Occasional Paper No. 1

'DOES HE KNOW HOW FRIGHTENING HE IS IN HIS STRANGENESS' :

A Study of Attitudes to Dementing People

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'Does he know how frightening he is in his strangeness?' :

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by

H. M. D. Petzsch

It is a source of special pride that we inaugurate this series of Occasional Papers with a revised version of an Honours dissertation by one of our students. The Rev. Hugo Petzsch's study of the pastoral care of demented people shows the quality of work which can be produced by an intelligent student utilising the numerous resources available within the University of Edinburgh. We are sure his piece will be of interest to many.

The next Occasional Paper will be published shortly. It will consist of papers delivered at a one-day Consultation on Family, School and Church in Religious Education which was held in March 1984. The contributors will be Dr. Leslie Francis of Culham College, Dr. Joseph Rhymer, one of our own recent postgraduate students, Mr. Douglas Osler, the first HMI in Religious Education in Scotland, and Dr. Ian McDonald of the Department. Future Occasional Papers will be published once or twice a session, and plans are being laid for Papers arising out of consultations on the future of welfare and social security.

Occasional papers may be obtained from the Department at the address above.

Duncan B. Forrester,
Professor of Christian Ethics
and Practical Theology.

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May, 1984

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ACKNOWLEDGMENTS

This study, first presented as a dissertation towards the degree of Bachelor of Divinity in the University of Edinburgh in 1983, arose from reflections following a clinical pastoral course at St. James's Psychiatric Hospital, Portsmouth, in the summer of 1981. There I worked as an auxiliary nurse on a ward for severely demented men and am grateful to the patients and staff, and especially the chaplain, the Revd Mike Clarke, for this opportunity to learn about care of the demented at first hand.

In connection with this study I visited several hospitals and homes for the elderly, among them the Royal Infirmary of Edinburgh, the Royal Edinburgh Hospital, the Elms (a Church of Scotland Eventide Home) and Braeburn (a Scottish Episcopal Church equivalent), both in Edinburgh, and am indebted to the staff who were always most helpful. Also several people whose relatives either had been or were dementing were kind enough to talk about their experiences and feelings and this was of considerable help.

I spoke with many Health Service workers about dementia and connected issues and wish here to record their generous assistance, particularly that of Professor James Williamson, Sister Glenda Watt and Dr Chris Gilleard.

Among clergymen with whom I talked about the pastoral care of the dementing, their relatives and related theological issues were the Revd Dr Alan Lewis, the Rt Revd Dr Francis Moncrieff, the Revd Fergus Smith, the Revd Murray Leishman and the Revd Stewart McGregor: I am most grateful for all their help and encouragement.

Hugo Petzsch

SECTION ONE : INTRODUCTION

John Brown had worked in banks all of his life. When he retired he had been the manager of a suburban branch for nearly fifteen years. About six months before he retired, although he seemed to perform, efficiently at work, he began to forget small matters of domestic life and occasionally confused the days, getting up at the weekend expecting to go to work. He also occasionally forgot things that had just been mentioned to him. Mary, his wife, who had recently retired from school teaching, at first thought this was just the natural memory loss of old age and fatigue at the end of a long and conscientous working life. However, after retirement things steadily got worse and in addition to a declining ability to remember recent events John started to behave inappropriately on occasion. This began merely with crude and obscene jokes at family gatherings and reacting with laughter when told by someone of their recent misfortune. This behaviour was compounded by bouts of depression and anxiety on John's part when he realised what he had done and what was happening to him. He had always looked forward to his retirement as a time when he would be able to devote more time to his wife, three children and his grandchildren. He had also wanted to devote more time to his duties as an elder in the parish church, something to which he felt he had never given enough of his energy. Eighteen months after his retirement he received a note from the session clerk saying that the minister and other elders thought that perhaps John would like to resign as an active elder until he felt better able to fulfil the duties of the office. This was quite a blow to John, although Mary was relieved because she was often a bit embarrassed by what she heard indirectly from people about John's behaviour. Even their friends tended to forget to invite John and Mary to parties or get-togethers because of his behaviour. They had been to the doctor and he had told Mary that it looked as though John had a form of senile dementia, which explained his memory lapses, periodic odd behaviour and his limited reasoning abilities. While it was something of a relief to Mary to know John had an illness, it was frightening for her to be told that he would never get any better, and that, unless he died of something else beforehand, he would probably live for another four or five years with his condition steadily deteriorating.

John's behaviour continued to decline. He became incontinent of urine and increasingly liable to bursts of odd behaviour, sometimes getting extremely angry to the point of grabbing and shaking Mary if she contradicted him, or bursting into tears at a slight rebuke. He seemed to live increasingly in the past. Mary felt he was drifting away from her while at the same time becoming ever more dependent. He could not find his way home anymore and had to be accompanied everywhere. He occasionally got up in the middle of the night, thinking it was daytime and tried to go out for walks. He walked around rooms incessantly. During this time the minister came to visit only once and Mary was glad when he left, for he had seemed embarrassed at not having anything to say and tried to behave as if everything was normal, ignoring John's odd behaviour and remarks.

The doctor did not call often either: he too had little to offer. The health visitor from his practice came frequently and became a trusted confidant of Mary. She managed to persuade Mary to accept help with the extra laundry, especially when John had become doubly incontinent. It was also the health visitor who eventually managed to persuade Mary to consider applying for a place for John in a day hospital. Mary was reluctant to accept this suggestion because she felt she would be letting John down by 'getting rid' of him for two or three mornings a week. John's attendance at the day hospital made Mary aware of something that surprised her; she was now so used to looking after John that she had become completely cut off from most of her old friends and interests. She could not travel to visit her children and grandchildren with only a day free here and there and since John had started dementing the children had not liked to let the grandchildren see their grandfather 'all in a muddle and a mess'. She also came to realise that the John she was looking after was not the John she had been married to for all those years. He was much the same body, yes, but somehow his personality seemed to have died. This idea confused and upset Mary very much. She did not know how to go on caring for him: she knew she had to but she felt she was looking after two men, the one a stranger, and in odd moments when they seemed to share a joke or catch one another's eye, the other who was the familiar man she had married.

Eventually, even with the day hospital relief and an occasion when the hospital had arranged for John to be taken in for two weeks to allow Mary to get away for a rest with one of her children's families, Mary found the caring for John too great a strain. The health visitor managed to persuade Mary that if she did not let John go on a waiting list for admission to a long-stay psycho-geriatric ward, Mary herself would soon not be in a position to look after him any more. Nine months later John was admitted to the local psychiatric hospital and Mary was relieved of the burden of looking after him, which by this time, four years after his retirement, had become almost intolerable. Now that John was in hospital permanently she was happier but she also did not know what to do with herself after she had sorted the house out and stayed for a bit with each of her children. She was left with the haunting scenes she saw on the ward when she went to visit John: men lying on the floor dribbling and groaning, others occasionally swinging a fist at a fellow patient and having to be sedated, men sitting in their own excrement because there were insufficient staff to look after them properly. The staff were friendly but apart from the charge-nurse they were mostly untrained youngsters working as nursing assistants while they waited for other jobs to turn up. John died after being in hospital for six months and Mary never really understood what had happened to them both.

This case study illustrates some of the problems affecting people who suffer from dementia and those who seek to care for them in our society. The number of such cases is increasing as the elderly population rises. This is happening to the extent that a few years ago a leading article in the British Medical Journal described dementia as 'the quiet epidemic'(2). Dementia which is feared by many elderly people more than death(3), is also the cause of much unhappiness and strain among those who care for sufferers of the disease. In an attempt to understand the problems of dementia from the practical theologian's viewpoint two possible lines of enquiry were considered and rejected.

The first examined standards of care for the demented and strains on the care agents. This led to a consideration of the allocation of financial resources within the Health Service, the lack of which in part accounted for the generally inadequate provision made for the demented. Although important such an enquiry would have led away from the demented towards a discussion of the assumption lying behind decisions of resource allocation within the Health Service as a whole. The second line of enquiry sought to present a theological critique of dementia in response to the question: where is God in dementia? In this endeavour theologians' understandings of providence, the nature of man, the problem of suffering were examined in relation to dementia. This exploration of where the demented might be accommodated in the theological perspective was interesting and challenging, but through pursuing it, it became evident that this study was colluding with a general reaction to the demented, namely one which sees them alone as the object of enquiry, seeing the demented, in terms of their predicament, as the cause of the problem. 'Their plight' did not seem to take account of the rest of society's role in the situation.

Instead, this paper will explore the problems raised for our understanding of relationship when challenged by a dementing human being and will make reference to original medical investigation, will seek illumination from the insights of theologians and will make use of three biblical models to illustrate and elucidate the wide practice and potential of our relationship and response to the dementing. In conclusion, it will be shown that the will to heal is largely masked by the ambivalent attitudes of primary care agents to the plight of dementing patients and that the problems and challenge of dementia cannot further be evaded.

SECTION TWO : THE CLINICAL PICTURE OF DEMENTIA

A variety of definitions of 'dementia' have been offered, most of which are of a general and non-specific nature: 'A species of insanity characterised by failure or less of the mental powers'(4); 'Irreversible deterioration of mental functioning in its intellectual, emotional and cognitive aspects'(5); 'An acquired global impairment of intellect, memory and personality, but without impairment of consciousness'(6). Of these the third and most recent is often now taken as a standard working definition in discussions of dementia. As these three sample definitions indicate dementia is a term generally used to describe the loss of various mental functions. It is a chronic disease principally affecting the brain and is usually gradual in its onset, of fairly long duration, ending only with the patient's death. The symptoms vary in their intensity and time of onset but can be described broadly under three headings: (a) the patients' loss of short-term memory, coupled with their inability to acquire new memories; (b) the patients' powers of reasoning are impaired and consequently they are unable accurately to assess their sensory input, that is they are liable to be disorientated in time and place and to have little or no insight into their predicament; (c) changes in feeling and conduct take place with the result that often patients' emotions may appear blunted and their social behaviour changes its character, often becoming coarse. These symptoms, while variable, are always present to some degree. However, their nebulous nature means that accurate diagnosis of dementia can be difficult and it is sometimes confused with other conditions which present in a similar fashion but are remediable.

The causes of dementia are obscure and it is not altogether clear whether it is a distinct pathological disease process or an exaggerated form of the normal ageing process. However, some rarer types of dementia such as neurosyphilis and Korsakoff's psychosis have discernable origins, the latter being in the gross over consumption of alcohol. A report submitted to the Medical Research Council in 1977(7) sums up the current confusion in the area of dementia by highlighting the spheres of limited knowledge, such as the origins or aetiology, the progress of the disease in its different forms and even the distinctions between identifiable forms.

The main division among the dementias is between the degenerative forms and arteriosclerotic or multi-infarct dementia. The degenerative dementias include Parkinson's disease, senile dementia and the pre-senile dementias. The latter include Pick's and Creutzfeldt's diseases, Huntington's chorea and Alzheimer's disease, although this last is no longer thought to be significantly different from senile dementia except in age of onset(8). Generally speaking these two groups differ in that the age of onset in the degenerative dementias, excepting Alzheimer's, is later than that of the multi-infarct dementia. Also in the former group more women tend to be affected while in the latter it is predominantly men. The course of the ailment also differs. The degenerative dementias follow a progressive decline without relief or interruption, with the early impairment of insight, intelligence and personality and usually few physical signs until late in the disease. The progress of multi-farct dementia on the other hand is often described as being like a step-ladder in that the patient experiences a sudden decline in abilities, usually following successive cerebro-vascular episodes, such as a fit or stroke, after which their condition remains relatively constant until the next episode. Patients with this form of dementia often retain their insight and intelligence much later into the disease than those with the degenerative dementias. The main pathological differences between these two broad groups are that in the degenerative dementias there exist senile plaques and neurofibrillary tangles in the brain, while in the multi-farct type there is evidence of infarction, that is destructive congestion of the small blood vessels in the brain.

These forms of dementia account for the majority of those diagnosed as dementing. Around fifty per cent of dementia is degenerative, and predominantly of the Alzheimer type; a further twenty per cent is accounted for by multi-infarct dementia and another twenty per cent is a mixture of both groups. The residual portion of sufferers often have a degree of dementia complicated by the presence of other disorders.(9)

Dementia can often be mistaken for acute confusional states arising from reversible or treatable phenomena, such as psychological stress, drug intoxication, infections, malnutrition (Vitamin B12 deficiency), or metabolic disorders such as diabetes or uraemia. There is concern among medical practitioners that all possible reversible conditions should be eliminated before a patient is diagnosed as 'dementing'. This diagnosis has on occasion been applied too hastily to confused elderly people.(10)

This study is mainly concerned with severely dementing patients. These are people in the later stages of the disease who, irrespective of their age or the probable form of dementia from which they are suffering, are heavily dependent upon help either at home or in a hospital ward. Physical disability may have added to their mental impairmnent and dressing and movement may often be difficult if not impossible for them without help. Depending on their home circumstances, it is usually at this stage of the disease that those dementing people who are admitted to long-term care often arrive in hospital.

SECTION THREE

THE HEALTH SERVICE RESPONSE TO DEMENTIA

In the following review of present Health Service provision for the demented statistics will be drawn from Scotland as these are accessible and clearly outlined in detail in the recent Timbury Report(11) to which frequent reference will be made. This report on services for the elderly with mental disability illustrates that there is an increasing number of the population aged sixty-five or more. Within this general increase there is a rise in the number of dementing people.(12) The Report notes that despite recent building programmes to provide adequate accommodation for the elderly mentally infirm this provision is still inadequate even for present needs. Considerable building of new hospitals and day units appropriate to this section of the population is required, both for present and projected needs, at a cost of around .44.65 million over a ten-year period in 1980.(13)

A vivid way to appreciate what the future may hold for the demented is to look at the state of present provision. The Timbury Report concluded that much of the present provision for those in institutional care and diagnosed as dementing is inadequate. It states that:

> Of the total of almost 7,000 elderly persons with mental disability requiring hospital care, some 3,000 who suffer from dementia are currently in mental illness hospitals in accommodation which is often overcrowded and of a quality unsuited to the type of care required. Another group of at least 750 such persons are inappropriately located in acute or geriatric hospitals, mainly because there are no available places in the psychiatric hospitals. An estimated 1,250 persons requiring considerable medical and nursing care are in homes provided by local authorities and voluntary organisations. In addition a sizeable number of people have unmet needs and probably require additional care.(14)

Two further areas of deficiency are highlighted by the Report.

First, the inadequate provision of assessment beds, which are of importance for the diagnosing of whatever illness the patient may be suffering. If the assessment beds are sufficient in number then the incidence of people mis-diagnosed as suffering from dementia would presumably decline.

At present such assessment is often carried out in unsuitable surroundings, such as the acute admissions unit of a psychiatric hospital, a busy general hospital ward or at worst, when the patient has been taken into hospital following some crisis, in a ward already full of severely dementing patients. The second shortage noted was that of day hospitals which have several useful functions in relation to the elderly mentally infirm, and especially the demented. Day hospitals are distinct from day centres where the emphasis is primarily social, while in the former it is 'medical'. Within the medically orientated day hospitals there are two main types with functions related to different people; first, day hospitals which aim at providing a short-term support to the acutely ill elderly who will probably be able to return to their normal routine after a while and, secondly, those which concentrate on supporting for limited periods each day patients who will eventually require full-time hospital care.(15) The second category of day hospital is particularly valuable in the care of the demented. Where such hospitals exist they enable the relative of the dementing person to have some, albeit limited, relief while the patient is in the day hospital for a few hours on a couple of days each week. While at the day hospital the patient can be assessed and the rate of decline in abilities can sometimes be slowed through such therapies as 'reality orientation', where the patient is kept mindful of the date, place and time to help maintain mental functioning in so far as this is possible.(16) It is however recognised that the day hospital system requires research into its cost effectiveness, especially as to whether it can postpone or even reduce the need for admission of the dementing to full-time hospital care. On the other hand it is acknowledged that they seem, in the eyes of those staffing them, to be fulfilling an important purpose and this contributes in turn to a relatively high level of job satisfaction among staff compared with those on long-stay psychogeriatric wards.(17)

The Timbury Report also refers to the fact that 'home care' services (of which eighty-five per cent of recipients were aged sixty-five and over) are in some areas being reduced in terms of the number of hours spent on each individual client. This trend is deplored and the Report not only urges that the 'home care' service be extended to seven days per week but that the system be given higher priority than has hitherto been the case.(18) The 'home care' service, like the day hospitals is seen as another means by which dementing patients can be cared for in their own homes where possible, by relatives.

The statistics for the number of dementing people cared for at home by relatives or friends are less precise than those quoted above for institutions and hospitals. Figures based upon the application to Scotland of results of surveys conducted elsewhere in the United Kingdom, but tested in an area of Scotland, indicate that there is a total of around 45,240 people with dementia, 23,300 of whom suffer from it in a severe form. This means that a minimum of around 18,000 severely dementing people are probably being cared for in the community (that is, at home, in nursing homes or in non-psychiatric hospital beds).(19)

The Timbury Report pointed out that in Scotland no co-ordinating policy statement exists for the care of the elderly mentally infirm. As a result care of this group, which includes the dementing, is based on four general assumptions which are inadequate in the face of the problem.(20)

The first assumption about responsibilities for care is that 'the general practitioner is the key figure in the domiciliary care programme'. This assumption shows an idealistic expectation of doctors, especially in urban areas, who increasingly work in teams from health centres.(21) Furthermore, the general practitioner tends now to operate on a system of appointments and crisis intervention which makes contact with the dementing patient less likely until the disease is fairly far advanced.(22)

The second and third assumptions may be discussed together: the rise in the number of elderly mentally infirm can be contained by home-care schemes provided through the co-operation of social workers, domestic nurses and doctors, and that this service can be co-ordinated while the caring agencies remain functionally separate. However, patients have fared badly as a result of poorly co-ordinated co-operation in the past and the economic and social arguments in favour of domiciliary care as compared with residential care are not conclusive.(23) The fourth assumption is that 'wards existing in mental illness hospitals can be used to accommodate such patients'. This practice takes insufficient account of the many disadvantages and inadequacies of using out-dated accommodation designed for a different purpose.(24)

Alongside concern about the increasing numbers of dementing people and the inadequate provision being made for them, is a continuing anxiety about the quality of direct nursing care offered. Since the outcry that surrounded the publication of Barbara Robb's account of life in English institutions for the elderly, Sans Everything(1967), and the Ely Report(1969), about a Welsh hospital for the mentally handicapped, there has been public concern about conditions in such long-stay units. In consequence the Government established the Hospital Advisory Service (now known as the Health Advisory Service) which has visited all English psychiatric and geriatric hospitals. Its annual reports indicate that where standards of care have been lowest, they have been accompanied by particular misfortune in the quality of staff, incidence of ill-treatment, shortage of financial resources for improvement of facilities and poor management.(25) The inappropriate nature of much accommodation for the demented in old mental illness hospitals has been mentioned and along with the overcrowding, this state of affairs leads to understaffing at the practical nursing level and consequently inability to provide appropriate care. This position will be examined further in the latter part of this section.

While the Timbury Report is important as a statement of the inadequacy of present care and points to the lack of appropriate future provision, a further major consideration is the state of medical knowledge and research. The Medical Research Council's report Senile and Pre-senile Dementias, published in 1977, outlines a lack of knowledge in basic areas of those diseases as mentioned in the previous section. As well as pointing to areas worthy of research the report makes a brief list of what are described as 'major obstacles to progress'.(26) Three of these are worth noting as they confirm and extend the impression given by the Timbury Report:

(a) the lack of multi-disciplinary co-operation;
(b) the remote location of many of the patients and the absence of central research enterprises;
(c) the lack of interested workers.

Thus, having reviewed the present state of Health Service provision for the demented it is seen to be seriously lacking in terms of both the immediate requirements and projected future needs. The number of demented in the community will rise as the number of elderly increase and already inadequate mental illness hospitals will become even more overcrowded and unpleasant. The decline of home care service and the inability of the severely demented to be cared for in the community is unlikely to change. The building and research programmes will get further behind. Why should this be the case?

The obstacles to research referred to above while casual in the inadequacy of provision of care for the demented are also indicative of other more general assumptions operating behind those outlined above. Since the 1940s(27) and with increasing vigour since the 1960s people have been predicting in articles and reports that the elderly mentally infirm would increasingly present a care problems for our society. Some provision has been made but on the whole it has been less than what is required and has been recommended. The care of geriatric patients has gradually been integrated into general hospitals instead of separate units,(28) but the demented are still a group very much on the periphery.

It is recognised that an inequality exists within the Health Service with regard to both the allocation of financial resources and, implicitly, the esteem or value accorded to particular fields of work(29). Broadly speaking, this inequality falls between those specialities concerned with cure, that is those providing aid for acute ailments such as road accidents or cardio-vascular accidents, and those concerned with long-term care of chronic illness. While units concerned with curing acute ailments tend to be accorded high prestige and consequently receive economic resources and have an attraction for able staff, those concerned mainly with the care of chronically ill patients are less attractive to both resources and able staff. It is clearly into this second category that the care of the demented falls and certainly the lack of financial resources would seem to bear out the distinction. There is also the low esteem in which such work is held. While this may account for the lack of financial resources it is also to some extent responsible for the difficulty in attracting able researchers to study dementia. This problem of recruitment in research is also reflected in the field of clinical practice where the lack of teaching posts in the speciality of psychogeriatrics means that it is very difficult to train new doctors in this field and to make other medical practitioners aware of the needs and challenges of caring for the elderly mentally infirm.(30)

The field of nursing is also one in which the problem of low esteem to the care of the demented is apparent. The considerable salary discrepancy between doctors who 'cure' and nurses who 'care' has been seen as evidence of the inequality of esteem accorded between the two roles within the Health Service generally.(31) Ways of maintaining morale of nurses is one of the main concerns of those trying to improve the standard of institutional care for the demented.(32)

It is however important to look further, beyond this discrepancy. Inadequate provision for the demented is seen to stem at least partially (or primarily, if the lack of financial resources is seen as causing the state of affairs which makes care and research unattractive) from the low priority accorded to care of the demented in terms of Health Service resources. This in turn arises from the lack of esteem in which such work is held. Again, the question must be asked: why is this the care?

One explanation might arise from an extension of the thesis that socially we do not like to be reminded of disease and decay. Michael Wilson's concept of the 'sanitated society' is interesting here:

> . . . conditions that we cannot cure we have tried to get rid of by institutionalisation. In the middle of the nineteenth century we developed a system to keep the mentally sick in custody in remote and shunned mental hospitals. The stigma of mental illness has diminished in the last twenty

> years but it is still common . . . Because we cannot cure or solve the problem of mental subnormality and old age we try to keep society free of trouble by a policy of 'putting away'. We adopt the technique of sweeping society clean. We aim for a <u>sanitated society</u>, not a healthy society.(33)

When applied to the predicament of the demented within the Health Service we see the same process in microcosm. The demented represent a group which is regarded as unacceptable because it cannot be contained in terms of or by methods which work when applied to the majority of clients. Dementia at present illustrates the limits of medical competence. The doctor's role is one of very limited contact with the patient and the bulk of the care, which is commonly described as 'management',(34) is carried out by practical nurses often with limited training. The nature of dementia, for which there is no known cure and no clean tidy or aesthetic form of treatment, challenges the medical view of individual physical freedom from ailment and threatens the self image of omnipotence among some medical practitioners. The medical model of man as machine, a consequence of the increasing surgical ability to replace organs in human beings in a manner not totally unlike the way in which a motor-mechanic repairs the worn parts of an engine, clearly fails where dementia is diagnosed.

Thus far it has been shown that dementia is a disease which affects a significant section of the population both directly and indirectly through those sufferers living in the community. The Health Service provision is not adequate either for present or future needs. Furthermore, there seems to be a strong distancing element in the Health Service's response to the demented, illustrated by low staffing levels and poor financial resources for care and research. This distancing may stem from the Health Service's inability to successfully encompass dementia within its sphere of competence or it may be a reflection of more widely held social assumptions. In either case it is clear that something more than further reports and recommendations is required. In examining this further the approach of another caring body; the Christian churches, will now be considered.

SECTION FOUR

THE CHRISTIAN CHURCHES' RESPONSE TO DEMENTIA

The churches' response to the predicament of the demented is conditioned by their theology of man as a rational being and affected by a priority of compassion for the agents of primary care. Pastoral commitment is sometimes diffused among groups of medical staff and relatives at the cost of attention to the patient and ministry is frequently influenced by medical opinion and attitude, rather than theocentric relationship with the sufferer. Some theologicans and pastors are beginning to confront this problem.

Seward Hiltner, a pastoral theologian, has called for work to be done on a 'theology of ageing' which he sees as a neglected area.(35) As part of the practical theologians' response to this plea William Clements' Care and Counselling of the Ageing(36) is intended as a pastor's introduction to ministry to the aged. As such it will be examined here as representative of pastoral theology in the field of old age, which might reasonably be expected include some reference to dementia. It is interesting to notice the absence of discussions of ministry to the dementing in many standard manuals of pastoral care.(37)

Clements is concerned to challenge the commonly held view of life which sees it as falling into a three stage pattern of low-high-low, in which the second half of life is regarded as nothing more than a decline to uselessness and deterioration. This view Clements sees as inadequate because it confuses the motion of personal wholeness with physical functioning and freedom from ailment. In this view the second half of life becomes a struggle against encroaching disability and disintegration rather than a continuation of the growth process, understood in terms of the whole person rather than mere physical health.(38) As a corrective to this former negative view Clements argues that the later years of life, which he charactrerises as being marked by a sense both of the absence of distant future and a diminution of the productive present, nevertheless are important in that they can provide space for the development of creativity and continued growth of personality. Thus the period towards the end of life can be one which is free from the pressures and strains that characterised the earlier and middle years when family and occupation demanded much energy. The space now available can be used for the reflective process of 'self-identification'.(39) Hence, not only can old people find their later years fulfilling through a deepened self-awareness, reflection, and integration of the past but they may also act within their community as useful sources of knowledge about past events or the origins of customs which may have been forgotten or gone unrecorded. This view of old age is certainly valuable as a corrective to that tendency which dismisses the elderly as uselessly burdensome. However, its limitations do become evident when applied to the demented. They lack, as far as we know, the rational mental and intellectual faculties to enable them to participate in the process of self-identification or to become a source for community history. Consequently the demented are excluded from this attemnpt to theologise the predicament of the elderly.

The second recent piece of theological writing to be examined here is W. H. Vanstone's The Stature of Waiting(40) as it is an attempt by an experienced pastor to reflect upon a new understanding of the atonement in the light of his ministry, especially with the sick and the unemployed in mind. Vanstone is concerned to illustrate that the image of God may be manifest in man when he is not active, indeed when he is at the mercy of the circumstances of his surroundings. It is this aspect of his argument which indicates that Vanstone's thesis suggests an understanding of the predicament of the demented which may be helpful to caring relatives and staff. His argument begins from a discussion of the references in the gospels to the role of Judas which takes its importance, it is argued, not from the act of betrayal which is one reading of the neutral Greek verb <u>paradidōmi</u> but from the 'handing over' of Jesus. This point is elaborated and illustrated from St. Mark and from St. John, where the same point is made in a slightly different wav The conclusion drawn is that these gospels identify the 'handing over', facilitated by Judas, with Jesus's transition from a active role to an outwardly passive one.(41) From this point the passion, that is the time from which Jesus was handed over until his death, is presented in the Marcan and Johannine narratives as the most significant phase in Jesus's life because through his self exposure to the wills of others and to suffering he demonstrates God's own will and intention to involve himself intimately and apparently even passively with his creation.(42) This notion contradicts the traditional concept of impassibility, by which God is thought to be unaffected by what happens in the world, but it offers a way of seeing afresh the limitations of two important aspects of Christian theology as it is commonly understood. Vanstone notes the extent to which both the sick and the unemployed become dependent upon others and in a sense powerless to exercise their will in their predicament. This frustrating state of affairs seems to be exacerbated by the popular and influential model of work or activity as something good in itself. He sees this model as having two strands. The first he dates to the Reformation when part of Christian theology developed a very strong work ethic. The second is the theological picture of God which emphasises his actions, such as creation and redemption.(43)

Vanstone challenges these notions with the idea of Jesus showing the waiting, passive nature of God: 'The most glorious activity of God is that He hands Himself over, and, in His free activity of loving, surrenders His own impassibility'.(44) This point Vanstone sees as being '. . . highly relevant to the recovery of man's sense of dignity and worth in those increasing areas of life in which he finds himself dependent upon others, exposed to factors beyond his control, waiting upon events, the object and recipient of what happens around him and is done to him.'(45) This last might also describe the predicament of a severely demented patient in a long-stay psychogeriatric unit; however, in Vanstone's study it does not. This is because of the importance attributed to the character of 'waiting'. described as: 'The experience of waiting is the experience of the world as in some sense <u>mattering</u>. as being of some kind of importance.'(46) This point is illustrated by contrasting the conditions of a severely depressed, and possibly schizophrenic youth who looked out on the world and all around him with expressionless eyes seemingly totally unconcerned at what might be happening. with that of an old bishop dying, requiring help in everything but still possessing that facility described as 'waiting' (47) It is clear that demented persons would come into the former category, for there is no way of ascertaining that they might have the faculty 'of experiencing the world as in some sense mattering' Thus, Vanstone's argument is important in its challenge to the view that the value of man depends on his ability to do and to be independent, but it still leaves the severely demented outside because it understands mental perception, an intellectual awareness, as integral to man's reflection of the image of God.

This may be considered unfair criticism of both Clements and Vanstone in that neither of them sought to treat specifically of the demented. Nevertheless, both seem to be working within implicit assumptions based upon an understanding of the imago Dei, that is, that the element of man thought to reflect the divine in him is his rational faculty. This concept of the imago Dei was common among theologians to the time of Aquinas, and broadly speaking it changed at the Reformation with the emphasis on the Fall eliminating the image, which was either redeemed by Christ or in man through relationship with Christ.

In this century the concept of imago Dei has been reviewed notably by Brunner and Barth, who although from different perspectives and with differing emphases have seen the image residing not in any substance of man, such as his intellect, but in his capacity for relationship with both God and his fellow man. Brunner's understanding of the nature of this relationship is however still very dependent upon a rational element which seems to exclude the demented:

> . . . the heart of the creaturely existence of man is freedom, selfhood, to be an 'I', a person. Only an 'I' can freely answer God. An automaton does not respond; an animal in contradistinction from an automaton, may indeed re-act, but it cannot re-spond. It is not capable of speech, of free self-determination, it cannot stand at a distance from itself, and is therefore not re-sponsible.(48)

Barth's thought on the imago Dei developed through his life and here consideration will be given to what he wrote in the third volume of the Church Dogmatics, as a late and full treatment of the subject. Like Brunner he saw the likeness of God in man in terms of relationship, but placed special emphasis upon the man-woman relationship as model for that between God and man.(49) What is not clear is the extent to which this relationship depends upon rationality within man. At one point Barth states that the text, upon which his understanding of the doctrine of the imago Dei is based, Genesis 1.26, makes no reference to the rational elements of man.(50) However, elsewhere in the discussion he talks of the nature of man in such a way that implicitly suggests the importance of the rational element as a prerequisite of relationship:

> He is the image of God in the fact that he is man . . . (God) willed the existence of a being which in all its non-deity and therefore its differentiation can be a real partner; which is capable of action and responsibility in relation to Him; . . . (51)

It would be inappropriate here to digress into a fuller discussion of theologians' changing views of the imago Dei, but the concept is important to the study of the problems of dementia, especially where it seems implicitly to be understood in a sense which might deprive the demented of their value as human beings.

Another assumption which may influence theological attitudes to the demented and certainly still forms part of society's view, is the connection between sin and illness. This connection, evident in some biblical narratives, was clearly set forth by Athanasius in his De Incarnatione. Here he outlines the tendency within man physically to decay and sees this as a direct consequence of the Fall.(52)

Having briefly reviewed some relevant theological thought it is now appropriate to examine the pastoral work of the churches. Ministry to the demented reflects the absence of theological work and practical manuals on the plight of dementing people. It is however difficult to assess the effectiveness of the churches' ministry to the demented and their relatives because so much of the work is carried out on an informal, individual and unrecorded basis, and for clergymen this is a small part of the large task of pastoral ministry.

At the institutional level the churches provide some of the homes for the elderly, described in government reports as 'voluntary care'. However, these homes tend to take only the relatively alert and mobile elderly and when patients begin to show marked signs of confusion that may well indicate dementia they are moved out as soon as possible into general or psychiatric hospitals. The grounds on which this approach is reasonably justified are that the church homes can only afford to pay enough staff to look after the alert and mobile elderly and to admit dementing people would place too much strain on the staff and consequently the welfare of the other patients would suffer. Several of these church homes do cater adequately for those old people with dementia in its early stages but are generally reluctant to admit anyone in this condition. The Church of Scotland recently opened a home for the elderly confused at Williamwood, near Glasgow, but in May 1983 the organisers did not seem to be clear whether or not dementing patients would be accommodated there.

Alongside the institutional care in homes which are not really designed for the needs of the demented there is the pastoral practice of the clergy. No survey of clergymen's attitudes towards and practice with the demented seems to exist. However, some indication of pastoral effectiveness in ministry to people with mental handicap is evident from a recent survey of 120 families with handicapped children of whom only two turned to the churches for help and the summary concluded that in this sphere the churches' role was described as 'influence and support, negligible'.(53) The difficulties in assessing pastoral practice have been mentioned and in this discussion evidence is drawn from the author's own notes and recollections of many conversations with experienced pastors, among them hospital chaplains, about ministry to the demented and their relatives.

The impression gained from these conversations is that, broadly speaking, the ministers' reactions and responses to the severely demented take two forms. Perhaps the most prevalent form assumes that the severely demented belong exclusively to the care of medical professionals and are beyond the conventional ministrations of the church. The minister instead devotes his energies towards those bearing the burden of primary care of the patients, that is the ward staff and relatives. Such ministry might, and sometimes does, involve the minister facilitating or participating in groups of both ward staff and relatives whether severally or together, which discuss the problems and strains of caring for severely demented patients and relatives. It is the hope that such sessions benefit patients indirectly. Also some churches have held talks about the care of the demented for people who might be having to deal with such a situation at home.

The practical implications of this approach just outlined, that is, ministry directed at the primary carers, are important for and included in the second broad form of ministry to the demented. This second form, distinct from the first in that it has the demented themselves as its primary focus of attention, recognises both a responsibility to minister directly to the dementing people and also that this is in an area of neglect in pastoral practice. The neglect stems from a recognition of the difficulty of ministering to people who appear to have lost most of their normal intellectual functions and who are consequently very difficult to relate to in the usual ways. One chaplain, whose approach is broadly that here described, referred to his own tendency, when visiting general hospital wards with dementing patients in them, to spend much more time with those people with whom he could have some form of dialogue. He went on to say that often he noticed visiting ministers tend to spend most of a visit talking to the patient rather than letting them talk. If these reflections are typical then we have a fairly bleak picture of the Christian ministry to the severely demented. Recognising the difficulty of dialogue with severely dementing patients, some ministers resort to the ministration of the sacraments and others to gentle and reassuring human touch. Such ministry is often visibly reassuring to the patients who responds to varying degrees by apparently becoming calmer and occasionally responding in a manner familiar to them before their illnesss, such as joining in at appropriate parts of the service.

However, while acknowledging that this second form of ministry is exercised among the demented, there are also problems with the approach of the churches in general to the demented. Many clergy to whom I spoke freely admitted, with greater or lesser degree of discomfort, that in taking the funerals of people who had been severely demented before death, they tended to ignore the dementia and concentrated on the positive aspects of the person's life. While the funeral oration is not the ideal place to review and renew the discomfort caused to relatives by the disease, it is also unfortunate if the demented stage of the person's life has to be ignored and cannot be spoken about in the context of remembrance before God. There are also the pastoral implications of ignoring the emotions of the close relatives who may have had a large part in the care of the dead person and who may be even more confused than normal in bereavement. The relatives who have cared for a dementia sufferer are likely to have a more complicated than usual bereavement experience. It is thought that bereavement often begins for them when they consciously allow themselves to acknowledge that the person for whom they are caring is no longer the spouse or parent they previously knew. However, they cannot grieve freely because the person is to some extent still present with them, requiring care and attention. Only with the actual death of the dementing person can the grief be fully acknowledged and worked through.(54) If the funeral service ignores the dementia as well as the death it will not help the relatives to come to terms with their feelings and to recover from the experience. It is a sad reflection on pastoral care that it frequently avoids confrontation with the actual problem, frightened of naming the 'bogey-man', be it death or dementia.

Another aspect of the churches' practice open to scrutiny in this area is the general provision of services for the severely demented. While it is recognised that many churches would find it practically impossible to accommodate the demented in their services it is worth pondering the reasons. A sobering contrast can be drawn between the churches' response to the demented and their response to young children. While both groups have in common a tendency at worst to be incontinent, smelly, noisy and difficult to control, a considerable amount of energy is expended on providing special services for the young and on integrating these to some degree into the congregations's main diet of worship on Sundays. It is not difficult to imagine the initial response of most congregations to a dementing adult or elderly person who was brought to a normal Sunday service. The implications of this parallel might lead one to think that the churches are implicitly endorsing a very materialistic view of man.
That is, that he is only of worth when he holds the ability or potential to contribute actively to society. While this is the case with children,

who are seen as the hope for the future, it is patently not the case with the severely demented who, whatever they may have contributed during their life before illness, are now regarded as being incapable of contributing to society.

Before concluding this brief survey of theological and pastoral responses to dementia it might be valuable to speculate upon an area in which theology contributes to medical attitudes: medical ethics. Given the perilous state of the dementing patient in terms of Health Service care and resource allocation and also the neglect in which they seem to be held by the Christian churches, how improbable is it that the logical extension of some medical ethical thought about malformed neo-nates might come to include the demented? The predicaments of malformed neo-nates and the demented are not dissimilar: both are dependent upon others for their survival, both are different from normal and consequently both are liable to be regarded as disadvantaged. Debate among medical ethicists on issues such as abortion and euthanasia often involves some reference to what constitutes a 'truly human being' or what standards are necessary for 'truly human life' to be so regarded. In an attempt to provide some guidelines in this field Joseph Fletcher, an American episcopalian clergyman who has written extensively in the field of Christian ethics, wrote an article in which he tried to outline some 'indicators of humanhood'.(55) He lists among ten 'positive human criteria' the necessity for a human to have an I.Q. of a specific level: 'Any individual of the species homo sapiens who falls below the I.Q. 40-mark in a standard Stanford-Binet test, amplified if you like by other tests, is questionably a person; below the 20-mark, not a person.'(56) He goes on to outline the importance of self-awareness, self-control, a sense of time, the future and the past and also a degree of control over one's existence: 'Invincible ignorance and total helplessness are the antithesis of humanness, and to the degree that a man lacks control he is not responsible, and to be irresponsible is to be subpersonal'.(57) Curiosity is also integral: 'indifference is inhuman'.(58) A problem with Fletcher's approach is that he seems to assume that the quality of human life cannot be assessed without it having first been defined what constitutes a human being. This leaves the problem of how to assess those being which look human but are not human in terms of Fletcher's criteria. What are they and how ought we to respond to them? This general principle, now accepted by other ethicists(59) presents problems when viewed, along with Fletcher's tentative criteria for humanhood, from the point of view of the demented. For if we accept Fletcher's criteria the demented never get to the point at which the quality of their human life is worth assessing because they are defined as being sub-human. This is worrying, but not nearly as frightening as some arguments referred to by Paul Ramsey which pertain to malformed neo-nates. Unlike Fletcher's points which at least centre upon the condition of the individual in question, some of those about which Ramsey writes are focused upon the attitudes of those around the individual, the dementing person or the malformed neo-nate, which determine his right to life. These suggested criteria include the 'loveableness' of the neonate(6), its potential to cause emotional suffering to parents or siblings, or financial burden to the same(61), and even the feelings of the nursing staff.(62) Should these criteria gain widespread acceptance among ethicists and medical practitioners then how unreasonable is it to expect their logical extension to all disabled members of society and especially the severely demented, who again according to the criteria outlined by Ramsey would have a slim chance of survival?

This excursus has attempted to illustrate what might as worst be a consequence of contemporary medical and theological attitudes to the demented when seen in the light of recent medical ethical thought on the predicament of severely deformed neo-nates. How much distinguishes the two groups of people? The severely demented are perhaps protected by their past lives, names and identity however fragile their hold on it may become. It is not so easy to exercise 'benign neglect' to the point of death when thinking of someone who was perhaps what we are. On the other hand a hospital chaplain mentioned the response of several general nursing students who upon completion of their psychiatric block study, which included work on wards for the severely demented, thought that it would be a kindness to slip these patients a pill to kill them.

Hence, there would appear to be a problem for theology which defines humanity in a way which excludes some homo sapiens, such as the dementing, on the grounds of intellect or rational faculty. This tendency is reflected both in the institutional and personal ministry of the churches and so encourages on the whole the distancing of helpers from sufferers.

SECTION FIVE

UNDERSTANDING RESPONSES TO DEMENTIA

The outlined response to dementia by the Health Service and churches alike reveals cause for concern to the extent that the predicament of dementing people is an area of neglect. Two biblical models illustrate the way in which caring services and institutions at worst reject and at best distance themselves from the dementing, and a third is presented as a paradigm of the will to heal. The models are here employed as metaphor rather than theological literalism.

(a) The Scapegoat

The first model is based upon the concept of the scapegoat (Leviticus 16). In the rituals there described, a bull and two goats were presented to the high priest at the Temple on the day of the feast of the Atonement. After the presentation of these two goats before Yahweh and the drawing of lots the first goat was offered to Yahweh and its blood was then taken into the Holy of Holies and sprinkled about in the same manner as the bull's blood had been in order to effect the expiation of the sins of the priesthood and people as well as to cleanse the sanctuary. The second goat was not killed and after presenting it again before Yahweh the high priest laid his hands upon the head of the goat, simultaneously confessing all the sins of the people of Israel, following which the goat was to be led out into the wilderness carrying with it the sins of the Israelites; the individual whose task it was to lead the goat out was regarded as unclean and had to cleanse himself upon his return (Leviticus 16.10, 20-22, 26).(63)

Three aspects of this outline are relevant to this study of dementia: the apportioning of sin, the banishment to the waste places, and the contamination of those who come into contact with the 'scapegoat'. There is no implication here that dementia is the product of particular or heinous sin in the sufferer. What is of interest, however, is the way in which dementing people are often regarded as if this were the case. Long after many people have ceased to regard sin as a factor of life, they continue to act out the ancient and primitive response to sin.

In the biblical account of the scapegoat the animal is depicted as carrying away the sins of society into the wilderness and consequently of cleansing the town from which it is led. The concept mentioned above of the 'sanitated society' in which the elements regarded as undesirable, such as criminals and the mentally ill, are placed in institutions removed from the centres of population is a good parallel to the banishment of the goat. The model starkly outlines the effect upon relationship with dementing people of caring organs which distance themselves from the suffering of the patient. Most importantly, it cuts through the haze surrounding the issue and highlights social tendencies to evade it. This evasion is most obvious when the demented are effectively 'banished' to old mental illness hsopitals which are often difficult to get to. This has the effect of increasing patients' isolation because relatives and friends have difficulty visiting.(64)

However, a more vivid illustration of this problem in microcosm is evident in observations reported from a forty-two bed psychogeriatric unit, caring for highly dependent patients, in the Manchester area.(65) The main findings were a generally low degree of both staff engagement with the patients and a low level of stimulation such as contact with visitors or listening to the radio. Alongside these observations was this one:

> Patients tended to be segregated according to their level of functioning, with those most deteriorated situated in geriatric chairs around the side of the dayroom, and the least deteriorated seated around a table near the staff common room, the main entrance to the ward and the hallway leading to the nursing office. This meant that the least deteriorated group were visited by the staff more frequently than all of the other patients, particularly those who were most deteriorated.(66)

In this cameo we see the distancing of the most severely dependent patients to places in the ward furthest from sight and consequently from the care they require. An example of this same exclusion in the sphere of church life is shown by the following account of a Scottish chaplain's experience when holding a communion service in a psychogeriatric ward. In preparation for the service the ward sister had arranged all the most alert and mobile patients around what was to be the communion table and at the same time had placed all the severely dementing patients in a side room out of sight where they would not be able to 'spoil' the communion for everybody else and especially not 'show up' the ward in front of the chaplain and his assistant. The sister had to be persuaded to allow the severely dementing patients to be brought back in to the ward to join the rest of the congregation.

This physical distancing is paralleled in speech patterns. To describe a patient as 'a geriatric' is to see them only in terms of their medical condition and their label as applied by health service statistics. While it is clear that such labelling is an administrative or verbal convenience it is potentially damaging to the subject so labelled in that there is the danger that those using the label forget that it applies only to a condition, the victim of which is a human being. Demented people would now seem to have been accorded their own label to distinguish them within the vast sea of geriatrics: it is not uncommon to read of patients, diagnosed as suffering from dementia, described as 'dements'.(67) For 'dement' we might easily substitute 'scapegoat'.

A further illustration of this distancing and one which to an extent parallels the unclean nature of the man whose role it was to lead the goat into the wilderness is the predicament of the primary care staff. A leading authority on the health care of the elderly, in describing the problem of maintaining the morale of the hospital primary care staff, goes as far as to state that: '. . . indeed, the low status of the elderly may be said to contaminate those who work with them'.(67)

Thus we have seen the distancing and perhaps even the notion of contamination present in our response to the demented. In these points we have adequate parallels with the model of the scapegoat, but we are now obliged to ask why we react towards the demented in this primitive manner. Here, the answer is provided by the element of the model so far unexplained: the role of sin. At the Temple the high priest places the sins of the people upon the goat's head before it is led out into the wilderness. Thus the sin was believed to have been removed. In our relationship with demented people, they are made to carry the full burden of the 'sin'. that is, of the responsibility for the breakdown in relationship between themselves and the rest of society, and as a consequence of this projection they are 'banished'.

The dynamics of this form of relationship seem complex but in essence they are quite straightforward because primitive. First, it is important to acknowledge that the dementing person can be a source of great strain to those people providing the primary care.(69) This is as true of hospital staff as it is of relatives, who in those cases where it is a close relative suffering from dementia have also to cope with their own gradual realisation that the person they are caring for is no longer, in anything except outward appearance, the person they formerly knew. As the disease progresses the situation worsens: 'With the disorganisation of thought, speech becomes more and more incoherent and the contact with the patient increasingly tenuous, until all that is left is a gabbling, fatuous, incontinent shadow of his original self.'(70) There comes a point at which it is unreasonable to expect the demented to be able to relate in the manner in which we are predominately used to relating to one another, that is conditionally. So many of our relationships are based upon the satisfaction of various conditions, generally unspoken ones, with the result that when someone is unable to conform to these conditions they might be seen as challenging us in making extraordinary demands which we are not prepared to meet. An illustration comes to mind of a couple not being invited to a dinner party because the man was in the early stages of dementia and could not be relied upon not to behave 'strangely'. What it is important to realise here is that certainly we cannot always relate to the severely demented in the normal ways and to some extent that is a consequence of the disease from which they suffer but it is also to do with our expectations of what constitutes a relationship. We think of a relationship in historic and rational or intellectual terms, as something which builds up over a period of time through predominantly verbal and intellectual interchanges and with a fairly limited amount of physical contact and then only usually in a private or intimate context. Severely demented people are largely excluded by their ailment from such relationships formed on strongly rational and conditional bases and we often distance them further by our inability to try to relate to them in ways that might be appropriate. In this way, then, we attribute them with the 'sin' which leads us to want to banish them or to pretend that they do not exist by ignoring their plight. We blame them wholly for the breakdown in relationship, brought about by their irrational, messy and unaesthetic predicament, without acknowledging our own part in the process. Sin, understood as alienation, is present in this situation because we choose to distance ourselves from the plight of the demented, not concerning ourselves overmuch with their needs or with our responsibility towards them as fellow human beings.

This image of our relationship with severely dementing patients might legitimately be criticised as something of a caricature for it does not take account of those attempts which are being made to improve the situation. However, as the illustrations demonstrate the model has a ring of truth about it when seen as indicative of the worst instance. There needs to be an interim model.

(b) The Suffering Servant

It will become clear that we are not here concerned with the messianic character, as it has been understood by either the Judiac or Christian traditions, of the servant songs of Isaiah 52.13-53.12.(71) Nor is it supposed that the poetry was composed with the demented in mind. Nevertheless the world imaginatively described is also their world:

> . . . he had no form or comeliness that we
> should look at him ,
> and no beauty that we should desire him.
> He was despised and rejected by men;
> a man of pains and acquainted with sickness;
> and as one from whom men hide their faces he
> was despised
> and we esteemed him not. (Is. 53.2b-3. RSV)

Along with the description of the servant's plight is, however, a recognition of the onlookers' response:

> Surely he has borne our griefs and carried
> our sorrows;
> yet we esteemed him stricken, smitten by God,
> and afflicted. (Is. 53.4)

This is the important phrase for this second model of our manner of relating to the dementing people, for it demonstrates an awareness not only of the suffering but also of the onlookers' place in that suffering; there is an acknowledgment of the collective nature of the problem. The cause for the alienation of the demented people lies not only in their unsociable behaviour but in society's attitudes towards them and recognising this is a first step towards challenging the alienation. Restoration of the relationship can begin only when we realise that our attitudes also play a part in the distancing of the demented. This is perhaps the basis upon which some health service and church work takes place.

The model provided by the suffering servant passage, in which the onlooker acknowledges the suffering of the demented and consequently their own part in the complexity of that predicament, can be paralleled in the health service response to the plight of the demented in at least three ways. First, and most obviously, is the proliferation of reports dealing with the inadequate treatment of and provision for the elderly mentally infirm. Such reports often indicate that in the years since their predecessor the improvement in response to the problem has been inadequate even where limited attempts have been made to better the predicament of the patients.(72) The reports make continuous reference to the particular areas of concern: inadequate finance, low staff morale, lack of co-ordination of services and the unsuitability of much present accommodation and resources.

Alongside this informed inertia, there is the work of the primary care team. Arie refers to the attitude among practical nurses on a high-dependency psychogeriatric ward where the nurses only felt they were working when they were doing something practical and physical for the patients such as dressing or toileting them. He acknowledges that this was in contradiction of the expressed ethos of the hospital which sought to encourage independ-

ence of choice and activity among patients and endeavoured to facilitate personal contact between staff and patients whenever possible.(73)
In this case the nurses recognised the plight of their patients and also that they had a responsibility to alleviate their suffering but they seemed predominantly unable to overcome an attitude which saw their patients as requiring little more than physical help and consequently they could feel that their job was well done when all physical needs of the patients had been met.

A third possible health service response which this model illumines is that of regarding the dementing patient as of value and in need of care in proportion as investigation of their predicament sheds light on other fields:

> . . . interest is growing, not simply because the problems of the elderly are becoming more manifest and pressing, but because it has been recognised that a close study of the process of ageing, especially its effects upon brain tissue, may enable a better understanding of psychiatric illness at all ages.(74)

In this process the elderly mentally infirm are in danger of being reduced to research material for the rest of mankind, while seemingly being cared for because of their actual ailments.

Ecclesiastical parallels are more difficult to find because the churches are not engaged in the primary tasks of nursing care and research. Until a cure is at hand most clergy are likely to respond in terms of the first model, and it is not clear that many pastors get beyond the stage described in one autobiography:

> By the time I arrived as a deacon he was senile and used to embarrass my inexperience and leave me not knowing what to do. I used to take him Holy Communion. At the short service I would say: 'Make your humble confession to Almighty God,' and instead of reciting the confession he would say: 'You were at Trinity College, Cambridge, weren't you?' It was difficult to know how to proceed.(75)

Here the plight of the demented person is recognised and the onlookers' responsibility to overcome the distance evident is acknowledged, but what to do next?

Both the 'scapegoat' model and that of the 'suffering servant' have been employed to illustrate our varied responses to severely dementing people but there is still obviously a problem, a gap to be overcome. The models show our rejection of the problem and the banishment of the sufferers and also attempts to remedy the situation which are not adequate. Too harsh a distinction should not be drawn between the 'scapegoat' and 'suffering servant' responses, as it is possible for a person to move in and out of both models of relationship, sometimes distancing sometimes aware. The third model will seek to show an approach which might lead to a more appropriate response to the problem of our relationships with dementing people.

(c) Dominical Acceptance without Condition

In turning our attention to Jesus's manner of relating to the outcasts of his day we find indications of what is required to remove the obstacles hindering an adequate approach to caring for the demented.

The story of the Gadarene demoniac in Mark 5.1-20, with parallels in Matthew 8.28-34 and Luke 8.26-39, provides a useful third model in this study. It is important to acknowledge various textual difficulties and to take into account the theory that the present account has been built up, with additions, from an amalgam of at least two stories, one of Jesus's healing a demoniac and another older folk-tale.(76) These are however only of secondary concern in this study, for here our interest lies with Jesus's response to the plight of the demoniac. As with the suffering servant it is not at all clear what the demoniac was suffering from and again that is not of importance, for what is clear from the text is that he was a man cast out of society and forced to dwell among the tombs. In his behaviour he was anti-social: 'Night and day among the tombs and on the mountains he was always crying out, and bruising himself with stones.'(Mark 5.5) He was also socially isolated in his home at the tombs which were regarded as the dwelling place of the dead and unclean, likely to contaminate those who touched them.(77) The plight of the demoniac has been described thus by one commentator:

> The ghastly and shocking power of the illness, the complete hopelessness of the disease, is illustrated by the fact that the afflicted man lived in the realm of the dead, among graves unclean to the Jews.(78)

Whatever his diagnosis is, he represents suffering which demented patients know well. Yet, when he rushed towards Jesus he was not rejected, told to go away so as not to contaminate people, nor was he ignored discreetly by man who walked away pretending he did not exist. Jesus accepted him completely and unconditionally, asking him his name, healing him and re-integrating him into society (Mark 5.19-20). Jesus's attitude to the demoniac in this incident is of central importance for it is from the initial acceptance and acknowledgment of the man in his plight that the healing follows. Jesus's recognition of the man in his predicament leads Jesus to bring healing to him, to end his alienation and rejection. In this incident it is the demonstration of the will to heal that is important in Jesus's attitude. The will stems from an unconditional acceptance of the man in his plight. Where society distanced the man in banishing him, Jesus met him, ended the alienation, and thus healed him.

This attitude has implications for our care of the dementing people in our society and supremely for the churches' theology and their pastors. As long as society persists in the distancing and the informed inertia outlined in the scapegoat and suffering servant models there is little chance of a corporate acceptance of the plight of the demented which is a prerequisite of the 'will to heal'. It is important to make clear that the phrase the 'will to heal' is not here understood to imply that dementia can be cured, but that 'healing' for the dementing means primarily unconditional acceptance which in turn will bring concern for their plight and the means or will to alleviate it.

If the dementing people are to find such help in our society, they cannot do it alone. Another pericope may serve to illustrate the point. The sick man at the pool of Bethzatha who although he had lain at the poolside for a long time could not get himself into it for a cure when the waters stirred because he had no friends to help him (John 5.1-9). Although the invalid lay by the pool, which was close to a gate into Jerusalem, there was an absence of helpers, people who had noticed his plight and were sufficiently concerned for him in it to take action. He might have lain by the pool for as long again had not Jesus arrived and seeing his predicament, dealt with it. As with the demoniac Jesus did not just see the problem, he met and overcame it.

This manner of relating to the dementing people is demanding and challenging partly because of the difficulty of accustoming ourselves to their predicament and also because of the question it forces us to ask about our own humanity which is threatened by admitting the existence of dementia. Furthermore, those who advocate this approach are at present a minority and they have to expend as much energy explaining what they are doing to their colleagues and those around them as they do on helping the demented. Examples of such people are to be found in both the community in general and the health services, where they constantly seek to improve the conditions of their patients, inform public opinion of the problem through official reports and articles as well as try to train new health service workers to take the problems of the demented seriously enough to do something about them.
I heard from a woman about her efforts to help her dementing father to remember who he was, who his family were and what his interests had been, by making up a large book of clearly labelled photographs. This book was also seen by the ward staff who through it came to realise something of the personality of their patient, beyond the faded exterior for which they cared day by day.

SECTION SIX

CONCLUSION

In both the Health Service and the Christian churches' response to dementia there is seen to be a distancing and a limited acknowledgment of the plight of the demented. Low resources and inadequate nursing conditions continue in spite of reports and recommendations from both medical and government bodies. The churches' response, in so far as it can be measured, is little better. The use of biblical models to interpret our many complicated and interconnected ways of relating to dementing people has revealed the origins of the shortcomings, especially through the 'scapegoat' and to a lesser extent the 'suffering servant' model. The second of these two can be seen as a transitionary model to the third; that of 'dominical acceptance without condition'. The apparent polarity of these models, however, does not exclude them from being together descriptive of one person's changing attitude. Responses may vary from the total distancing of the 'scapegoat', resulting in alienation, to the acknowledgment in the 'suffering servant' of both the predicament of the dementing people and of our own part in that, to the acceptance shown by Jesus. Unfortunately the dominical paradigm is rare and most fleeting. The problem is how to attain the unconditional acceptance that leads to the will to heal.

A central prerequisite is the removing of those obstacles which prevent right relationship between the severely demented and the rest of society. Only this can the environment be created in which the 'healing' of relationship may take place. The removing of obstacles has practical implications on two connected levels, the personal and the social.

The demented must be valued for themselves and this must be seen by society to be the case. In practical terms this would mean regular visits to dementing people in hospital and being prepared to sit with them for a time, perhaps holding their hand and talking with them. This would reinforce the commitment of ward staff to care for their patients, resulting in improved general morale and care for the whole ward. Such visiting could be done by relatives and friends or even members of a dementing person's old congregation. It begins to overcome the distance between the old mental illness hospital ward and the rest of society.

Part of such visiting would be an awareness of the person's own reaction to the condition of dementia in the patients and the way this affected their manner of relating to them. Such awareness is important especially among the primary care agents, be they relatives or nurses, and a sensitivity towards the strains and problems that can arise through caring for the demented is valuable. These insights should be discussed by both nursing staff and relatives. In Edinburgh, at both the Royal Victoria Hospital and the Jardine Day Clinic at the Royal Edinburgh Hospital, such groups have proved extremely valuable for all concerned in providing an acceptable expression for some of the frustations and anxiety dementia can arouse in nurses and relatives. These groups, along with the 'home care' services, seem to enable relatives to sustain a dementing person in the community at home for longer periods without crises. This is work in which some chaplains are involved, and which could well be extended into the community by church groups.

Distancing of the demented may be further reduced by the formation of bodies like the Alzheimer Disease Society which helps relatives to learn about the disease and its problems. Such societies and bodies might to a greater extent than is presently the case seek to inform society more widely of the nature of the disease and the manner in which its sufferers are treated. Well organised information and public presentations of the issues involved would serve to awaken social concern which in turn would provide a stimulus to finding more financial resources for both care and research. Dementia is not a 'fashionable' disease like cancer and does not attract the same attention or resources. It is perhaps unrealistic to assume that there will ever be enough money available, even in the best of all possible worlds, to provide the ideal services for the dementing at home and in institutions, but better use could be made of existing resources and co-operation between agencies responsible for the demented should be developed as a matter of priority.

When dementing people are seen to be valued, cared for and accepted for themselves rather than shunned, then society's fear of them may be abated. Only when their humanity is acknowledged through deeds as well as words can the re-integration and the healing of relationship begin.

ABBREVIATIONS

BJHM	British Journal of Hospital Medicine
BMJ	British Medical Journal
HB	Health Bulletin
JME	Journal of Medical Ethics
NT	Nursing Times

In the end notes and bibliography the place of publication of books is Britain unless otherwise indicated.

Endnotes

(1) From Edwin Morgan's poem 'In the snack-bar'; found in The Second Life:selected poems of Edwin Morgan, Edinburgh University Press 1968.

(2) BMJ, 1978, 1, 1.

(3) Ronald Blythe, The View in Winter, Penguin 1981, p.143

(4) Shorter Oxford English Dictionary

(5) W. Mayer-Gross, E. Slater & M. Roth, Clinical Psychiatry, Balliere, Tindall & Cassell 1977, third, revised edition, pp.490-491. This text has now been superseded by Lishman's work referred to in the next note but it is still valuable for its accurate and well written descriptions of symptoms.

(6) W. A. Lishman, Organic Psychiatry, Blackwell 1978, p.9

(7) Senile and Pre-Senile Dementias, compiled by W. A. Lishman, Medical Research Council 1977, pp.3-8

(8) Lishman, Organic Psychiatry, p.527

(9) G. F. Adams, Essentials of Geriatric Medicine, OUP 1981, second edition, p.37

(10) M. Roth & D.H.Myers, 'The Diagnosis of Dementia', BJHM, 2, 1969, pp.705-717. Also Organic Mental Impairment in the Elderly, A Report of the Royal College of Physicians by the College Committee on Geriatrics, Royal College of Physicians (1981), pp.21-22.

(11) Report on Services for the Elderly with Mental Disability in Scotland, Scottish Home and Health Department & Scottish Education Department 1979. Hereafter cited as the Timbury Report, by which name it is commonly known. Statistics for England and Wales, which do not demonstrate a significant proportional difference, may be found summarised in N.E.J. Wells, Dementia in Old Age, Office of Health Economics 1979.

(12) Timbury Report, pp.12-13

(13) Ibid, pp. 1, 6-7, 9-11

(14) Ibid, p. 1

(15) For a detailed description of the work of one such day hospital in Edinburgh see: Glenda M. Watt 'A Family-Orientated Approach to Community Care for the Elderly Mentally Infirm', NT, 78, 1982, pp. 1545-1548

(16) Ibid, p. 1547

(17) Changing Patterns of Care: a report on services for the elderly in Scotland, Scottish Home and Health Department & Scottish Education Department 1980, pp. 65-66

(18) Timbury Report, pp. 29-30

(19) Ibid, p. 11

(20) Ibid, pp. 16-19

(21) For an indication of the problems with this approach see: J. Williamson et al, 'Old People at Home: their unreported needs', Lancet, 1964, 1, pp. 1117-1120

(22) K. Bergmann, 'The Epidemiology of Senile Dementia', BJHM, 2, 1969, p.732 and Timbury Report, p. 17

(23) Ibid, pp. 17-18

(24) For an extensive list of deficiencies in old mental illness hospital accommodation see: Timbury Report, pp.58-59

(25) T. Arie, Psychogeriatrics: How and Why?, The Fotheringham Lectures in the University of Toronto 1979, unpublished typescript, pp. 14-16

(26) Senile and Pre-Senile Dementias, pp. 9-10. These points are also made in Organic Mental Impairment in the Elderly.

(27) A. Lewis, 'Ageing and Senility: a major problem of psychiatry', Journal of Mental Science, 92, 1946, pp. 150-170

(28) B. Isaacs (ed.), Recent Advances in Geriatric Medicine, 2, Churchill Livingstone 1982, pp. 3-4

(29) Michael Wilson, Health is for People, Darton, Longman & Todd 1975, pp. 9-12. Also Alastair V. Campbell & Roger Higgs, In That Case, Darton, Longman & Todd 1982, p.39

(30) Shortfalls in the present state of English medical education in this field and ways of improvement are outlined in Organic Mental Impairment in the Elderly, pp. 21-24

(31) Wilson, op. cit., p. 9

(32) Viz. T. Arie, op. cit., pp. 21-23

(33) Wilson, op. cit., pp. 4-5

(34) B. Pitt, 'Management problems in psychogeriatrics', BJHM, 24, 1980, pp. 39-46

(35) S. Hiltner (ed.), Towards a Theology of Ageing, a special issue

of *Pastoral Theology*, 24, 1975, pp. 97-101

(36) Philadelphia:Fortress Press, 1979

(37) See for example, the standard work by Howard Clinebell, *Basic Types of Pastoral Counseling*, Nashville: Abingdon 1966, and also H. P. Steer *Caring for the Elderly*, SPCK 1966

(38) Clements, *op*. *cit*., pp. 17-20

(39) *Ibid*., pp. 23-27

(40) W. H. Vanstone, *The Stature of Waiting*, Darton, Longman & Todd, 1982

(41) *Ibid*., pp. 1-3

(42) *Ibid*., pp. 69-100

(43) *Ibid*., pp. 34-68

(44) *Ibid*., p. 99

(45) *Ibid*., p. 67

(46) *Ibid*., p. 103

(47) *Ibid*., pp. 67-68, 103-104, 112-113

(48) Emil Brunner, *Dogmatics*, II, Lutterworth Press 1952, p. 56

(49) Karl Barth, *Church Dogmatics*, III part 1, T. & T. Clark 1958 p. 186

(50) *Ibid*., p. 185

(51) *Ibid*., pp. 184-185

(52) Athanasius, *De Incarnatione*, I, 4-5

(53) Referred to in: E. A. Bladon, 'Plugging a gap in the pastoral field', *Church Times*, 15th October 1982, p. 11

(54) This is still in many respects an un-charted area and I am particularly grateful to Dr Chris Gilleard of Edinburgh University's Department of Psychiatry, who is researching in this field, for explaining some of the strains of relatives of dementing people.

(55) Joseph Fletcher, 'Indicators of Humanhood: a tenative profile of man', *Hastings Centre Report*, 2, 1975, pp. 1-4

(56) *Ibid*., p. 1

(57) *Ibid*., p. 2

(58) Ibid.

(59) A. G. M. Campbell & R. S. Duff, JME, 5, 1979, p. 141

(60) Paul Ramsey, Ethics at the Edges of Life, Yale University Press 1978, p. 206

(61) Ibid., p. 230

(62) Ibid., p. 231

(63) An extended discussion of this ritual practice and of the textual problems is to be found in Roland de Vaux, Ancient Israel: its life and institutions, Darton, Longman & Todd 1980, second edition, pp. 507-510. See also M. Noth, Leviticus, SCM Press 1977

(64) Timbury Report, p. 59

(65) M. Burton, 'Evaluation and change in a Psychogeriatric Ward through Direct Observation and Feedback', British Journal of Psychiatry, 137, 1980, pp. 566-571

(66) Ibid., p. 567

(67) E.g., K. Bergmann, art. cit., p. 728

(68) Arie, op. cit., p. 20

(69) Ibid., p. 32

(70) Mayer-Gross, Slater & Roth, op. cit., p. 491

(71) For a thorough treatment of the main issues in the Servant Songs see Morna D. Hooker, Jesus the Servant, SPCK 1959; also interesting particularly on the problem of identity is D. J. A. Clines, I, he, we and they: a literary approach to Isaiah 53, Journal for the Study of the Old Testament 1976, pp. 25-33

(72) Compare the following reports of the Royal College of Physicians of Edinburgh, Care of the Elderly in Scotland (1963) and Care of the Elderly in Scotland: a follow up report (1970). See also the Timbury Report, pp. 2, 6-7, on its predecessor the Millar Report

(73) Arie, op. cit., pp. 21-22

(74) I. Moyes, The Psychiatry of Old Age, Smith, Klein & French Laboratories 1980, p. 1

(75) H. A. Williams, Someday I'll Find You, Mitchell Beazley 1982, p. 104

(76) Hugh Anderson The Gospel of Mark, Oliphants 1976, pp. 146-147; I. Howard Marshall The Gospel of Luke, Paternoster Press 1978, pp. 335-336

(77) John Fenton, Saint Matthew, Penguin 1963, pp. 374-375

(78) Eduard Schweizer, The Good News According to Mark, SPCK 1971, p.113

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