

# Out of the closet, into a difficult place in later life

Eve's story demonstrates the particular difficulties and ethical predicament faced by the LGBT community and professionals caring for transgender people with dementia. **Allison O'Kelly, Dr William Fullick and Dr Giles Richards** discuss the tricky issues involved.

**E**ve was a woman in her sixties who had bi-parietal Alzheimer's dementia, referred to the old age psychiatry team for help with managing progressively challenging behaviour in her residential care home.

She had initially been diagnosed with dementia in 2011 following increasing difficulties with memory, language, sequencing, social and behavioural changes and a degree of passivity. At that time she had been living at home with her partner, but unfortunately her condition had continued to progress and she had moved into a residential home in November 2012. Her partner obtained lasting power of attorney for Eve, who was relatively well from a physical health perspective, suffering only from hypertension, for which she was well controlled on an ACE-inhibitor.

But Eve did face other challenges, namely those confronting older people who are transgender and the wider lesbian, gay and bisexual (LGBT) community if they are affected by dementia. She had undergone a gender reassignment procedure in her 40s and subsequently took female sex hormone therapy long-term. She had stopped taking Donepezil, but was taking Mirtazapine, Zopiclone and PRN Diazepam as well as oestrogen and progesterone.

When she was referred to the psychiatry team Eve was unable to hold a coherent conversation, struggling significantly with language and not at all orientated to place, time or person. Staff also reported that she was starting to find difficulties with object recognition unless she was assisted. She was unable to recall any behavioural problems and did not feel low in mood, although she acknowledged that she felt sad sometimes. She certainly did not present as depressed, distressed or exhibiting any hallucinations.

On several occasions, however, she cheerfully referred to herself as a man. The staff at the residential home reported that Eve was displaying intermittent agitation and aggressive behaviour with no

apparent triggers, but also that she had started to display a degree of stress and confusion regarding her gender. She would refer to herself with male pronouns on a semi-regular basis, although without necessarily demonstrating any understanding as to what this might mean. She had also become physically and verbally upset with the fact that she was wearing female clothes on several occasions, and most recently had expressed curiosity and a degree of distress regarding her breast implants while she was being assisted with personal care by staff at the residential home.

These episodes had all been relatively short-lived – generally about thirty minutes in duration – after which she would seemingly return to her usual self. However, staff were worried that they could potentially become a significant stressor to Eve if they were to persist for longer periods of time. She was due to move to a nursing home in the near future as staff in her residential home did not feel that they could meet her needs.

When she did move she settled well in her new environment. It was reported that she had not apparently suffered from any further issues around her gender-identity and seemed generally happy. Unfortunately her cognition had remained poor and she was unable to understand any questioning about her distress, nor remember any times when she had become agitated or upset. She died suddenly two weeks later with an unrelated and new illness.

## At first referral

When Eve was first referred to memory assessment services in 2010 she was fiercely protective of her gender identity and, although she appreciated that some information would have to be shared with other professionals, she consented only to limited disclosure about her gender reassignment. In health care this can be problematic as holistic assessment and documentation are gold standard; however, the Gender Recognition Act 2004

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(GRA) is precise on what may or may not be shared. Unlawful disclosure applies not only to direct communication by word of mouth but also to uncontrolled access to paper or computer files. A transgender person may consent to you disclosing the information if they decide that it is in their interests for you to do so. However, such consent must be explicit and not assumed.

The GRA gives legal recognition to transgender people in their acquired gender. If an application to the Gender Recognition Panel is successful, the transgender person's gender becomes for all purposes the acquired gender and they will receive a full gender recognition certificate (GRC). The GRC allows for the creation of a modified birth certificate reflecting the holder's new gender. Eve had a new birth certificate and was legally female despite being born male.

Gender is not a uniquely binary construct of male or female, a point clearly demonstrated by the social networking site Facebook where a choice of 50 different identities of gender awaits new members. Terminology regarding gender identity is fluid with some terms being more in vogue than others. Transgender is acknowledged as a collective term referring to individuals whose birth sex is not harmonious with their gender identity. Gender identity is a subjective perception rather than being objectively apparent, Virginia Prince (2005) putting it succinctly by describing gender as happening between her ears and not between her legs.

Transsexuals tend to identify with the opposite sex; however, the term is not used so much as there is an association with sexuality rather than with masculinity or femininity. For individuals who have had sex reassignment surgery (SRS) they may be known as 'transmen' (female to male) and 'transwomen' (male to female) although within the transgender community there can be objection to the 'trans' prefix.

The earliest recognised recipient of male to female SRS was 'Dora-R' in 1921 when aged six he tried to castrate himself. Eventually, in 1930, he had his penis removed and six months later the grafting of an artificial vagina completed the conversion. But it was probably the very public transformation from male to female by author, singer and actress Christine Jorgensen in the 1950s that cemented the concept that an individual's gender identity may be that of the opposite sex and not what they were anatomically born with (Persson 2009).

At the time SRS was only available in Europe. It is now obtainable worldwide and since 1979 subject to the requirements set out in Standards of Care (World Professional Association for Transgender Health (WPATH) 2012). Treatment outcomes have improved over the years and the procedure is no longer perceived as controversial (Department of Health 2008). Criteria for hormone therapy and reassignment surgery include persistent, well documented gender dysphoria and the capacity to make an informed decision and consent to treatment. Before male to female surgery individuals would have had at least 12 months of reversible testosterone suppression therapy combined with 12 months of continuous living in the gender role complementary to their gender identity. Although not an explicit criterion, counselling or support by a mental health or medical professional is also recommended.

These safeguards are essential to ensure people fully understand the life changing physiological and psychological choices they are making. Interestingly, there is evidence that joining a support group with other transgender people can lead to individuals trying to speed up their own transition often without giving due consideration to the pros and cons of the process (Jokić-Begić *et al* 2014).

In this context there were several issues for Eve, not least the fact that she no longer had the capacity to consent to the continuation of her hormone therapy. Staff, in agreement with her partner using the lasting power of attorney, would have been acting in her best interests in dispensing and administering the

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## Eve had come out of the closet many years previously, but then dementia began to rob her of the reason why she was in there in the first place

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medication. This did present a dilemma, however, as she seemed actively on occasion to reject her previous gender choice, although for most of the time she was content.

The bigger question was, why was dementia having this effect? We can only speculate. It is well known that people with dementia will often revert to earlier states because of deterioration in their memory, so possibly Eve was periodically taken back to a time where she was male. This may have been a happier, safer and less complicated stage of her life. Eve had SRS later in life and would only have been anatomically female for roughly a third of her existence. She would have had rather longer to come to terms with her self-understanding and gender choice, but less time to adjust to the visual outcome or possible complications of her surgery. Another suggestion, although less likely, is that Eve's gender dysmorphia was misdiagnosed in the first place.

### Needs differ significantly

Although very little quantitative or qualitative research exists regarding the specific care needs of lesbian, gay, bi-sexual or transgender individuals living with or caring for someone with dementia, studies suggest both that their needs may differ significantly from those of heterosexual individuals in a similar situation, and that these needs are not always met by mental health or support services.

There are no concrete figures to tell us how many of the 850,000 people with dementia may be gay, lesbian, bisexual or transgendered, but applying an estimate of 5-7% of people in the general population (Mackenzie 2009) provides a figure of 42,500 to 59,500 LGBT individuals who have dementia, with that number only set to increase alongside figures for the general population.

Most LGBT people affected by dementia will have lived through a time when identifying as homosexual or transgender was not only socially frowned upon, but

actually illegal. The 1967 Sexual Offences Act made homosexuality legal for men over the age of 21 in England and Wales, but it was not until 1980 and 1982 that homosexuality was decriminalised in Scotland and Northern Ireland respectively. In 2000 the age of consent for homosexual activity was lowered to 16 to match the age of consent for heterosexual activity.

Modern attitudes towards people from the LGBT community have improved markedly, but, although it is illegal to discriminate against anyone based on their sexuality or gender identity, people do still experience this kind of discrimination. It may still be difficult for the partner of a LGBT person to obtain next of kin status, especially if there is no legally binding framework for the couple. In 2014 same sex marriage became legal yet LGBT individuals and couples are more likely to be isolated or estranged from their families and removed from "traditional" heteronormative support networks. They may therefore be reluctant to discuss their sexual orientation or gender identity for fear of the potential consequences. One survey indicated that only 35% of the LGBT individuals felt that health care professionals were likely to be positive towards gay or lesbian service users (Heaphy *et al* 2003).

Price (2010) attempted to identify what issues gay and lesbian carers had experienced, and how they had attempted to manage any problems arising from either disclosure or non-disclosure of their sexuality. The study divided participants into groups based on their method of disclosing their sexuality to services: active disclosure; passive disclosure, active non-disclosure and "outed by dementia". Being "outed by dementia" meant, for many of the respondents, that the mental state of their friend, partner or relative no longer provided any choice in the matter. The person with dementia would openly discuss sexuality in a way that made it impossible to conceal or avoid. This method of disclosure did not attract any positive comments during the study, with recipients quoted as saying that it made them feel under suspicion and scrutinised in such a way that would not apply to a heterosexual couple. One respondent was even subject to homophobic verbal abuse by a resident of the home in which his friend resided.

There appears to be almost no research into whether these problems are encountered by transgendered or intersex individuals or couples, but it seems likely that many will have had the same dilemmas over whether to discuss gender identity or sexuality with health care providers. The little research that does ➤

► exist suggests that attitudes seem to range from, at best, a well-meaning disregard for the potential differences and new hurdles, and, at worst, ignorance and overtly bigoted opinions that may actively discourage individuals from discussing sexuality and gender identity with their health care workers.

### Physical care needs

Transgendered individuals may also have other physical health care needs of which providers have no experience. This is an issue that is likely to become more prevalent and an avenue of research that should be taken into account when considering the social needs of dementia patients and their carers.

The health research that is available is mostly focused on younger people and homosexual men, and the dearth of knowledge regarding transgender people needs addressing. As a society we are looking at a typically 21st century dilemma, a newly visible and unique cohort of people who may have a higher risk of developing a dementia than the general population. The WPATH 2012 standards indicate that in male to female SRS there are risk factors associated with hormone therapy, including venous thromboembolic disease, weight gain, hypertriglyceridemia, cardiovascular disease, hypertension and type 2 diabetes. There may be other health risks such as an increased chance of breast or prostate cancer.

Social isolation and loneliness increase the risk of Alzheimer's disease and trans people have an above-average chance of being socially outcast and lonely. A couple of European studies have shown that post-SRS trans individuals are at a considerably higher risk of mortality, suicidal behaviour, and psychiatric morbidity than the general population (Asscheman *et al* 2011; Dhejne *et al* 2011). Although these studies were not particularly robust and may be difficult to generalise, they do suggest a need for high quality long-term psychological care as recommended by the WPATH standards and acceptable to the individual.

Since over time it is likely that more LGBTs will present with a form of dementia, the caring professions will need to be more aware of their differing needs and respectful of their choices. Being LGBT has taken four decades to evolve from a criminal act or mental illness to an accepted variation in emotional and social development. Evidence shows there is still residual prejudice and stigmatisation, one answer to which is staff training on the issues faced by the LGBT community. Encouraging LGBTs to partake in social and health research would help to ensure

they become epidemiologically visible and enable a better understanding of the challenges posed by ageing.

A recommendation for practice worthy of consideration would be improved pre-hormone therapy or SRS counselling to incorporate the possibility of developing dementia and loss of capacity. As observed by O'Kelly *et al* (2015) the use of advance care planning is another way to capture and document future gender and care choices. As this case study has shown, Eve had come out of the closet many years previously but then dementia began to rob her of the reason why she was in there in the first place. ■

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# Evaluating

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As well as promoting early diagnosis, the National Dementia Strategy in England (Department of Health 2009) emphasised support for people with dementia to live at home for as long as possible. As the disease progresses, people with dementia increasingly rely on family carers, but stress in the caring role is a major factor in people with dementia entering institutional care (Banerjee *et al* 2003).

Various interventions have been devised to support carers of people with dementia, including psycho-education, social and emotional support, practical advice, and training in communication and coping strategies. Although there appears to be a good case for supporting and training carers of people with dementia in this way, scientific evidence remains scarce (Thompson *et al* 2007).

One solution may be the 'SPECAL' person-centred approach to the care of people with dementia, which could have potential to reduce carer stress and lead to significant improvements in quality of life both for people with dementia and their carers. We have devised a research programme to find out, but first it is worth considering the background to SPECAL and the controversy around it.

### Background

Tom Kitwood was a major influence on the development of SPECAL, the person-centred approach to the care of people with dementia to be discussed here. When he qualified as a psychologist in the 1980s the literature on dementia was dominated by neuropathology, whereby cognition and behaviour are determined by the disease process. Against this discourse, Kitwood (1997) famously developed his philosophy of person-centred dementia care at University of Bradford.

He observed that people with dementia are profoundly affected by their environment and relationships with others. He described a process of "malignant social psychology", a set of negative attitudes and

# the SPECAL approach to care

**Niall McCrae** and colleagues consider the rationale for the SPECAL person-centred approach to the care of people with dementia, and outline plans for an evaluation

behaviours towards people with dementia, including disempowerment, infantilisation and banishment. Perceived as lacking rational judgement, the person with dementia is stripped of roles and responsibilities regardless of retained abilities. Kitwood asserted that people with dementia have a right to personhood, which he defined as a "status that is bestowed upon one human being, by others, in the context of relationship and social being".

This philosophy has, of course, profoundly influenced policy on dementia care, and it is now widely acknowledged that personal and social factors have much influence on the experience and course of dementia (Bellchambers & Penning 2007).

## Origins and purpose of SPECAL

SPECAL (originally an acronym for Specialised Early Care for Alzheimer's) is a model of dementia care developed by Penelope Garner. Inspired by caring for her mother, Garner joined the local Alzheimer's Disease Society as a volunteer and in 1990 became their representative in a new psychogeriatric facility at Burford Hospital, an 11-bedded cottage hospital in Oxfordshire. In 1992, while developing her approach with people with dementia at Burford, Garner met Kitwood, who helped her to formulate a model of care. When the NHS withdrew clinical services from Burford in 2000, the then secretary of state for health recommended that SPECAL should have NHS support. Unfortunately suitable relocation was not found in the NHS and the project remained in situ on a temporary basis.

In 2002, with the support of the Alzheimer's Society, SPECAL became an independent charity, and in the following year a local benefactor enabled it to secure the Burford site as a base for care, coaching of family carers and training of health and social care staff. The charity was renamed Contented Dementia Trust in 2012, with a mission of promoting lifelong well-being for people with dementia. As well as directly providing for people with dementia and their carers, the charity disseminates the SPECAL method nationally and internationally.

People with dementia are prone to agitation and distress when communication fails and their needs are frustrated.

## Two ways to find out

### Interaction A

Mary: Did you ring your sister today?

Tom: Ring my sister?

Mary: She left you a message yesterday.

Tom: Nobody told me.

Mary: I did tell you. She wanted to come round to see you today.

Tom: Well, she can come if she likes.

Mary: It's too late now.

Tom: Is that my fault again?

### Interaction B

Mary: I see your sister rang yesterday – she left a message.

Tom: Did she? What did she want?

Mary: I think she wanted to see you today, but don't worry – she can arrange another time.

Tom: I'd like to see her.

Mary: Yes I would too. Shall we call her now? She would like to hear from you.

However, Garner observed that much of the mind and self of people with dementia remains intact, potentially functioning as well as ever. The main problem, according to Garner, is the person's increasing failure to store new factual information, although feelings continue to be stored as before. The person's natural response is to make random, intermittent and increasingly frequent use of past memories to make sense of the present, thereby compensating for their disability.

The SPECAL Photograph Album (Garner 2008) uses an analogy to help carers understand how someone experiences dementia by explaining how normal memory works, how this changes with age, the dramatic change caused by dementia, and how the person with dementia responds to such adversity. Gaps increasingly appear in the later pages of the 'album', as recall of recent experiences is progressively impaired. If the person with dementia is confronted by memory loss, this may cause distress. This experience becomes a memory not of contextualised facts but of feelings, triggering memories of previous traumatic events.

Two alternative conversations provide a simple illustration, contrasting an instrumental approach with a more

engaging dialogue (see box, left). The wife (Mary) of a man with dementia (Tom) has returned from a day out, and wants to know if he has responded to a telephone message she had discussed with him on the previous evening.

In the first interaction Tom is reminded of his memory loss, and he is likely to feel that he has done something wrong. The negative experience of being asked questions or contradicted provokes an emotional response, instead of rational dialogue. If repeatedly confronted in this way, the person may develop persistently challenging behaviour. In the second interaction, Mary has anticipated that Tom has not responded to his sister, and deals with the situation in an engaging and supportive way, while nurturing the relationship.

The SPECAL approach is counter-intuitive in an instrumental world that prioritises fact over feeling. Meaning is more important than detail. By following SPECAL's 'three golden rules' the carer can ensure that the person is unlocked from confusion in the present, making it possible to find contentment in dementia:

- Do not ask direct questions – facts that the person needs may not have been stored.
- Learn from the expert – listen and discover what is important to the person with dementia.
- Do not contradict – validate feelings first, before considering the facts.

The SPECAL method elucidates themes from the person's life story, including a key positive theme. This source of empowerment is brought to the fore through idiosyncratic vocabulary and body language, using past experiences to contextualise the present and protect the person from an otherwise bewildering world. By avoiding direct questions or contradiction, listening carefully to the questions asked by the person with dementia and finding responses that are most acceptable, the carer can open fertile lines of communication, consultation and relaxed dialogue. As a positive disability model, the SPECAL method builds on individual strengths and resilience, enabling the development of an individualised care plan, which potentially sustains contentment for the person with dementia throughout their life. There are ►

► two provisos: everyone coming into contact with the person with dementia must follow the three golden rules and a document called the 'care profile' must be followed.

Creation of an individualised care profile begins with a period of assessment. SPECAL Observation Tracking (SPOT) is a personalised form of dementia care mapping (DCM), in which a small group of people with dementia is observed in five-minute time frames for periods of several hours using coding frames to record activities and well-being. In DCM, the evaluator must have no caring role.

SPOT has an individual rather than group focus and is designed as an ongoing carer tool to observe the person's behaviour, mood and expression. Observations are assessed in conjunction with SPECAL's Background Biographical Questionnaire, to produce a detailed life story and behaviour profile. Interventions are devised, implemented and refined, ultimately creating an individualised strategy of care, encapsulated in a SPECAL care profile. The care profile is simplified over time, and is summarised in a single sheet if the person's care is transferred to an institutional care setting.

### Limited evidence

To date there is limited scientific evidence for the SPECAL method. A preliminary, mostly descriptive study by Pritchard and Dewing (2001) found that people with dementia were able to stay at home for longer, with less use of drugs to manage behaviour, while carers were more confident and felt less guilt when the person with dementia moved into institutional care. Elkins (2011) described impressive outcomes from SPECAL in the Good Care Group, a private domiciliary service enabling people with dementia to remain in their own homes. According to Dearnaley and Elliott (2009), the SPECAL focus on a primary theme alleviates stress caused by continual reminders of impaired memory and comprehension. A practical guide to SPECAL was presented by clinical psychologist Oliver James in the book *Contented Dementia* (2008), and positive personal accounts have also appeared in the media such as Julian Taylor's in *The Spectator* (23 March 2013).

But SPECAL has received a lukewarm response from old age psychiatry and opposition from the Alzheimer's Society. In a review of James' book for the Alzheimer's Society, Graham Stokes described SPECAL as a simplistic and flawed approach, arguing that depriving a person with dementia of information contravenes the principle of empowerment enshrined in the Mental Capacity Act 2005. The Alzheimer's

Phase	Purpose	Objectives	Schedule
0	Developmental work	Devise manualised SPECAL intervention and train members of NHS clinical staff as SPECAL coaches for family carers	May 2015-August 2015
I	Feasibility study	Test viability and acceptability of intervention and assessment process	August 2015-August 2016
II	Exploratory trial	Randomised, controlled trial (RCT) comparing SPECAL with conventional carer training, indicating effect size for definitive trial	August 2016-August 2017
III	Definitive trial	Multi-centre RCT to compare SPECAL course with usual care for family carers	August 2017-August 2019

### Specal evaluation timetable

Society website acknowledges elements of the SPECAL method, regarding it as a single intervention among many but unsatisfactory as a model. Until recently the website claimed that the SPECAL method was deceitful, but after complaints this was modified. However, the current statement ([alzheimers.org.uk](http://alzheimers.org.uk)) concludes that SPECAL is 'controlling and prescriptive' and that it disempowers people with dementia.

In response, the Contented Dementia Trust argues that the Alzheimer's Society misunderstands the method; for example, the SPECAL Photograph Album is erroneously portrayed as a form of reminiscence therapy. In 2009 an all-party parliamentary group met to enquire into the SPECAL method. Garner and James presented the case for SPECAL but the meeting was dominated by members of the Alzheimer's Society, who were generally critical. However, in a House of Lords debate on dementia in 2009, Lord McColl of Dulwich highlighted the potential benefits of SPECAL over other interventions for dementia.

Clearly SPECAL is a controversial approach to dementia care. Independent, systematic evaluation of this method would contribute to knowledge on developing psychosocial interventions in caring for people with dementia. Introduction of SPECAL to mainstream healthcare may be challenging due to the contrast in organisation, resourcing, practices and culture between the small-scale operation at Burford and highly-pressurised NHS mental health services for older people. Although SPECAL is not inherently complex, specialised training is necessary to reorientate care staff and to ensure fidelity to the model. Ongoing individual or group work may require a higher level of input than is normally provided. Yet SPECAL has potential to reduce resource use in the longer term, through a person-centred approach that optimises functioning,

relationships and quality of life.

### Programme of evaluation

Our evaluation programme will test the feasibility and efficacy of a SPECAL course for family carers of people with dementia in a NHS mental health service for older people. An important message from research is that training provided in groups may be more effective than individual sessions, as experiences are shared in a supportive setting where members learn from each other (Carradice *et al* 2003). Following Medical Research Council (2008) guidelines for evaluating a complex intervention, the programme entails an incremental process with four distinct phases (see box above).

To investigate process and outcomes, the evaluation combines quantitative and qualitative methods. The first three phases of the study will be conducted in Oxleas NHS Foundation Trust. A research worker will be appointed for recruitment and data collection.

### First phase: developmental work

Following an introductory presentation by the Contented Dementia Trust, members of clinical staff in memory clinics and other Oxleas mental health services for people with dementia were invited to apply to work on the project as group facilitators. Four candidates will be selected for training as accredited SPECAL practitioners (ASP). Trainees will apply the principles of the approach in clinical practice, recording their experiences in a reflective diary, and they will observe a demonstration course for carers facilitated by experts.

The structure and process of the course will be shown in an ASP manual. Eight carers, recruited by Oxleas NHS Trust staff, will receive a guidebook, emphasising the three golden rules and new communication skills. Trainees will participate in debriefing with course facilitators after each session. Assessment will include trainees' reflection

on applying the SPECAL approach and situational questions, those achieving the desired level of competence becoming accredited as ASPs. The ASP manual and guidebook for carers will be reviewed by the research team, and refined if necessary for the next stage of the evaluation.

#### Second phase: feasibility study

Objectives of the feasibility study are to:

- Test feasibility of delivering a SPECAL course to family carers through a NHS mental health service for older people.
- Evaluate acceptability of the SPECAL course for carers of people with dementia.
- Indicate sensitivity and appropriateness of outcome measures.

The SPECAL course, as demonstrated in Phase O, entails eight weekly sessions over a two-month period for groups of eight carers. Two ASPs will facilitate each session. The target population comprises people recently diagnosed with dementia and their carers, who will be asked by Oxleas staff whether they are willing to be approached by the study team. The research worker will visit the carer and person with dementia, and seek consent from both. Should the latter appear to lack mental capacity (at the outset or at any time during the study), the carer may agree to act as personal consultee. The recruitment target is 30 people with dementia and their carers, although, allowing for a dropout rate of 20% between consent and start of the intervention, 24 pairs will participate in SPECAL training (three groups of eight).

In summary, assessments will be conducted by the research worker in the home of the carer and person with dementia at three time points: at baseline, immediately after the eight-week course has ended, and further assessment eight weeks later. The Standardised Mini-Mental State Examination (Molloy and Standish 1997) will be used as a provisional measure of the degree of dementia. The primary outcome measurement for carers is degree of stress related to the caring role, measured by the Zarit Carer Burden Inventory (Zarit *et al*, 1985). Primary outcome measurements for people with dementia are quality of life and agitation, which will be measured using DemQOL (Smith *et al*, 2005) and the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield *et al* 1989)

#### Third phase: exploratory trial

Informed by the feasibility study, an exploratory randomised control trial (RCT) will compare the SPECAL course with conventional carer training, already provided in Oxleas in the form of the Caring and Coping with Loss model. Devised at the University of Sheffield

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## Whatever the outcomes of our evaluation, we envisage significant contributions to the evidence on training and service provision

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(Moore *et al* 1998), this model helps carers to adjust emotionally to the diagnosis of dementia and presents coping strategies for communication difficulties and challenging behaviour.

For study purposes, Caring and Coping with Loss groups will be run simultaneously with SPECAL courses and the recruitment process will be the same as in the feasibility study. Once again, the target will be 30 people with dementia and their carers in pairs. Allowing a 20% dropout rate, three groups of eight pairs would participate in each arm of the study.

#### Fourth phase: definitive trial

Depending on results of the exploratory trial, a multi-centre RCT will be conducted to determine clinical and cost-effectiveness of the SPECAL intervention through comparison to 'usual care'. The trial will include at least four NHS trusts offering conventional carer training, such as the Carer Information and Support Programme (Alzheimer's Society). The sample will be sufficient to detect a clinically-significant difference in primary outcome measures. Procedures for recruitment, randomisation, assessment and analysis will be similar to those in the exploratory trial.

#### Conclusion

While SPECAL is an established method of caring for people with dementia, it has not been introduced in mainstream services. A major factor is the lack of systematic evaluation and it may also be seen as problematic in principle and practice: the Alzheimer's Society may not be the only opposition to the SPECAL philosophy, and although the method is not necessarily labour-intensive for staff, it requires training and supervision to ensure proper delivery.

However, there are promising indications that SPECAL transforms relationships between carers and people with dementia, enhancing functioning and quality of life,

and guiding a person-centred approach throughout the course of dementia. This revolutionary method could be the radical change that is needed to improve care for people with dementia. Whatever the outcomes of our evaluation, we envisage that significant contributions will be made to evidence on training for carers of people with dementia, and on service provision. ■

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