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EDITORIAL

Forgetful and Forgotten?

Over the past 5 years the field of Old Age Psychiatry has had some welcome fillips. Undoubtedly the arrival of anti-dementia drugs was a milestone. With its strong anti-ageist stand and a whole section devoted to mental health the English National Service Framework for Older People (NSF-OP) (Department of Health, 2001) too injected enthusiasm. Catching some of this, *Forgetful but not Forgotten* (2001) was the title of a Royal College of Psychiatrists' initiative on dementia, emphasizing quality in assessment.

Yet there were also less healthy undercurrents. In 2000 the Royal College of Psychiatrists published *Institutional abuse of older adults* (Garner & Evans, 2000) in response to '… increasing concerns about the care of elderly patients in long-stay settings ….' and the Commission for Health Improvement (CHI) reported to the Secretary of State for Health on abuse of older people at the North Lakeland Healthcare NHS Trust. I co-authored (with colleague Jane Garner) the Faculty of Old Age Psychiatry's response, emphasizing the role of the psychiatrist in trying to prevent abuse or taking action if it was suspected.

Were these merely scratches on the otherwise smooth shiny surface of mental health care for older adults or symptoms of something deeper and more disturbing? Enter CHI again, who in September 2003 published an Investigation into matters arising from care on Rowan ward, Manchester Mental Health & Social Care Trust. Now I am a commentator not on events elsewhere but on allegations in my back yard, for Rowan ward, formerly part of a neighbouring acute Trust, is now within the city-wide mental health organization for which I work.

In Manchester, CHI did not investigate allegations of abuse on Rowan ward, since these were unproven and, unlike North Lakeland, no criticisms are made of individual staff. Yet depressingly, there are many areas of overlap. In both reports older people with dementia were let down by a comprehensive failure of management systems (up to and including the (Strategic) Health Authorities). Relationships between key players were 'dysfunctional' and clinicians were not encouraged to take on key roles in service development. Commissioning arrangements were inadequate and insufficiently informed by professional views. Both organizations lacked the experience and skills to deliver mental health care and in Manchester CHI doubted that the Care Trust should ever have existed in the first place (in Manchester older people were specifically excluded from integrated social and health care arrangements). In both Manchester and North Lakeland the starting point was neglected wards for older people with dementia. The conditions for abuse – isolated wards with poor fabric, a lack of person-centred care, poor staff training and support along with inward looking cultures – were present in both organizations. Preoccupation with reorganization deflected effort away from clinical care, the Trust Boards were weak and financial cut-backs distorted priorities, leading to under-resourced middle management, seen as a soft target for savings.

How can we avoid our forgetful patients becoming forgotten? When the North Lakeland report was published several colleagues I spoke to commented, 'there but for the grace of God ...'. This is an understandable reaction but it left me then and leaves me now feeling uncomfortable, as if something important is being avoided. However sophisticated our society seems there will always be attacks on those who are seen to be the least productive - usually they are also the most vulnerable. Often this is unconscious but destructive impulses reside in all of us to a greater or lesser degree. Recognising this is a start – in a sense we are all part of the problem. So is acknowledging just how difficult and demanding is the task of nursing demented patients with challenging behaviours and to what extent such care can stir up feelings which no-one wants to admit to. Much easier to be a doctor, psychologist, social worker or manager who 'dips in' to a ward for minutes or hours at best. Abuse should never be explained away but nor should we scapegoat those who are doing such a tough job. This not to encourage guilt, as this is rarely productive, but to suggest that we think creatively of ways to bring professions together, for, as CHI comment in the Rowan report, professions can continue to work separately paying only lip service to teamwork. Multi-professional training and support along with strong professional leadership are ways of lowering professional barriers.

But there are organisational and structural issues too. Inpatient wards are not fashionable; they are easy targets for accountants. Community is where the action is and sadly community and hospital are sometimes seen as mutually exclusive. Perhaps now is the time to pause and take stock of where we are going with mental health services for older people. If we want quality services then inpatient care has to be part of that and it must be properly funded. Unfortunately it is the experience of many mental health services for older people that since the NSF-OP there has been either no new investment or even cut-backs. Older peoples' services are now disadvantaged compared to those for younger adults, which did receive additional funds from the mental health NSF. Perhaps key professional, carer and user groups should unite to advocate for investment. The Manchester CHI investigation may seem like another blow but this well written and thoughtful report deserves to be read and acted upon by all who are involved with the mental health care of older people, including those who hold the purse strings.

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*Forgetful but not forgotten: assessment by a specialist service diagnostic assessment and investigation of suspected dementia by a Specialist Old Age Psychiatry Service – A Consensus Statement, 2000/2001 (*Prepared by a Working Group of the Faculty for the Psychiatry of Old Age of the Royal College of Psychiatrists, England). London, Department of Health.

Garner, J. & Evans, S. (2000) *Institutional abuse of older adults.* Royal College of Psychaitrists Council Report CR84). London, Royal College of Psychiatrists.

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ARTICLE

But When Can I Go Home?

This paper draws on, and endeavours to further develop the ideas behind, material presented on three previous occasions:

- a talk given to Scottish psychiatrists and philosophers on 19 September 2001 regarding the assessment of incapacity in dementia
- a poster displayed during the “Dementia: Mind, Meaning and the Person” conference in Newcastle from 31 October 2002 to 1 November 2002 addressing philosophical aspects of assessing InCapacity (i.e. capacity or incapacity) in dementia
- a lecture given on 19 August 2003 at the 11th International Psychogeriatric Association meeting in Chicago as a component of a symposium on ethical aspects of competence.

In this latter setting four very different speakers quite separately and independently chose as their clinical example the situation of someone with dementia wanting to return from hospital to live alone at home. I focused on the specific context of the Adults with Incapacity (Scotland) Act 2000[1] (AWI) but this scenario is appearing more and more in “old age” publications as comparable English legislation draws closer.[2,3]

As the first major act of the new Scottish Parliament, AWI rests upon five basic principles which I have chosen to express as follows:

- Any proposed intervention should benefit the adult and not be readily achievable otherwise.
- It should be the least restrictive option available.
- Account should be taken of the adult’s present and past wishes as far as these can be ascertained.
- The views of other significant persons should be considered “if reasonable and practicable”.
- The adult should be encouraged (and helped) to exercise and develop skills in relevant areas of decision making.

Under AWI, adults may be deemed incapable, by means of mental disorder or inability to communicate because of physical disability, of any or all of the following five components of a specific, defined issue:

- Acting
- Making a decision
- Communicating that decision
- Understanding (implications of) any decision made
- Retaining memory of the decision

The patient’s wish to return home from hospital is likely to be in the face of perceived risk and frequently also of objections from relatives. The individual might or might not

intermittently assent to alternative placement while clearly unhappy regarding this. The ethics of either capacity or risk considerations over-ruling clearly expressed preferences point to the need for further debate and for a robust mechanism to help make such determinations. It appears doubtful that a statutory process such as Welfare Guardianship for every person with dementia entering a care home is either necessary or appropriate but the parallels with Bournewood & Zinermon are clear.
A typically difficult patient would be capable of:

- acting on a decision made (especially when able to recall their address)
- expressing/communicating a decision (often repetitively and forcibly)
- possibly retaining memory of the decision (a critically difficult issue if this is the only basis on which to question capacity)
- partially understanding a decision (the broadest and perhaps the most important term under consideration and one which has attracted the most detailed consideration at UK level with specific legal opinions having shaped subsequent clinical practice)
- making (i.e. appearing to arrive at) a decision (although arguably this might even be a superfluous term, already covered by the preceding four).

One seemingly important idea which emerged gradually over the period of preparing this article was that a course, or even courses, of “treatment” should at least be attempted for the underlying mental disorder before an incapacity decision, with long-term consequences such as institutionalisation, is finally taken in a patient with dementia. Given still relatively patchy uptake of the anticholinesterases, not to mention memantine, and somewhat different approaches to Guardianship or contracts across local authorities, a whole different range of postcode variabilities might be envisaged.

Uncertainty also exists in general about acceptable legal tests or even appropriate clinical criteria against which to assess capacity to decide where, and using what support from whom, to live “independently”. The deficits of self care which can accompany dementia may be amenable to rectification by family or professional carers unless loss of insight causes such assistance to be rejected. The necessary criteria for acceptably safe domestic existence are far from fully clear but recurrent fire risk and frequent wandering without regard to the prevailing weather conditions are often the triggers to intervention. Access is obviously necessary in order to have a chance to dispose of out-of-date food and to assist with medication compliance. Risk itself is not sufficient to justify a finding of incapacity but inability to factor it into decisions may be.

It feels particularly difficult to take a final decision on care home entry following acute admission to a general hospital, a long period of deskilling and no “rehabilitative” opportunity based on maximally assisted community living. The practical test of checking whether in reality necessary assistance is actually accepted would be more in keeping with capacity assessment as a facilitatory and dynamic process. Whether certain aspects of decision-making capacity can even be fairly assessed in the abstract, when deficits of executive function are among the most frequently encountered in dementia, appears a moot point. A trial discharge may be most fully in the spirit of maintaining autonomy and the presumption of capacity while conducting a realistically rigorous multidisciplinary assessment under immediately

practical conditions. The particular value of skilled Occupational Therapy input to such a process cannot be overstated.
Arguably the grounds for entry into care for an individual with dementia might be:

- wishing this and being able to purchase it
- wishing this and being assessed as requiring it
- being assessed as requiring this and being persuaded to accept it
- being assessed as requiring this and being compelled to accept it.

Even this latter requires a degree of assent and is particularly contentious if the reason for not attempting a trial placement at home relates to insufficient resource for 24 hour support. A comparable complication in relation to the capacity assessment process itself might be seen as the shortage of clinical psychologists and difficulties of access to speech and language therapy.

Advance directives are not considered explicitly under AWI though the principles of the Act obviously require that they be taken into consideration. The use of off-licence antipsychotic medication in patients unable to give informed consent is another contentious topic, especially when lack of appropriate resources or expertise for a non-pharmacological approach are contributory factors. The issue of how best to conduct such assessments and that of developing the patient’s abilities to take key decisions are attracting increasing interest.

The specific task of taking appropriate steps to optimise the patient’s general decision-making capacity for application to such a major step as entering care is thus raised here for consideration and debate in respect of one specific piece of legislation but hopefully also with broader potential utility.

Other aspects of AWI legislation may potentially impact on this scenario though in more theoretical fashion. Were an individual, for instance, to be deemed unable to decide to live independently while still being seen as able to give direction for the use of finances, then he or she might choose not to accept the monetary consequences of compulsory care decisions. The ethical issues of charging someone for care they have been assessed as needing, but manifestly do not want, not to mention the administrative and legal costs of the assessment process itself, are in stark contrast to comparable situations arising under mental health legislation.

In the absence of case law with such new legislation it is likely that close adherence to the principles of AWI, and to the chosen definition of incapacity, will be of prime importance in disputed situations. The relative lack of precision of the term ‘retain’ may come to be an important factor in following guidance strongly weighted towards preservation of autonomy though the interaction with risk is likely to be examined in more detail as implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003[4] proceeds from April 2005. Questions of assent rather than consent and passive acceptance or active resistance are likely to be trawled over in a range of clinical settings but given the crucial importance of dementia to ongoing increases in emergency admissions of the very old to general hospitals, and subsequent concerns over delayed discharge, few issues are likely to be of greater importance than determining who will remain at home with appropriate support and who requires care home placement. The dilemmas for medical staff appear almost as much ethical as technical and the requirement for appropriately rigorous but sensitive training remains pressing.

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CURRENT KEY ISSUES

Is large-scale community memory screening feasible? Experience from a regional memory-screening day

Lawrence, J. *et al*. (2003) Is large-scale community memory screening feasible? Experience from a regional memory-screening day. *Journal of the American Geriatrics Society* 51, pp,.1072–1078.

The objectives of this programme were to identify whether it was possible to identify successfully people in the community who would have a high probability of having dementia and who would therefore gain some benefit from further assessment. Ten sites were assessed in New England on the 29th October 1999 (consisting of clinics, churches, and day centres). Four-hundred and ninety-seven people were interviewed on the screening day, with a further 162 assessed during the following month. The 7-minute screen was used, after appropriate training of staff.

16.7% of everyone who was screened were found to score highly on the instrument, and were advised to seek more advice at follow-up; 64% of those people reported that they had sought further investigation, and further follow-up showed that ten (9%) had been diagnosed with probable Alzheimer’s disease, and an additional nine (8%) who had had a previous diagnosis were correctly identified by the 7-minute screen. Anecdotal evidence reported that the participants valued the intervention, including the educational talk and the possibility of early detection of disease. The main conclusion of the study (sponsored by Janssen, Pfizer and Eisai) was that, while acceptable and indeed enjoyable, this form of screening was a relatively inefficient way of screening for people with dementia.

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Contribution of informant and patient ratings to the accuracy of the Mini-Mental State Examination in predicting probable Alzheimer's disease

Tierney, M. *et al*. (2003) Contribution of informant and patient ratings to the accuracy of the Mini-Mental State Examination in predicting probable Alzheimer's disease *Journal of the American Geriatric Society* 51, pp.813-818

The objectives of the study were to assess whether patient and informant ratings of cognitive problems could increase the accuracy of the Mini-Mental State Examination predicting future Alzheimer's disease. A longitudinal study over two years included people referred to a university teaching hospital who did not have dementia. One-hundred and sixty-five people were included, and after two years twenty-nine met the criteria for Alzheimer's disease. The baseline assessments included the Mini-Mental State Examination and both an informant and patient rating scale of cognitive difficulties. The results showed that the best predictive model included the informant reading scale and the Mini-Mental State Examination, with a sensitivity of 83% and a specificity of 79%. A model which included two items each from the Mini-Mental State Examination, the patient rating scale and the informant rating scale produced a significantly better model than the one with the full test scores – sensitivity 90%, specificity 94%. The results indicated that the inclusion of informant ratings in the Mini-Mental State Examination significantly improved its accuracy at the prediction of probable Alzheimer's disease.
The six items were: the delayed recall and day of the week test in the Mini-Mental State Examination; the informant question (using the CAMDEX) of managing money and remembering short lists; and the patient questions from the CAMDEX of finding the right word and mood change.

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BOOK REVIEW

Early-Onset Dementia: a multidisciplinary approach

Hodges, John R.(2001) *Early-Onset Dementia: a multidisciplinary approach*
Oxford: Oxford University Press. 477 pages. ISBN 0192630342

Over the past decade or so there has been a growing clinical interest in the previously neglected field of early onset dementia. Alongside this interest has been a desire to develop services which are relevant to meeting the needs of younger people who present with a cognitive impairment. Such services need to not only be specialist in the assessment, diagnosis and treatment of early onset dementia but display a recognition and understanding of the challenges faced by such patients.

The book is well thought out and structured in such a way as to encompass the diversity of disciplines which contribute to the growing body of knowledge regarding early onset dementia. There is, perhaps naturally, a strong bias towards the bio-medical disciplines and the emerging 'social' model, which has made great efforts to understand the ‘lived experience’ of early dementia, has been almost neglected. Despite this the publication does recognise most of the needs of the patient and in the most part offers a detailed, comprehensive and engaging review of the subject.

The body of the text is 469 pages divided into 20 chapters which encompass a wide range of related subjects. Everything from the epidemiology of pre-senile dementia to its assessment, pathology, diagnosis, treatment and practical management is included. All chapters are well written by recognised experts and the overall style is informative and engaging. Chapter one on epidemiology, written by Richard Harvey, exemplifies this style. The chapter offers not only details the results of major epidemiological studies but also explains the specific methodologies and their direct application to early onset dementia.

Although clearly written for the medical practitioner the style of the writing will have appeal to a much wider audience; whilst the content is of sufficient breadth and depth to be pertinent to those with existing interest, knowledge and experience of the field.
Overall it is an attractive publication with much to offer and will be welcomed by clinicians of many disciplines.

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WEBSITE REVIEW

OMNI subject gateway

OMNI (Organising Medical Networked Information) is the UK gateway to high quality Internet information in Health and Biomedicine. It is part of the Resource Discovery Network (RDN) and is offered free to all. The RDN was set up in 1998 by JISC to provide students, researchers, academics and practitioners with sites that are evaluated for accuracy and authoritative content. OMNI is created by a core team of information specialists and subject experts based at the Greenfield Medical Library at the University of Nottingham.

A subject gateway seeks to collect together Internet resources which have been selected for quality and relevance to a particular target audience. Sites are then reviewed and resource descriptions given which are stored with accompanying metadata in a searchable structured database. The OMNI gateway currently contains over 7500 records, links to health and biomedical sites. These links are regularly checked.

OMNI offers a searchable catalogue of live links to Internet sites covering health and medicine and can be searched in a number of ways. First, the user can enter his/her own search term into the search box; entering ‘dementia’ produced 61 results comprising links to sites of organisations, academies, institutions from the UK, US and Australia, as well as to the full-text of monographs, patient education handouts, practice guidelines, electronic journals and research funding sources. One very important feature of this is the link to the full-text of the electronic journal Bandolier. Bandolier provides quality evidence-based resources relating to medical issues – of special interest here may be that the Bandolier documents for Neurological Disorders and Older People are accessible from this listing. Access to the full-text of *Health Evidence Bulletin* is also possible from here. Using the Advanced Search facility gives the user the opportunity to limit the search by specifying what type of publication is needed. You can choose from journals, software, databases (bibliographic and non-bibliographic), reports, books, practice guidelines, systematic reviews, and patient information leaflets among others. Entering ‘dementia’ but restricting the results to ‘practice guidelines’ resulted in three hits, access to the full text of these guidelines was available at a click of the mouse.

You can also search according to two kinds of subject headings depending on whether you require broad or specific categories. For very broad subject headings use the National Library of Medicine (NLM) headings – under ‘psychiatry and psychology’ there are 791 entries. For narrow search terms you can use the MeSH headings which are very specific – using ‘geriatric psychiatry’ produced five results.

OMNI produces a helpful booklet, *Internet Resources in Health and Medicine* which gives numerous examples of quality sites; this is useful as a ‘taster’ for the site, but visiting OMNI itself gives you access to an additional 7000 or so online resources. You can download the booklet from:
http://biome.ac.uk/about/publications.html#booklet

OMNI is a continually growing resource and the compilers are interested in hearing about sites not included at present but which you think would be a worthwhile addition to the resources given. Its growth has meant that its coverage no longer has biological or biomedical content it did when it was launched. These subjects are served by another gateway, BioResearch. However, to assist those who wish to include these topics in their search strategy, the OMNI Advanced Search facility allows searching across the two gateways.

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YOUR PROBLEM ANSWERED

How to win friends in the Editorial Office:

The job of an editor (and an editorial assistant) is made much easier if certain simple guidelines are followed when submitting papers for publication. By taking note of these suggestions, you can save yourself and the editorial office much time and trouble.

1. Obtain a copy of “Instructions to Authors”. For most journals these can be downloaded from the Internet. Read them carefully and follow the instructions for submission.

2. Ensure that the manuscript and references are in the “house style” of the journal. Journals have different criteria and it is worth taking the time to get this right at the outset and save yourself work later.
3. Number the pages – if manuscripts need to be photocopied this is a double check that all pages have been copied. It is also useful for referees to be able to state a page number in their reviews
4. Make sure that you have submitted to the journal the correct number of copies of the manuscript and have included an electronic copy. It is very time consuming for the editorial office to have to make extra copies/photocopies and does not endear you to them!
5. Most journals require a **structured** abstract (i.e. Objective, Method, Results, Conclusion). Make sure you include this, as if it has to be done at a later stage it can delay publication. Time taken on this is well spent as the abstract should give the editor a clear idea of what your paper is about and therefore to whom it should be sent for review.
6. Remember to add up to 10 keywords and up to 4 key points if requested by the journal
7. Include a “Copyright Transfer Agreement” if this is required. Having to ask for this at a later stage can also hold up publication.
8. Include your up-to-date e-mail address for ease of communication. It is worth bearing in mind that some editorial offices are only manned on a part-time basis so communication by e-mail is better than by telephone. In addition, many publishers now like to send out proofs by e-mail to save time.
9. Remember that the editorial office is very much at the mercy of its reviewers/referees. We cannot move forward with a paper until the referees have replied and as they are busy people, they often keep us waiting. Reminders are sent at regular intervals but referees sometimes do not respond and we therefore have to start all over again. *(see point 12)*
10. When revising your manuscript, address the comments of the referees and enclose a list of the changes you have made, with your resubmission. This makes the job of the editor much easier.
11. Once your paper has been accepted you will receive proofs for checking. Check these carefully and return them promptly to ensure speedy publication. This is the time to check for typos, minor errors and misprints and is not the time to make major changes to the paper
12. **A final point:** If you are asked review a paper yourself, try to return it to the editorial office within the specified time. Remember how frustrated you became when waiting for a decision on your own paper!

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