Celebrating 20 years of supporting people with young onset dementia 1998-2018
Helen’s message

My husband Clive (pictured) was diagnosed with frontotemporal dementia when he was 45. It was soon clear that there was no age appropriate support available for him or our family.

Clive’s army friends used to come round and take him out, so he could enjoy the company and activities he used to be able to do. Tessa’s research showed there were other people who needed this kind of support.

We decided to set up on our own and fundraised a few thousand pounds to take on three part-time support workers. We struggled for a name, but finally chose The Clive Project in memory of Clive.

Look how it has grown. The logic of providing a practical, useful support service proved itself. Dementia is a very isolating illness, and even more so when the person is of working age. The support we were providing highlighted more people in need, and gave us ammunition that this group of people existed, needed support, and we could provide it.

Clive died in April 1999, and I moved away from Oxford in 2008, but I am delighted that YoungDementia UK is still going strong; surviving the austerity years, and has a name and influence far beyond Oxfordshire. I hope it will continue to thrive.

Helen Beaumont, Founder

We are a unique, successful charity with a strong message and twenty years of experience to share.

Jean Ware Morphy, Founder

The founders of The Clive Project were Helen Beaumont, David Birch, Elizabeth King, Betty Rostance and Jean Ware Morphy. We would like to place on record our appreciation for the very significant contribution that they and others have made since the early years of the charity, now known as YoungDementia UK.

In the last twenty years

★ We have grown from a team of 4 to over 30
★ We have supported over 1300 people in Oxfordshire
★ Our longest support relationship lasted 12½ years
★ We created the largest dedicated young onset dementia information website in the UK
★ We launched the collaborative Young Dementia Network
Tessa’s message

Life for the extraordinary Clive Beaumont could have continued adventurous and fulfilling. This need not have ended with a diagnosis of young onset dementia. Instead his inspirational wife Helen had to fight for a life worth living for Clive, herself and their two young children. This lack of support triggered my research in 1996. The creation of The Clive Project followed in 1998. Individual support for the person with young onset dementia was the priority and following on from this, our award-winning, Oxfordshire service for people aged under 65 was born.

Twenty years on, and a name-change to YoungDementia UK later, here I am - still enthralled by the determination of the people we serve. Much has changed though our values have not. We have grown to meet an increasing need. The collaborative Young Dementia Network, our website and social media, has enabled us to reach far beyond Oxfordshire.

The profile of young onset has risen, fallen and is emerging again. It is appalling that many people are ‘lost’, neglected - even with the increasing willingness of some to powerfully advocate for themselves and others. With reducing resources, are they anyone’s priority? They are ours.

YoungDementia UK has become a trusted lifeline. We applaud the few services, organisations and groups that recognise that dementia in mid-life is different and offer support that is appropriate. Sadly, we know that there are people who still do not have the support that they need – just like Clive and Helen. So as we celebrate our 20th anniversary, the need for our national young onset dementia charity is greater than ever.

Working with people living with the condition, we have ambitious plans for the next decade and are determined to continue supporting people ourselves, raising awareness and improving services.

It remains my hope, as in 1998, that all people affected by young onset dementia will have the support they need to live fulfilling lives.

Tessa Gutteridge, Director

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Tessa Gutteridge, Director

In the last year

- Membership of the Young Dementia Network grew by 150%
- Over 2300 people received our news and information each month
- Nearly 90,000 people visited our website, an average of 245 a day
- In Oxfordshire
  - Provided 5945 hours of individual support
  - Supported 175 people living with young onset dementia and 201 family members
  - Had over 1345 attendances at our groups and socials
  - Launched Adapt, a new service for people who are recently diagnosed
Donna’s story

I joined YoungDementia UK in June 2017 as National Development Manager. The role excited me as I’m somebody who enjoys a challenge and I’m very ambitious. To have the opportunity to work collaboratively at a national level and make a difference to people affected by young onset dementia, was perfect for me.

Since joining YoungDementia UK’s fantastic team, I’ve taken a lead role in the Young Dementia Network which aims to provide opportunities for members to share knowledge and experience and encourage improved young onset services across the UK. I’ve worked alongside people affected by young onset dementia and professionals from across the country and have had the pleasure of meeting people who deliver young onset services both nationally and internationally.

I’ve connected over 60 professionals who are now sharing good practice, ideas and challenges. I’ve also put in touch parents and adult children of people living with the condition with others in similar circumstances. In a nine month period, people from over 30 areas of the UK asked for our input in delivering groups and for advice on best practice for people under 65.

Membership of the Young Dementia Network, launched in September 2016, has grown steadily to nearly 1600 members. In the last twelve months, the Network has produced a Decision-Making Guide for GPs which aims to speed up onward referrals. We have created a leaflet for Diagnostic and Memory Clinics to be given to people on diagnosis that shares national sources of support so they feel less isolated. We have also developed a young onset research area on the Network section of our website.

The Network featured at a number of major dementia conferences in 2017 and we have a busy year ahead promoting the Network’s activities. We are hosting the Young Dementia 2018 conference in Birmingham in September in collaboration with the Journal of Dementia Care. We are currently working on a public awareness raising project for GP surgeries. Lastly there is the potential for us to start a new group in Yorkshire later in 2018, so exciting times ahead. Watch this space!

In our recent survey, 93% of respondents recommend joining the Young Dementia Network.

Find out more about the work of the Young Dementia Network
network@youngdementiauk.org
www.youngdementiauk.org/young-dementia-network
Des and Valli’s story

Des was diagnosed with Lewy body dementia at the age of 60. He lives in Oxfordshire with wife Valli, and their two children Yasmina, 19 and Yousef, 15. Des’s GP referred them to YoungDementia UK following his diagnosis. Des and Valli tell their story.

‘In the early stages, I was worried I was going to die within a month. I was very worried about getting my accounts and Will sorted out and putting in applications for benefits.

‘But I wasn’t sure how to go about doing anything. If YoungDementia UK’s Young Onset Dementia Advisor Emeline hadn’t been around, I would have been completely lost. She has been a huge support with all the paperwork.

‘I would’ve retired in another five years but I’ve decided to stop work which has a massive impact on us financially. We’re both self-employed, have school fees to pay and my daughter is due to go to university in September.’

Valli continues, ‘I’m still working, although I’m working less. But no regrets about it. It is what it is. I just wanted to be at home, not only for Des but for the kids. Telling them was our main worry. We told friends and family first to create a comfort zone around the kids, so they don’t only have to come to us if they have questions, or concerns.’

‘Dementia has affected me in different ways,’ says Des. ‘It means I get more tired, I also lose things constantly; but my life is still remarkably busy. There are lots of medical appointments and I really do enjoy the YoungDementia UK get-togethers and groups.

‘They have given me confidence. People have been very affirming; I’ve learnt a lot from them. I don’t want to be melodramatic about this, but I could be at home, waiting to die, whereas I’m still living my life.’ Valli adds, ‘By going to these meetings, we can see that there is a world out there, there are people to meet and it’s nice to connect with them.’

Des continues, ‘I also get post-diagnostic support from the charity’s Adapt Project Worker, Mandy. She’s a great listener and has been very good at helping me to calm down and be in the moment.’

‘The key thing about Mandy,’ says Valli, ‘is that Des has got a space to talk to somebody who is not his wife, a family member, or friend. Mandy takes Des as he is now. The safe space for emotional and psychological support is so vital.

‘Des also sees his YoungDementia UK support worker, Liz, three hours a week. She comes to our home and he does whatever he wants to do.’

Des adds, ‘We are blessed beyond belief in all of your support; it is extraordinary.’

Supporting people in Oxfordshire

For more information about our Oxfordshire support service, groups and socials support@youngdementiauk.org | www.youngdementiauk.org/our-services-oxfordshire
How you have supported us

2017 got off to a flying start with Polly Yoncheva and Emma Williams running the London Marathon for us. The first of many supporters who ran and walked through the year. The number of fitness based challenges peaked during September with companies and individuals taking on our Every Step Challenge.

We continue to be amazed by the variety of challenges our supporters take on from head shaves (thank you Kimberley!) to making and selling Christmas cards (thanks Foster!). Music was a theme with a Music Hall night and a Soul Sisters evening among others.

A special thank you to Lyndsey Mann and her team of volunteers who arranged a major Golf Day in October and to all the companies and groups of friends who took part. After all that energy we finished the year with Coffee & Cake month. A nice sit down with a cuppa and a slice, and an opportunity to raise money and awareness.

We would like to express our gratitude to everyone who has volunteered, donated and fundraised for us this year. Every penny we received has been so vital in helping us achieve the successes mentioned in this review.
How your money is spent

**Income**

- 35% Trusts and Foundations
- 18% NHS and Dementia Oxfordshire contracts
- 21% Members
- 20% Community Fundraising
- 6% Other

**Expenditure**

- 80% Service development and delivery including staff and support activities
- 14.5% Cost of raising funds
- 5% Administration / e-office
- 0.6% Governance

In 2017-2018 our charity’s income was £438,099 and our expenditure was £470,736. It was a real challenge to reach the income we had forecast and we needed to spend funds in order to grow and evolve.

We now have a strong fundraising team in place and are ensuring that we have the resources, infrastructure and capacity to fulfill what people with young onset have asked of us - over the long term.

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**Special thanks to the following organisations**

- All Souls College
- Ammco Trust
- Ardwick Trust
- Avicenna
- Banbury Charities
- Bartlett Taylor Charitable Trust
- Blake Morgan
- BMW Group Oxford
- Bothwell Charitable Trust
- Banbury Charities
- Bartlett Taylor Charitable Trust
- Blake Morgan
- BMW Group Oxford
- Bathwell Charitable Trust
- Costello Medical Consulting
- Cotton Trust
- Cumber Family Charitable Trust
- DEEP Involvement Fund
- Doris Field Charitable Trust
- D’Oyly Carte Charitable Trust
- Esmée Fairbairn Foundation
- Forte Charitable Trust
- Helianthus Charitable Trust
- Henry Smith Charity
- Invesco Cares Foundation
- James Wise Charitable Trust
- Kirby Laing Foundation
- Lloyds Bank Foundation
- Lloyds Banking Group plc
- Lunaria Trust
- Lynn Foundation
- MCIAP Dance
- Miss WE Lawrence 1973 Charitable Settlement
- Mortgage Brain
- Mr and Mrs JA Pye’s Charitable Settlement
- N Smith Charitable Settlement
- Pangbourne College
- Persula Foundation
- Rayne Foundation
- Rotary Club of Oxford Spires
- Shanly Foundation
- Sir Jules Thorn Charitable Trust
- Sobell Foundation
- Sopra Steria
- Souter Charitable Trust
- The Good Care Group
- The Midcounties Co-operative
- Tudor Trust
- Wallingford Bridge Club
- Wardington House
- Wessex Translations
- Woodroffe Benton Foundation

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“The help that Dad and I received was super. My siblings and I wanted any money donated for Dad in his memory to go to YoungDementia UK so you can help other families in the same way you helped us.”

Sarah

For more information about how you can donate or raise funds for YoungDementia UK: fundraising@youngdementiauk.org www.youngdementiauk.org/get-involved