be argued that this reflects an inadequate assessment of the contribution made by family and friends.

On the basis of his calculations Rickard concluded that there is a powerful economic argument for increasing the resources devoted to domiciliary care if this strategy leads to a postponement of the time when patients would otherwise have to be



**Table 16** *Cost comparison of long-stay hospital and domiciliary care (£), 1972*

|   | <i>Costs per week</i> |                |              | <i>Annual total cost</i> |
|---|-----------------------|----------------|--------------|--------------------------|
|   | <i>Current</i>        | <i>Capital</i> | <i>Total</i> |                          |
| Long-stay hospital  | 38.90                 | 18.09          | 56.99        | 2,971                    |
| Local authority home (plus nursing and medical care)                | 19.87                 | 7.24           | 27.11        | 1,414                    |
| <b>Domiciliary care*</b>  |                       |                |              |                          |
| Observed number of nursing visits, higher capital value             | 12.85                 | 17.67          | 30.52        | 1,591                    |
| Observed number of nursing visits, lower capital value              | 12.85                 | 4.50           | 17.35        | 905                      |
| Daily nursing visits, higher capital value                          | 15.72                 | 17.67          | 33.39        | 1,741                    |
| Daily nursing visits, lower capital value                           | 15.72                 | 4.50           | 20.22        | 1,054                    |
| Observed number of nursing visits and constant attendance allowance | 17.85                 | 4.50           | 22.35        | 1,165                    |
| Daily nursing visits and constant attendance allowance              | 20.72                 | 4.50           | 25.22        | 1,315                    |
| Observed number of nursing visits and opportunity cost of help      | 30.90                 | 4.50           | 35.40        | 1,846                    |
| Daily nursing visits and opportunity cost of help                   | 33.77                 | 4.50           | 38.27        | 1,995                    |

\*Nursing, occupational therapist, home help, meals, general practitioner and prescription drugs.

Source Rickard 1979.

admitted to hospital.<sup>29</sup> It should, however, be emphasised that such analyses do not take account of many important issues – notably variations in patient needs and preferences and in the capacity of families to provide support. Furthermore, the data do not reflect the quality of care: domiciliary nursing staff participating in Opit's (1977) study considered that 30 per cent of their cases received inadequate or inappropriate care. Although cost studies may play an important part in defining the boundaries within which decisions have to be taken, it is clear that the determination of the most appropriate means of care for specific individuals embraces a wide range of economic, medical, social and ethical considerations and is beyond the scope of any single analytical technique.

### **Social implications**

Most elderly demented persons live at home but they do not of course constitute a homogeneous group – the severity of the condition varies between individuals and, indeed, over time and while some are able to rely on relatives and friends for support others have to fend for themselves. The latter are particularly vulnerable. The loss of skills of communication inherent in dementia greatly impedes the capacity to maintain or replace lost social contacts resulting in a progressively isolated existence lacking both internal and external sources of stimulation. Concurrently, a diminishing ability to cope with everyday tasks generates a heavy dependence on the domiciliary care services. Eventually, as the need for assistance and supervision becomes more pressing, the only feasible solution, often precipitated by the occurrence of a crisis, lies in admission to residential care in spite of the further social and emotional upheaval that such a move may entail.

Elderly patients being looked after by their relatives may give rise to equally taxing problems. From an economic point of view, loss of employment, the provision of extra food, warmth, the cost of making the home safe and additional expenditure on laundry can increase significantly the financial burdens of the household.

29 Day hospitals may play an important role in delaying admission to long-term care. In an economic context, however, Ross (1976) demonstrated that when attendance is necessary for four or five days per week, the financial advantage of this type of care diminishes and may, depending on the assumptions made, become negative. Furthermore, Peach and Pathy (1978) have suggested that the potential economic benefit to be derived from day hospitals is dependent, in part at least, upon a successful reduction in the amount of social service support given to patients as they become more independent. Consequently, the allocation of day hospital places to the elderly demented is unlikely to result in substantial financial gain.

The social problems created within families, although not so readily quantifiable, are just as important; in particular resentment may develop because opportunities for the supporter or other members of the family are foregone as a consequence of the disproportionate amount of time and energy which has to be allocated to the care of the elderly relative. These social and economic pressures are of course tolerated to widely varying degrees, reflecting past relationships, current commitments and a variety of practical considerations. In some instances the first opportunity to relinquish the care of an elderly relative – perhaps provided by an acute hospital admission – is taken but in others, as is sometimes the case when severe disability or behaviour disorder is involved, it may be difficult to persuade those providing support that institutional care is the only alternative for their elderly relative if potentially damaging stress and disruption within the family are to be avoided.

In a study of two services differing in the frequency with which admission to hospital was recommended (52 per cent of referrals compared to 14 per cent), Sainsbury and Grad (1966) found that on all measures employed a service emphasising extramural care placed more burden on the family, though this was not the case when only those patients imposing the heaviest burden on referral were considered. In 50 per cent of cases relatives felt that their own mental health had been adversely affected and in 25 per cent of cases family income had declined by at least 10 per cent.

Sainsbury and Grad concluded that, while it was demonstrated that a community-based service could effectively reduce the frequency of admission to hospital without necessarily affecting the community adversely, this was only achieved at the expense of imposing a considerable burden on the relatives of some patients. That 61 per cent of families had tolerated the problems reported on referral for more than two years suggests that some families are carrying a considerable load even before specialist referral is initiated.

There is little documented information on the type and frequency of problems encountered by individuals supporting dependent relatives or their attitude to the latter's long-term welfare. Sanford (1975), however, recently interviewed 50 supporters of individuals admitted to the geriatric units of University College Hospital and Whittington Hospital following the development of an intolerable domestic situation and found that 92 per cent of the former group could identify the factors that required alleviation. (Dementia contributed to debility in 31 of the 50 patients.) Sleep disturbance was the most frequently encountered – cited in 62 per cent of cases – and one of the most poorly tolerated

problems (Table 17). Urinary incontinence occurred in more than half of the patients studied but was well tolerated. On the other hand, supporters were markedly less prepared to endure faecal incontinence (associated in most cases with senile dementia). Because of the difficulty of treatment this particular factor implies a poor prognosis for future home-management. Dangerous and irresponsible behaviour, which may threaten disaster to the patient and to others, was mentioned in 32 per cent of cases but most supporters felt able to contain it by practical measures such as turning off gas supplies at the source and locking outside doors. Among supporters anxiety and/or depression were observed in 52 per cent of cases and this was usually attributed to looking after the dependant.

On the basis of the results of his survey Sanford suggested that seeking and adopting appropriate solutions to those problems identified by relatives could reduce the geriatric ward population by as much as 12 per cent. These measures might include for example the use of sedatives, more widespread availability of an incontinence laundry service and the provision of aids and adaptations to promote mobility. Restriction of social life was frequently noted. Many supporters had been without a holiday for a considerable period of time and others felt unable to leave their dependant for more than an hour, precluding virtually all activity outside the home. These observations emphasised the value of facilities for 'respite' accommodation and identified the provision of a 'sitting service' as a major unfulfilled need. The establishment of relatives support groups such as the one described by Fuller and his colleagues (1979) at the German hospital in London could also help to relieve the burden of care imposed on families by providing a forum for discussing problems and obtaining advice.

## Scientific understanding of dementia

The principal neuropathological findings in dementia, as revealed by post mortem examinations, are a shrinkage of brain substance and disintegration of grey matter, both of which are usually considerably more marked than in the brains of unaffected people. Davison (1978) found that the mean brain weight of 18 controls with an average age of 80.6 years was 1,160 grammes compared to 1,082 grammes for 17 individuals with a mean age of 83.2 years who had suffered from senile dementia.<sup>30</sup> In the latter the brain atrophy is more generalised than in multi-infarct dementia although there is a tendency for the frontal, occipital and temporal regions to be particularly affected. Bio-

**Table 17** *The nature and frequency of dependants' behaviour problems as identified by those caring for them before admission to hospital*

|  | <i>Frequency (per cent of cases)</i> | <i>Tolerance (per cent of supporters able to tolerate problems)</i> |
|--|--------------------------------------|---|
| Sleep disturbance                      | 62                                   | 16  |
| Night wandering                        | 24                                   | 24  |
| Micturition                            | 24                                   | 17  |
| Shouting                               | 10                                   | 20  |
| Incontinence of faeces                 | 56                                   | 43  |
| Incontinence of urine                  | 54                                   | 81  |
| Falls                                  | 58                                   | 52  |
| Inability to get out of bed unaided    | 52                                   | 35  |
| Inability to get into bed unaided      | 50                                   | 40  |
| Inability to get on commode unaided    | 36                                   | 22  |
| Inability to get off commode unaided   | 38                                   | 21  |
| Dangerous, irresponsible behaviour     | 32                                   | 38  |
| Inability to walk unaided              | 18                                   | 33  |
| Inability to walk at all               | 16                                   | 13  |
| Personality conflicts                  | 26                                   | 54  |
| Physically aggressive behaviour        | 18                                   | 44  |
| Inability to dress unaided             | 44                                   | 77  |
| Inability to wash and/or shave unaided | 54                                   | 93  |
| Inability to communicate               | 16                                   | 50  |
| Daytime wandering                      | 12                                   | 33  |
| Inability to manage stairs unaided     | 10                                   | 60  |
| Inability to feed unaided              | 12                                   | 67  |
| Blindness                              | 2                                    | 0   |

*Source* Sanford 1975.

30 With increasing age the weight of the male brain drops from about 1,400 grammes at age 30 years by approximately 5 per cent at age 70, 10 per cent by 80 and 20 per cent by 90 years (Bowen and Davison 1978). Measurements of the reduction in normal brain weight with age have inspired what has been described as one of the best known pieces of 'neuromythology', that more than 100,000 neurons die during each day of adult life. However, Konigsmark and Murphy (1970) found no change in the number of neurons with age in the human ventral cochlear nucleus and they emphasised that there is still no conclusive evidence that loss of brain weight, volume or even function in the latter decades of life can be ascribed to neuronal loss. On the other hand, there may be loss in other areas of the central nervous system; Corsellis (1976) has found a loss of Purkinje cells beginning at about 60 years of age.

chemical research at the Institute of Neurology, for example, has suggested that between 26 and 36 per cent of the nerve cells may be lost from the temporal lobe (Bowen *et al* 1979).

As more sophisticated techniques of measurement become available it should be possible to identify more precisely those areas of the brain which are particularly affected in dementia and to differentiate disease-related neurone depletion from those changes which might be expected in the normal ageing brain. However, the presence or absence of cells is a relatively crude measurement of neurological integrity, consequently the significance of other related histological findings is also a target of current research efforts. It is unclear, for example, which elements of neuronal tissue itself – the cell body, axon, dendrites or terminals – are involved in the pathological process. The development of plaques and neurofibrillary tangles also has yet to be fully understood. The former are minute areas of disintegrating tissue scattered in variable, but often vast, numbers through the cerebral cortex and to a lesser extent through the deep grey matter and the brain stem. The tangles consist of abnormally thickened neurofibrils which swing round the cell nucleus and tend to take up the roughly triangular or circular shape of the cytoplasmic outline. They appear to be derived from tubulin (Grundke-Iqbal *et al* 1979) the constituent of neurotubules.

On light microscopy the plaques and tangles are indistinguishable from those observed in 'normal' ageing and their ultrastructural appearances and probably their chemical composition are also identical (Dayan 1978). The most important distinction between senile dementia and senescence is thus a quantitative one: the numbers of both tend to be much greater in dementia and appear to increase with disease severity. The problems of exact measurement are formidable, not least those due to the uncertainty whether to assess the entire cerebral cortex or just those areas which are suspected of being more extensively affected. Considerable disagreement still remains about the quantitative significance of such losses at different sites and even about the relative clinical importance of plaques, tangles and of other neuronal changes. It may well be that the factor which ultimately causes the cerebral dysfunction is neither of these lesions *per se* but the associated disruption of neuronal connection.

### **Biochemical findings**

One of the most potentially significant developments in recent years has been the accumulation of evidence for an impaired synaptic function in senile dementia. Considerable interest has focussed in particular on choline acetyltransferase (CAT), a key enzyme in the synthesis of the neurotransmitter acetylcholine,

following the publication of three independently undertaken investigations (Bowen *et al* 1976, Davis and Maloney 1976, Perry *et al* 1977) which reported reduced activity in the cerebral cortex of CAT. Bowen and his colleagues, investigating the temporal lobe, suggested that since the observed reduction in CAT activity was twice as much as the loss of nerve cells, there is probably a selective loss of cholinergic neurones and since acetylcholine has been implicated in memory processes, such selective depletion might be relevant to the clinical features of dementia. This group also demonstrated in dementia cases that as the intensity of senile degeneration (plaque and tangle formation) increased the CAT activity fell. Furthermore, there is evidence, based on biopsy samples and necropsy material from presenile and less severely impaired cases, to suggest that the transmitter system is affected at an early stage of the disease.

Subsequent work by Perry and her colleagues (1978) confirmed that choline acetyltransferase and acetylcholinesterase activities decreased significantly as the mean plaque count rose, and in depressed and demented subjects the reduction in choline acetyltransferase activity correlated with the extent of intellectual impairment as measured by a memory information test. The authors also pointed out that the effects of certain drugs may be indicative of a possible hypoactivity of cholinergic function in senile dementia. Thus anticholinergic drugs may induce or increase confusion in elderly patients and, clinically and experimentally, induce memory deficits and senile intellectual changes in normal adults. Furthermore, antipsychotic drugs (presumed to antagonise dopaminergic activity) have been reported as having fewer extrapyramidal side effects (thought to reflect relative cholinergic hyperactivity) in demented compared to normal patients.

A leading article in the *Lancet* (1977a) commenting on the earlier findings emphasised that insufficient knowledge about cholinergic neuronal systems in the cerebral cortex posed difficulties for an accurate assessment of the new information. Acetylcholine can stimulate or inhibit, according to the type of receptor on which it acts so the consequences of a loss of cholinergic nerve endings do not lend themselves to straightforward prediction. There is also uncertainty about the functional significance of the change in CAT activity for the enzyme may not be the rate limiting factor in acetylcholine synthesis (Tuček 1978). Whether or not other selective changes (for example in the serotonergic system) are critical factors also requires further study. Nevertheless, biochemical research increasingly suggests that in normal ageing the quality of the nerve cell processes, rather than the number of neurones, declines with advancing age, while in

organic 'senile-type' dementia there is usually marked and selective loss of neurones. In other words, senile dementia appears to be a primary degenerative nerve cell disorder and not the result of accelerated ageing.<sup>31</sup>

### Senile dementias?

The parenchymatous and multi-infarct forms of cerebral degeneration in old age have been shown to be broadly distinct but it is unclear whether the former constitutes a single disease entity. Some observers consider that it may in fact comprise several different degenerative processes and that variations in the prominence of certain manifestations of dementia may reflect selective impairments within the brain (Agate 1977). One subgroup for example appears particularly to involve primary memory impairment, sometimes called the dysmnestic syndrome. Another type involves depressed reflexes and flexor plantar responses, perhaps the consequence of inhibited neuronal conduction. Yet another form is characterised by bilateral pyramidal signs. There might also be a parietal lobe type where there is dysphasia and eccentric behaviour. Further insight into the nature of senile dementia might therefore be gained by a 'classification' of presenting symptoms and correlating this data with variables such as age and mode of onset, disease duration and neuropathological findings at autopsy.

Another area of uncertainty is whether Alzheimer's disease in late middle-age differs from parenchymatous senile dementia in matters other than age of onset. Larsson and his colleagues (1963a) were unable to discover any cases of Alzheimer's disease occurring in the families of senile demented, suggesting that the two disorders are genetically different. However, Corsellis (1977) has concluded that the two 'cannot be distinguished on histological grounds, all the difference being of emphasis or of quantity rather than intrinsic'. In this context, Victor (1978) has suggested that it may be helpful to think in terms of a senile dementia/Alzheimer's disease complex, because this clearly couples a clinical syndrome that consists of a slowly and inexorably progressive deterioration of intellectual function with a pathologic process that is characterised by loss of cerebral cortical neurones or granulovacuolar changes in the remaining neurones and formation of senile plaques and neurofibrillary tangles in other neurones. Consequently, it becomes illogical to define this clinical pathologic entity as presenile dementia if it begins at age 59 years and as senile dementia if it begins at the age of 61 years.

31 Biochemical indication of atrophy and nerve cell loss is not significant in vascular type dementia (Bowen *et al* 1979).



## Aetiology

The disease processes responsible for the pathological changes observed in dementia have not been identified and many possible avenues for research remain open. The aetiological potential of toxic processes, for example, has generated considerable interest with attention focussing on aluminium in particular in recent years following reports of elevated concentrations of the element in some parts of the brain in Alzheimer's disease (Crapper *et al* 1973, 1976). The hypothesis that aluminium toxicity may be causally significant in senile dementia also appears to gain credibility from studies of the relationship between this particular trace metal and haemodialysis encephalopathy syndrome. Elliott and his colleagues (1978) observed that the incidence of the latter was confined to geographical areas where the concentration of aluminium in the water supply (used in the preparation of the dialysis fluid) was greatly increased by the addition of aluminium sulphate. Furthermore, research undertaken in Newcastle (McDermott *et al* 1978) found significantly raised brain-aluminium concentrations in patients dying with dialysis encephalopathy.

Aluminium salts are neurotoxic in some species, both by systemic administration and by direct injection into the central nervous system. Neurofibrillary degeneration, similar although not identical to that seen in Alzheimer's disease, is the main pathological feature of this aluminium-induced encephalopathy in cats and rabbits. In rats, however, neurofibrillary degeneration does not occur even at several times the brain-aluminium concentration required to produce the disease in other species. Consequently it cannot be assumed that the human central nervous system will respond to aluminium intoxication by the production of intraneuronal tangles. Further doubt has been cast upon the proposed aluminium-dementia link by the work of McDermott and his colleagues (1977). They were unable to demonstrate any significant difference in aluminium concentration between nine normal brains and ten brains from patients with dementia, in the material as a whole or in the regions rich in neurofibrillary degeneration (hippocampus and frontal and temporal cortex). It was suggested that high aluminium levels are therefore related to age rather than dementia.

Metabolic aberration originating within or outside the brain may be a primary factor although there has been little systematic study of either possibility. One feature of potential significance is the focal deposition of amyloid both within the plaques and elsewhere in the brain. Its origin is unknown but the frequent occurrence of plaques in close proximity to small blood vessels might suggest a derivation from extracranial sources.

The possibility of a viral aetiology has been highlighted by the study of the transmissible spongiform slow virus encephalopathies. Kuru for example is associated with the ritual cannibalism of human brains in New Guinea whilst Creutzfeld-Jakob disease – a rare, rapidly progressive dementia occurring predominantly in middle age – is a related condition which has also been transmitted from man to primates. In addition, Traub and his colleagues (1977) have managed to transmit two cases of familial Alzheimer's disease to two chimpanzees although in the process they experienced about 30 failed attempts and there is also the possibility that the successes were not in fact examples of this disease. Given the current state of uncertainty Davison (1978a) has concluded that the possibility of some kind of slow virus having a causative role in dementia is not proven and that the cases in which transmission of an agent has been achieved are at the same time both exceptional and equivocal.

Recently, Renvoize and his colleagues (1979) have proposed that cytomegalovirus (CMV) infection may be implicated in Alzheimer's disease. CMV infection in the foetus, neonate and in immunosuppressed adults can cause severe brain damage and there is evidence that some slow infections such as subacute sclerosing panencephalitis may be caused by conventional viruses acting in an unusual way. Murine CMV suppresses humoral, cell-mediated and interferon responses of the host to other antigens, and its possible involvement in disease need not be related to its direct cytopathogenic effect but could result from the initiation of an abnormal immune response, or by acting synergistically with other viruses.

Immunological processes associated with dementia have so far received little attention. It is known that cell mediated immunity declines with age and that older people become more susceptible to infection. However, the status of immunological competence in the dementias and the role, if any, of autoimmune factors in neuronal damage and loss is still obscure.

Finally, there is little understanding of the genetic background of dementia.<sup>32</sup> Nevertheless, the possible relationship between chromosome loss and ageing has attracted research interest for a number of years. There is broad agreement that chromosome

32 Huntington's chorea is an exception. It is usually classified within the presenile group of dementias, onset generally occurring between the ages of 30 and 50 years. It has a prevalence of between 4 and 7 per 100,000 population and is classically characterised by progressive uncontrolled movement and dementia. Huntington's chorea is an autosomal dominant condition, implying that each child of an affected parent has a 50 per cent chance of developing the disease in later life. The identity of the chromosome which carries the mutant gene is unknown.

deficit is more extensive in individuals over the age of 65 years than in younger persons, raising the possibility that this could be a source of interference with various metabolic functions, thereby contributing to the pathological changes associated with advancing years. What is not clear is the direction of causality, that is, whether the cells affected by chromosome loss contribute directly to some of the features of ageing or whether the loss is a by-product of ageing mechanisms.

## Diagnosis and treatment

The hazards of inappropriate diagnostic labelling are well known and are particularly relevant in the context of dementia. Misdiagnosis of characteristic symptoms as irreversible dementia when in fact they are a result of some other mental disturbance or physical disease may mean that potentially treatable illness remains undetected. Furthermore, the clinical designation of dementia, in the absence of any effective treatment, has sometimes been shown to generate defeatist attitudes on the part of those with responsibility for the care of affected individuals. The balance of concern may become tilted towards consideration of where such patients should be looked after and away from seeking ways in which the latter can be assisted to achieve more satisfactory life-styles. In spite of these dangers, however, the use of the term dementia as a diagnostic category implying a state of irreversible cerebral degeneration appears frequently to have lacked circumspection.<sup>33</sup>

Such diagnostic imprecision may be explained by a number of factors. One of the principal problems is that the range of neurological, general medical and psychiatric conditions which can give rise to a suspicion of a primary dementing illness is wide. Symptoms associated with toxic confusional states, which may stem for example from infections or excessive or inappropriate medication, and depression can mimic closely those found in irreversible dementia, especially in the earliest manifestations of the disease. The latter has also to be differentiated from natural

33 An investigation of 52 patients thought to be suffering from dementia when first seen as neurological outpatients found tumours in four cases and that in a further five dementia was due to a reversible cause (Victoratos *et al* 1977). Livesley (1977, 1978) has argued that for the vast majority of affected elderly patients 'dementia' is an unacceptable term because it is often too readily diagnosed on inadequate grounds, unnecessarily stigmatising them with the hopelessness of an irreversible condition, and that (potentially treatable) cardiac dysrhythmia is one of the most commonly undetected causes of 'dementia'.

senescence. Benign forgetfulness and other comparatively harmless features associated with ageing may be misconstrued as the initial phase of the dementing process.

A clear distinction between irreversible cerebral degeneration and potentially remediable conditions with presenting symptoms which resemble the former—deceptively closely—may be achieved by a careful construction of the patient's behavioural and medical history based on information obtained from relatives and/or other appropriate individuals and by undertaking a few basic diagnostic tests. However, to discern those rarer diseases which generate dementia-like symptoms but at the same time have reversible causes, may necessitate the employment of an extensive range of biochemical and other investigative procedures as well as a variety of psychological tests. The ascertainment of an accurate diagnosis may consequently become a resource-consuming process. In certain circumstances, which may be determined in large part by local shortages in professional manpower and appropriate facilities, assessment on such a comprehensive scale may be judged unwarranted when in reality it is simply designed to exclude as many potential alternatives as possible in order to confirm a rather nebulous diagnosis for which the remedial possibilities are strictly limited. It may also be considered unjustifiable to expose some elderly patients to the discomfort caused by certain investigative techniques. Indeed, Drinkwater (1976) has noted that some physical diagnostic procedures can involve quite significant morbidity and mortality risks for the aged.

### **The role of medicines**

The damage inflicted on the brain in dementia is, in the current state of knowledge, irreversible either pharmacologically or by any other means. But wide fluctuations in mental state in relation to physical condition and the demented brain's susceptibility to hypoxia has prompted much research at improving cerebral function (*Lancet* 1977). Most of the drugs promoted for this purpose are aimed at the multi-infarct type of dementia in particular and act either by dilatation of the cerebral vessels or by reducing the brain's need for oxygen. However, cerebral vasodilators have proved disappointing in clinical practice and may also give rise to undesirable side effects. A recent leading article in the *British Medical Journal* (1979) thus concluded that 'on present evidence simple vasodilators have no place in the treatment of vascular dementia'. On the other hand, cerebral activators, which in theory improve the brain's utilisation of oxygen and glucose, have been reported to generate improvements in mental function. But inconsistent results, a lack of knowledge

about pharmacological mode of action and problems in identifying those patients who might benefit from such therapy have raised doubts about the routine use of the medicines currently available (*Drug and Therapeutics Bulletin* 1975). A number of workers (for example, Judge 1977) have, nevertheless, found that in selected patients certain drugs do appear to be of value although at the same time they have emphasised that the availability of such preparations should not inhibit thorough investigation and treatment of reversible conditions or the deployment of services and personal support for affected individuals.

The problems involved in evaluating the potential of drugs for dementia constitute a major barrier to further advance in the treatment of this condition. Of these the selection of patients is particularly difficult. Research has suggested that senile dementia may not be a single disease entity but important neuropathological differences remain unidentified until necropsy. The selection of patients at an advanced stage of disease may make it hard to demonstrate the efficacy of pharmacological intervention and further complications may stem from the presence of unrelated physical illness and the concurrent use of other medication. The solution would not necessarily lie in confining attention to younger patients: this would lengthen the time gap between clinical assessment and necropsy findings so that the latter may not accurately reflect the condition at the time of treatment. Environmental and other unknown variables may mean that the choice between patients living in the community and those in institutional care is another significant factor in sample selection.

The employment of appropriate criteria of effectiveness is also of fundamental importance in drug evaluation. One of the major clinical features of senile dementia is socially undesirable behaviour (Issacs 1979a) and so relevant indicators would include the drug's ability to reduce such deviance and to retard progression without side effects and compliance difficulties. But behavioural measures are both arbitrary and subjective and may of course be affected by factors extraneous to the drug or the disease. Furthermore, they are removed by several stages from the level at which drug activity takes place.

Nevertheless, alternative measures may be impracticable such as cerebrospinal fluid measurement to identify biochemical changes, or unreliable as is the case with EEG in assessing clinical improvement and EMI scanning or air studies because the presence of large ventricles has been observed in alert and able persons. Davison (1978a) has concluded that at the moment mental tests remain of paramount value in measuring the effectiveness of drugs for dementia but, in line with the view of the Medical Research Council, further research is required in this

area to establish a consensus about the design and methodology of clinical trial procedures.

### **Symptomatic relief**

Medicines have a more clearly defined role in the relief of unpleasant symptoms. In this context Powell (1977) has suggested that there are four principal indications for drug prescription. These include agitation, that is behaviour caused by distress to the patient, aggression leading to distress in others, behavioural disturbance stemming from abnormal thought patterns (hallucinations and delusions) and mood alterations which predominantly take the form of depression.

Tranquillisers may be helpful in managing over-active states in dementia but they require careful selection and dosage: for example chlordiazepoxide (one of the benzodiazepines which in turn constitute one of the three main groups of tranquillising agents in current use, the others being the phenothiazines and the butyrophenones) may be 'confusionogenic' in the elderly (Judge 1977) and haloperidol, although particularly useful for agitation, may cause rigidity. Hypnotics may play a particularly useful role in controlling nocturnal restlessness which Sanford (1975) has shown to be one of the most pressing problems faced by caring relatives. Alternatively, stimulants such as methylphenidate, fencamfamin and pemoline may alleviate symptoms of apathy and withdrawal. In all cases the use of such medicines in the elderly demented, whether directly to benefit the latter or as a manoeuvre to make life more tolerable for caring relatives or nursing staff, requires caution and regular review in order that appropriate modifications can be made as changes occur in the clinical state.

### **The future**

The discovery of biochemical abnormalities in the brains of persons who have suffered irreversible dementia during life has generated hopes for a better understanding of the aetiology of the condition(s) and has important implications for therapeutic advance. Defects in cholinergic nerve cells or a deficiency in choline acetyltransferase suggest that the use of certain drugs, such as the phenothiazines and others with anticholinergic activity, might exacerbate dementia. Of potentially greater significance these findings and the observation that cholinergic receptors remain intact raise the possibility that appropriate corrective therapy may be able to halt the decline of or even facilitate improvements in mental functioning in dementia, in a manner analagous to the use of levodopa to control akinesia in Parkinsonism.

In theory there are two broad approaches to raising acetylcholine levels. One might involve the direct administration to affected individuals of the substance itself, the enzyme involved in its production or one of its precursors. Alternatively, the acetylcholine that is present might be made more effective either by reducing its enzymatic degradation by cholinesterases or by inhibiting those systems which oppose the cholinergic system (Kendall 1979).

The use of precursors is the only technique to have been employed so far but clinical trials have failed to show any definite improvement in cognitive function in either severely affected individuals given choline chloride (Boyd *et al* 1977)<sup>34</sup> or in patients with more moderate symptoms treated with choline bitartrate (Etienne *et al* 1978). It has also been pointed out that treatment over a period of two or three years may generate problems of choline toxicity (Davison 1978) and that lecithin – a phospholipid hydrolysed within the body to choline which, in animals, has been shown to raise plasma choline and brain acetylcholine concentrations – may be a preferable alternative (Davison 1979). More generally, the complexity of the anatomy, physiology and pharmacology of the brain is such that attempts to restore the biochemical balance at a specific site may well create imbalances elsewhere. However, until the underlying causes of the biochemical defects are themselves identified and prevented or controlled, continued research into neurotransmitter activity in normal and demented brains currently offers one of the best prospects for therapeutic advance.

## Conclusions

For the majority of the population irreversible dementia is unlikely to pose a major threat to health in old age; nine out of ten among those aged 65 years or more remain unaffected as do almost eight out of ten among the over 80s. Nevertheless, there are currently in excess of 700,000 individuals experiencing a deterioration of intellect, memory and personality caused by the disintegration of brain tissue and of these half are severely impaired. Furthermore, demographic trends indicate that the numbers of demented, particularly among the very old, will increase significantly over the remaining years of this century. The wide ranging social and economic costs inherent in the care of affected persons may escalate to a disproportionately greater

34 This group of workers did nevertheless observe that some of their patients became more manageable – that is, less irritable and more aware of their surroundings – during the course of treatment.

extent. Yet the study of dementia in old age has been conspicuously neglected with only limited research into fundamental and applied problems.<sup>35</sup>

The dearth of basic knowledge inevitably inhibits more advanced research. There is a pressing need to identify the different disease entities involved, to determine whether they can be recognised individually during life and to understand how radically different they may be one from another and from the processes of normal senescence. The clarification of such problems is central to many other aspects of research endeavour – to the discernment of the clinical associations of the various disorders, to the investigation of possible metabolic aberrations or toxic influences, to the furtherance of epidemiological studies and the unravelling of genetic associations, and to paving the way for more intensive pathological, biochemical and other laboratory studies. A firm nosology would also assist the application of therapy arising from research to appropriate groups of patients, and of empirical treatments to individuals affected by a common disease process.

The inadequacy of research efforts can be attributed to a combination of factors. One of the major barriers has been and continues to be the multidisciplinary nature of investigation required. Neurologists, psychiatrists, neuropathologists, geriatricians, geneticists, pharmacologists and biochemists are all involved, thus those undertaking relevant work are seldom found in the same location. As a result of this and other factors it may also be difficult to integrate and assess the findings of individual research specialists. In this context the establishment of a multidisciplinary centre with adequate clinical and laboratory facilities for living patients, normal and abnormal, combined with arrangements for post mortem follow-up with neuropathological and neurochemical investigation, would represent a major advance although given current economic constraints it is unlikely to be achieved in the foreseeable future (Corsellis 1979).

A further obstacle to research stems from the difficulties in identifying and then observing the early manifestations of dementia. At the other extreme the more severe cases have

35 It is not possible to calculate the cost of current research activities directed towards dementia because such a specific category is rarely, if at all, identified in research budgets. A breakdown of the Medical Research Council's expenditure in 1977/78 did, however, estimate the value of research into ageing at £224,000, which was equivalent to 0.5 per cent of the overall figure in that year. Findings in many other areas of research (for example, the central nervous system – £2.5 million in 1977/78 – and psychiatric disorders, £2.1 million) may of course facilitate advances in the understanding of dementia even though the latter was not the principal target of investigation.



tended to be relegated to grossly understaffed hospitals where the data collection process is almost impossible to organise and where the staff may lack the exacting qualities necessary to attract research funds (Issacs 1979). Finally, the division of the clinical burden primarily between psychiatry and geriatrics means that the dementia in old age may tend to be overshadowed in the priorities drawn up by either speciality alone.

Against a background of inadequate research and trends in the age structure of the elderly population which have significant implications for the prevalence of dementia (according to epidemiological data which could now appropriately be updated), the Psychiatry Committee of the Medical Research Council established a subcommittee to examine ways of overcoming the barriers to a better understanding of the dementias. The subcommittee's report was published in 1977 and it recommended that research in this field and into ageing should be designated areas of high priority and that the council should support posts for key clinical personnel within institutions (geriatric and psychiatric) caring for demented patients with the primary aim of organising research and liaising with laboratory workers.

Of equal priority is the need to ensure that adequate provision is made for the management of the elderly demented. DHSS guidance on this matter suggests that there are three principal areas of need, determined by the degree of severity and the presence or absence of unrelated physical disease and that each of these requires a particular pattern of care. However, in many instances, currently available resources fall short of the nationally suggested targets. As a consequence pressures are being experienced not only in those areas of the health and personal social services which supply care more or less specifically for the demented but throughout health care provision as a whole (BMJ 1978). Thus the shortfall of places in local authority homes, which are themselves having to cope with more intensive workloads as a consequence of the ageing of the population, means that some demented patients requiring residential care are being looked after (inappropriately) on geriatric wards. The effect of this situation is to inhibit the transfer after treatment of patients who may be most suitably cared for in long-term geriatric beds from other wards in the general hospital which in turn become blocked.<sup>36</sup> But perhaps the most pressing 'cost' is that borne by families caring for demented relatives. In many instances substantial burdens are tolerated for a long time before advice and assistance are sought from the health and social services. Even then inadequate resources may mean that little can be done to provide relief for the families concerned.

An increasing number of reports published in recent years indicate, however, that effective services for the elderly mentally infirm can be developed in spite of resource shortages.<sup>37</sup> Arie and Dunn (1973), for example, demonstrated the possibility of establishing a joint unit by a rearrangement of existing facilities without any need for extra resources. The nature of the services described by the various authors depends greatly on the historically available equipment and buildings, the personality and interests of the main driving force (usually initially a single consultant) as well as the demographic characteristics and needs of local populations. They have also emphasised different aspects of care. Nevertheless, a number of general requirements for success have emerged (Jolley and Arie 1978). It is important to define the population to be served in terms of, for example, geographical territory and diagnostic categories. Domiciliary consultation is clearly an essential aspect of many services: assessment of patients in their home environment facilitates a more comprehensive understanding of their problems and needs than might be achieved in unfamiliar surroundings. Furthermore, readiness to see referred patients without delay has been shown to help avoid crisis-inspired action which can often prejudice more preferable longer term care strategies. But perhaps one of the most important requirements is for interspecialty co-operation because of the intricate mixture of medico-socio-psychiatric disorder in the elderly. In this context the proposed guidelines on collaboration agreed between the Royal College of Psychiatrists and the British Geriatrics Society may be seen as an important step forward (Arie 1979).

At the same time, debate has intensified concerning the need

36 During a nine month study, 160 out of 482 bed weeks in an acute medical ward in a Glasgow teaching hospital were accounted for by 11 elderly patients who no longer needed to be there (McArdle *et al* 1975). They had spent an average of 1.4 weeks in the ward for medical reasons compared with an average of 14.5 weeks waiting for after care accommodation. Three of the patients had been admitted not for medical reasons but because the appropriate units were unable to accommodate them. Burley and his colleagues (1979) have suggested that the attachment to acute medical wards of consultants in geriatric medicine may help to resolve the 'bed-blocking' problem. The establishment of such a scheme in an Edinburgh teaching hospital led to significant reductions in mean lengths of stay of elderly patients without any accompanying increase in transfers to geriatric departments. The authors considered the following factors, among others, to be important: multidisciplinary assessment of the patient; the experience in the psychiatry of old age that the geriatric team was able to bring to the ward; early planning arrangements to facilitate return to the community and familiarity of the geriatric team with the local community resources and how to mobilise them.

37 A comprehensive list of references is given in the review article by Jolley and Arie (1978).

for a specialty of psychogeriatrics. In 1977 the Royal College of Psychiatrists Group for the Psychiatry of Old Age was granted full section status (although it had in fact been formed in 1971). A year later it was estimated that there were approximately 70 psychiatrists specialising in this field (MIND 1979) – psychogeriatricians or, more recently, ‘geriatric psychiatrists’ – but this clearly fell short of the group’s recommended minimum of 200 in England and Wales, or one for each health district. Doubts about the creation of a new specialty have focussed on the problem of raising the necessary additional resources, the potential increase in competition for already existing resources, the question of redefining catchment areas and difficulties of staff recruitment. However, it is argued that there is a need for an identified person to act as specialist resource for other parts of the service and who has the ability to mobilise and maintain adequate levels of the diverse range of resources required in the care of the elderly mentally infirm. In fulfilling similar functions a number of professionals who would regard themselves as having ‘a special interest in the psychiatry of old age’ (DHSS 1975) have already pointed the way to relieving some of the long-standing neglect in this field.

The demand for services for the elderly demented is currently outstripping the supply. In the foreseeable future it will probably do so to an even greater extent given the demographic trends and the apparent inadequacies in the provision of community and institutional care outlined in this paper. Whilst an expansion of that part of the health and social services budget allocated to the care of the elderly would clearly help to relieve some of the immediate pressures, negligible economic growth and the imposition of strict limitations on real increases in public expenditure imply that additional resources are unlikely to be forthcoming on a scale sufficient either to match fully the growth in demand or to permit a general upgrading of services. Consequently the successful management of dementia in old age will increasingly depend on the establishment of efficient local psychiatric services for the elderly which facilitate rational networks among related services and make the best use of available resources. At the same time these deficiencies will probably necessitate a closer examination of needs and a tighter ordering of priorities although this may be to the detriment of certain groups within the elderly demented population.

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