

## ARTICLE

# Recovery and person-centred care in dementia: common purpose, common practice?

Laura Hill, Glenn Roberts, Joanna Wildgoose, Rachel Perkins & Susan Hahn

**Laura Hill** is a specialist registrar in general adult and old age psychiatry at the Peninsula Deanery in Devon, UK. **Glenn Roberts** is a consultant in rehabilitation and recovery in Devon. **Joanna Wildgoose** is a consultant in old age psychiatry in Devon. **Rachel Perkins** is Director of Quality Assurance and User/Carer Experience at South West London & St George's Mental Health NHS Trust, UK. **Susan Hahn** is Mental Health Recovery Lead at the Centre for Recovery in Hertfordshire, UK. **Correspondence** Dr Glenn Roberts, Wonford House Hospital, Dryden Road, Exeter EX2 5AF, UK. Email: glenn.roberts@devonptrns.nhs.uk

## SUMMARY

With the launch of the Fair Deal for Mental Health campaign in 2008 the Royal College of Psychiatrists made a commitment to ensuring that 'training for psychiatrists promotes the recovery approach'. National guidance emphasises the universal applicability of the recovery values for anyone of any age who has a significant mental health problem. Yet there has been little thinking as to whether the recovery approach is applicable to old age psychiatry and particularly to dementia care. This article explores the striking similarities between a recovery-oriented approach and person-centred care, the particular challenge posed in dementia care and the benefits of a collaborative approach in pursuit of common purposes.

## DECLARATION OF INTEREST

None.

## Current opinion

'Recovery' is not a word often associated with dementia and although a Google search on 17 April 2008 for 'recovery and dementia' yielded almost half a million URLs, they were overwhelmingly associated with either rare but treatable brain disorders constituting the differential diagnosis of Alzheimer's, or offers of unlicensed remedies of dubious provenance offering cure.

To get a snapshot of current opinion, clinicians attending an old age psychiatry conference in south-west England were asked to participate in a '5-minute survey of their views on recovery' (Box 1). This shows some evidence among old age psychiatrists in support of the relevance of a recovery approach but also doubt and concern. This is consistent with an editorial in this journal (Roberts 2007), which re-emphasised the Royal College of Psychiatrists' support for the national guidance paper on recovery (Care Services Improvement Partnership 2007) but acknowledged both enthusiasts and detractors.

The Social Care Institute for Excellence (2006) has offered more unequivocal support for a recovery orientation in their guidance *Assessing the Mental Health Needs of Older People* (Box 2). This principled proposal contrasts with the serious concerns raised by a multidisciplinary focus group convened by two of us (L. H. and J. W.) to explore the attitudes to recovery of practitioners in old age psychiatry in south-west England (Box 3). This had resonance with the experience of the Alzheimer's Society (2004), which was inundated with calls from angry and shocked carers following the broadcast of the documentary 'Fighting for Care' (BBC *Panorama* 2004), in which the health minister Stephen Ladyman stated that people with Alzheimer's disease can 'get better' and 'experience a period of recovery'.

However, there is broad acceptance and application within old age psychiatry of the principles of person-centred care and there are striking similarities with a recovery approach (Table 1). Both approaches are fundamentally about a set of values related to human living applied to

At first glance it may be thought that the current emphasis on promoting 'recovery' does not apply to older people's mental health and definitely has little relevance for those with dementia and other progressive organic illnesses. However, there are striking similarities between the values and aspirations pursued by recovery-oriented practitioners in adult mental health services, as previously examined in *Advances* (Roberts 2007), and the principles of person-centred care that guide dementia care pathways in the National Health Service (NHS) (National Collaborating Centre for Mental Health 2006; Department of Health 2008b).

The two approaches appear to be following a parallel journey towards the humanistic management of long-term conditions, which is applicable across the age spectrum. But are these tram-tracks that never meet or might there be benefits in looking for links and connections that would support collaboration and learning about progressive practice and service development? The purpose of this article is to examine whether a recovery approach is genuinely 'open to all', as this journal has previously explored (Roberts 2004), or whether there are essential limits of application that would exclude old age psychiatry from consideration.

**BOX 1 Views of clinicians in old age psychiatry on 'recovery'****Sample**

A 5-minute survey was included in the delegate information pack at a conference on old age psychiatry in south-west England in April 2008. Thirty-three clinicians (73% of delegates) from a multidisciplinary background completed the survey, 15 of whom were consultants in old age psychiatry.

**Views**

Only 2 out of the 15 consultants in old age psychiatry had not heard of the recovery approach, compared with one-third of staff grade and associate specialist doctors.

The majority of consultants thought that the recovery approach was either partly or wholly applicable to old age psychiatry.

There was a trend for non-consultant grade doctors to find recovery more problematic or to regard it as inapplicable.

**Positive comments**

'This is the approach we've been using for years.'

'To say recovery cannot apply to older people is paternalistic and ageist.'

'Knowing the individual and helping them achieve their maximum potential is just as relevant as in adult psychiatry.'

'We need to manage people's ability in dementia, not measure deficits. In that way we can shift dementia from an illness model.'

**Negative comments**

'It's trendy and we will get money if we use the word.'

'The phrase is badly used for old age psychiatry.'

'There is not much future left for older people. Therefore the scope for recovery is that much less for them.'

'Yes [recovery is relevant] in depression and functional illness, but not in dementia.'

the pursuit of health and wellness and both would strongly endorse the emerging emphasis across the whole of healthcare on 'personalisation' (for more on personalisation see [www.integratedcarenetwork.csip.org.uk/Personalisation](http://www.integratedcarenetwork.csip.org.uk/Personalisation)). Both are being widely adopted by health and social care services as a support for hope, purpose and direction for future services. Recovery and person-centred care appear to offer common ground and a common purpose for these otherwise divergent disciplines.

**Echoes and parallels between recovery and person-centred care****Origins**

According to Roberts & Wolfson (2006) the recovery philosophy as applied to mental healthcare can be traced back to William Tuke, a Quaker and lay

reformer who established The Retreat in York at the turn of the 18th century and demonstrated the benefits of a family-like healing environment based on kindness, respect and a personalised therapeutic approach. The more recent history of person-centred care has its origins in client-centred therapy, described by Rogers as 'the releasing of an already existing capacity in a potentially competent individual' (1951) and with an emphasis on genuineness, unconditional positive regard and empathic understanding. Kitwood (1997) built on this understanding when he used the term 'person-centred' in the context of dementia care, thus making a leap comparable to that made by Tuke by

**BOX 2 Assessing the mental health needs of older people**

'Even for conditions where there is as yet no cure, as with dementia, improvements in care and treatment are achievable and can make a significant difference to older people's quality of life.'

"Recovery" and wellbeing approaches to mental health issues developed by younger adult service users and working-age mental health services are equally applicable to older people. "Recovery" does not imply "cure", but builds on the personal strengths and resilience of an individual "to recover optimum quality of life and have satisfaction with life in disconnected circumstances" ... Recovery is about the development of coping skills, and about social inclusion, making it possible for people to have quality of life and a degree of independence and choice, even those with the most enduring and disabling conditions.'

(Social Care Institute for Excellence 2006: pp 19–20)

**BOX 3 Focus group to explore the attitudes to recovery of practitioners in old age psychiatry in south-west England**

The multidisciplinary focus group included an old age psychiatrist (J. W.), a rehabilitation psychiatrist (L. H.), community psychiatric nurses, an occupational therapist and a psychologist who all work with older people, and carer representation. All had shown an interest, with varying degrees of scepticism, in the recovery approach and its applicability to older people's mental health.

The group met twice to explore the relevance of 'recovery' in older people's mental health and particularly dementia. They contrasted the principles of person-centred care and recovery with reference to all stages of dementia, from early diagnosis to end-of-life care, and explored factors that help and hinder the application of these value-based practices.

The main themes to emerge were:

- Serious concerns about the term 'recovery' (including the possibility that it may build unrealistic expectations in carers, relatives and the client; that those caring for loved ones with more advanced dementia might recoil at the language; that attempting to promote the concept of recovery could be taken to negate or undermine the devastating consequences of the global deterioration seen in dementia)
- that dementia offers a particular challenge to the recovery approach in view of the progressive deterioration
- that the principles of recovery can be applied from early diagnosis through to end-of-life care
- that an individualised, flexible approach is essential.

**TABLE 1** Comparable principles in recovery-oriented practice and person-centred care

Recovery <sup>a</sup>	Person-centred care <sup>b</sup>
Recovery is fundamentally about a set of values related to human living applied to the pursuit of health and wellness	A value base that asserts the absolute value of all human lives regardless of age or cognitive ability
The helping relationship between clinicians and patients moves away from being expert–patient to clinicians being ‘coaches’ or ‘partners’ on an individual’s journey of discovery	The need to move beyond a focus on technical competence and to engage in authentic humanistic caring practices that embrace all forms of knowing and acting, to promote choice and partnership in care decision-making
Recovery is closely associated with social inclusion and being able to take on meaningful and satisfying roles in society	People with dementia need an enriched environment that both compensates for their impairment and fosters opportunities for personal growth
People do not recover in isolation. Family and other supporters are often crucial to recovery and should be included as partners wherever possible	Recognises that all human life, including that of people with dementia, is grounded in relationships
Recovery approaches give positive value to cultural, religious, sexual and other forms of diversity as resources and supports for well-being and identity	An individualised approach – valuing uniqueness. Accepting differences in culture, gender, temperament, lifestyle, outlook, beliefs, values, commitments, taste and interests

a. Sources: Care Services Improvement Partnership 2007; Shepherd 2008.

b. Sources: Kitwood 1997; McCormack 2004; Brooker 2007.

applying the values and principles of humanistic psychotherapy to dementia.

Both philosophies have gathered momentum over the past 10 years through the advocacy and writings of people who have used mental health services (Biernacki 2007; Care Services Improvement Partnership 2007). This increasingly includes people in prominent public positions ‘coming out’, for example Mike Shooter, a past President of the College, describing his experience of severe depression in the pages of this journal (Roberts 2004), and popular author Terry Pratchett, best known for his satirical *Discworld* novels, disclosing his diagnosis of Alzheimer’s disease in 2007.

### Identity

The process of sustaining or developing a sense of self separate from a diagnosis of mental illness and establishing a positive sense of personal identity is central to both recovery-oriented practice and person-centred care. There is a characteristic risk in severe illness and disabilities of all kinds that they eclipse an awareness of the person who has the problem and provide an alternative and defining identity.

Kitwood (1997) described being appalled by the misleading image of dementia as ‘death that leaves the body behind’ and the negative discourse used to describe people with dementia such as ‘victims’, ‘dements’ or ‘elderly mentally infirm’. He stated that the time has come to recognise men and women with dementia in their full humanity, describing the frame of reference as ‘PERSON-with-dementia’ rather than ‘person-with-DEMENTIA’. This is mirrored by changes in adult psychiatry with a shifting emphasis on schizophrenia.

There has also been a sustained effort to correct media representations that conflate people with the

diagnosis of their condition, specifically seeking to challenge dehumanising descriptions of people as ‘schizophrenics’, ‘manic depressives’, ‘PDs’ or worse.

National charities have also emphasised the importance of upholding an emphasis on the person rather than the disease as a means of reducing the stigma experienced by so many.<sup>†</sup> The Alzheimer’s Society was known as the Alzheimer’s Disease Society until 1999, when members voted to change the name. Similarly, the National Schizophrenia Fellowship changed its name to Rethink in 2002 following consultation that identified schizophrenia as a stigmatising diagnosis and a barrier to the charity offering hope and empowerment to people with severe mental illness.

Gaining or sustaining a secure sense of the identity of the people who become patients is potently supported by narrative approaches that are common to both recovery and person-centred care. Stories convey meaning, worries, hopes and ambitions and emphasise the importance of the individual journey of recovery, as this journal has previously investigated (Roberts 2000). They also form the foundation of reminiscence work (Kitwood 1997).

### Social inclusion

Donne’s famous observation (Box 4) concerning our essential interconnectedness arose following his recovery from a time of severe illness that he thought he would not survive and that was accompanied by a painful sense of separation from his fellow men. This finds rich resonance in contemporary concerns about social inclusion and about changes to end-of-life care (Department of Health 2008a) such as those pioneered by the hospice movement.

<sup>†</sup>An image from Scotland’s ‘see me’ campaign illustrated just this point on the front cover of the January 2010 issue of *Advances* (<http://apt.rcpsych.org/content/vol16/issue1/cover.dtl>). Ed.

**BOX 4 No man is an island**

'No man is an island, entire of itself; every man is a piece of the continent, a part of the main. If a clod be washed away by the sea, Europe is the less, as well as if promontory were, as well as if a manor of thy friend's or of thine own were. Any man's death diminishes me, because I am involved in mankind; and therefore never send to know for whom the bell tolls; it tolls for thee.'

(John Donne 1623: *Devotions Upon Emergent Occasions*, Meditation XVII)

Traditional approaches to illness and treatment are almost exclusively focused on individual variables such as symptom changes in response to drug or psychotherapeutic treatment, and virtually the whole of what is regarded as 'evidence' is individualistic. By contrast, both recovery (Care Services Improvement Partnership 2007) and person-centred care (Brooker 2007) re-emphasise contextual and relational issues. Kitwood identified the importance of maintaining 'personhood', defining it as 'a standing of status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood 1997: p. 8). He acknowledged the particular difficulties in dementia care, where declining mental powers challenge interconnectedness.

Involvement in local communities rather than segregated services is central to the recovery philosophy (Shepherd 2008) and meaningful occupation is seen as a major route to recovering an ordinary life (College of Occupational Therapists 2006; Perkins 2006). Sustaining realistic goals with shifting expectations is key in dementia care and although tasks may become more modest or mundane they can still minimise the boredom and lethargy that is experienced by many people with dementia (Sheard 2008).

Traditionally people with severe mental illness have been cared for through segregation, exclusion and isolation. There are striking links between the work of Kitwood (1997) and that of Goffman (1974), who looked at the social-psychological processes to which patients were subjected in mental hospitals. The modernising agenda has been to close the asylums, but by merely doing things *in* the community rather than *with* the community it has so far failed to deliver genuine community care.

Many alternative care settings based on the principles of person-centred care and recovery offer hope and potential for ordinary living in mainstream housing (Care Services Improvement

Partnership 2007) or suitable non-stigmatising but supportive accommodation. In Northern Ireland for example, person-centred approaches have driven the design of specific housing to give people with dementia the opportunity to continue living independently with assistive technology and community support to minimise and manage risk (Belfast Health and Social Care Trust 2002).

**Co-working**

Recovery approaches recontextualise professional helpers as mentors, coaches, supporters, advocates and ambassadors (Care Services Improvement Partnership 2007) with an operational stance of being 'on tap not on top' (Shepherd 2008). This shift towards co-working is mirrored in person-centred care, where clinicians attempt to understand the world from the perspective of the person with dementia and to respect that perspective (Brooker 2007), promoting choice and partnership in care decision-making (McCormack 2004).

The co-working role is equally applicable for informal carers, who almost universally struggle with their experiences and altered expectations. Killick (1999) underlined the risk that carers become overprotective because of the history of their relationship with the person. Yet frequently it is only the carers who understand the person and retain an awareness of their life and story. The College has emphasised the importance of this role through its campaign 'Partners in care' ([www.rcpsych.ac.uk/campaigns/partnersincare.aspx](http://www.rcpsych.ac.uk/campaigns/partnersincare.aspx)). Similarly, in her book *Dancing with Dementia* Christine Bryden (2005) writes about her personal experience of living with a diagnosis of dementia and adopts the term 'care partner'.

There is also increasing emphasis on the development of peer-supportive relationships between people with lived experience of mental health problems and services (Corrigan 2008). At their best these are based on a mutual understanding of the difficulties faced and a shared commitment to learn and grow (Copeland 2004). Recovery and person-centred approaches value these relationships and recognise the benefits of self-help groups such as the Hearing Voices Network ([www.hearing-voices.org](http://www.hearing-voices.org)) or those offered for people newly diagnosed with dementia (Harris 2005).

**Self-care and self-management**

Supporting people to look after themselves is a key component of the NHS Improvement Plan's vision for a patient-centred care system (Cayton 2007), which was introduced following recognition that self-management can reduce severity of symptoms and improve life control and satisfaction.

<sup>†</sup>Advance statements in adult mental health will be discussed in *Advances* later this year by Jelena Jankovic Gavrilovic et al. Ed.

Recovery approaches place value on all aspects of self-management. The most widely accepted and utilised tool is the Wellness Recovery Action Plan (WRAP; Copeland 2005), a structured framework for coping with mental illness. There are parallels in person-centred care with the Mental Capacity Act 2005 (Department of Health 2005a) and provision for advance statements<sup>†</sup> that recognise that it is essential to understand the preferences of people with dementia so that decisions can be made on their behalf when they become incapable. The National Dementia Strategy (Department of Health 2008b) and Alzheimer's Society emphasise the importance of early diagnosis to allow people to plan for their future but this does not release the clinician from the obligation of responding to and trying to make sense of preferences expressed non-verbally, for example through behavioural disturbance, in later stages of the illness.

### The challenge of putting principles into practice

Understanding the principles of recovery and person-centred care in adult and old age mental health is a small step compared with the challenge for practitioners of applying these principles in practice, particularly at the further end of morbidity and disability.

#### Maintaining hope

The reality of both severe mental illness and progressive dementia are often such as to defeat hope. Holding hope in such circumstances may seem naive or mistaken and thus a challenge to clinicians trying to uphold recovery or person-centred values in older people's services.

Alzheimer's disease and other dementias are progressive disorders and, regardless of quality of care, people with the disease are likely to decline over time across all dimensions of living. The inevitability of this decline can make it difficult for staff to see their actions as therapeutic (Marshall 2001). The human tendency in circumstances where cure is unachievable is to ignore or deny the difficulties, exacerbating the individual's sense of alienation and distance from society. However, the universal observation of the placebo effect, even improving neurocognitive performance in dementia (Elkan 2008), continues to demonstrate the sensitivity of such long-term conditions to hope and belief.

Developing an awareness of recovery principles enables clinicians to be more in tune with the experiential reality of living with dementia. They can become more intimately connected with the person and the changing realities of their existence,

leading to genuinely person-centred care. They can also get alongside carers, understanding their feelings of sadness and despair, prompting more rewarding conversations. The paradox of recovery and person-centred care is to value the enhanced sense of intimacy that such personal approaches permit so as to remain in touch with the losses and face the full tragedy of the illness but also to find hope and sustenance in the quality of the interaction and connection.

#### Risk, choice and responsibility

Recovery and person-centred approaches emphasise the importance of empowerment and handing back control and authority to the individual. The College's guidance emphasises that 'risk management must recognise and promote the patient's strengths and should support recovery' (Royal College of Psychiatrists 2008a). This is increasingly compatible with Deegan's requests that professionals 'embrace the concept of the dignity of risk and the right to failure if they are to be supportive' (Deegan 1996). Yet general adult and old age psychiatrists often find themselves in a position where they have a responsibility to deny people freedom of choice by imposing compulsory care and treatment in the service of safety.

There have been differing perspectives on this from people who use mental health services and their advocates. Some assert that there can be no recovery as long as people are detained against their will and subject to force, others that there should be no 'recovery-free zones' in mental health services. Roberts *et al* (2008), exploring this dilemma in *Advances*, developed a view that compulsory care and treatment, when needed, are compatible with a recovery-oriented approach.

Person-centred approaches adopt a similar pragmatic stance. Acknowledgement of the 'Bournewood gap', where people with dementia have been detained *de facto* but without a legal framework to appeal (Department of Health 2005b), has been an important step. In institutional settings where freedom and personal choice can be heavily constrained, small choices may produce a disproportionately large contribution to well-being (Roberts 2008) and there is evidence that people can make reliable decisions about long-held preferences well into their dementia (Brooker 2007).

Paradoxically, in circumstances of incapacity (Church 2007) a high degree of restriction may be more supportive of recovery and personhood than leaving people to 'rot with their rights on' (Davidson 2006). Leave restrictions and detention provide boundaries to support safety planning and choice in keeping with premorbid preferences.

Technological advances such as electronic tagging for people with dementia have provoked much debate but potentially offer increased freedom, independence and dignity, and reduce the worry of carers (Alzheimer's Society 2007).

### *Cultural shift*

Disconnected or isolated change will have little impact. Person-centred care, like recovery-based practice, requires a 'whole systems' approach (McMurdo 2007), delivered or facilitated by staff on the ground, through the clinical and managerial hierarchy to service planning, finance and administration at an organisational level (Baker 2003b). Few would argue against recovery and person-centred philosophies in principle but changing years of ingrained practice poses a challenge to policy advisors, managers and clinicians. In addition, organisational, environmental or societal obstacles can leave staff or carers feeling helpless (Baker 2003b).

Some people who have used mental health services who would define themselves as survivors of psychiatry or activists have expressed concern over ownership of the recovery approach. They resist invitations to engage in collaboration and co-working, preferring instead to talk of colonisation of their recovery by professionals (Mind 2008). In its Fair Deal for Mental Health campaign (Box 5) the College has called for 'recovery to become a better understood and accepted approach across all mental health specialties' (Royal College of Psychiatrists 2008b: p. 27). Yet if this is really to happen, it will need to be developed in partnership with the people who use mental health services. It is perhaps encouraging that the renewed 'service user' group in the College is called the 'Service User Recovery Forum' (SURF), and the aspiration of the Future Vision Coalition (2008) includes asking for the 'full adoption of the "recovery approach" across the full spectrum of care'.

Some of the misunderstanding over use or adoption of the word 'recovery' has parallels in person-centred care, where the word 'care' suggests paternalism, which can result in confusion for staff regarding their role (Sheard 2008). Neither recovery nor person-centred care should be thought of as a new thing 'to do' to others; they emphasise instead how 'to be' person-centred or recovery-oriented.

Superficial or tokenistic engagement is a common pitfall in recovery and person-centred working. There is justifiable anger and critique from service users and staff alike if the transformation is no deeper than changing the name of the service and printing new stationery. Claiming that computerised pre-prepared care plans are

### **BOX 5 The Fair Deal campaign**

The eight priority areas of the Royal College of Psychiatrists' Fair Deal for Mental health campaign are:

- Funding
- Access to services
- In-patient services
- Recovery and rehabilitation
- Discrimination and stigma
- Engagement with service users and carers
- Availability of psychological therapies
- Linking physical and mental health

(Royal College of Psychiatrists 2008b)

individualised through the addition of the person's name at the top of the form is contemptible and colludes with depersonalisation while appearing not to (Baker 2003a). Genuinely to pursue the values, practices, principles and standards of both recovery and person-centred care is a challenge for all involved and one met all the better for doing so in partnership with the people who use mental health services and their families.

### **Implications for service development**

Given their comparable nature it is not surprising that both recovery and person-centred care are guiding the developing framework for commissioning mental health services in their respective fields.

Recovery has become the key organising principle underlying mental health services in New Zealand (Mental Health Commission 1998), the USA (Department of Health and Human Service 2003), Australia (Australian Health Ministers 2003), Ireland (Mental Health Commission 2005) and Scotland (Scottish Executive 2006). Several leading mental health trusts in England have begun to incorporate recovery ideas into their principles of operation (Shepherd 2008) and many of the core mental health professions have made commitments to recovery values and approaches (British Psychological Society Division of Clinical Psychology 2000; College of Occupational Therapists 2006; Royal College of Psychiatrists 2008b).

Older people's mental health services have been built on a foundation of person-centred care. It forms Standard 2 of the National Service Framework for Older People (Department of Health 2001), underpins dementia care mapping (Bradford Dementia Group 2005; see below) and is highlighted as the principal foundation of care

in the National Institute for Health and Clinical Excellence (NICE) dementia guidelines (National Collaborating Centre for Mental Health 2006). It is also the guiding purpose for an increasing number of structured and therapeutic activity-based interventions (Brooker 2007). Pockets of inspirational practice exist (Sheard 2008) and many services have used dementia care mapping to identify behaviour that undermines personhood and to reinforce person-centred interactions.

### *Innovations*

Person-centred approaches challenge the historical practice of treating behavioural and psychological symptoms of dementia with antipsychotics. An independent report commissioned by the Department of Health concludes that 'the use of these drugs in those with dementia has substantial clinical risk attached, including a conservative estimate of 1,800 extra deaths and 820 extra serious adverse events such as stroke per year' (Banerjee 2009: p. 58). Alternative psychological approaches driven by person-centred care principles are increasingly recognised. An innovative example is that of Penny Garner's experience of caring for

her own mother, which led to the development of a specific interpersonal approach. This not only supports and promotes well-being but may enable less use of medication the role of which is to suppress the distressing confusion, fear and anger often accompanying progressive dementia. Garner's Specialised Early Care for Alzheimer's (SPECAL) ([www.specal.co.uk](http://www.specal.co.uk); James 2008a) focuses on carefully shaped personal interactions that assume the individual is making sense of present experiences through past memories. Her approach is based on three guiding principles that aim to de-escalate the fear and to offer instead a platform for a more contented experience of life and well-being, even in the context of advancing dementia (Box 6).

This lends itself to what initially appear to be collusive and unethical interactions, but James (2008a) argues the opposite by asserting that experiential well-being, even if based on the contentment of past roles or experiences, is of higher value than endlessly irreconcilable disputes over present truth. The SPECAL approach takes this further by also seeking to see through apparently 'mad' or 'delusional' assertions. It helps people make sense of their bewilderment by matching current cues to past experiences rather than insisting on the ungraspable present.

This has achieved publicity and popular recognition because again it portrays the preservation of valued human contact as a support of humane care and treatment. It also holds hope for both carers and people who have the disease, who speak of the dual benefits of feeling empowered by knowing how to interact more successfully and relieved at the consequent benefits to the well-being and contentment of their relatives (James 2008b).

Creative and artistic expression in all its forms is virtually absent from evidence-based guidelines for all disorders. Stories from people in recovery are full of creative, expressive and artistic endeavours (Leibrich 1999), from poetry, painting and music to gardening, craft activities, home-making and care of pets and other animals – a moment's self-reflection underlines for all of us what it is that constitutes our quality of life and supports our hope in living. There is little emphasis on any of this in standard texts on severe mental illness in any age group but both are substantially emphasised in recovery and person-centred approaches, leading to significant improvements in quality of life (Box 7).

End-of-life care also improves with input from person-centred care and recovery. The end of life care strategy (Department of Health 2008a) promotes a change of practice and culture that seeks to sustain a person-centred approach until death. It recognises that it is at death we part, yet

### **BOX 6 SPECAL's 'three commandments' and their application in practice**

- 1 Do not ask a person with dementia questions
- 2 Never contradict what they say, as this will clash with what they see as reality
- 3 Learn to love their tendency to repeat themselves.

#### **Application**

The following extracts appear in an article on SPECAL by the psychologist Oliver James.

'Caroline Spruce, 45, a teaching assistant, is another offspring who has found Specal much better than drugs. Caroline was perplexed last Christmas when she visited her mother at her care home. Thelma Lee, 77, who has vascular dementia, had recently been put on anti-psychotics to make her less agitated, but was having severe side effects. Fortunately, the staff were willing to stop the drugs and accept Caroline's Specal-based alternative.

She asked them to record the anxious questions her mother most frequently asked. These were "Where's my daughter?", "Can I go home?" and "Where's my son?" Caroline prepared a list of answers to be used by the staff every time they were asked.

Her daughter "has gone to pick up the kids from school" and "yes, you can go home, we'll phone your daughter to sort it out". The whereabouts of her son was presented as "he's gone to work". This latter is interesting, since he has recently died of cancer.'

...

'In Thelma's case, it would be hugely destructive to her to demand that she confront the death of her son, especially since she would have no memory of you having her told her about it but could be left with a huge sense of distress that something awful has happened. Likewise, if she believes herself to be only staying at a hotel for a few days, rather than living in a nursing home, what is ethical about imposing your reality on her?

This is no clever-dick philosophising. As Caroline puts it, "Specal has been utterly empowering for me personally. But above all, it has enabled my mother to be reasonably contented."

(James 2008b. Copyright Guardian News & Media Ltd 2008)

pessimism, isolation, alienation and detachment which can result from severe illness in older people can create a premature separation and extinction of hope and connection. Indeed, we are more familiar with the idea that death occurs as a failure of treatment. This is supported by Riley's (2008) observation that 'medical professionals like to think that they give patients control but this impression is countered by evidence that patients do not die where they would prefer to'. The majority of people say they would like to die at home but at present nearly 60% of the 500 000 people who die in England each year do so in hospital (Department of Health 2008a). Riley proposes a cultural shift towards seeing dying as part of living and supports the person-centred approach within the new strategy that promotes choice, improved openness, communication and information to enable advanced directives to be constructed and a care pathway response that includes death rather than one that stops just short of it.

The gradual inclusion of person-centred care and recovery principles in policy design, service provision and informal care is encouraging. Various organisations are also embracing the principles (Social Care Institute for Excellence 2006; Age Concern 2007) and pilots in several trusts (Devon Partnership Trust, South West London and St George's) are exploring the applicability of recovery-oriented approaches to older people's mental health (Box 8).

### *Outcome measurement*

There is a broad shift across the whole of medicine towards an interest in outcomes rather than activity. Patients, carers and commissioners all share an interest in health and well-being rather than treatment and care. Traditionally, measures for all age groups have focused on documenting disability and measuring shifts in symptoms and service usage over time.

More useful and enlightened measures that are sensitive to people's experience of both their health problems and mental health services have grown out of recovery and person-centred care. Dementia care mapping is a well-recognised method for evaluating care through formal observation and was described by Kitwood (1997) as a serious attempt to take the standpoint of the person with dementia. The Commission for Social Care Inspection (2008) has worked with the University of Bradford to understand dementia care mapping and create the Short Observational Framework for Inspection for use in care homes. This is a tool for capturing the experience of care of people who would otherwise be unable to communicate this to an inspector. The Short Observational

### **BOX 7 Creativity and dementia**

During 2001 the community nursing team at Ysbyty'r Tri Chwm, a mental health unit based in Ebbw Vale in Wales, identified the need for recreational activities for older people with mental health problems. A project was established to explore how creative arts could enhance their lives. The project aimed to maintain a healthy living ethos, provide stimulation, assist cognitive ability, increase self-esteem and provide respite for carers.

The project has had positive outcomes. Dance classes, for example, increase social contact, self-esteem and a positive outlook, build confidence, improve concentration and enhance feelings of identity. There are also positive physical outcomes such as

improved strength, coordination and muscle tone. The project won a Queen's Nursing Institute award in 2003 for creativity and innovation.

The group subsequently extended its activity to include creative writing using reminiscence and local community visits to farms and parks. Photographs were taken during these visits and a collage was produced which was used to prompt discussion of the events and highlights of the day. The visual impact of the photographs supported active engagement and improved communication.

(Social Care Institute for Excellence 2006; Dementia Services Development Centre Wales 2010)

Framework for Inspection, like dementia care mapping, is based on person-centred approaches to care, evaluating the mood and engagement of people using services and staff communications that undermine or enhance a person's sense of well-being. In addition, there is a move towards promoting active participation of older people in service evaluation and development, with work

### **BOX 8 Elements of a recovery-based approach to older people's mental health: South West London and St George's NHS Trust**

South West London and St George's NHS Trust has been implementing the recovery model across their older people services with the aid of a multiprofessional steering group. In addition to training staff in the principles and practice of the recovery model, a number of other projects have been implemented:

- Focus groups have been run with older people who have rebuilt their lives following depression. Their recovery stories have been documented to help others in the future by fostering hope and encouragement
- The recovery stories have also helped in producing written recovery information, tailored to the experiences and needs of older people
- Further work is being implemented to encourage greater focus on the retention of skills during in-patient admissions and helping people to plan meaningful and valued activity on their discharge from hospital
- Training has been piloted to help staff in the use of life-story work with older people. Life stories have been used to help preserve self-identity, celebrate lifetime achievements and leave legacies for loved ones. The process helps to individualise care and foster good relationships between the person and care staff
- A post-diagnosis information booklet for people with dementia and their carers is being piloted across the Trust, focusing not only on the practical aspects of the disease process but also on the emotional impact and adjustment
- A booklet has been produced to document important information about a person's likes, dislikes and preferences in preparation for the need for future professional care. This is in essence an advanced directive for the way people wish to be cared for in the future. This booklet has received much positive feedback from people with dementia and their carers.

by the Care Services Improvement Partnership Older People's Mental Health Programme (2007) and the Partnerships for Older People Projects (Department of Health 2008c).

Recovery has a long-standing tradition of recognising the importance of user-led evaluation and input. The Developing Recovery Enhancing Environments Measures (DREEM; Dinniss 2007) is one of an emerging group of personal, practice and organisational measures that enable people who use mental health services to reflect on their own recovery and give feedback to the service.

A focus on quality of life rather than symptom resolution can highlight unexpected but important experiences. There is a non-linear relationship between memory loss and well-being, and subjective life satisfaction can improve with advancing dementia (Jetten 2010). Likewise, some people with long-standing systematised delusional beliefs find an enhanced sense of meaning and purpose in life (Roberts 1991).

## Conclusions

Until now the recovery approach and older people's mental health have occupied very different spheres but the proposition, exploration and findings of this article have led us to observe a curious process of convergent evolution.

It seems that the recovery-oriented adult psychiatrist and the person-centred old age psychiatrist have much in common. They are potential collaborators and co-contributors to a broad and humane movement towards a form of values-based practice that recognises, respects and responds to the integrity of the person regardless of the difficulties and disorders with which they are struggling. At the leading edge of practice and service development they uphold a broadening of emphasis from seeking to offer more effective treatment to fully recruiting the person and their social world in working for hope, life and living within the limits of their capacity. Both approaches emphasise a sustained awareness of the person in the context of their history, relationships and environment, and both resist the endemic tendency for people to become overidentified and eclipsed by their diagnoses.

These parallels are re-emphasised in the Fair Deal Manifesto (Royal College of Psychiatrists 2008b), which calls for 'a necessary shift of emphasis from being clinically and profession centred to being user or person centred' and in seeing the applicability of a recovery approach across all mental health specialties. Yet the term 'recovery' remains awkward and uncomfortable in the context of old age psychiatry, and the risks of

misunderstanding what is intended may make it unhelpful to attempt incorporation without further qualification. Preferred terms are far less important than the values they support and it may be useful for these parallel developments in adult mental health and old age psychiatry to retain an allegiance to recovery and person-centred care as descriptors of their ambitions for practice and service development. Or there may be further philosophical and conceptual developments that would find both approaches uniting in an emphasis on 'repersonalising' or 'recovery of the person' that bridges age and diagnostic considerations. Regardless of the need for clarification and exploration of definition and meaning, there seems a secure basis for observing that core aims, values and objectives are held in common and for the stimulating possibility of learning together and borrowing from one another's ideas and discoveries in pursuit of a common purpose.

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## MCQ answers

1 d 2 e 3 a 4 b 5 c

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## MCQs

Select the single best option for each question stem

### 1 The recovery approach is:

- a not applicable to older people
- b only applicable in functional disorders of old age
- c applicable only in the early stages of dementia
- d similar to person-centred care
- e an acceptable term to carers of people with dementia.

### 2 The recovery-oriented and person-centred practitioner both value:

- a the person becoming independent and managing without support
- b getting back to normal
- c being cured

- d a clearly defined diagnosis
- e an individualised approach.

### 3 Retaining hope is:

- a a challenge in dementia care
- b impossible during the late stages of dementia care and end-of-life care
- c a realistic goal only if medication can lead to illness remission
- d naïve and mistaken in dementia care
- e of no benefit in improving neurocognitive function in dementia.

### 4 Embedding recovery and person-centred values in dementia care:

- a is the sole responsibility of clinicians who work in older people's services

- b requires a 'whole culture' approach
- c is the primary responsibility of the hospital managers
- d is simply about individualising paperwork
- e does not require involvement of service users.

### 5 Specialised Care for Alzheimer's (SPECAL) involves:

- a asking the person with dementia questions to clarify what they are thinking
- b contradicting any beliefs they have that clash with reality
- c learning to love their tendency to repeat themselves
- d colluding with delusional beliefs
- e giving medication to reduce distress.