

Young onset dementia media round-up June-July 2016

In the UK news / press

The Telegraph – [‘Surgical menopause’ linked to poor memory and early onset dementia](#)

The Telegraph – [How three footballing families are enduring the agony of dementia](#) – article includes story of Frank Kopel, diagnosed aged 59

The Telegraph – [‘I assumed he was being scatty:’ My husband was diagnosed with dementia aged 50](#) – interview with Jayne, Chris Roberts wife

BBC News NI – [Dementia NI: New charity to help those living with the condition](#)

Doncaster Free Press – [Debilitating illness comes decades early for Doncaster woman](#) – article about Wendy Sharps, diagnosed aged 40

Doncaster Free Press – [Doncaster mum shares dementia story](#)

The Courier – [Honorary degree for Frank's Law campaigner Amanda Kopel](#) – Amanda's husband Frank Kopel was diagnosed aged 59 and died 5 years later, she is fighting for free healthcare for under 65s in Scotland

From America

[Family helps early onset Alzheimer's patient cope, carry on](#) – Brian LeBlanc speaks about how he has coped since receiving a young onset dementia diagnosis and his strong and positive connection with his step-children.

[Behaviour changes offer clues dementia could be brewing](#)

[Dealing with dementia](#) – one woman's experience of young onset dementia, shows impact on family and friends

[What 18 year old Alice wants you to know about being a dementia care friend](#) – article Alice's best friend who is 53 and is living with dementia

[Pat Summitt, legendary Tennessee basketball coach, dies at 64](#) – Pat was diagnosed with young onset dementia in 2011

[Man diagnosed with Alzheimer's at 29; family share their battle](#)

From Australia

[Dementia diagnosis is not the end, advocate for human rights says](#) – article about Kate Swaffer, diagnosed aged 49

[Snail farm in South Australia's Mallee offering 'hope' to early onset dementia sufferers](#)

Online

BBC iplayer – [Panorama – Living with dementia: Chris's story](#) – watch the BBC documentary about Chris Roberts and his family

BBC Blog – [Panorama – Living with dementia: Chris's story](#) – blog about the BBC documentary featuring Chris Roberts

Huffington Press - [BBC's 'Panorama: Living With Dementia' Captures The Reality Of Life After Diagnosis](#) – blog about documentary featuring Chris Roberts

Age UK – [The four faces of dementia](#) – interview with Keith Oliver who was diagnosed aged 55

Wendy Mitchell – [My ramblings to help someone newly diagnosed with dementia](#) – Wendy was diagnosed with dementia aged 59 and writes a fantastic blog

[How to be a Dementia Friendly Employer](#) – excellent short animation that includes young onset dementia

Belfast Live – [Rare Disease Day 2016: Belfast woman opens up about her daily struggle with rare form of dementia](#) – article about PCA

Unforgettable.org – [Craig's dementia story: 'Cherish each moment you have](#) – TV DIY man and Big Brother winner Craig's mum Brenda was diagnosed aged 59

Unforgettable.org – [Maureen's journey: 'We have a positive attitude – we'll try anything once!'](#) – article about Mike's diagnosis with PCA & Alzheimer's disease at the age 59, and their recent Dementia Adventure holiday

Salford Online – [Dementia campaigner Joy Watson honoured by University of Salford](#)

National Children's Bureau – [Dementia epidemic hits young carers](#)

Unforgettable.org – [Social clubs fill in gap in dementia support](#) – Attending social and recreational clubs when you have dementia, particularly young onset, can help you feel more empowered, according to researchers by the University of British Columbia in Canada

Unforgettable.org – [Dan's story: 'Dementia scared us, but made us so much closer too'](#) – Dan's father was 59 when he was diagnosed with dementia

Unforgettable.org – [Kathryn's story: 'Cherish the love, treasure the fun – and accept the rest'](#) – Kathryn's mum Bonnie was diagnosed with dementia when she was 62

New websites & apps

[Rare Dementia Support](#)

[Dementia NI](#)

[Dementia Citizens](#) - Dementia Citizens is a new project that aims to help people with dementia and those who care for them, using apps on smartphones and tablets

BBC News – [App aims to help dementia patients' memories](#)

Books

[Helga Rohra – Dementia Activists, Fighting for our rights](#) - Helga Rohra turns dementia stereotypes on their heads with this candid memoir. Speaking about her diagnosis, day-to-day life and experience of advocacy, she proves that a dementia diagnosis doesn't mean you have to give up on life. With helpful advice and practical tips, this book is a testament to living well with dementia.

£10.99, Jessica Kingsley Publishers

[Norman McNamara – The Lewy Body Soldier](#) – Norman says, 'This book will be my last ever book and you can see why on the back cover of the book. We have to deal with the cards we are dealt and try to make the best of it. I hope this book inspires others and they can now understand WHY a diagnosis of dementia is not the end, but can be the beginning of a new adventure, where there is life, there will always be hope my friends.'

£9.13, Amazon

Research projects

[IDEAL](#) - IDEAL is a research project led by the University of Exeter. It is a major, five-year study of 1500 people with who have dementia or an associated condition, and the family members or friends who provide support throughout the UK. The aim of the project is to find out what makes it easier or more difficult for people to live well with dementia, and what can be done to help more people to live well with dementia.

[Caring For Me & You](#) - Caring For Me & You is research project for carers of people with dementia which is evaluating the effectiveness of online cognitive behaviour therapy, with or without telephone support and an educational and support programme. The study is open to anyone in the UK who is aged over 18 and provides support to someone with dementia and is comfortable using a computer. Find out more via the link below.

[RHAPSODY](#) - The University of Surrey is looking for volunteers who look after a relative or friend who has been diagnosed with dementia under the age of 65 to take part in a research study to test a new online source of information and support designed for dementia carers.