

JDC asks...

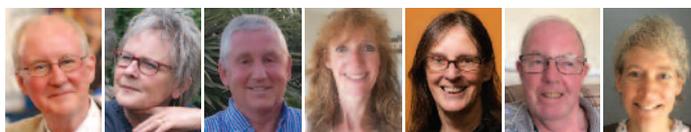
As our Young Dementia Annual Conference approaches, we ask: “What is the single change to services and public life that would make the most difference for people with young onset dementia?”

As someone living with young onset dementia, I remember being given very little knowledge of my condition at the time of diagnosis. In fact, all I had to go on was the obscure label identifying my condition: Lewy body dementia, a neurodegenerative disease. All the rest was Google!

This minimal knowledge told me little about how my condition would affect my daily life. Would I be able to continue to work? How would this revelation impact on my family and on my financial circumstances? Most significantly, what would my prognosis and my future be like? For many painful months, these questions rattled around in my head, lacking an adequate response from the specialists. Instead, it fell to my wife to assume the role of Google detective, desperately searching for clear answers.

While the news of my diagnosis left me both numb and shocked, I nevertheless felt relieved that, at last, my long-held suspicions were valid and significant. Prior to diagnosis, many people, including my family, had had difficulty taking my symptoms seriously, laughing them off, albeit in a well-meaning way. In response, my diagnosis somehow legitimised my concerns. As humourist Spike Milligan’s gravestone stated: “I told you I was ill.”

Looking back at the onset of my dementia, I now recognise that the single change that would have made a significant difference to my experience centres on information and communication. Information: frank, clear and practical – it’s at the heart of the relationship between service providers and people living with dementia. Communication: trusting,



From left: Desmond O’Sullivan, Tessa Gutteridge, Dave Laxen, Jacqueline Hussey, Jan Oyeboode, Mick Whitfield and Jo Scarle

Young dementia conference

Our Young Dementia Annual Conference, organised by Young Dementia UK and the *Journal of Dementia Care*, takes place at The Studio, Birmingham, on 20 September. Many of the contributors to this section will be speaking there. Our conference will showcase some of the latest thinking and practice in young dementia care, focusing on achieving improvement in young onset dementia support. For programme and bookings go to www.careinfo.org/youngdementia

empathetic and compassionate – it’s pivotal to the person living with dementia in their public life. Tell us the truth. Take us seriously.

Desmond O’Sullivan lives with young onset dementia

Whatever the next 20 years brings, please let us not repeat the mistakes of the past two decades – just this once! Cease the convenient pretence that people who experience dementia in mid-life can be supported by existing generic services. Cease hanging on to the idea of a “person-centred” approach, as if that alone will be enough to make a life worth living.

What is also needed is sufficient knowledge of the rarer dementias and a true understanding of the emotional, social and economic impact on younger people, their families and relationships. Most people with young onset dementia that I know want a life that continues to offer a rich and varied array of experiences and opportunities for personal growth.

So rather than waste time,

effort and resources, let’s accept that dementia experienced at an earlier stage in life demands a different response from us all and that it is in everyone’s interest to provide it. Let’s embed support that works and put our energies into making these supports flourish.

And then, because it is challenging to offer enabling and supportive options to unique individuals, dispersed and hidden with a multitude of different needs, wishes and circumstances, let’s work together to make it happen across the UK. Join the Young Dementia Network.

Tessa Gutteridge is director of Young Dementia UK and chair of the Young Dementia Network

After a diagnosis of early onset Alzheimer’s, it is clear that this is an emotional rollercoaster and that it severely knocks your confidence. You feel totally lost and quite useless at times and there is little anyone can say to make you feel any better. You feel lonely and very isolated most of the time. I can vouch for that, having been diagnosed

nearly four years ago now and having had to give up work at the age of 59.

One thing that would be a huge support is if there was more funding and a way to link up with a trained volunteer (a buddy) to help you continue with activities you enjoy doing but may not feel quite confident enough to do on your own. Even to the point of having someone to call and just have a chat to. A round of golf or someone to pop to the pub with on a sunny day with and who understands your situation.

People often need someone to provide practical help with light chores, cooking or shopping, and emotional support to tackle feelings of isolation or loneliness. I am still quite well and enjoy going to the gym, but there are many things I don’t do due to the lack of confidence and lack of funds. To be able to continue doing something I love would make all the difference!

Dave Laxen lives with young onset dementia

People want to feel included and treated the same regardless of illness. When dementia affects people at a younger age, it is at a time of life when they may have otherwise expected to be in employment and socially active. The same applies to family members who, by association, face social isolation and stress.

What would make the biggest difference is UK-wide commissioning and provision of age-appropriate psychosocial intervention for younger people living with dementia. Respite for carers should be part of it.

Age-appropriate psychosocial interventions take many forms and can include education about dementia at a younger age, peer support and, most importantly, engagement

in meaningful activities. These activities need to be appropriate to the interests and physical activity requirements of younger people and provide a sense of community and role.

GPs are more likely to refer people to services they perceive to be effective. Age-appropriate activities have been shown to reduce social isolation, apathy and behavioural and psychological symptoms of dementia, and to facilitate peer support, empowerment, inclusion and wellbeing. It would also enable carers to remain in work for longer with associated economic benefits.

Currently, there are few services that offer such provision – let's make it the norm wherever people live.

Dr Jacqueline Hussey is consultant in old age psychiatry, Wokingham and YPWD Berks

I'd like to see local health and social care commissioners set up contracts with third sector organisations so that every person diagnosed with young onset dementia and his or her supporters could be provided with a well informed, specialist "young onset dementia PA" (YOD-PA). The YOD-PA would be alongside the person and family, as needed, during the unwelcome "journey" of life with young onset dementia.

At present, people with young onset dementia have a raw deal. They are dealt an unexpected, untimely diagnosis and then are all too frequently discharged without suitable services and support.

The YOD-PA would be introduced following diagnosis, and over time become a touchstone, ready to respond when the person or family encountered a new need.

She or he would know how to listen and hear what is needed by the person and family. They would be well embedded with local communities, would know about young onset dementia and its impact, and local systems and services, and would have flexibility to provide, find or advocate for emotional or practical support.

This is not a novel idea – dementia advisers and Admiral Nurses perform this role - but arrangements remain too haphazard. Whether someone finds a YOD-PA is too frequently left to chance or too easily blown away by reorganisation. It would be essential for commissioners to allocate long-term contracts to ensure continuity.

Cloud cuckoo land? Surely it's not rocket science.

Jan Oyebode is professor of dementia care at the University of Bradford.

I feel the change which can make the greatest difference is to combat loneliness, as finishing work at a younger age when your peers are still working can be very isolating. The provision of enjoyable activity to participate in with others, for example exercise classes or creative activities such as painting and pottery, makes such a difference.

This support could be provided through groups or one-to-one. Groups provide company and peer support from others who can truly understand. Groups need to be in places where you feel safe and secure and where you experience no fear – you are able to just be yourself and not be judged. I like to be open and honest about my diagnosis as I find this generally helps.

Staff who provide support need to have empathy and understanding. I really feel that greater awareness and openness about dementia, such as through the media, is making a difference in changing attitudes.

I strongly believe that the support I've received from attending groups and from my family has enabled me to stay socially active, which has really assisted me to maintain my independence. I'm sure this has helped to slow down the progression of my illness.

Mick Whitfield lives with young onset dementia and writes with support from Jo Scarle, young onset dementia development officer, Worcestershire Health and Care NHS Trust

Dementia Diaries



People living with dementia from groups in the UK-wide DEEP network are using their phones (mobiles, landlines or sometimes 3D-printed phones) to record their thoughts and experiences of living with dementia as they occur. In this column the Dementia Diarists share some of their audio diaries, with the aim of highlighting the diversity of their lives, prompting dialogue and promoting understanding.

This month, three Diarists talk about specific things they have recently found stressful.



Dory Davies reflects on a noisy day. "I'm just sitting outside and relaxing after a very stressful day... I've required a walking stick lately because I'm not seeing steps and curves. Well, I lost it about three times, I lost it at different stores in the market, people were getting very impatient with me in being there at the cash, the checkout..."



Chris Norris reflects on one of the ways his frontotemporal dementia has affected him over the past five years: "I can be far blunter in my responses and less sympathetic. I seem to be losing the filter that we all have to prevent a controversial comment being said or action taken. Mostly, I am aware of this... but occasionally not... What I have been thinking or believe to be important has to be said or acted on there and then. If this does not happen, then I can become annoyed and agitated."



And Carol Fordyce recounts the recent day when she had to make the difficult decision to give up driving. "Something happened to me which shocked me. I stopped in the middle of the five-way junction and saw a red light so came to a halt. I then realised I had gone through the first set of lights but had no recollection of them... So I sat where I was and then realised the traffic coming out of the Morrisons road could not get round me, so I moved up to the island as much as I could, to let them pass.

"I then went on my green light and parked in Morrisons car park. I was shaken and just could not remember what I had done. I sat for a few minutes and then went in for my shopping. I managed to drive myself back home... I handed my keys to Brian and said, 'Put these away, I am surrendering my licence'... I made the decision, it was mine to make and I think it is the right one. So that's it, I'm now a non-driver!"

The Dementia Diaries project was started by On Our Radar and is now part of DEEP, with support from Innovations in Dementia. Find out more and listen to the Dementia Diaries at www.dementiadiaries.org. DEEP is a growing user movement of influencing groups of people with dementia, "The UK Network of Dementia Voices". For more information on DEEP visit www.dementiavoices.org.uk.

Finally, are you - or do you know someone who is - living with dementia who may like to become a Diarist? We're always looking to recruit more people, and it's very simple to record your own reports. Or you may have ideas about using the Diaries for research, media, education or other projects. If so, do contact philly@myid.org.uk. Thank you for your support!

Philly Hare, director, Innovations in Dementia