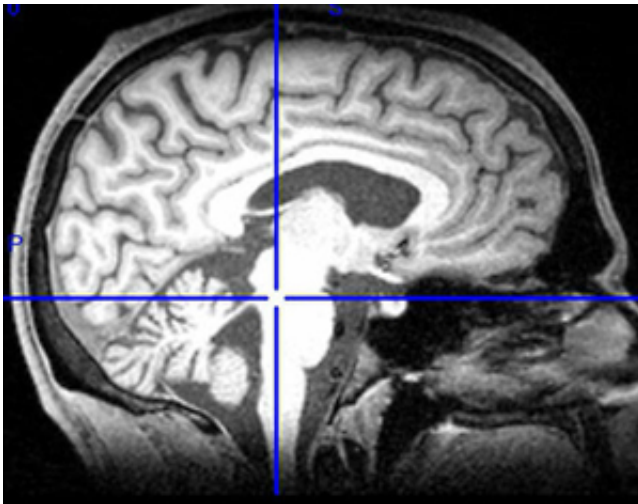


New home guide to help 'overwhelmed' dementia carers

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Berkshire Healthcare and the University of Reading have teamed up to produce a new clear and accessible guide to support people who care for those with dementia.

The design and content of the Dementia Handbook for Carers is based on direct feedback from those affected. This means for the first time carers have all the [information](#) they need in one place, including contact information, coping strategies, legal advice and medication information.

Carers were consulted at every stage of the development process

including the design and format, the information they wanted and the language used. Researchers from the University's Centre for Information Design Research interviewed dozens of carers in the region. They heard that diagnosis information exists for carers but it's not easily accessible and can be confusing. Also, due to time-pressure and a lack of access to or confidence in the web, many had not used the information they had been given.

There are currently 800,000 people with [dementia](#) in the UK. By 2021 there will be more than a million people with the disease. In the west of Berkshire alone there are more than 5,000 people with dementia and this is due to rise to almost 9,500 by 2030, an increase of more than 80 per cent. When you take into account family carers there are thousands more people who will be affected dementia.

Dr Luke Solomons, the Berkshire Healthcare consultant psychiatrist who led on the project, said: "Carers repeatedly tell us they feel overwhelmed by the information out there and we just want to ensure that they have information from a trusted source, in a format written by them, not professionals. We hope this will stop them feeling they are alone in the wilderness. Carers have such a vital role and we wanted to give them the support they deserve.

"At Berkshire Healthcare we believe in working together with people to deliver innovative solutions. By working with the carers themselves we are confident this guide should give them what they need."

Carol Munt, from Reading, was one of the carers involved in the project. Her mother had [vascular dementia](#) giving Carol real expertise about caring for someone with dementia. Carol said: "I am passionate about better dementia awareness and care. I would say to anyone in a similar situation to get help before you think you need it and this guide will give them all the information they need to make sure they get that help."

Professor Alison Black, from the University's Centre for Information Design Research, led the design project. She said: "New circumstances and an unpredictable future mean it is a difficult time for carers. Working closely with carers gave the research team crucial 'first-hand' insight into the issues they face at home. It was eye-opening to discover that their needs are not being met. Information is provided too late and mass collections of leaflets and recommendations for web sites to consult are confusing - all this during a time of great stress.

"Our task was to create a handbook that offered as much clear guidance as possible. Early feedback has been extremely positive. We hope the handbook makes a difference to the lives of people with dementia and their carers both in Berkshire and potentially across other regions of the UK."

Berkshire Healthcare and the University of Reading have formed a unique partnership to fight all aspects of the disease from research into causes, diagnosis and cures, to supporting carers and people with dementia through projects like the handbook.

Dr Solomons added: "Our collaboration with the University of Reading is a blueprint for tackling dementia and supporting those affected. Berkshire should consider itself at the forefront of the UK's aim of tackling the dementia time-bomb."

The project was funded by the Berkshire West Confederation of Clinical Commissioning Groups as part of their response to the Prime Minister's Dementia Challenge.

The guide is being launched at a special event. The Living Well with Dementia event is being held on Thursday (25 September) between 3pm and 7.30pm at the Best Western Reading Moat House in Wokingham. The free event is open to people with dementia, their families, friends

and carers and will include expert speakers and stands from charities, councils and health services.

More information: The guide is available online:
[www.berkshirehealthcare.nhs.uk ... ge_sa.asp?fldKey=344](http://www.berkshirehealthcare.nhs.uk...ge_sa.asp?fldKey=344)

Provided by University of Reading

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