



## **Dying with dignity:** palliative care in dementia



**Jonathan Hillam**  
*Consultant in Old Age Psychiatry,  
 The Julian Hospital, Norwich*

# Errors and judgement

As I write this, the National Institute for Health and Clinical Excellence (NICE) has just published its guidance on dementia.<sup>1</sup> In it, there is much that is laudable, much that is already accepted as good practice, and much that we should aspire to. And then there is the guidance on the use of cholinesterase inhibitors. NICE states that these drugs should only be prescribed for patients in the moderate stages of Alzheimer's disease; that is, those with a Mini-Mental State Examination (MMSE) score of between ten and 20. But there is a proviso that instructs clinicians not to rely on the MMSE where patients with an MMSE of above 20 have 'significant' functional impairment. It does not, however, define 'significant'. So it seems that a workable compromise has been reached, which gives clinicians greater flexibility and the opportunity to use their own judgement when making prescribing decisions. It goes some way to addressing the undue prominence attached to MMSE scores as highlighted in Ajay Upadhyaya's article on page 3. The question of whether it represents a totally fair decision is another matter.

## Palliative care

In recent years we have tended to focus on the early diagnosis and treatment of Alzheimer's disease, perhaps at the expense of patients at the other end of the disease process. The NICE guideline clearly states that people working with patients with dementia must adopt a 'palliative care approach'.<sup>1</sup> This issue of *Old Age Psychiatrist*

highlights the principles and practices of palliative care and end-of-life issues, and brings to a wider audience some of the proceedings of a very successful open forum on palliative care, organised by the Faculty in September 2006.

## Readers' letters

It has always been a slight disappointment that *Old Age Psychiatrist* receives so little correspondence. So I am pleased to publish not one, but two letters to the Editor in this issue (and one from Toronto!) Unhappily, both letters draw attention to errors in the last issue (*Old Age Psychiatrist* 44). One is a case of mistaken identity. A photo of Tom Arie was used instead of a photo of David Jolley on page 7. Both have seen the funny side and legal action is not expected. More seriously, on page 5, the therapeutic range of lithium in the blood was incorrect. It should, of course, be 0.6–1.0 mmol/l (and not 0.6–2.8 mmol/l). Thanks to both David Jolley and Kenneth Shulman. Finally, in *Old Age Psychiatrist* 43, Ross Overshott is described as a Consultant in Old Age Psychiatry. He is not (yet). My apologies to him for any embarrassment caused.

Please feel free to write to me at the address below if you have any comments on *Old Age Psychiatrist* (not just correcting errors), the Faculty, the College, or on any issue that you believe will be of interest to our readership.

### Reference

1. National Institute for Health and Clinical Excellence. *Dementia: supporting people with dementia and their carers in health and social care*. London: NICE, 2006.

◉ A workable compromise has been reached ◉

Cover image: xxxxxxxx

### Honorary Editors

Professor Brice Pitt, Dr Nori Graham

### Editor

Dr Jonathan Hillam,  
 Consultant in Old Age Psychiatry,  
 The Julian Hospital, Norwich

### Website editor

Dr Anand Ramakrishnan, Sutton Health Centre,  
 Sutton-in-Ashfield, Nottinghamshire

### Editorial Board

Dr Chris Fox, Consultant in Old Age Psychiatry,  
 Folkestone Health Centre, Kent

Dr Henry O'Connell, Senior Registrar,  
 Limerick Mental Health Services,  
 Limerick, Ireland

Dr Kallur Suresh, Consultant in Old Age  
 Psychiatry, North Essex Mental Health  
 Partnership NHS Trust

### Address for correspondence

Dr Jonathan Hillam, Consultant in Old Age  
 Psychiatry, The Julian Hospital,  
 Bowthorpe Road, Norwich NR2 3TD  
 email: Jonathan.Hillam@nwmhp.nhs.uk

Produced by Hayward Medical Communications  
 on behalf of the Faculty of the Psychiatry of Old Age  
 of the Royal College of Psychiatrists.

**Old Age Psychiatrist is sponsored by  
 Pfizer Ltd/Eisai Ltd.**

*Old Age Psychiatrist* is produced four times a year. Contributions should be submitted in a recognisable Windows format by email. Shorter typed contributions are acceptable. The Editors reserve the right to edit contributions as deemed necessary. Please limit contributions to a maximum of 1,500 words unless agreed with the Editor. Authors are encouraged to include a (returnable) colour photo of themselves. Letters should not exceed 200 words. Opinions expressed in the newsletter are of the authors and not of the College or the publisher, unless expressly stated. Each article remains the copyright of its author but the College reserves the right to reproduce the article on the Faculty website pages.

# The antimentia drugs lottery: a personal view

Of the principles of ethical medical practice, justice is perhaps the most fundamental and also the most difficult goal to achieve. In the area of health-care funding, where demand outstrips resources, cost-effectiveness is the mantra, driving policy on priority setting and resource allocation. The recent guideline from the National Institute for Health and Clinical Excellence (NICE), *Dementia*,<sup>1</sup> on the prescribing of acetylcholinesterase inhibitors in Alzheimer's disease, effectively banning them for mild Alzheimer's and restricting their use to moderate disease, is a prime example of this. The calculations of cost-effectiveness in the field of dementia – which causes profound changes in the individual and has far-reaching effects on not only the patient's family, but on society as a whole – are fraught with difficulty and were rightly challenged during the consultation period.

## How workable is the guideline?

Let us assume for a moment that the health economists have got it right. The real test of success for the guideline lies in its implementation. In other words, how workable the guideline is in practice. There are several difficulties in implementing this guideline, many of which have been recently discussed in the media. I wish to highlight some unintended consequences, which would eventually erode the principle of fairness, which is probably the central virtue of the NHS.

Dementia is a progressive condition which is described in terms of mild, moderate and severe stages. In reality, these stages merge imperceptibly into each other without sharp boundaries and we currently do not have a reliably measurable biological marker of severity of dementia. Clinical staging of dementia lacks the precision of grading of, for example, renal failure or cardiac failure.

## Guideline limitations

The NICE guidelines give a range of Mini-Mental State Examination (MMSE) scores to define the moderate stage of Alzheimer's disease. Although the limitations of MMSE score in grading the severity of dementia are well recognised in professional circles, the prominence given to the MMSE score in the

guideline is likely to lead the patient's family to wrongly suspect clinical judgement is at fault, when it does not accord with their own understanding of the situation.

## Implementation challenges

As fundamental decisions to deny an effective treatment will be based on imprecise staging, there will be considerable potential for disagreement. I anticipate complaints from families or advocates, challenging the clinician's opinion on the exact stage of dementia; the clinician will then have to bear the brunt of their resentment. There would be many requests for second opinions for patients denied treatment on the basis of clinical judgement. This will sour the relationship between the professionals and the patients' families and, in extreme scenarios, turn them into adversaries.

I fear that the most vocal and articulate group will succeed in overturning decisions to deny antimentia drugs to their loved ones, who are in the 'grey area' of mild dementia. I cannot help thinking that – in this era of the *Patients' Charter*<sup>2</sup> – the articulate and vocal group will have an unfair advantage over the silent and undemanding lot.

## Austere but fair?

In formulating the policy on antimentia drug use, the aim of NICE – to provide the best value for money allocated for management of dementia – is laudable. However, I wonder whether the very ideal of fairness in resource allocation that drove NICE to rigorously apply the principle of cost-effectiveness, is defeated by its own guidelines. Having witnessed first hand the disparities of access to, and quality of, healthcare in the USA, I have often comforted myself with the thought that the NHS may be austere, but at least it is fair. In other words, the austerity applies fairly across the board. We berate American healthcare, which is biased in favour of people who have the means to pay for the ever rising cost of healthcare, in contrast with the NHS, where ability to pay is irrelevant. On second thoughts, though, are not the people who are most able to pay, also the most articulate and vocal?

## References

For a full list of references, please email: [edit@hayward.co.uk](mailto:edit@hayward.co.uk)



**Ajay Upadhyaya**

Consultant in Old Age Psychiatry, North Essex Mental Health Partnership NHS Trust

---

*“I wonder whether the very ideal of fairness ... is defeated by its own guidelines”*

---



**Julian C Hughes**  
*Consultant in Old Age  
 Psychiatry, North Tyneside  
 General Hospital,  
 Tyne and Wear*

---

• *The emphasis is on the relief of symptoms and the approach is holistic* •

---

# What the Dickens?

The open forum on palliative care, organised by the Faculty of Psychiatry of Old Age, was held at the Royal College of Psychiatrists on 28 September 2006. It gave us a taste of the interest and enthusiasm concerning palliative care in dementia. This can be seen, not only among old age psychiatrists and in the Alzheimer's Society, but also in the increasing number of publications and meetings being organised within the national hospice movement itself. Furthermore, one of the aims of the NHS End of Life Care Programme is precisely to improve palliative care for those people dying from conditions other than cancer.<sup>1</sup> However, before the movement becomes unstoppable, it is worth asking two initial questions: first, what does palliative care in dementia mean? And second, do we need it?

## What is palliative care?

There have been several definitions of palliative care. The most recent definition from the WHO states that, 'Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems'.<sup>2</sup>

When this is fleshed out, advocates of palliative care say that the aim is to affirm life and to regard death as a normal process. The emphasis is on the relief of symptoms and the approach is holistic, the aim being to integrate the psychological, social and spiritual with the physical. Palliative care offers active support to people who are dying and their families. The underlying principles focus on quality of life and a whole person approach, with respect for autonomy and open, sensitive communication with patients, informal carers and colleagues.

## Sounds familiar?

To people working in dementia, this will sound familiar; it sounds rather like good-quality, person-centred dementia care. Indeed, if we look at the psychological needs identified by Tom Kitwood<sup>3</sup> as being integral to person-centred care, they can be mapped onto elements of the definition of palliative care. Kitwood talked about attachment, and palliative care is keen on active support. Kitwood recognised the impor-

ance of comfort, which equates in part to symptom control. Maintaining the identity of the individual with dementia is central to Kitwood's message, as is the integration of care as a way of supporting the whole person in the hospice approach. A key tenet of palliative care is the affirmation of the person as someone who is worthwhile. Finally, Kitwood talked about inclusion and this is reflected in the holism that includes consideration of the family and other informal carers in the palliative care approach.

## Three components

Some people have split palliative care into three components: the straightforward palliative care approach, palliative interventions (such as radiotherapy for bone pain), and specialist palliative care, which refers to the technical knowledge that might be required to manage symptoms in the terminal stages of a disease. When we move to dementia care it is easy to see that the palliative care approach, which is necessary for any non-curable disease, is essentially the same as good-quality dementia care. The requirements for specialist palliative care would be much the same in the terminal phases of dementia.

The interesting thing to consider, therefore, is what might equate to palliative interventions in the field of dementia care. One obvious candidate would be the management of behavioural and psychological signs of dementia (BPSD). Just as palliative care physicians have become experts in the management of pain, so too may old age psychiatrists be expected to become experts in the management of BPSD. The management of pain requires a broad approach, as does the management of BPSD, which will require not only psychosocial, but also pharmacological approaches.

## Suboptimal treatment

The second question was whether we need palliative care in dementia. The answer seems to be an emphatic 'yes'. A study in the UK found that 40% of people with dementia are dying in the community, with under 2% of people in hospices having dementia.<sup>4</sup> Many people receive suboptimal treatment of their symptoms. Studies have also shown that carers need considerable support, which is often lacking. There is compelling evidence that the care of people with dementia,

especially towards the end of their lives is less than optimal in the UK. Recent studies in America have shown a greater use of non-palliative interventions in people with dementia, even though they are approaching death. There is inadequate treatment of some symptoms and a lack of advance care planning in comparison with people dying from other conditions. The sort of symptoms and signs experienced by people with dementia in the last year of life include confusion, urinary incontinence, pain, low mood, constipation and loss of appetite. Only about 19% of people with dementia die in their own homes.<sup>5</sup> Most of the population, if asked, would probably express the wish to die at home, or would say that they would like to receive hospice care, but the figures show that these wishes are certainly not fulfilled for people with dementia.

### Inequity in palliative services

Whatever the general public might be saying, the Health Committee of the House of Commons in 2004 said that the lack of palliative care for non-cancer sufferers was '... the greatest inequity of all in palliative services'.<sup>6</sup> In 2004, the WHO said, 'Every person with a progressive illness has a right to palliative care'.<sup>7</sup>

There certainly seems to be a need for palliative care and something needs to be done. Moreover, there is a compelling vision that moves many to hope that people with dementia might be enabled to die with more dignity if the need for palliative and hospice care were to be pursued with vigour. And yet there are still questions to be asked. For instance, apart from in the terminal phase, what makes palliative care uniquely different from good-quality person-centred dementia care? The likely answer is something to do with continuity and advance care planning. A further, crucial question concerns how palliative care in dementia should be provided. The open forum was part of the process of working out the answer to this question. The work is ongoing!

#### References

1. www.endoflifecare.nhs.uk (last accessed 21 November 2006)
2. www.who.int/hiv/topics/palliative/PalliativeCare/en/ (last accessed 14 November 2006)
3. Kitwood T. *Dementia reconsidered: the person comes first*. London: Open University Press, 1997.
4. McCarthy M, Addington-Hall J, Altmann D. The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* 1997; **12**: 404-409.
5. Kay DW, Forster DP, Newens AJ. Long-term survival, place of death, and death certification in clinically diagnosed pre-senile dementia in northern England. Follow-up after 8-12 years. *Br J Psychiatry* 2000; **177**: 156-162.
6. House of Commons Health Committee. *Palliative care: fourth report of session 2003-04*. London: The Stationery Office, 2004.
7. World Health Organization. *Better palliative care for older people*. Copenhagen: WHO, 2004.

# Letters to the Editor

If it has not already been mentioned to you, I would highlight an error in the Winter 2006 (issue 44) edition of *Old Age Psychiatrist* in the article 'Psychotropic medication use in older people with renal failure' (pages 4-5) by Kennedy *et al*. In the section on 'Mood stabilisers', lithium levels are listed as 0.6-2.8 mmol/. This should have read 0.6-0.8 mmol/l. I'm sure that most clinicians would be aware of this but just in case someone is not familiar with lithium levels, this should be corrected. Moreover, many geriatric psychiatrists use even lower levels of lithium. However, systematic data is lacking for this age group.

The article really did not do justice to the ongoing debate about the relationship between chronic lithium use and chronic renal failure. This is still an area of uncertainty, although most nephrologists seem quick to implicate lithium in any patient who appears to be developing higher creatinine levels with age.

This minor quibble notwithstanding, let me take the opportunity to congratulate you on the quality of the newsletter ■

*Kenneth I Shulman, Lewar Chair in Geriatric Psychiatry, Sunnybrook Health Sciences Centre, University of Toronto*

.....

The Christmas edition of *Old Age Psychiatrist* (issue 44) will be confirmed a collector's item, which I shall treasure and pass on to children and grandchildren. It provides the first published evidence that dedicated effort can be repaid by total success; as a student (David Jolley) can, in time, become transformed into the mentor and inspiration whom he has sought to emulate (Tom Arie). It is a wonderful thing. Wonderful, too that the article illustrates how we continue to seek and find new ways of understanding mental health and disorders in later life and new ways to bring services to bear upon them.

People might be reassured to know that, though Tom and I share much in spirit, our faces and bodies remain identifiably different as we go about our separate lives ■

*David Jolley, Professor in Old Age Psychiatry, Wolverhampton University*





**Elizabeth Sampson**

MRC Research Fellow, Royal Free and University College Medical School, London

6 *Models of care that work for patients with cancer may not be the best approach* 9

# Why, when, where and who?

Over the last five years there have been numerous policy documents and reports aimed at improving and increasing the availability of good end-of-life and palliative care for older people (see Box 1). Many have noted how those with dementia have particular difficulty accessing these services. At the recent open forum at the Royal College of Psychiatrists, I had the opportunity to discuss our developing research programme in this field.

## Disturbing findings

Many people with dementia die while on acute hospital wards. We started our exploration of these issues by doing a very simple case note study to see whether the quality of end-of-life care differed between people with and without dementia.<sup>1</sup> This was a small study, but our findings were disturbing: older people, who died after admission to acute hospital wards, and who were documented in their medical notes as having dementia, received significantly fewer palliative medications or referrals to palliative care teams before death. In those patients where dementia was noted, there was less attention to spiritual needs and religious background.

## More policies than papers

Given the number of reports and policy directives, we carried out a systematic review to examine if these were based on any evidence.<sup>2</sup> We found very little empirical research on the best way to provide palliative and end-of-life care for people with dementia. There were many review articles, reviews of reviews, opinion pieces

and editorials. We used very broad inclusion criteria to 'capture' the maximum number of papers but found only four studies that had attempted to evaluate or carry out trials of palliative care for people with dementia. This finding was interesting in itself: there are actually more UK government policies than there are published papers in existence.

Three of the four studies were carried out in the USA. This provides difficulties in interpreting the findings. Health services are configured and funded differently, and separate legal frameworks exist in every individual US state. For example, in some states, a person with dementia must have a parenteral feeding tube inserted if they stop eating or drinking (unless they have signed an advance directive while competent, saying they do not wish such measures to be taken).

The four studies mainly involved increasing the prescription of analgesics, decreasing the number of people with dementia transferred to the acute hospital sector and limiting the use of antibiotics. In general, the findings were positive in that patients' discomfort was reduced and more were able to die in a familiar setting.

## Top-down approach

What I find striking about these studies and the general climate in terms of policy is that they feel very 'top-down'. A policy or intervention is introduced to the health service and rapidly put into practice with little evidence of effectiveness or acceptability. Although intuitively it feels very important to increase the availability of palliative care

### Box 1. Policies and reports

- Department of Health. *National Service Framework for Older People*. London: DoH, 2001
- House of Commons Health Committee. *Palliative care: fourth report of session 2003–04*. London: The Stationery Office, 2004
- Care Services Improvement Partnership. *Everybody's Business. Integrated mental health services for older adults: a service development guide*. London: DH, 2005
- [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk) (last accessed 21 November 2006)
- NHS End of Life Care Programme. *Introductory guide to end of life care in care homes*. London: DH, 2006
- Department of Health. *Our health, our care, our say: a new direction for community services*. London: TSO, 2006

to people with dementia, models of care that work for patients with cancer may not be the best approach. There are a whole range of different issues, such as competency and different disease trajectories, which need to be considered when people are frail and cognitively impaired. Any intervention aimed at improving care is likely to be complex and would benefit from being developed slowly in a more 'bottom-up' way, so that it is tailored to the needs of our patients.

We are fortunate to be funded by the British United Provident Association (BUPA) foundation to do this. We are starting with a series of detailed qualitative studies interviewing a range of nursing, medical and therapy staff who care for people with advanced dementia in the acute hospital sector and in nursing homes. We will develop palliative care interventions that are pragmatic and feasible with the existing resources. As well as improving 'hard' outcomes, such as increasing the use of analgesics and decreasing acute hospital admissions, it is important that our approach is person-centred and attends to the spiritual and emotional needs of patients and the carers and staff looking after them.

## Should we be providing palliative care?

This is a developing field. Colleagues in other specialties such as cardiology and renal medicine are also having to deal with these issues and improve end-of-life care for patients who reach the terminal phase. Obviously, specialist palliative care services will be unable to manage all dying patients and thus there is a policy shift towards 'generalist' palliative care services whereby clinicians will be expected to manage end-stage illness. Our discussions as a faculty are, therefore, vital at this stage. At the open forum the talk was lively and enabled us to formulate many questions, such as: 'Do we, as old age psychiatrists, think we should be providing palliative care?', 'Do we have the skills?', 'Is this just part of the good-quality care that we should be providing anyway?' and, 'Given the loss of continuing care beds, should we be doing this in nursing homes?' We are looking forward to trying to provide some answers.

### References

1. Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing* 2006; **35**: 187-189.
2. Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatr* 2005; **17**: 31-40.

# Article 14! Evaluators required

**The Royal College of Psychiatrists is in the process of setting up a large forum of psychiatrists from all specialties to assist with the assessment of article 14 applications.**

The College's role is to assess individual applications for specialist registration in psychiatry according to the conditions set out under article 14 of *The General and Specialist Medical Practice (Education, Training and Qualifications) Order 2003*. The College works closely with the Postgraduate Medical Education and Training Board (PMETB) to ensure that a robust system of assessment is established for all applicants who apply for specialist registration under this route.

The evaluator's role is to assess applicants' qualifications, training and experience under all six 'Good Medical Practice' headings and to determine whether the applicant meets the criteria specified by the PMETB and the College, and to further determine whether their

competences are equivalent both in clinical and theoretical content to those of a UK holder of the Certificate of Completion of Training (CCT) in psychiatry.

### Specific responsibilities

The evaluator's role is to:

- Review individual applications for article 14 and apply the agreed standards, according to the evaluator's assessment notes
- Recommend any further training, experience, examinations, assessments or other tests of competence necessary to demonstrate the applicant's equivalency to a qualified specialist in the UK.

Each application is normally scrutinised by three College evaluators. The time

allocated to complete the assessment is three weeks. We particularly need evaluators in general adult psychiatry.

Although the College has already appointed a large number of evaluators, this has proved insufficient to cope with the high number of applications we regularly receive from the PMETB. The PMETB has set strict deadlines that the College is obliged to meet under the current arrangements with the Board.

We therefore need evaluators who are reliable, IT competent, comfortable with working with complex documents on screen and able to devote four to five hours (or more) per application. All applications are sent to evaluators on a CD-rom ■

If you would be interested in offering your services to assist the College please contact Miss Lena Hartley (details below) for an evaluator remit and further information.

**Miss L Hartley, Article 14 Administrator,  
Royal College of Psychiatrists,  
17 Belgrave Square, London SW1X 8PG  
Tel: 020 7235 2351. Ext: 139  
email: lhartley@rcpsych.ac.uk**



**Clive Evers**

Director of Information and Education, Alzheimer's Society, London

# Reflections from the Alzheimer's Society

It is recognised that end-of-life care for people with dementia is in need of development. This is supported by anecdotal reports from carers. While in some cases people with dementia receive excellent end-of-life care, all too frequently, carers report that their relative or friend did not receive appropriate care and support. Too many people with dementia are denied a death where maintenance of optimum dignity and comfort is paramount, and carers can feel unsupported or uninvolved.

With these and related issues in mind, the National Council for Palliative Care and the Alzheimer's Society have jointly published a discussion document called *Exploring palliative care for people with dementia*.<sup>1</sup> Key points emerging from the document indicate that all professionals need to be aware of, and be able to manage, dementia as a significant comorbidity in a range of conditions.

## Different and complex needs

Unpaid carers deliver most of the care for people with dementia and palliative care models that have been developed for people with cancer may not be appropriate for those with dementia. A strong case can be made for a palliative care approach for people with dementia at an individual level. For example, people with different types of dementia have different individual needs. Furthermore, older people – the majority of people with dementia – have different and more complex needs than others. There are significant numbers of people with dementia whose underlying cause of death is a condition other than dementia. Additionally, a case for addressing palliative care needs at a population level can be made.

## Difficulties and uncertainties

Uncertainty in prognosis is a major issue when considering a palliative care approach for people with dementia. Carers often find this uncertainty difficult to deal with. It is difficult to assess the point at which a person stops living with dementia and starts dying from it, and this can make decisions around treatment and care difficult. It also highlights why it is important that services do not use expected length of life as part of their eligibility criteria if they are to meet the

needs of people with dementia. Developing methods to predict the approach of death would enable better planning of care, particularly in moving from actively treating the condition to the palliative approach; it would help to avoid the inappropriate use of aggressive, life-sustaining treatment.

The use of checklists of clinical indicators for people who would benefit from a palliative approach needs to be encouraged and it is important that these tools are used in all care settings. The *Gold Standards Framework*<sup>2</sup> includes such a checklist. An increase in the uptake of this would be a positive step.

## Specialist nurses

End-of-life care for people with dementia will inevitably involve a range of professionals across the social services and the NHS. To support the seamless provision of an effective package of care, the Alzheimer's Society believes that the key worker model should be explored.<sup>3</sup> The National Institute for Health and Clinical Excellence (NICE) clinical guideline on supportive and palliative care also recommends that nominating a person to take on the role of 'key worker' to co-ordinate care should be developed.<sup>4</sup> The NICE clinical guideline on dementia also suggests that specialist palliative dementia care nurses may be required to co-ordinate care, in whichever location the individual is being cared for.<sup>5</sup> The Alzheimer's Society supports these recommendations. As well as improving the co-ordination of care, the development of this role would also provide one key contact for the carer, a need frequently highlighted by our members.

## Sharing learning

The Alzheimer's Society believes that the way forward is to enable people to be cared for where they wish. There is a crucial need to share experience, training and care. The fields of palliative care and dementia care can learn much from each other by sharing care practices and learning. The high proportion of people with a variety of conditions experiencing dementia, highlights the need for all generalists and specialists to understand and be able to manage dementia.

## References

For a full list of references, please email: [edit@hayward.co.uk](mailto:edit@hayward.co.uk)

It is difficult to assess the point at which a person stops living with dementia and starts dying from it



# What can old age psychiatry do?

The basic precepts of palliative care are to affirm life, accept natural death, reduce distress and preserve independence and function wherever possible. Its goal is to achieve the best possible quality of life for patients and their families.<sup>1</sup> The term 'palliative care' generally applies to the last year or two of life, whereas 'terminal' care applies to the last few days of life and involves symptom reduction, including the use of syringe drivers, with which we are all familiar. Treatments that might have a negative effect on lifespan and ability may be acceptable if they result in a significant reduction of severe distress.

## Dementia and palliative care

Dementia is a terminal condition and should qualify for palliative expertise in the same way as cancer, heart failure and neurological disorders. But while palliative care for cancer may last weeks or months, for dementia it can last several years. However, much of what we already do as old age psychiatrists should be seen as palliative care and we have the resources to provide it.

## Severe distress

Pain management technology was developed for cancer sufferers, as pain is a central issue in cancer. In comparison, there is good evidence that we identify and treat pain in dementia less well than we ought to. This is despite the fact that pain itself is, in part, a cognitive process. However, distress in dementia can include much more than physical pain (see Box 1). All the causes of severe distress need to be considered, identified and managed.

## Antipsychotics and antidepressants

If psychosis is severely distressing, then a palliative model would demand that it is effectively treated even if (as we know to be the case) the appropriate medicines may cause harm (such as stroke, sedation, falls and so on). It should, therefore, be acceptable to treat such distress and that is why we should continue to use antipsychotics in dementia. If depression is present we should seek to use the relatively safe selective serotonin reuptake inhibitors (SSRIs) to reduce its impact.

In our study of patients with advanced dementia, who were cared for at home until they died, it was antipsychotics and antidepressants that were rated as more useful than any other class of medication.

## The 'hope for home' initiative

Our 'hope for home' service has supported 30 or more people at home, through to death. Some went home after being discharged from nursing homes, some had brief stays in hospital and others remained at home continuously. Supporting this is a worthwhile challenge and we have had some excellent outcomes. The right appliances at home such as hospital beds with pillow raisers and hoists, carer support, dietary advice and the right medicines are all crucial. Most of all, a mentally healthy carer is important for success. We have found that the opportunity to die at home has been welcomed.

## Better nursing home care

Capacity in hospices is nowhere near the capacity of dementia care settings. But lessons can be learned. The admission of dying people to hospital via A&E is a key concern of acute and primary care trusts (PCTs). Better illness planning and discussion should help to reduce this. Building confidence in nursing homes as palliative care settings will also help. Once again, good palliative care aimed at the key causes of severe distress is essential. There is a huge amount for our discipline to learn about palliative care and pain is only one, albeit crucial, aspect. We will excel if we take the holistic approach of which we have always been proud.

Further information is available from [www.ncpc.org.uk/publications/index.html](http://www.ncpc.org.uk/publications/index.html)

### Reference

1. [www.who.int/hiv/topics/palliative/PalliativeCare/en](http://www.who.int/hiv/topics/palliative/PalliativeCare/en) (last accessed 20 November 2006)



**Adrian Treloar**

Consultant in Old Age Psychiatry, Oxleas Mental Health Trust, London

---

“Much of what we already do as old age psychiatrists should be seen as palliative care”

---

### Box 1. Causes of severe distress in advanced dementia

- Poor understanding
- Poor environment
- Psychosis
- Depression
- Pain
- Hunger
- Continence and elimination problems
- Boredom, isolation and spiritual need
- Medication
- Immobility

# Balint's syndrome in Alzheimer's disease

## Parkavi Chellappa

Senior House Officer, Glan Clwyd Hospital, Rhyl

## Petra Gutting

Consultant in Old Age Psychiatry, North West Wales NHS Trust, Bangor

## Manikarasa Devakumar

Consultant in Old Age Psychiatry, North West Wales NHS Trust, Bangor

Alzheimer's-type dementia mostly presents with memory impairment and a gradual decline in levels of functioning. There have been reports in the literature about the presence of symptoms similar to Balint's syndrome in the early and middle stages of Alzheimer's disease. A study in 1990<sup>1</sup> estimated that symptoms of Balint's syndrome are found in as many as 20% of patients with Alzheimer's disease.

### What is Balint's syndrome?

Spatial disorder of attention, paralysis of gaze and optic ataxia together form the syndrome, which was first described by Reszo Balint in 1907. It first received the eponym 'Balint's syndrome' in 1954.<sup>2</sup>

Spatial disorder of attention is an inability to perceive, at any one time, several items in a visual scene. It is compared with simultanagnosia – defined by Wolpert in 1924 as an inability to interpret the totality of a scene, despite the ability to apprehend individual portions of the whole.<sup>2</sup>

Psychic paralysis of gaze is the inability to shift one's gaze voluntarily to objects of interest despite unrestricted eye rotations. This resembles the descriptions of spasm of fixation and acquired ocular apraxia (impairment of eye movement control hinders the person to track a moving object with their eyes).

Optic ataxia refers to difficulty in reaching for objects under visual guidance, despite normal limb strength. Objects can be seen but not localised in space, causing problems in judging distances.

### Where and how does it occur?

The brain region affected in Balint's syndrome is usually the bilateral lesion of the angular gyrus (the parieto-occipital junction or posterior parietal lobe). Also, features of Balint's syndrome have been reported with bifrontal lesions and pulvinar lesions.

There are different causes leading to this syndrome such as watershed infarctions, butterfly glioma, radiation necrosis, penetrating missile injuries, strokes involving posterior parietal branches of the middle cerebral artery and cerebral degenerative disease, these being bilateral.

### Case history

A 72-year-old man with Alzheimer's disease and visual disturbances was referred to our services for reassessment as he had become agitated, with recent episodes of aggression and suspected visual hallucinations.

His problems started as an intermittent blurring of vision in both eyes when he was 58 years old. He was seen by ophthalmologists over the next four years for various visual problems, including eye pain and burning sensations, and was diagnosed as having presbyopia, abnormal tear film and mild blepharitis. His symptoms persisted despite treatment. Possible cognitive deficits were queried at the time but no further investigations were initiated.

### Visual problems

Suddenly, when he was 63, he had to stop his car in the middle of the road as he was unsure where the car was in relation to the road. He has not driven since. He was referred to a neurologist, when he complained of difficulties with household chores, worries about veering to one side when walking and that he could only read one word at a time. He had ophthalmologic electrodiagnostic tests to rule out gross retinal disorder and an MRI scan, which was reported as showing 'some degree of occipital atrophy'.

### Panic attacks

He developed panic attacks and was prescribed a selective serotonin reuptake inhibitor (SSRI) by his GP. At 67 years of age, a psychiatric opinion was sought as, by then, his ability to function had deteriorated and despite antidepressant medication his mood was low and his panic attacks persisted.

He described difficulties with focusing on objects in space, photophobia and difficulties with maintaining balance and coordination. He was well oriented in time, place and person but had significant problems with concentration. His short-term memory was impaired but his long-term memory seemed intact. A repeat MRI scan (Figures 1 and 2, opposite) showed marked generalised atrophic changes, which were prominent in the parieto-occipital junction. Neuropsychological testing, together with



Figure 1.



Figure 2.

the clinical picture and absence of any cardiovascular risk factor, led to a diagnosis of probable Alzheimer's disease.

### Marked decline

He was started on donepezil and remained stable, with minimal support, until his presentation four years later with increasing agitation and restlessness, leading to his informal admission to our hospital. A repeat neuropsychological assessment reported a marked decline compared with the previous assessment. He described being able to see objects but seemed to have difficulty with orienting himself towards these objects in space. When shown a pen he was able to name it, but when shown a pen and a spoon he only appeared to see one of the two objects at any one time. He was also unable to track a moving object with his eyes.

### Difficulty with orientation

While on our unit, he clearly showed difficulty with orientating himself in space and he was, although not blind, unable to see his

surroundings fully and could only recognise one thing at a time. His general mental state settled during his hospital stay. His visual problems continued but he seemed less anxious and distressed. He was able to return home but continues to attend our local unit for regular weeks of respite.

## Symptoms consistent with Balint's syndrome

Our patient's symptoms were consistent with Balint's syndrome. His initial complaint was, for several years, of a visual nature and his symptoms could have well been seen as anxiety related. The memory problems and general cognitive decline only became apparent at a later stage of the illness, leading to the diagnosis of Alzheimer's disease with Balint's syndrome. This is a relatively uncommon condition and most of the literature on it is case reports. It is difficult to assess with standard tools. Although brain imaging can be helpful, CT and MRI scans can be normal. A positron emission tomography (PET) scan might show hypometabolism of the posterior parietal lobes but PET scans are not readily available for our patients.

## Misinterpreted experiences

A person who has difficulty seeing a variety of objects simultaneously and is unable to judge the position of things in space will have problems with navigating, even in familiar environments. If this person also develops cognitive problems, their ability to compensate for their impairments will be very much affected. Also, their understanding of their difficulties might be impaired and experiences misinterpreted.

Through our case report we wanted to raise awareness of the possible problems a person with Alzheimer's disease can experience when symptoms of Balint's syndrome occur at the same time. Often, this condition is not recognised and the person's difficulties could be easily misinterpreted as behavioural problems or anxiety, leading to additional medication being prescribed, rather than supportive measures being implemented.

### Reference

1. Mendez M, Tomsak R, Remler B. Disorders of the visual system in Alzheimer's disease. *J Clin Neuroophthalmol* 1990; **10**: 62-69.
2. Rizzo M, Vecera SP. Psychoanatomical substrates of Balint's syndrome. *J Neurol Neurosurg Psychiatry* 2002; **72**: 162-178.

### Further reading

Hecaen H, de Ajuriaguerra J. Balint's syndrome (psychic paralysis of visual fixation) and its minor forms. *Brain* 1954; **77**: 373-400.

Rafal R. Balint's syndrome. In: Behrmann M (ed). *Handbook of Neuropsychology*, 2nd edn, vol 4: Disorders of visual behaviour. Amsterdam: Elsevier, 2001.

Rizzo M. Balint's syndrome and associated visuospatial disorders. *Baillieres Clin Neurol* 1993; **2**: 415-437.

---

“His initial complaint was, for several years, of a visual nature”

---

# Dementia: mind, meaning and the person



**Lucy Watkin**  
Specialist Registrar in Old Age Psychiatry, Royal Free and University College Hospitals, London

**Julian C Hughes, Stephen J Louw and Steven R Sabat (Eds)**  
Oxford: Oxford University Press, 2006

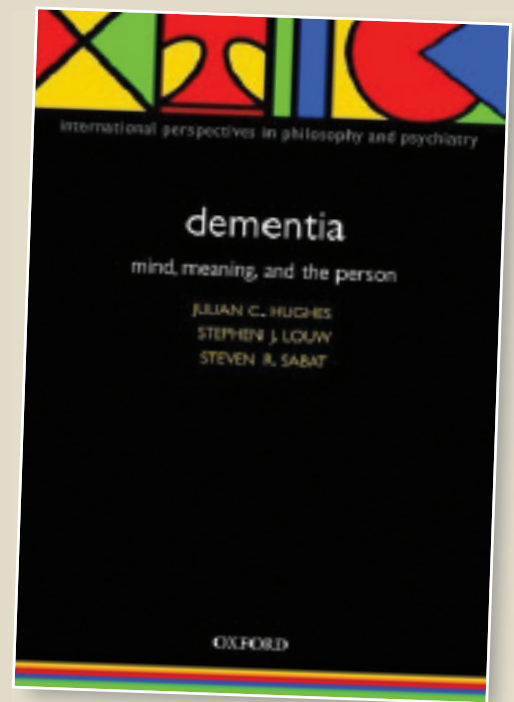
## Am I still me?

Dementia is an illness that holds great fear for some people, as it encapsulates not just the loss of independence but that of the 'self' and the 'self as seen by others'. How does society cope with this dreadful illness? By rationalising it, minimising it, or even idealising it as a return to a childlike state. To what extent are our reactions to the illness affected by our 'healthy' status? Do we have coping mechanisms to tolerate the illness better or to make difficult decisions – such as the need for long-term care – a little easier? If it were for us, we might well consider this care sub-standard. What is it really like to experience this disorder? It led me to start thinking about many things. If I am me – and a product of my brain – then what happens if my brain globally degenerates? Am I still me? Am I something less human, or the same?

## Fascinating and peppered with quotes

The book arose in the wake of a joint meeting between the Faculty of Psychiatry of Old Age and the Philosophy Special Interest Group in 2002. It is not solely a book for doctors, being very much aimed at a multidisciplinary team, and I enjoyed the contributions from a diverse range of authors including a priest, an occupational therapist, a social worker and professors of psychiatry and psychology. The book is fascinating and peppered with quotes, relevant research and diverse ideas that are relevant to clinical practice. For example, research has shown that nurses spend less time with and talk less to the more severely impaired than they do with those who are less severely cognitively impaired.

The book covers malignant social psychology and labelling. There is a discussion around whether Alzheimer's disease sufferers are, in fact, more intact than they appear to be,



Do we have coping mechanisms to tolerate the illness better?

but are assumed to be worse due to failure of communication. To illustrate this, there is a description of one woman who, having responded to dementia medication, could then recall the content of previous consultations at which she had appeared quite inanimate. There are excellent patient accounts that I often found quite touching. They describe a profound sense of fatigue that is suffered by many and examine the problems caused by fluctuating ability. The distress and isolation at the breakdown of familiarity with the world, as objects and their meanings become difficult to place, is described, as is the sense of agitation that arises when the mind becomes blank and filled with nothing.

## A thought-provoking read

The book is further enriched by vignettes, court cases, quotations and other literature, which bring to life this complex subject. At 310 pages, it is a good length, has many excellent references and a detailed index. This book has improved my understanding and has prompted me to think about dementia and my sense of self. In short, *Dementia: mind, meaning and the person* is a thought-provoking and recommended read ■