

Can online therapy reduce distress in dementia carers?

March 22 2017



Caring is both rewarding and demanding. Credit: University of Exeter

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A new study is inviting people who care for someone with [dementia](#) to help investigate whether an online therapy can help carers cope with feeling of stress, anxiety or depression.

Researchers are looking for up to 750 carers from anywhere in the UK to sign up and assess whether an online programme called 'Caring for Me and You' can effectively reduce feelings of distress in carers.

The programme is comparing three different packages that have been tailored for people who support someone with dementia - a

computerised Cognitive Behaviour Therapy (cCBT) package, with or without [telephone support](#) and an online psycho-education package.

Cognitive Behavioural Therapy (CBT) works on the principle that our thoughts, feelings and behaviour affect one another and therefore influence the way we provide care and support. Each package has written, audio and video information for carers to use. The packages are 20 sessions in total and each session lasts about 20 minutes, which can be completed at a time which most suits the carer over a period of up to six months.

The research is co-led by the Oxford Health NHS Foundation Trust and the Alzheimer's Society.

Clive Ballard, Professor of Age-Related Diseases at the University of Exeter Medical School, is one of the lead investigators on the study, involved in the design and development of the study. He said: "Caring for someone with dementia can be rewarding, but also be stressful and frustrating. It can result in anxiety or depression, both in carers and in people with dementia. We need to find effective ways to support carers in looking after their own needs as well as the person they care for.

"Carers have traditionally found advice sessions helpful and early evidence indicates that online Cognitive Behavioural Therapy could also help reduce distress in carers, and we now need people to sign up to our trial to find robust answers on whether rolling this out could make a real difference and improve lives."

Dr Jane Fossey, Associate Director of Psychological Services at Oxford Health NHS Foundation Trust, said:

"We have consulted carers and used the latest evidence to tailor both the therapy and the educational package to the needs of people who care for

someone with dementia"

"We now want to know how effective they are, and whether the online approach works to give convenience and flexibility. By signing up, carers will receive tailored online support, whilst helping us collect the evidence to create strategies that really help support carers."

Participants will receive either CBT sessions online, or a high-quality education and information package online, with a sub group also receiving telephone support. The three arms of the study will allow researchers to analyse whether any of the three approaches makes a meaningful difference to carers.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said: "Even in areas where face to face therapy is available, carers tell us finding time to attend sessions or organising cover for the person with dementia can be very challenging or stressful. Being able to log on at home and access online therapy has the potential to transform the lives of tens of thousands of carers and help support their health and wellbeing which can often be overlooked.

"We're calling on carers to join the study to help us find out what kind of online support can help carers to manage stress, anxiety and depression."

The research team is looking for carers who provide practical or emotional support to someone with dementia and are experiencing some stress or low mood. Participants must be over 18, live in the UK, and be comfortable using a PC or Windows laptop and have an internet connection.

Heavy toll of dementia care

The strain of caring for two parents with dementia took a heavy toll on

Madeleine Maddocks. At her depths, she became severely depressed and was diagnosed with Graves Disease, an overactive thyroid exacerbated by stress.

Mrs Maddocks, who lives in South Devon, was 42 when her father was first diagnosed. She described the physical and emotional drain of caring remotely for her parents, Stuart and Jan, who lived between Bristol and Bath. Although more than 100 miles away, Mrs Maddocks was on call 24/7 and often made the trip when her phone rang in the middle of the night.

Her father, Stuart, was diagnosed in 2005, at the age of 71 and died nine years later in 2014. The lowest ebb for Mrs Maddocks was when her mother, Jan, also received a diagnosis of Alzheimer's in 2013. She died just 18 months after her diagnosis.

Mrs Maddocks said she grieved her parents from the point of diagnosis, while trying to cope with the emotional drain of caring for them. "I was incredibly depressed, anxious and completely exhausted all the time. My husband said he felt like he was a carer for me. I became a victim – I was just so crushed by it all. At that point I was diagnosed with Graves Disease, which has particular complications when combined with stress. "I experienced symptoms such as extreme fatigue, forgetfulness, eyesight deterioration, hand tremors and trouble sleeping."

Mrs Maddocks tried counselling and [cognitive behavioural therapy](#), but said the service seemed over-subscribed and she was constantly afraid an appointment would clash with the need to head off to attend to her parents. "I really welcome the online nature of the Caring4MeandYou programme," she said. "When you're in that position, it's hard to find the strength, confidence and time to go to [support](#) groups. Having something online is much more flexible and accessible. I think it will help a lot of people, as a vital first step."

Mrs Maddocks is now starting to rebuild her own life. "I used to wonder if I would ever feel happy again. Now I do have moments of happiness, but I'll always carry the sadness of those years."

More information: To find out more, visit
www.caringformeandyou.org.uk

Provided by University of Exeter

Citation: Can online therapy reduce distress in dementia carers? (2017, March 22) retrieved 9 April 2024 from
<https://medicalxpress.com/news/2017-03-online-therapy-distress-dementia-carers.html>

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