

# 25 years and counting...

**Natasha Clarke** and **Roy Jones** share the learning from offering courses for family carers for 25 years at the Research Institute for the Care of Older People (RICE) in Bath

The Research Institute for the Care of Older People (RICE) in Bath, established in 1985, began providing memory clinics locally in 1987 and conducts research to advance knowledge, treatment and care surrounding dementia. As a diagnosing memory clinic, we try to give as much information as possible when making a diagnosis of dementia but, inevitably, clinicians cannot cover all information and resources available in the appointment slot they have. Additionally, the resources that are available to people with dementia and carers can be overwhelming. It can be difficult for them to take in all relevant information during a consultation, and people may not be inclined to ask questions during a formal doctor's appointment.

The need for more in-depth support for carers led to the launch of the RICE Carers Course in 1989, with the main aims of providing information on memory loss and practical advice for living with someone with dementia. Since it began the course has gone from strength to strength, and is currently providing information and support to approximately 75 carers of people with dementia every year. As we reach the 25th anniversary of the course it seemed an appropriate opportunity to reflect on what we have learned and share best practice.

## Course structure

The RICE Carers Course runs over four weeks, with approximately 25 carers attending the centre one afternoon a week for two hours, with two speakers at each session. Courses are held three times a year, in March,

June and October. Currently, talks cover the following areas:

- What is dementia?
- Legal aspects of being a carer
- Brain and behaviour
- Benefits and allowances
- Day care
- Memory problems in dementia and what we can do
- Who cares for the carer?
- Assistive technology.

Two of the eight talks are conducted by members of RICE staff: a doctor and neuropsychologist. The remaining six talks are conducted by external speakers, including a representative from the local carers centre, a dementia support worker from the Alzheimer's Society, a local day care manager and a solicitor, among others.

Securing reliable speakers has been a challenge faced throughout the course, but this has been overcome through effective communication and the building of relationships. For example, we always send written 'thank-yous' to the speakers following each course. Attendance can also be beneficial to presenters and their organisations as a way to identify potential service users and make initial, informal, face-to-face contact with individuals who might otherwise slip through the net.

Recently, organisations such as the local carers centre have also started to refer carers to the course, so that we can reach more individuals, including those who may not have attended the memory clinic. Attendees referred to the course from external organisations currently represent 10 per cent of participants; however, as the memory clinic for the local area we have contact with a high number of people with

dementia and their carers. Referrals from external support services may therefore be higher in other areas looking to run a course.

## Research into practice

Poulshock & Deimling (1984) propose a model for explaining the strain caring for a person with dementia can place on the caregiver, with 'lack of knowledge' as an exacerbating factor, and 'practical support' as a protective factor. The RICE Carers Course attempts to meet both of these objectives by providing knowledge both about dementia and the disease process, as well as about support services and how to access this practical support.

Furthermore, Brodaty *et al* (1997) outline three main crucial elements of caregiver support. Two of these, psychological and educational support, are met through talks such as 'Who cares for the carer?' and 'What is dementia?' respectively, with other talks also falling into these categories. The third, developing a support system, is continually evidenced in feedback received from attendees. People benefit from the chance to meet and interact with other carers in the same situation, and this is undoubtedly a valuable aspect of the course as people realise they are not alone. This demonstrates the efficacy of providing an informal opportunity for carers to develop a support system, without the need for a separate support group or more socially focused intervention.

In 2006 the National Institute for Health & Clinical Excellence (NICE) and the Social Institute for Excellence released a guideline to support people with dementia and their carers,

outlining the support that should be offered to carers, with interventions addressing a range of identified problem areas. The RICE Carers Course specifically meets one of the components of interventions outlined: 'training courses about dementia, services and benefits, and communication and problem solving in the care of people with dementia' (NICE/SCIE 2006).

The recent report from the Carers Trust (2013) is an excellent resource detailing the needs of carers. An in-depth literature review, surveys and focus groups led to evidence-based conclusions regarding the need for information about dementia and services, legal and monetary issues, understanding behaviour, and practical ways to increase stimulation and communication among other needs, including training in lifting a person. This highlights the need for evolving support for carers, which is evaluated and improved upon to ensure real needs are met.

## Evaluation

Following each session attendees complete a short evaluation form, the results of which help to improve subsequent courses. For example, early on in the course, participants gave feedback that they wanted information on more practical ways to cope with living with dementia. To this end, a local charity now provides a talk on assistive technology that is available, and the RICE neuropsychologist's talk centres around the idea of analysing the meaning behind behaviour displayed by the person with dementia, in order to tailor response and have a positive impact on the behaviour. Feedback also led



us to compile a booklet of all slide presentations and information provided in the course that participants receive on the first day, as opposed to separate hand-outs or relying on written notes, and we are currently looking into providing audio recordings of talks for carers who are visually impaired. Timing of courses is also a challenge; we have found that courses held in December and January are less well attended.

After each session attendees are asked if 'the information provided was useful and will be of benefit to me'. Analysis of combined data across all three courses we ran in 2012 found that a minimum of 83 per cent and average of 94 per cent either strongly agreed or agreed with this statement for each session. Attendees were also asked if they would recommend the course to someone in a similar situation to themselves; 100 per cent stated that they would.

### Providing for the person with dementia

Early on, it became clear that many people could not attend the course since they could not leave the person they cared for alone; there was also little provided in the area that could help overcome this. Since then, RICE has been able to re-locate to a purpose-built building, with dedicated parking and more space than before. With this move, we were able to offer a sitting service for people with dementia during the sessions, and feel this is an invaluable aspect of the course that allows carers to attend who otherwise would not be able to.

RICE also runs Cognitive Stimulation Therapy (CST) courses for people with dementia, and we take the opportunity of the sitting service to use activities from this course, if suitable, for those present. This ensures that time spent at RICE is potentially beneficial and engaging for both the carer and person with dementia. We typically have six to nine attendees at the sitting service, representing approximately one-third of the carers present at the course, demonstrating how valuable a service it is. These participants often go on to attend a full CST course or day care centre, having previously been reluctant. Since there is also now much greater provision of support for people with dementia available generally, centres considering running a carers course may like to consider collaborating with other local support services such as day care or carers centres. This would also be beneficial for keeping down costs.

### Expenditure and funding

Inevitably there are costs involved in the running of any course. We budget for the use of space at RICE, travel expenses of speakers, publicity, and staff time in the run up to, and during, the course. This involves one secretary organising the course and two members of staff covering the sitting service, typically a psychologist and a nurse, amounting to approximately £3,000 per course. We have previously received funding from trusts, local businesses and community groups. Each

course is dependent on gaining this vital support, and so far we have been successful in providing three courses a year on average, but in the current economic climate it is something most centres, especially charities, will need to consider.

The RICE Carers Course has been running for nearly 25 years and is in high demand, but it is clear that more is needed nationally to address the needs of carers for individuals with dementia. It is hoped that what we have learned and implemented throughout this time, transforming research into practical course delivery, can be used to inform other memory clinics and dementia services so they can develop their own course for carers. ■

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## Feedback about the course

A selection of comments from carers about the course, taken from the past three years:

*I was overwhelmed with dementia and all that goes with it. I feel I have now accepted the problem and view her illness differently.*

*I really enjoyed the course and now understand what Alzheimer's is. I can put myself in the sufferer's shoes and understand what life is like for them.*

*Very interesting and helpful. We now have the information and contacts of the aid that is available.*

*The financial information was very useful; I had previously underestimated the possible financial problems.*

*It was nice being among others who are experiencing similar problems. I normally feel quite defensive when discussing mum's behaviour with people outside the family but here it is nothing out of the ordinary. Hearing other people's experiences helps to put your own into perspective.*