



Young onset dementia media round-up July & August 2017

In the UK news / press

Manchester Evening News - [In a sickening insult a woman with dementia praised by David Cameron has had her benefits cut by Tories](#) - Joy Watson from Salford is 59 years old and was diagnosed with dementia four years ago. Her PIP benefits have been stopped following reassessment.

Mirror - [Brave woman is 'coping too well' with dementia so the DWP have axed her benefits](#) - article about Joy Watson and members of her line dancing group

Daily Record - [Former Aberdeen boss Jimmy Calderwood diagnosed with younger onset Alzheimer's disease](#) - Former Aberdeen manager and ex-professional footballer Jimmy Calderwood, aged 62 has revealed he was diagnosed with young onset Alzheimer's disease nearly two years ago

BBC Sport - [Playwright moved to tell Kopel's story](#) - Amanda Kopel has fought for free personal care for under 65s in Scotland. Playwright Iain MacRae was so moved by Amanda and Frank's story, he's hoping to write a play about them

The Telegraph - [Brain scanning could improve dementia diagnosis for two thirds of patients, study finds](#)

The Sunday Post - ['We're stronger together': Couple remain positive after early onset dementia diagnosis](#) - Susie was diagnosed aged 65

The Sunday Post - [Meet the 'Demi Girls', each facing up to the challenge of living with a husband who has early-onset dementia](#) - inspiring article about a group of women whose husbands all have young onset, showing value of peer support

Oxford Mail - [Inspirational artist shares tips and tricks on living life to the full with dementia](#) - article about YoungDementia UK member Jacqui Peedell

BBC News - [Frank's Law: Holyrood member's bill seeks law change](#) - ex-footballer Frank Kopel's wife Amanda has been fighting for free personal care for under 65s in Scotland for a number of years. A bill has been put to the Scottish government calling for the same free personal care that older people receive.

Express - [Early onset dementia - are you at risk of developing symptoms before 65?](#)

Online

YoungDementia UK - [statement in response to cuts to PIP benefits for people living with young onset dementia](#)

Alzheimer's Society – [Personal Independence Payments assessments are failing people with dementia](#) – statement from the Alzheimer's Society

Alzheimer's Research UK blog – [Getting a test for familial Alzheimer's at 25](#) - Jess's family are affected by a hereditary form of Alzheimer's disease.

Alzheimer's Research UK – ['I feel like the unluckiest person in the world. I've won the world's worst lottery.'](#) - Mum in her 30s speaks out about the realities of life with a 75% chance of Alzheimer's

Alzheimer's Research UK blog – [Alzheimer's stole my dad from me](#) - Chrissi's dad was diagnosed at the age of 46. She wrote a letter when she was 16, not long after her dad passed away, and she shares it in this blog post

Alzheimer's Research UK - [Loving carer is forced to communicate with her 49-year-old partner using coughs, eye contact and children's toys because of rare dementia](#) - Adele's husband Lance is 49 and has behavioural variant frontotemporal dementia

Alzheimer's Research UK blog - [Why we must be educating people in midlife about reducing their risk of dementia](#) - ARUK are calling for dementia risk information to be part of the NHS Health Checks from age 40 onwards

Elder – [Tommy Dunne, Living with dementia, not suffering with it](#) – interview with Tommy from Liverpool who was diagnosed aged 58

Huffington Post – [Completing my wife's bucket list after losing her to dementia at 43](#) – a sad but heart-warming article about Steve and Michelle, Michelle was diagnosed with dementia aged 38

Huffington Post - [Teacher becomes one of youngest to die from dementia at 40 years old](#) - Gareth Wilmot from Barnsley died having lived with frontotemporal dementia for five years

Alzheimer's Society - [A carer who has supported her family through some extremely tough times](#) - Simon was diagnosed with young onset Alzheimer's in January 2016, aged 48. This interview with his wife Louse, aged 47, talks about life since Simon's diagnosis

Evidently Cochrane – [I have dementia and I take part in dementia research. Here's why](#) – Wendy Mitchell her involvement in dementia research

BT Including You – [feature on YoungDementia UK](#) – interview with Kate Fallows, includes the Young Dementia Network and GP guide

Me Included – [Living with dementia](#) - Tracey Shorthouse talks about living positively with young onset dementia

Mum has dementia blog – [R-E-S-P-I-T-E – Find out what it means to me](#) – blog piece about the difficulty of finding suitable respite options for mum with young onset

TV and video

Short film – [Dementia and sensory challenges – My life living with dementia](#) – featuring Agnes Houston who is living with young onset

BBC's Victoria Derbyshire Show – [featuring Joy and Tony Watson talking about the cuts to Joy's PIP benefits](#) – the feature begins 1 hour 13 mins into the programme

Peter Berry from Suffolk was diagnosed with dementia aged 50. He is recording a [weekly video diary](#) in which he discusses how dementia affects him

Dementia Diaries – [Keith Oliver's report from Geneva](#) following visit to the UN

[My Life Films](#) make free, personal films about the lives of people who are living with dementia. They have funding to work across London, Brighton and Hove, with a focus on South West London and are very keen to work with people living with young onset. Contact Jo Foster of My Life Films via email jo@mylifefilms.org or tel 020 8948 7560.

From abroad

The Daily Telegraph (Australia) – [The pain of living with Alzheimer's – how it takes a heavy toll on relationships](#) - Mike was diagnosed at the age of 58. This article features the impact the diagnosis has had on his wife of 40 years and family

Illawarra Mercury (Australia) - [Younger onset dementia a tough road for John Bartninkaitis](#) - John was diagnosed with young onset frontotemporal dementia (FTD) at the age of 55

Lancaster Online (USA) – [Early onset Alzheimer's, a devastating blow to 46 year old Lancaster chef Steve Drake](#)

Nextavenue (USA) - [Early onset Alzheimer's doesn't thwart these advocates](#)

Being Patient (USA) - [Is it Early Onset Alzheimer's? New Instruments for Detection Being Developed](#)

16WNDU (USA) - [New therapies aim to slow Alzheimer's in younger patients](#) - New therapies aim to slow Alzheimer's in younger patients - familial Alzheimer's drug trial

Research, surveys and petitions

[The Angela Project Survey](#) - research study that aims to improve diagnosis and post-diagnostic support for younger people with dementia, families and supporters. Open to anyone who lives with a diagnosis of dementia received before the age of 65; or people who are related to, or supporting someone with a diagnosis of young onset dementia.

Anne Scott was diagnosed with dementia aged 46. She has set up a [petition](#) calling for a review of services to end age discrimination for people aged under 65.

Innovations in Dementia [survey](#) about relationships and dementia.

Martin Lewis, the money saving expert, is asking people who have set up power of attorney in the last couple of years to complete a short [online survey](#). It takes around five minutes to complete.

Plays, books and groups

Descent by Linda Duncan McLaughlin is a play about love and young onset dementia. It was performed at the Edinburgh Fringe Festival in August. Find out more [here](#).

The [Ally Bally Bee Project](#) has created a personalised book designed to help explain dementia to children. You can customise your story with real names, relationships and behavioural traits so that whoever it is in your family that is living with dementia, the story will be personal to you.

Alzheimer's Society – [Frontotemporal dementia \(FTD\): Understanding your diagnosis](#) – new publication from the Alzheimer's Society

[Heeley City Farm FTD Carers Group, Sheffield](#) – for people who support someone with frontotemporal dementia. Meets in the community room at Heeley City Farm on the 2nd Tuesday of the month, 6.30-8.30pm.

[West Dorset under 70s group](#) – peer support group based in Bridport area, programme of activities up to Christmas.

Dry Water Arts run integrated participatory arts programmes in the north east of England and have a particular specialism in projects for people with young onset dementia and their family and friends. Their '[Curiosity Cafe](#)' enables participants to explore a range of arts including movement, visual arts, photography and is led by the interests of the group. Further information email info@drywater.org or tel 07711 669294.

Sandwell Young Onset Dementia Activity & Support Group meets fortnightly at West Bromwich Baptist Church. The main focus is encouraging participation in meaningful activities and providing advice and support to help people live well. Family members / carers are very welcome to attend. Call 0121 543 4295.

Younger People with Dementia Group – meets at Your Bike Shed, Micklegate, York on the last Wednesday of the month, 2.00-3.30pm. Peer support group for under 65s and their family members / carers.