

Young onset dementia media round-up September 2017

In the UK news / press

The Daily Mail – ['There is not much of our old Becky left': Family reveal the rapid decline of bubbly ski instructor, 32, who was struck down by rare dementia in 'one of the youngest cases doctors had ever seen'](#)

The Daily Mail - ['One day I will not know who I am, but I don't think about that': Dementia patient diagnosed at just 48 writes a heartbreaking account about living with the condition](#) - Debbie, now 53 who developed dementia following a stroke.

The Telegraph - ['At 31, my sister is one of the youngest people in Britain to get dementia'](#) - Becky was diagnosed with frontotemporal dementia aged just 31. In this article her sister Sophie shares their story.

Daly Record - [East Kilbride family battle to raise awareness of early onset dementia after mum's shock diagnosis](#) – The family of Anne Duke, who was diagnosed with Alzheimer's disease at just 56, climbed Ben Nevis in a bid to boost funds for dementia charities.

Irish Examiner - [Forget me not: Kathy Ryan talks about living with early-onset Alzheimer's](#) - Kathy is 57 and was diagnosed with dementia in 2014. She is one of 5,000 people in Ireland, aged under 65 living with a young onset dementia diagnosis.

Hereford Times - [Young Dementia Herefordshire is coming out of the shadows, spreading the word about the incidence of dementia among the under 65s](#) – article about young onset support group, Young Dementia Herefordshire.

BBC Wales – [Friendly Face for Flintshire under 70 dementia patients](#) - Teresa who is living with young onset has launched a peer support helpline for people in Flintshire.

Daily Post - [Plucky gran marks early onset dementia diagnosis with comical fitting tattoo](#) - Teresa from Flintshire was diagnosed four years ago with young onset dementia.

BBC News - [Widow 'ecstatic' over Frank's Law personal care victory](#) - Amanda Kopel has campaigned for many years for 'Frank's Law' to bring free personal care for people in Scotland who are under 65.

The Scotsman – [Leader comment: Our debt of gratitude to Amanda Kopel](#) – article highlights the needs of younger people living with dementia

BBC News – [Welsh cinemas start dementia-friendly screenings](#)

Online

[Wendy Mitchell's blog](#) – sharing her day at the Young Dementia Network steering group meeting on 27 September

BBC News – [Fearing dementia in your 40s](#) - Sophie Leggett is 41 years old and has a 50% chance of developing Alzheimer's disease in the next few years. She's taking part in research to try to find a cure for families like hers and others affected by the condition.

Alzheimer's Research UK blog – [Talking about dementia](#) - Denise's mum was diagnosed with FTD at the age of 59. Now 65, her mum has lived in a care home for the last year.

Huffington Post - [What Is Early-Onset Alzheimer's Disease? Symptoms, Causes And Treatment Explained](#)

Join Dementia Research - [Understanding frontotemporal dementia: an interview with Professor James Rowe](#) - an interview discussing frontotemporal dementia and current research into the condition.

Money Saving Expert.com – [Revealed: Councils overcharging 10,000s who are 'severely mentally impaired'](#) – report reveals that a council tax rebate that can be claimed by people living with dementia isn't being implemented correctly

Alzheimer's Society blog – about Peter who was diagnosed with young onset dementia aged 58 – in three parts, [Part 1](#), [Part 2](#) and [Part 3](#).

NIHR case study - [Meet Tracey...Who was diagnosed with early-onset dementia and now spreads the word about research](#) – interview with Tracey Shorthouse who was diagnosed with PCA in her mid 40s.

Alzheimer's Society – [Memories with Grandma](#) - a new animation to help raise awareness of dementia for 7-11 year olds. Whilst it features a grandparent affected by dementia, not a younger person, we feel the animation could still be a helpful way to explain dementia to children.

From abroad

The Duluth News Tribune - [How Alzheimer's affects families: Adult children challenged, especially when disease hits parents at a younger age](#) - article shares the difficulties faced by the grown up children of a man who was diagnosed with young onset dementia aged 57.

The Seattle Times - [John Janda inherited the mutated gene that stole his mother's mind. UW researchers want to know why he is doing fine](#) – article about familial FTD.

Aged Care Guide - [Diagnosed with dementia and doing something with a difference](#) – Greg, 61 is living with FTD and plans to ride a motorbike across Australia.

Film / video / audio

[BBC's Victoria Derbyshire programme](#) - Jayde Green is 27. Genetic tests suggest she will develop young onset Alzheimer's, as her father did. In this short video, Jayde

speaks to the BBC about her fears for her one-year-old son, and how she is preparing for the future.

Dementia Diaries – [Keith Oliver 'being busy and living well'](#) – discusses the Young Dementia Network

AFTD - [Olivia's mum had FTD](#) - this video is part of their Think it's Alzheimer's? Think again campaign.

AFTD - [Not all dementia is Alzheimer's](#) - Katie Brandt's husband was just 29 when he got his FTD diagnosis

Research, surveys, petitions, newsletters and booklets

[National Dementia Carers Day](#) – 10 September

[World Alzheimer's Month / Day](#) – 21 September

['This is killing me inside': The impact of having a parent with young-onset dementia](#) – new research study examines what it means to have a parent with young onset dementia

Zipabout is building an app to help people living with dementia to travel with less anxiety. They are asking anybody who would like to be a part of the design process to get in touch. For more information click [here](#).

RSAS is looking for family members who fulfil a care role to a relative living with dementia to take part in a new three-day residential support programme. Sessions are being held in hotel venues in Birmingham, Solihull and Wiltshire. For more information, download [flyer 1](#) and [flyer 2](#).

Amanda was just 18 when her 48 year old mum was diagnosed with young onset dementia. Having become her mum's full-time carer, she struggled financially spending nearly half of her carer's allowance on bus fares visiting her mum in hospital. She has launched a petition calling for all carers to be given free access to public transport, click the link to sign her petition - [Concessionary transport for all carers](#)

YoungDementia UK – quarterly [Oxfordshire News](#) newsletter

The Alzheimer's Society has published a booklet titled 'Frontotemporal dementia: Understanding your diagnosis'. Click [here](#) to download a copy.

Young onset groups

YODA - A new weekly group is launching for people living with young onset and family members in Halifax. The first gathering will be on Friday 6 October, 2-4pm. For more information, click [here](#).

Keystone is a support group for family members / carers of under 65s living with dementia based in Crosby, Merseyside. It meets on the third Tuesday of the month,

2.00-3.15pm at All Saints Church Community Hub, L23 9TJ. There is also an evening Keystone Group for carers who work on the 1st Wednesday in the month, 6.00--7.30pm and a memory café on the second Thursday of the month for both for people living with young onset and their supporters at 2.00-3.30pm. Contact Kath Rogers on kathrogers.assfchurch@gmail.com to find out more.