



# *University of* **HUDDERSFIELD**

## **University of Huddersfield Repository**

Jolley, D. and Kendal, Sarah

Time out of mind

### **Original Citation**

Jolley, D. and Kendal, Sarah (1991) Time out of mind. *Nursing the elderly : in hospital, homes and the community*, 3 (1). pp. 20-22. ISSN 0956-8115

This version is available at <http://eprints.hud.ac.uk/id/eprint/22458/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

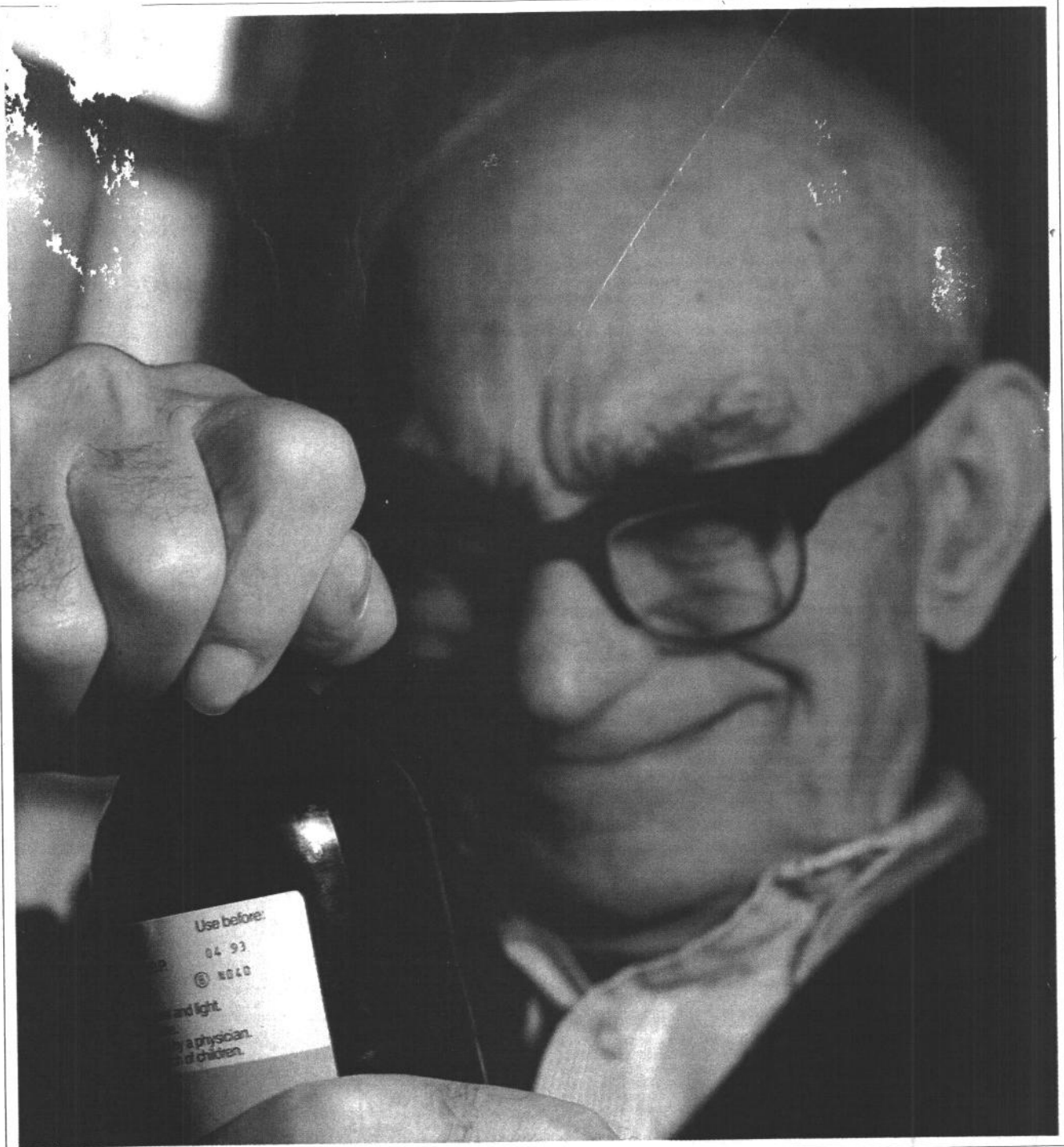
- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: [E.mailbox@hud.ac.uk](mailto:E.mailbox@hud.ac.uk).

<http://eprints.hud.ac.uk/>

# Nursing the Elderly

in hospital, homes and the community



January/February 1991

**SELF-MEDICATION TRIALS**

**NURSING  
Standard**  
PUBLICATIONS

# Nursing The Elderly

'Long stay' care - an essential component of services  
for patients suffering from severe dementia.

Sarah Kendal B.A.

Student Nurse

David Jolley BSc FRC Psych

Consultant

Cheadle Royal Hospital, near Manchester  
and Withington Hospital, Manchester

FOR: Nursing the Elderly

Paper 4

Dementia is not a rare condition in old age, few people are affected before the age of 60 years and even in the sixties only one or two percent of the population become seriously impaired, yet for those who survive into their seventies and eighties the risk increases to more than one in five (1). Dementia is best regarded as a syndrome: characterised by an acquired change of personality function and always including a decline in memory and other aspects of cognition but having a number of possible underlying causes and prognoses (2, 3). Most elderly people presenting with these problems are found to be suffering from one of the major dementing illnesses - Senile Dementia of the Alzheimer Type, Multi Infarct Dementia, but all should be investigated thoroughly to seek treatable components of their problem (4).

Despite the crippling and disabling characteristics of dementia, most elderly sufferers live for most of their time with it in their own homes, with their immediate family and/or with support from others (5, 6). Many are never seen by a specialist psychiatric service and if care away from home becomes necessary the evidence is that this has been provided by a rest home, nursing home, perhaps a geriatric ward, but very rarely a psychiatric ward (7). Indeed the barren dormitories of distant Victorian asylum buildings have little to recommend them for this client group. Yet the comprehensive range of skills brought together in a multi professional specialist team is desirable when faced with the management needs of those relatively few people who survive to become most severely disabled and disturbed by their dementia.

It is possible to describe and note the behavioural changes associated with dementia using numerical scales (8). The Crichton Royal Behavioural Rate Scale (CRBRS) has been used to demonstrate that severely altered elderly people are found in all sorts of 'residential care' from rest homes through geriatric wards to psychogeriatric wards (9). In total the number of severely damaged individuals in other forms of care far outweighs the few in psychogeriatric facilities, yet the concentration of problems there is much greater than elsewhere and it is probable that there are nuances of the nature and severity of their problems that differentiate between them and others.

It may be helpful to use a combination of clinical descriptions and a rating scale (CRBRS) to convey both the very individual characteristics of patients and the way they have evolved to facilitate an 'overview' comparison with people managed elsewhere. We have attempted to do this with seven patients who were the special responsibility of S.K. whilst attached for training to a long stay ward:

John is young, strong, mobile and difficult. Douglas much older, strong of spirit but crippled by multiple physical pathology. Margaret's marriage includes fiercely ambivalent emotions which continue and are exacerbated by her ailment and disability. Flora is suffering from a strange, rapidly progressive illness. Sarah has been ill and institutionalised for over thirty years. May and Edith have reached the end of their trial.

## JOHN

John is a physically strong man in his early sixties suffering from Alzheimer's disease. At present he is detained under Section 3 of the Mental Health Act, a potential danger to himself and others. Never an easy man to live with, his behaviour deteriorated insidiously in his late fifties so that he became so irritable, short tempered and prone to explosions of irrational violence that his wife moved out of the family home for her own safety. As time passed it became clear that his memory as well as his emotional control was fading and he coped less and less well and a daughter returned home with her grown up sons to try to care for him. She found herself mistaken for her own mother by father who, therefore, expected a sexual relationship with her and became angry and aggressive when denied this or when frustrated in other matters. On occasion he attempted to fondle teenage grandchildren in a sexually explicit way. Living with the tensions resulting from these difficulties was difficult when they remained within the family and became impossible when John began to wander away from home and become involved with groups of young children who were terrified. His daughter attempted to keep him at home, eventually resorting to sleeping on a settee placed near the front door. She became exhausted and found that even her devotion to what she felt to be her duty was insufficient to the task.

On the ward the main behavioural problems he presents to his carers are restlessness and wandering, resistance to nursing interventions - mainly with hygiene and elimination needs, and impulsive, sometimes aggressive behaviour. He has had grand mal fits - a new development. He is extremely confused, not always recognising or responding to his family when they visit, and can be disinhibited. For example, he will remove his clothes regardless of the circumstances if he finds them uncomfortable. Aggression and impulsiveness is closely linked with false interpretations of his surroundings, but there are severely disabled patients on the ward whom he may, in his confusion, attempt to strike believing that they are threatening him. He frequently leaves the ward and because he walks quickly there is always the danger that he may get lost

or encounter traffic before the nursing staff can retrieve him. For ethical and legal reasons the ward does not lock its outer doors and at busy times of the day, such as mealtimes, it can be difficult for a team of perhaps four staff adequately to attend to other patients and to keep a constant check on his whereabouts. Persuading him back toward the safety of the ward takes time, tact and persistent professional skill.

#### DOUGLAS

Douglas is a retired postman, now in his eighties. Both femurs have been broken in falls in the past - he might have died on either occasion but he is astonishingly tough though suffering from heart disease, arthritis and a bowel disorder which causes frequent faecal incontinence.

His character changed and disturbed by multi infarct dementia, he shouts out loud, obscene, sexual expletives and makes vulgar gestures toward female staff whom he catches sight of. At night, in bed, he masturbates noisily and smears himself with faeces. Less disrupting is his habit of taking off his shoes and socks during the day, perhaps because his arthritis makes his legs feel hot.

Douglas is disorientated and unable to wash and dress himself. He needs increasing help at mealtimes. Conversation with him is more difficult because he is deaf but he has keen eyesight and is usually very alert and observant. On the whole, he seems happy and settled on the ward. He is affectionate and likeable and can be very amusing. However, his good mood is a little fragile and he has periods when he is very distressed and cries for his mother. Douglas has many physical and emotional needs for which he depends on the ward team but despite this he requires less nursing input than other more able patients.

#### MARGARET

Margaret is in her late seventies, a Lancashire woman married to a driving Scot. She is suffering from multi infarct dementia and her strokes have thus far produced a hemiplegia and impairment in memory, orientation, concentration and reasoning. She presented to us three years ago, already well known to local physicians, geriatricians, speech therapists and community workers. An early stroke had impaired her comprehension of written words and this dreadful and puzzling loss of ability (she had been an avid reader) had released a syndrome of insatiable agitation, constant demand for attention, reassurance and 'treatment'. Her husband with whom she had enjoyed a relationship of muted combat at the



best of times found himself wakened repeatedly from sleep and faced with shouted, desperate demands for help which he couldn't provide. He resorted to quietening her with substantial measures of brandy and took a little to calm himself. Its good effects were short lived and gave way to irritability with an enhanced drive. That was three years ago. It became possible to live with her symptoms as a day patient for two years with help from physiotherapists and others and modification of her mood with antidepressants. Catastrophe struck in the form of an intercurrent illness that required operation. The operation was a 'success', but Margaret took a long time to recover from the anaesthetic and survived much more damaged by further areas of cerebral infarction. 'A cabbage' cried her husband.

Over a period of months she has regained some abilities though she remains heavily dependent. Her husband chooses to spend most of his time on the ward and the two of them daily engage in a power struggle which they agree is as old as their marriage: he arrives on the ward - she seems to fall asleep - he talks loudly about her 'problems' to anyone within earshot. He gets up to leave - she screams at him for going. He brings her food - she refuses it. She dresses up for him - he says nothing. Their relationship is apparently very stressful, yet within it they support and sustain each other.

Margaret often screams and swears at the top of her voice and this disturbs the whole ward community. She is able to understand that the noise she makes is unreasonable but even with repeated reminders forgets after a few moments. At nighttime she wakes often, confused, disorientated, frightened and noisy. Her physical handicap might not of itself merit permanent hospital treatment but her unresolved, seemingly unresolvable disorders of mood and behaviour and the precarious balance of hostilities and affection that ebb and flow between husband and wife strain the resources of our multi disciplinary team and permanent in-patient care, alternated by occasional visits home has seemed the only acceptable strategy for the present.

#### FLORA

Flora, a widow in her early sixties, deteriorated rapidly over a matter of weeks to require in-patient care for a dementia that has crippled her physically and mentally.

Her neck muscles have contracted so that her chin touches her breastbone and her face looks at the floor. Eating and drinking are therefore problems for her, she has become unable to feed herself adequately and so she has to be fed. Her speech is indistinct though a pronounced Glaswegian accent

remains evident amongst her ramblings which often seem related to hallucinatory experiences.

The rate at which her symptoms are developing and changing is so fast that her visitors do not always recognise her from one visit to the next and they can be alarmed and distressed by her appearance. This unusual clinical picture, together with characteristic EEG abnormalities suggest that she is suffering from Creutzfeld-Jacob disease (10), a rare dementia which has now tenuously been associated with Bovine Spongiform Encephalopathy - the so-called 'mad cow disease' (11). Two typical features of the dementia are its rapid development and muscular spasticity. Flora is not difficult to nurse, though when her rare disease was first diagnosed there was an amount of uncertainty amongst the staff concerning safe nursing practice, due to lack of information about how the disease is transmitted. Though unsteady on her feet, she leaps into action at the sound of Scottish music. She can and does express her preferences and whilst generally co-operative, is not afraid to scold the staff if she sees good reason. There are moments when she gains fleeting insight into her circumstances and these are distressing to her, her family and to staff. Sadly, the prognosis for Flora is poor; Creutzfeldt-Jakob disease leads to an early death and she is not expected to live for more than two or three years.

#### SARAH

Sarah who is also in her early sixties spent many of her middle years in psychiatric hospitals and then a colony for epileptics which closed, throwing her into welfare accommodation for the elderly. Within a Part III home no epileptic fits were observed, nor have we seen any since referral some five years ago. What stumped the staff at the Rest Home and continues to challenge us is her ambivalent negativistic behaviour and extraordinary affect. In addition she confides bizarre beliefs that her body is plant-like and experiences the traumas of pollination, germination etc. It seems likely that she is suffering from chronic schizophrenic - dementia praecox with hebephrenia, catatonic as well as paranoid features. Sarah is alert and observant of all the ward's goings-on. Because she suffers very badly from arthritis, getting up in the mornings is obviously painful for her, but it has become repeatedly the scene for ear-splitting screams and incredible physical resistance sometimes spiced by throwing herself forcibly to the ground sufficient to produce heavy bruising. She refuses to accept oral analgesics or indeed any other sort of medication which might alleviate her pains or other conditions. Mealtimes are another problem as Sarah likes to binge and starve, sometimes becoming alarmingly thin, at others making herself sick with boxes of biscuits or



chocolates. A behaviour programme has been designed to encourage her to eat regularly and moderately. Sarah is very skilled at coaxing staff to break our own rules and gains great pleasure from this achievement. She demonstrates tremendous willpower: for the most part chairfast, apparently because of arthritis, she will walk if sufficiently motivated (by anger or a desire for chocolate biscuits) though at all other times even two strong physiotherapists can be frustrated. Members of her family (nieces) visit but rarely for they feel rejected and humiliated when she remains mute and apparently disinterested or oblivious of their presence.

Nursing Sarah is a considerable challenge but it can be fulfilling and stimulating and her stubborn streak and willingness to play games with the staff, though admittedly frustrating is to be admired.

#### MAY

May, a childless widow had survived into her late seventies before first coming to the attention of hospital services - thin and frail she was found in a collapsed state and was hypothermic on admission to an acute medical ward. Neighbours had been helping her for some time for they knew that she was forgetful and didn't eat properly unless they brought in food for her. Happily she recovered well from this life threatening event and returned home, determined to be 'independent' in her own home.

For seven more years, ever more precariously, she enjoyed this freedom but only because William, a neighbour, and his wife came to her four or five times each day to chat, tidy up, bring in food, undertake cleaning, washing and reassurance. By summer of 1989 she was viewed with fear and fascination by local children as a local 'witch', wandering perplexed and dishevelled in her front garden, often smoking a cigarette and screaming at intruders in a fearful, fearsome manner. In the early hours of a winters morning a policeman found her wandering on a nearby major road: not knowing of William's devotion he took her home, phoned her next of kin (a niece who visited rarely) and raised considerable alarm. William was able to save that day but repeated wandering, falls, cigarette burns and May's increasing terror whenever left alone in the bewildering world she could hardly recognise as home became too much. Admission was offered and accepted in the hope that with regular all-day supervision and reassurance, food and company, she might regain some composure and happiness.

May had moments of lucidity when she would enjoy a quiet chat but these were few and far between. Always a nervous person, she sought constant affection but her lack of memory robbed

our reassurances of any lasting effect. What she liked was to have someone sit with her and hold her hand but no amount of this was ever enough, for a moment later she would have forgotten it and demand more.

She misinterpreted nursing interventions and felt threatened by them. She resisted our attempts to feed her even though she lacked the skills required to feed herself so she sometimes felt hungry. She tried to use her spectacles to eat with. Though she was a chain smoker by habit, she dropped her cigarettes and could not distinguish between the lit and unlit ends, so even with someone to help her she was unable to enjoy a cigarette safely. She annoyed and alienated other patients by pulling at their clothes and was so unsteady on her feet that she was felt to be unsafe even to walk on her own. She became verbally and physically aggressive at attempts to help her into warm clothes when she was cold. When incontinent she could not believe it and interpreted nurses' efforts to help her with her hygiene needs as assault.

May was one of the most time consuming and emotionally draining patients on the ward. Of all the problems, the most difficult aspect of nursing her was in seeing basic physical and emotional needs go unmet, despite the greatest efforts. She surprised us by surviving three or four debilitating chest infections in the days leading up to Christmas - but eventually died - peaceful at last early in the new year.

#### EDITH

Edith, like May, had been known to us for several years - from her late eighties into her nineties - but we'd kept in closer touch. She was a warm and friendly widow who had enjoyed a full life and liked music and dance. Her greatest pleasure was to waltz around her own front room with her wonderful and intuitive home help. Christmas was always a difficult time, for though very muddled she understood the tinsel and carols pouring from her alternative companion - a small television screen and she would get ready to go to the Town Hall Ball - 'wandering.' Recurrent crises had been ridden and her excellent niece was committed to help her achieve her long stated wish - 'to live and die at home.' Extra help was brought in through private agency nurses but it wasn't possible to cover all of the twenty four hours of every day. Left alone she sat, unable to stand surely and becoming weaker. She was eating very little - though much was offered and her bowels and bladder overflowed as she declined to use a commode under the direction and supervision of 'strangers' (the private nurses). Frail, weak, in distress she gladly accepted the offer to come into care. At home she had looked to be about to die - but doing it slowly and in fear if alone

- we expected to see her die within hours or days of admission. Miraculously - if briefly - she rallied. Clean and fresh with new friends (nursing staff on the ward), bowels cleared, appetite improved, a twinkle returned. This was burnished to a sparkle when her lovely home help came to visit - offering the prospects of more dancing, more music. From hopelessness new hope appeared. No doubt still frail, no doubt very vulnerable - but should we seek a future in care for her or make arrangements to explore the prospects of a return home.

The night before a planned visit to home to assess the possibilities a sudden and severe chest infection completed her dying - in our care.

The Crichton scale 'total' scores classify all but Sarah and Edith when she had rallied, within the heaviest range of disability. Some people can be supported at home with similar scores, others in rest homes, nursing homes or geriatric wards but they are never in such concentration as in psychogeriatric longstay care (9).

Component scores are helpful in reflecting main areas of difficulty for individuals, e.g. John is seen as mobile but incapable of self care because of confusion and is resistive to help. Margaret is less mobile, less muddled, more able to communicate but less settled in herself.

In addition component scores indicate the main areas of nursing activity required by a group of patients: there is an almost universal need for help with dressing, more variation on other measures, but hardly any component where there is not a fairly high demand. No where else do nurses meet patients with such a breadth and depth of sustained need.

#### **DISCUSSION:**

For all these people their life on our long stay ward represented only a part of the care offered to them by the service. For most it would be a terminal aspect of care, short for May, Edith and probably Flora, perhaps a decade or more for John and Sarah. The management of death for such people is never easy (12), the management of the life leading up to it demands the exhibition of sustained, multifaceted, skilled care. This is a central and essential ingredient of any service claiming to offer a competent, comprehensive service to old people suffering from severe mental disorder in old age. It is to be hoped that the enthusiasm of some Health Authorities to devolve all 'long stay' care to nursing homes outwith the direct responsibility of specialist services can be deflected. There is nothing to be said for such a manoeuvre on clinical grounds, it's rationale is a cynical redefinition of financial responsibility away from Health Authorities towards individuals who are very ill and to Social Security benefits which were designed to meet the bone fide needs of other groups (13).

## REFERENCES:

- 1 Eastwood R and Corbin (1985) Epidemiology of mental disorders in old age. in Arie T (ed) Recent Advances in Psychogeriatrics. Churchill Livingstone. London p17-32
- 2 Lishman W A (1978) Organic Psychiatry. Blackwell Scientific Publications. Oxford
- 3 Dodwell D (1986) Alzheimer's disease: the clinical picture in Pitt (ed) Dementia. Churchill Livingstone. London
- 4 Hodgson S P and Jolley D (1985) Psychiatry of the Elderly in Pathy (ed) Principles and Practice of Geriatric Medicine. John Wiley. Chichester
- 5 Kay D W K, Beamish P and Roth M (1964) Old age mental disorders in Newcastle upon Tyne. British Journal of Psychiatry 110, 146-158
- 6 Foster E M, Kay D W K, Bergmann K (1976) The characteristics of old people receiving and needing domiciliary services. Age and Ageing 5. 345-355
- 7 Kay D W K et al (1970) Mental illness and hospital usage in the elderly. Comprehensive Psychiatry. 1.
- 8 Wilkin D and Thompson C (1989) User's Guide to Dependency Measures for the Elderly. University of Sheffield Joint Unit for Social Services Research and Community Care. 26-35
- 9 Wilkin D, Jolley D (1978) Mental and Physical Impairment in the Elderly in Hospital and Residential Care. Nursing Times 74. 29-34
- 10 Knight R (1989) Creutzfeldt-Jakob disease. British Journal of Hospital Medicine. 41, 165-171
- 11 Matthews W B (1990) Bovine Spongiform Encephalopathy. British Medical Journal. 300, 412-413
- 12 Black D and Jolley D (1990) Slow Euthanasia? Deaths of Psychogeriatric patients. British Medical Journal 300. 1321-1323
- 13 Jolley D (1990) The psychiatric situation. In: A caring home - improving quality and standards of care in homes and hospitals for the elderly. Care of the Elderly Supplement.



# Time out of mind



## *The Royal College of Psychiatrists*

**D**ementia is not a rare condition in old age; few people are affected before the age of 60 and even then only 1-2 per cent of the population become seriously impaired. But for those who survive into their seventies and eighties, the risk increases to more than one in five (1).

Dementia is best regarded as a syndrome, characterised by an acquired change of personality function and always including a decline in memory and other aspects of cognition, but having a number of possible underlying causes and prognoses (2,3). Most elderly people with these problems are found to be suffering from one of the major dementing illnesses – senile dementia of the Alzheimer type, multi-infarct dementia – but all should be investigated thoroughly to seek treatable components of their problem (4).

Despite the crippling and disabling characteristics of dementia, most elderly sufferers live for most of their time in their own homes, with their immediate family and/or with support from others (5,6). Many are never seen by a specialist psychiatric service and if care away from home becomes necessary, the evidence is that this has been provided by a residential care home, nursing home, perhaps a geriatric ward, but very rarely a psychiatric ward (7).

Indeed, the barren dormitories of distant Victorian asylum buildings have little to recommend them for this client group. Yet the comprehensive range of skills brought together in a multi-professional specialist team is desirable when faced

*'Long stay' care is an essential component of services for patients suffering from severe dementia, argue David Jolley and Sarah Kendal.*

with the management needs of those relatively few people who survive to become most severely disabled and disturbed by their dementia.

It is possible to describe and note the behavioural changes associated with dementia using numerical scales (8). The Crichton Royal Behavioural Rate Scale (CRBRS) has been used to demonstrate that severely-altered elderly people are found in all sorts of 'residential care', from homes through geriatric wards to psychogeriatric wards (9). In total, the number of severely damaged individuals in other forms of care far outweighs the few in psychogeriatric facilities, yet the concentration of problems there is much greater than elsewhere.

### Characteristics

It may be helpful to use a combination of clinical descriptions and a rating scale (CRBRS) to convey both the very individual characteristics of patients and the way they have evolved to facilitate an 'overview' comparison with people managed elsewhere. We have attempted to do this with patients who were the special responsibility of Sarah Kendal while attached for training to a longstay ward.

John is a physically strong man in his early

sixties suffering from Alzheimer's disease. At present he is detained under Section 3 of the Mental Health Act, a potential danger to himself and others. Never an easy man to live with, his behaviour deteriorated insidiously in his late fifties so that he became so irritable, short-tempered and prone to explosions of irrational violence that his wife moved out of the family home. As time passed, it became clear that his memory as well as his emotional control was fading.

A daughter returned home with her grown-up sons to try to care for him. She found herself mistaken for her own mother and, therefore, her father expected her to have a sexual relationship with him. He became angry and aggressive when denied this or when frustrated in other matters.

On occasion he attempted to fondle teenage grandchildren in a sexually explicit way. Living with these tensions was extremely difficult when they remained within the family, but became impossible when John began to wander away from home and approached groups of young children who were terrified of him. His daughter attempted to keep him at home, eventually resorting to sleeping on a settee placed near the front door. She became exhausted and found that even her devotion to what she felt to be her duty was insufficient to the task.

On the ward, the main behavioural problems he presents to his carers are restlessness and wandering, resistance to nursing interventions – mainly with hygiene and elimination needs – and impul-

sive, sometimes aggressive behaviour. He has had grand mal fits – a new development. He is extremely confused, not always recognising or responding to his family when they visit, and can be disinhibited. For example, he will remove his clothes regardless of the circumstances if he finds them uncomfortable.

He frequently leaves the ward and because he walks quickly, there is always the danger that he may get lost or encounter traffic before the nursing staff can retrieve him. Persuading him back toward the safety of the ward takes time, tact and persistent professional skill.

## Impairment

**Margaret** is in her late seventies, a Lancashire woman married to a driving Scot. She is suffering from multi-infarct dementia and her strokes have thus far produced a hemiplegia and impairment in memory, orientation, concentration and reasoning. She presented to us three years ago, already well known to local physicians, geriatricians, speech therapists and community workers. An early stroke had impaired her comprehension of written words and this dreadful and puzzling loss of ability (she had been an avid reader), had released a syndrome of insatiable agitation, constant demand for attention, reassurance and 'treatment'.

Her husband, with whom she had enjoyed a relationship of muted combat at the best of times, found himself wakened repeatedly from sleep and faced with shouted, desperate demands for help which he couldn't provide. He resorted to quieting her with substantial measures of brandy and took a little to calm himself. Its good effects were shortlived and gave way to irritability with an enhanced drive. That was three years ago.

It became possible to live with her symptoms as a day patient for two years with help from physiotherapists and others and modification of her mood with antidepressants. Catastrophe struck in the form of an intercurrent illness that required operation. The operation was a 'success' but Margaret took a long time to recover from the anaesthetic and survived much more damaged by further areas of cerebral infarction. 'A cabbage!' cried her husband.

Over a period of months she has regained some abilities, though she remains heavily dependent. Her husband chooses to spend most of his time on the

ward and the two of them engage in a daily power struggle which they agree is as old as their marriage. He arrives on the ward – she seems to fall asleep. He gets up to leave – she screams at him for going. He brings her food – she refuses it. Their relationship is apparently very stressful, yet within it they support and sustain each other.

Margaret often screams and swears at the top of her voice and this disturbs the whole ward community. She is able to understand that the noise she makes is unreasonable but even with repeated reminders, forgets after a few moments. At night she awakens, often confused, disorientated, frightened and noisy.

Her physical handicap, itself, might not merit permanent hospital treatment. But her seemingly unresolvable mood and behaviour disorders, and the precarious balance of hostilities and affection that ebb and flow between husband and wife, strain the resources of our multidisciplinary team.

Permanent in-patient care, alternated by occasional visits home, has seemed the only acceptable strategy for the present.

**Flora**, a widow in her early sixties, deteriorated rapidly over a matter of weeks to require in-patient care for a dementia that has crippled her physically and mentally. Her neck muscles have contracted so that her chin touches her breastbone and her face looks at the floor. Eating and drinking are a problem for her; she is unable to feed herself adequately and so she has to be fed. The rate at which her symptoms are developing

and changing is so fast that her visitors do not always recognise her from one visit to the next and they can be alarmed and distressed by her appearance. This unusual clinical picture, together with characteristic EEG abnormalities, suggest that she is suffering from Creutzfeldt-Jacob disease (10), a rare dementia. Two typical features of the dementia are its rapid development and muscular spasticity.

Flora is not difficult to nurse. When her rare disease was first diagnosed, however, there was an amount of uncertainty among staff concerning safe nursing practice. This was due to a lack of information about the transmission of the disease. Though unsteady on her feet, she leaps into action at the sound of Scottish music. She can and does express her preferences and while generally co-operative, is not afraid to scold the staff if she sees good reason.

There are rare moments when she gains fleeting insight into her circumstances and these are distressing to her, her family and to staff. Sadly, the prognosis for Flora is poor; Creutzfeldt-Jacob disease leads to an early death and she is not expected to live for more than two or three years.

## Neighbourly care

**May**, a childless widow, had survived into her late seventies before coming to the attention of hospital services. Thin and frail, she was found in a collapsed state and was hypothermic on admission to an acute medical ward. Neighbours had been helping her for they knew that she was forgetful and didn't eat properly unless they

Crichton scale-scores of patients:

Problem	Range	John	May	Mgt.	Flora
Mobility	0-4	0	2	4	2
Orientation	0-4	4	4	2	3
Communication	0-4	3	3	1	1
Co-operation	0-4	4	4	2	1
Restlessness	0-4	2	3	3	1
Dressing	0-4	4	4	4	4
Feeding	0-3	1	3	1	3
Continence	0-4	4	4	2	3
Total	0-31	22	27	19	18

brought in food for her. Happily, she recovered well from this life-threatening event and returned home, determined to be 'independent' in her own home.

For seven more years, ever more precariously, she enjoyed this freedom but only because William, a neighbour, and his wife came to her four or five times each day to chat, tidy up, bring in food, undertake cleaning and washing and offer reassurance. By summer of 1989 she was viewed with fear and fascination by local children as a 'witch', wandering perplexed and dishevelled in her front garden, often smoking a cigarette and screaming at intruders in a fearful, fearsome manner.

## Bewilderment

In the early hours of a winter's morning a policeman found her wandering on a nearby major road. Not knowing of William's devotion, he took her home, phoned her next of kin (a niece who visited rarely) and raised considerable alarm. William was able to save that day, but repeated wandering, falls, cigarette burns and May's increasing terror whenever she was left home alone, (a bewildering world she could hardly recognise), became too much. Admission was offered and accepted in the hope that with regular full-day supervision and reassurance, food and company, she might regain some composure and happiness.

May had moments of lucidity when she would enjoy a quiet chat, but these were few and far between. Always a nervous person, she sought constant affection, but her lack of memory robbed our reassurances of any lasting effect.

She liked to have someone sit with her and hold her hand, but no amount of this was enough, for a moment later she would forget and demand more.

She misinterpreted nursing interventions and felt threatened by them. She resisted our attempts to feed her, even though she lacked the skills required to feed herself, so she sometimes felt hungry. She tried to use her spectacles to eat with. An habitual chain smoker, she dropped her cigarettes and could not distinguish between the lit and unlit ends. She was unable to enjoy a cigarette safely, even with help. She annoyed and alienated other patients by pulling at their clothes and was unsteady on her feet. She became verbally and physically aggressive at attempts to help her into warm clothes when she was cold. When incontinent, she

interpreted nurses' efforts to help her with her hygiene needs as assault.

May was one of the most time-consuming and emotionally draining patients on the ward. Of all the problems, the most difficult aspect of nursing her was in seeing basic physical and emotional needs go unmet, despite the greatest efforts. She surprised us by surviving three or four debilitating chest infections but eventually died – peaceful at last.

The Crichton scale 'total' scores classify all these people within the heaviest range of disability. Some people can be supported at home with similar scores, others in residential homes, nursing homes or geriatric wards, but they are never in such concentration as in psychogeriatric longstay care (9).

Component scores are helpful in reflecting main areas of difficulty for individuals: John is seen as mobile, but incapable of self care due to confusion and resistance to help; Margaret is less mobile, less muddled, more able to communicate, but less settled in herself.

In addition, component scores indicate the main areas of nursing activity required by a group of patients. There is an almost universal need for help with dressing, more variation on other measures, but hardly any component where there is not a fairly high demand. Nowhere else do nurses meet patients with such a breadth and depth of sustained need.

## Discussion

For all these people, life on our longstay ward represented only a part of the care offered to them by the service. For most it would be a terminal aspect of care, short for May and probably Flora, perhaps a decade or more for John. The management of death for such people is never easy (11), the management of the life leading up to it demands the exhibition of sustained, multifaceted, skilled care.

This is a central and essential ingredient of any service claiming to offer a competent, comprehensive service to old people suffering from severe mental disorder in old age. It is hoped the enthusiasm of some health authorities to devolve all 'longstay' care to nursing homes outwith the direct responsibility of specialist services can be deflected.

There is nothing to be said for such a manoeuvre on clinical grounds; its rationale is a cynical redefinition of financial responsibility away from health

authorities towards individuals who are very ill and to social security benefits which were designed to meet the bona fide needs of other groups (12).

**Sarah Kendal BA** is a student nurse, South Manchester Health Authority; **Dr David Jolley BSc FRCPsych** is Consultant, Cheadle Royal Hospital and Withington Hospital, near Manchester. Dr Jolley is a member of the Public Education Committee of the Royal College of Psychiatrists.

## References

1. Eastwood R (1985) 'Epidemiology of mental disorders in old age' in Arie T (ed) *Recent Advances in Psychogeriatrics*. Edinburgh, Churchill Livingstone.
2. Lishman W (1978) *Organic Psychiatry*. Oxford, Blackwell Scientific Publications.
3. Dodwell D (1986) 'Alzheimer's disease: the clinical picture' in Pitt B (ed) *Dementia*. Edinburgh, Churchill Livingstone.
4. Hodgson SP, Jolley D (1985) 'Psychiatry of the elderly' in Pathy J (ed) *Principles and Practice of Geriatric Medicine*. John Wiley, Chichester.
5. Kay DWK, Beamish P and Roth M (1964) 'Old age mental disorders in Newcastle upon Tyne'. *British Journal of Psychiatry*, 110, 146-158.
6. Foster EM, Kay DWK, Bergmann K (1976) 'The characteristics of old people receiving and needing domiciliary services'. *Age and Ageing*, 5, 345-355.
7. Kay DWK et al (1970) 'Mental illness and hospital usage in the elderly'. *Comprehensive Psychiatry*, 1.
8. Wilkin D, Thompson C (1989) *User's Guide to Dependency Measures for the Elderly*. University of Sheffield Joint Unit for Social Services Research and Community Care.
9. Wilkin D, Jolley D (1978) 'Mental and physical impairment in the elderly in hospital and residential care'. *Nursing Times*, 74, 29-34.
10. Knight R (1989) 'Creutzfeldt-Jakob disease'. *British Journal of Hospital Medicine*, 41, 165-171.
11. Black D, Jolley D (1990) 'Slow euthanasia? Deaths of psychogeriatric patients'. *British Medical Journal*, 300, 1321-1323.
12. Jolley D (1990) 'The psychiatric situation'. In: 'A caring home – improving quality and standards of care in homes and hospitals for the elderly'. *Care of the Elderly Supplement*.