

Older people with long-standing mental illness: the graduates

David Jolley, Nick Kosky & Frank Holloway

Abstract People who survive into late life with chronic or relapsing illnesses, which had their onset in youth or middle age, have special needs. In the past, those most severely affected often lived out their lives in mental hospitals. The mental hospital closure programme led to discharges to alternative care, and the successes and failures of these have been monitored by some services. Subsequent generations are at risk of falling between the care of general psychiatry, rehabilitation psychiatry and old age psychiatry. These patients are uniquely disabled by a combination of personal, social, mental and physical health disadvantage. The Royal College of Psychiatrists has produced guidance to highlight the special needs of these 'graduates', encouraging every locality to investigate its own performance in their care and bring it into line with best practice in the light of local strengths and resources.

Mental health and mental illness in late life

Late life, operationally defined as age 65 years or older, is recognised to be a time when people may acquire illness and disability. Survival into late life has become commonplace as life expectancy for both women and men in the developed world has extended to 75–80 years old. Other countries are achieving a similar profile over a shortened time span (Kalache, 1996). The accumulation of pathological change and disability in old age is seen as 'age-related', crossing the boundaries of physical, mental and social morbidity. Thus it is that the National Health Service (NHS) has structured its plans for services to include a specific National Service Framework (NSF) for Older People (Department of Health, 2001). This provides a comprehensive approach to the health needs of older people, which often arise from combinations of pathologies, and complements the guidance aimed at particular conditions (cancer, coronary artery disease, mental health, etc.).

Two conditions associated with ageing – stroke and dementia – are dealt with only within the NSF for Older People. This has the potential to produce difficulties for younger people with these conditions. Certainly, the exclusion of older people from consideration within the NSF for Mental Health (Department of Health 1999), which focuses

exclusively on people of working age, has disadvantaged some patients and made differentials of service quality based on age (ageism) difficult to avoid. This is most apparent for people who survive to become old despite their experience of mental disorder from an earlier age, the so-called 'graduates' of the mental health system.

Services for people with mental illnesses

Mental health services in the UK and other parts of the world have been remodelled during the past 50 years in response to advances in knowledge and therapies and changes in philosophy and government policies (Freeman, 1999). Specialisation has occurred to facilitate the best and most economic use of skills and resources. Special services for older people with mental health problems began to appear during the 1960s. However, it was only in 1988 that old age psychiatry was recognised as a specialty within the NHS. There are now more than 400 consultants working as old age psychiatrists and almost every health community boasts a dedicated service for older people (Royal College of Physicians & Royal College of Psychiatrists, 1998). This has the advantage of bringing psychiatric expertise firmly and generously into the wide range of social, health and voluntary agencies working for the welfare of older people.

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General psychiatry has given rise to a number of subspecialties addressing, for instance, the psychiatry of substance misuse, eating disorders and the puerperium. It has also developed the practice of community psychiatry and specialised rehabilitation services for patients with enduring symptoms or disability (Department of Health, 1999).

Long-stay patients in mental hospitals (the original graduates)

People afflicted by serious mental illness in the UK in the first half of the 20th century relied on care provided within a system of county asylums. By 1964, 2.8 out of every 1000 in the population of England were housed in its mental hospitals (Department of Health and Social Security, 1974). Progress in therapy, together with altered philosophies and painful awareness of the undesirable aspects of asylum life, led to more treatment without admission or with only brief hospitalisation. People becoming ill for the first time were most likely to benefit from the new approaches. Others, disabled by symptoms that had become chronic and complicated by secondary and tertiary handicaps associated with institutionalisation, needed more sustained, multi-dimensional, multi-agency treatment programmes if they were to be discharged. This latter work became the role of rehabilitation psychiatry. Patients with longer experience of illness were least likely to respond to these new approaches. Older people were inevitably among the treatment-resistant few who remained in hospital.

In addition, the dementias, including Alzheimer's disease, vascular dementia and Huntington's chorea, have remained without effective pharmaceutical or other treatment until very recently. Thus, older people were differentially retained within mental hospitals as 'old long-stay' patients and continued to accumulate within cohorts of 'new long-stay' patients from the 1970s onwards (Department of Health and Social Security, 1985).

Pioneering old age psychiatry services usually originated in a mental hospital (Arie & Jolley, 1982). Several wards, each housing 40 or more older patients, usually of one gender but of mixed history and diagnosis, would be offered to the new service as a 'working capital' of beds often running into the hundreds. Discharge or death produced beds available for further admissions or allowed resources to be released so that bed numbers could be reduced and/or the staff-to-patient ratio improved.

Older people living in other wards remained the responsibility of the undifferentiated general psychiatry service or might be included in a rehabilitation service. In many instances these patients were

managed quite passively. They were not mentioned in guidance and planning documents of the period. It was assumed that they were content to live out their lives in the milieu which had been their home for many years, and that they would not be replaced.

Greater interest was taken in their characteristics and needs when it became clear that their natural decline was not progressing as quickly as was convenient for managers and politicians determined to close mental hospitals to a targeted timescale. There were problems of logistics and economics in running down several hospitals within each region. Every hospital included many wards and hundreds of patients. Losing a few patients at a time meant fewer patients per ward, increasing staff-to-patient ratios and sustained or even increased overhead costs. It was felt that money and skills could be used to better effect in alternative community treatment programmes and that a speedier 'managed' closure of the mental hospitals was essential. This was achieved by discharging long-stay patients, including the elderly, to alternative accommodation.

Numbers

In 1971, there were 104 638 people resident in mental hospitals in England; 53 353 of these had been resident for 5 years or longer (Department of Health and Social Security, 1978). By 1975, the total had reduced, but there were still 41 864 who had been in hospital with no interruption for at least 5 years, of whom 21 239 (51.2%) were aged 65 years and older.

Numbers of beds in mental hospitals continued to fall: by 35% between 1975 and 1982 and by roughly 50% every 6 years from then on (Department of Health and Social Security, 1985). Yet psychiatric case registers reported persistently high numbers of older people with chronic psychoses into the mid-1980s. There was a considerable variation in prevalence between different health communities: 11 per 100 000 in Oxford, 60 per 100 000 in Salford. The average for England was estimated to be 31 per 100 000. Thus, 'graduate' elderly people with chronic psychosis contributed between a quarter and a half of mental illness bed usage by older people (Gibbons *et al*, 1984).

Characteristics

Campbell has written knowledgeably and sympathetically about the clinical characteristics and needs of mental hospital graduates (Campbell & Ananth, 2002). Diagnostically, this group was made up predominantly of people with chronic schizophrenia (50–70%), fewer with unstable mood disorder (10–15%), a significant accumulation of people with dementia, often of early onset (5–20%),

and a ragbag of other syndromes, including personality disorder, alcohol dependence, brain damage and multiple pathology.

Among the patients with chronic schizophrenia, active delusional beliefs continued to be evident in 36% (compared with 63% on admission), hallucinations in 40% (similar to the rate on admission) and negative symptoms were demonstrated by more than 70% (compared with 60% on admission). Thought disorder and negative symptoms were less evident in late-onset schizophrenia, but persisted in patients who had endured their illness since early life (Howard *et al*, 1993). Several studies have demonstrated cognitive deterioration together with ventricular enlargement and cortical atrophy in graduates with chronic schizophrenia (Dale & Burns, 1997).

The social lives of these graduates were characterised by long contact with mental health services, broken roots and little involvement with their biological families, and fragmentation or absence of career or work history. Many had never married, marriages that had occurred had failed, and most could identify nowhere but hospital to call home.

Many demonstrated poor impulse control and were judged still to pose potential risk to themselves by self-harm or to others because of violence. In addition, most were lacking in initiative and motivation and would neglect the basics of self-care and hygiene without supervision and prompting. They lacked insight into their limitations and the impact their behaviour might have on ordinary people.

Their physical health was often poor for, although tuberculosis was no longer the scourge of mental hospitals that it had been, other illnesses remained more prevalent than in the general population. Surveys revealed particular deficiencies of oral and foot health, and studies using the Salford case register confirmed that excess death rates are associated not only with suicide and other forms of violence, but with diagnoses from most ICD chapters, most markedly circulatory disorders (Baxter, 1996).

Thus, graduates are socially vulnerable and have ongoing need for treatment of barely contained psychiatric disorders and physical health problems associated with age, self-neglect and a life of stress and underprivilege.

Outcomes of deinstitutionalisation

Mental hospitals offered very rough and ready facilities to their residents, especially those long-stay patients living on 'back wards'. Bedrooms might be dormitories for 50. Wards were usually single-gender, mixed diagnosis and mixed age group. Older patients were deemed no longer in

need of occupational therapy, physiotherapy or any other therapy other than basic medicines. They were retired from industrial units, but might find a role as 'trusties' within the ward.

Closure of these hospitals destroyed what had appeared to be the natural environment for graduates. In many instances, discharge from one form of institution (a hospital sponsored by the NHS budget) was simply to another, smaller, less specialised institution: a hostel, residential home or nursing home funded through social security benefits, social services or other, sometimes mixed, means (Hafner & An Der Heiden, 1986). These smaller units usually provided better physical facilities than the old asylum: single or shared bedrooms instead of huge dormitories, smaller, better-furnished sitting rooms, easier access to everyday shopping and leisure facilities available to the general public, and exposure to and involvement with the general public. Of the 50 elderly graduates discharged from hospital in York, 40 were found to be content with their new lives, although still very disabled (Jones *et al*, 1986).

Several publications from a project by the Team for the Assessment of Psychiatric Services (TAPS), set up by the North East Thames Regional Health Authority, have catalogued the outcomes for elderly long-stay patients discharged from Friern Barnet hospital. Treiman *et al* (1996) found that only 71 out of 130 were alive 3 years later. Half of these had returned to hospital, but the survivors in the community were well settled and functioning better than those who had stayed in hospital. Mortality rates for those discharged were no higher than for those remaining in hospital, although one person died by suicide and one had been imprisoned. Survivors in the community could name more friends, had more social contacts and were happier with their treatment and accommodation than their peers who had been left in hospital (Anderson *et al*, 1993; Dayson, 1993). At least 6 of the 278 in Dayson's cohort became vagrants within a year of discharge and there remains concern that mental illness results in homelessness and neglect of older people as well as younger people, although only 14% of elderly homeless were deemed mentally ill by Crane (1990) compared with 26% of younger homeless people.

New-generation graduates

Although the TAPS project and other studies documented the outcomes for elderly graduates discharged from the closing mental hospitals, there has been much less systematic investigation of the newer generations of graduates accumulating in

contemporary community psychiatric services. If discharged from hospital into supported accommodation, these patients' after-care may have remained the responsibility of the agencies and professionals involved in their initial care or discharge, but it often falls to others. Some placements are geographically distant from the patient's place of origin or from the mental health service that has cared for them for decades. Serial reorganisations of the NHS and redrawing of local authority boundaries has added to the weakening of links, and individual professionals, who may have maintained personal interest and relationships, move on by promotion, relocation and retirement. Patients with chronic mental illness no longer in hospital become the responsibility of a general practitioner, supported by a primary care team and a community mental health team. Funded placements are likely to be monitored by the social service department responsible for the initial placement, but coordination with the local community mental health team may be poor. Specialist teams are less likely to remain involved with patients who are provided for in residential or nursing homes and pose little or no problems over a number of years. Rehabilitation services usually view their involvement as relatively short-term and successful placement within the community may be seen as an end-point, after which others with longer-term responsibilities to the individual and catchment area take over. Neither general psychiatry nor rehabilitation has expected to take on substantial numbers of older people since the strong development of specialised old age psychiatry services (Wattis *et al*, 1999). However, old age psychiatry services have not traditionally taken on patients with enduring illnesses, well established as users of general psychiatry and rehabilitation services. Certainly, pioneer old age services saw people with dementia as their first responsibility and progressively widened their vision to include other disorders arising during late life. This latter category quickly came to include patients suffering relapse of (usually mood) disorders in old age after a period of stability. The issue of responsibility for graduates has become pressing, with all three psychiatric specialties having relevant skills and expertise, but major commitments elsewhere and inadequate staff and other resources to meet the demands made of them (Box 1).

The elderly graduates of the past were defined by their long stay in particular accommodation (a mental hospital) and by their clinical and social characteristics. Subsequent generations have similar clinical characteristics: unresolved positive and negative symptoms of psychosis, relapsing or enduring disorders of mood, disabling cognitive loss

and coarsened, disinhibited personalities. They are prone to physical ill health and may be stigmatised by the side-effects of long-term treatment with anti-psychotic medication. Socially, too, they may be just as disabled and destitute of personal contacts and supports, as were previous generations of graduates (Abdul-Hamid *et al*, 1999; Holloway *et al*, 1999). There are striking similarities in the socioclinical profiles of graduates drawn by Campbell & Ananth (2002) and of mentally ill homeless people described by Timms & Balazs (1997).

An added hazard for the new generation of graduates is the lack of a champion. As long as they remain peaceful, causing no trouble to others, even if they themselves are suffering, no one takes notice.

If they become physically ill, their mental disorder may make recognition of their illness and its treatment problematic.

If their mental state decompensates in response to physical illness, change in social circumstances, change of medication or simply spontaneous change with time or in association with age-related cerebral disease, crises may occur that the services are ill-equipped to handle.

What is required is a system of care, treatment and support that promotes and maintains best function and adjustment, rather than responds reluctantly to crises.

Box 1 The curse of general psychiatry

These are the words of a consultant psychiatrist:

'It's an interesting time to be a general psychiatrist – interesting perhaps on the lines of that ancient curse: "May you live in interesting times". Public expectation, a real rise in the prevalence of some non-psychotic disorders, changing referral patterns and technological advances mean that we are busier than ever before. Politically driven initiatives which lack clinical merit and a thriving blame culture have led to cynicism, exhaustion and defensive clinical practice in all of us at some time, and some of us almost all the time. When burdened, the natural desire is to shed some of the load. There can be a sense of relief when a patient crosses the threshold criterion for transfer to another service. We must, however, try to see matters through the eyes of the patient and their carers and keep them at the centre of all we do. Sixty-five is a good time to step back, reconsider and decide what will best meet their needs for the future.'

Responsive and responsible services

Since 2000, the specialties of general psychiatry, rehabilitation psychiatry and old age psychiatry have been working together to identify best practice at this interface and to begin the process of establishing acceptable standards to be applied nationally (Jolley & Measey, 2001).

Guidelines need to be flexible, as different places are at differing stages of development in the specialisation and organisation of mental health services. What suits and works well in one locality may be entirely alien or impracticable in another. Some areas accommodate many patients: some originating within the locality, others placed there from elsewhere many years ago. Other areas have few at present, but may see greater numbers in the future as a consequence of new policies.

Services where old age psychiatry is strong will have agreed that most older patients will transfer to their care on or soon after their 65th birthday. Where old age psychiatry is weak and general psychiatry or rehabilitation psychiatry remains strong, one of the latter will naturally continue to support their older long-term patients unless or until additional frailty or dementia produce radically different needs.

On occasion, the availability of facilities is less important than the interests of influential key professionals, who may be determined to include, or exclude, particular individuals or a category of patients from their orbit of responsibility. Matters are not easy where there is general lack of resources. No guidance paper from the 1960s onwards has specified investment or development for graduate long-term patients. They have been wished away in the minds of planners, convinced of the efficacy and power of new treatments and new systems of care. It is likely, however, that the absolute number of people taking these characteristics into late life has risen over the past 50 years, as those with mental illness share in the population's improved life expectancy.

Elderly graduates are not a high priority for general psychiatry services that feel beset on every front with demands to take responsibility for more and more risky styles of service, wider definition of patients to be treated, less and less control, less and less recruitment, and more and more litigation. Acute in-patient wards may be particularly unsuitable for the care of frail older people.

It is necessary to face facts and to provide modern services that are sensitive, responsive to the real needs of current populations and properly resourced to establish systems that will ensure the future remodelling of services in anticipation of predictable needs.

There are two main groups of patients to consider. First, there are the patients who have fallen out of touch with specialist mental health services, but have a history of chronic or relapsing illness and have had extensive involvement with specialist services in the past. They might be quite well and have no need for further help, or they might be suffering from treatable symptoms or have resolvable social or physical health problems passively ignored if they are not posing obvious problems in the quietude of a hostel or residential home. They might continue to receive antipsychotic medication without specialist medical review and be experiencing side-effects that could be avoided by modern medication. Old age services may have protocols agreeing to take responsibility for such patients if they re-present to secondary mental health services after an arbitrary interval (typically, 2 years).

Second, there are the patients who are under the care of specialist mental health services, where there is conflict or uncertainty about their best care. These people too might be at risk of passive management that accepts symptoms, side-effects and physical or social disadvantage as inevitable and to be tolerated as long as the patients do not cause trouble. The discontinuity associated with passage from care within the mental health services of health and/or social services has been compounded since the sponsorship of better and more expensive care packages for patients in the community promoted by the NSF for Mental Health. Brutal transfer from one service to another can terminate relationships with much loved carers who provided a generously sponsored programme of support and rehabilitation and replace them with unknown, changing faces working within a threadbare system shared with large numbers of much older, physically frailer patients. The system providing health and social care for older people may not give weight to the needs of graduates, for they are so different in kind from those of its mainstream clients, who are likely to be further advantaged, in the competition for resources, by having family members prepared to act as advocates.

In a Council Report encouraging good practice in the care of graduates (the product of 3 years' collaborative discussions by the Faculties of Old Age Psychiatry, General Psychiatry and the Section of Rehabilitation and Social Psychiatry), the Royal College of Psychiatrists asked agencies responsible for commissioning and providing mental health services to take action to identify both groups of graduates within their populations (Royal College of Psychiatrists, 2002). The Report recommended that every individual be fully reviewed so that their physical, mental and social needs could be understood and optimally met. Thereafter, it recommended

that their needs remain under review within a care programme approach framework.

Authorities will need to address the issue of transfer of responsibilities for patients between specialties as they enter old age. This must be done taking into account particulars of local resources and dynamics and the wishes expressed by both carers and patients. Figure 1 offers one example of a transition protocol that can be used to ensure that each individual's needs are considered systematically by all relevant parties. It confirms that this is an iterative process rather than a once-for-all-time decision conference. No change of supervision or care and treatment should be to the disadvantage of the patient.

If this approach can be effected nationally, it should become possible to quantify the graduate phenomenon and to identify different patterns of care. Within these, some may emerge as preferable in particular circumstances and some measure of cost-effectiveness will become apparent.

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Multiple choice questions

- As regards the diagnostic and symptom profiles of elderly graduates:**
 - they do not include dementia
 - more than half show a diagnosis of schizophrenia
 - they show less thought disorder than those of people with late-onset schizophrenia
 - they show more evidence of cerebral atrophy than those of other older people
 - they show a lower prevalence of hallucinations than when the patient was first admitted to psychiatric care.
- As regards social characteristics of elderly graduates:**
 - numbers within different localities are consistently similar
 - patients remain the responsibility of the health commissioners of their place of origin
 - currently homeless people with mental health problems have features in common with elderly graduates
 - elderly graduates have poor personal and social skills
 - elderly graduates have close ties with their families.
- As regards the physical health of elderly graduates:**
 - life expectancy for graduates is no different from that for other older people
 - dental hygiene is a particular problem

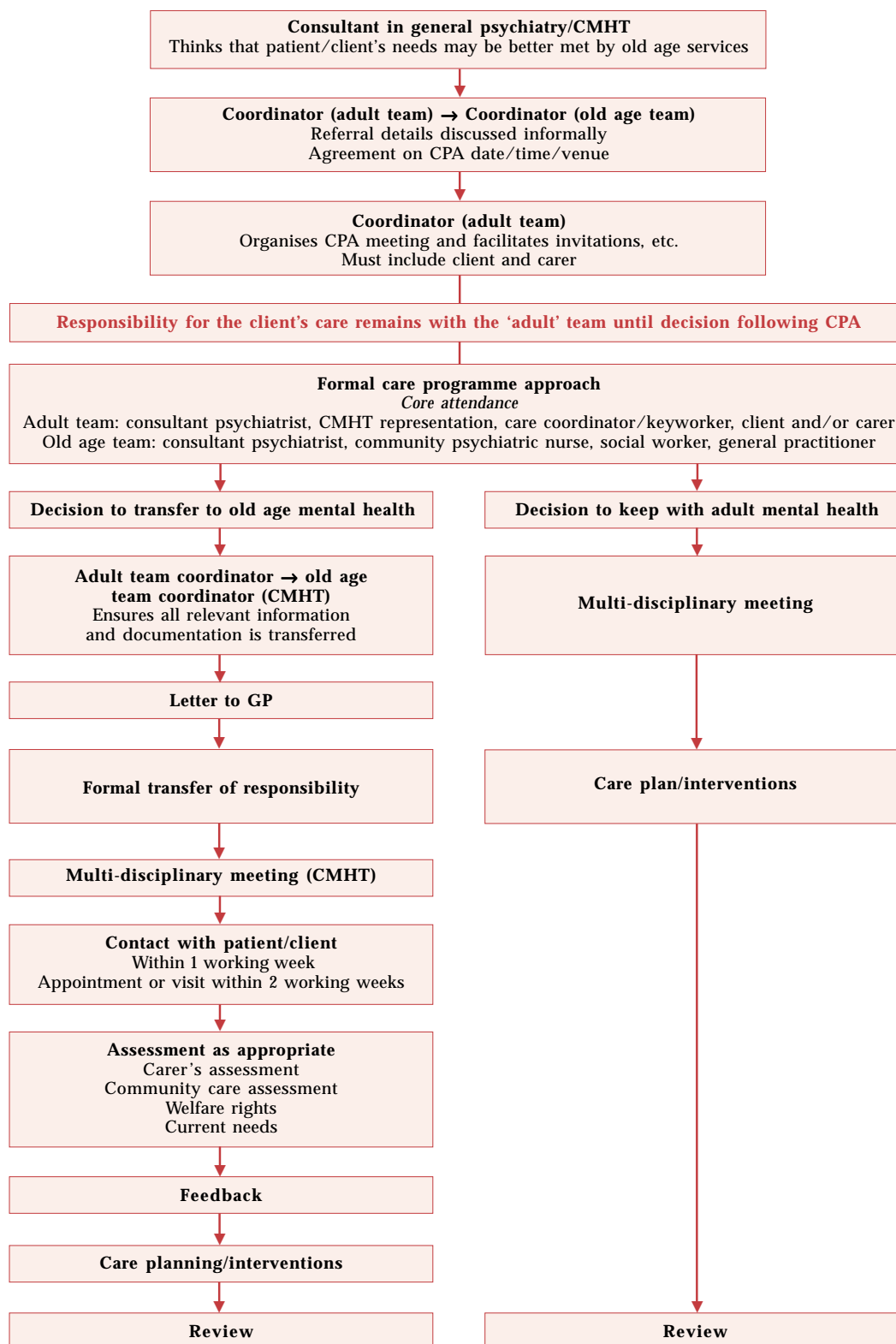


Fig. 1 Protocol showing the transition of patients already known to psychiatric services from general psychiatry to old age psychiatry. Adult, general adult psychiatry; CMHT, community mental health team; CPA, care programme approach; GP, general practitioner. (Developed by D. Jolley and colleagues, Wolverhampton, 2001.)

- c foot care is a particular problem
- d most deaths are related to violence or suicide
- e presentation of symptoms and management of physical illness may be difficult because of their mental disorder.

4 Outcomes of discharge from hospital:

- a discharged patients can name more friends and social contacts than similar patients who remain in hospital
- b 40% of graduates become homeless after discharge
- c discharged patients have a higher death rate than similar people remaining in hospital
- d the TAPS project found that 50% returned to hospital within 3 years
- e the most likely placement is within a private dwelling.

5 Guidance:

- a the needs of elderly graduates have been addressed consistently by guidance papers issued along with the closure programme for mental hospitals
- b elderly graduates are specifically excluded from consideration by the NSF for Mental Health

- c elderly graduates are specifically excluded from consideration within the NSF for Older People
- d the Royal College of Psychiatrists advises that all health and social care communities undertake a systematic review of numbers and needs of elderly graduates
- e the College advises that all elderly graduates should become the responsibility of old age services.

MCQ answers

1	2	3	4	5
a F	a F	a F	a T	a F
b T	b F	b T	b F	b F
c F	c T	c T	c F	c F
d T	d T	d F	d T	d T
e F	e F	e T	e F	e F

INVITED COMMENTARY ON Older people with long-standing mental illness: the graduates

The article by David Jolley and his colleagues (Jolley *et al*, 2004, this issue) raises a number of issues about older people who have enduring mental illnesses. The following contribution aspires to be a complementary article and attempts to expand on some areas that may be of relevance. These concern the disabilities that ‘graduates’ have (including cognitive deficits), comorbidity, prognosis and management, ending with a note on future research directions.

Social disabilities

Elderly patients with schizophrenia in long-term institutional care are known to suffer from a number of social disabilities. Wing & Furlong (1986) identified five factors that contributed to these disabilities:

- risk of harm to self and others
- unpredictability of behaviour and liability to relapse

- poor motivation and reduced capacity for self-management or performance of social roles
- lack of insight
- low public acceptability.

Different studies have shown social functioning in schizophrenia to both improve and deteriorate over time (Ciompi, 1980; Huber *et al*, 1980; Harding *et al*, 1987). Some aspects of daily living such as coping skills and socialisation with family members tend to improve with age (Cohen, 1993; Cook *et al*, 1994), but most elderly patients with schizophrenia continue to have disabilities in the higher domains of functioning such as finance, transportation, shopping and grooming (Klaplow *et al*, 1997). These all make community rehabilitation a challenge.

Cognitive impairment

Cognitive deficits are well known to be associated with schizophrenia (Cassens *et al*, 1990; Goldberg