20 years on and still going strong!
This year is a big year for YoungDementia UK – 2018 marks our 20th anniversary!

The charity started in 1998 as The Clive Project, inspired by the unmet needs of Clive and Helen Beaumont from Oxfordshire (Clive is pictured above with their two children). Clive was diagnosed with young onset dementia in his forties. At that time there was no support available that was right for him and his family.

In 1998, with just four support workers, our Oxfordshire-based young onset dementia support service was born. Now, with a team of over 30 people, we believe we are the biggest young onset service in the country and have supported over 1300 people in Oxfordshire during our first two decades.

We will be celebrating this 20-year milestone at our garden party on 13 July. We’re also planning a 20th anniversary fundraising campaign - watch this space!

Garden Party invites
We very much hope you will be able to join us for our 20th celebrations at the annual garden party ...

Friday 13 July, midday - 3pm
The Abbey, Sutton Courtenay, Oxfordshire, OX14 4AF.
Please bring a plate of finger food to share.

If you receive this newsletter by post your invitation will be enclosed. If we email you your copy, Oxfordshire members will be sent an invitation via email.
Join our next Walk & Talk
Roger’s next three Walk & Talks will see us following the canal at Thrupp in June; strolling across beautiful Port Meadow in August and Boars Hill will be our destination in September. Join us at Annie’s tea room in Thrupp on 13 June at 11am or email Roger for information. rogerstammersx987@gmail.com

Turtle Song showstopper
The final performance of the current series of Turtle Song sessions will be on the 22 June.

A drum roll for Trevor
Kay recently began to support Trevor who has frontotemporal dementia. Trevor is passionate about football and music.

During a recent support session, Trevor needed a new guitar string so he and Kay went into Oxford. Whilst in the music shop Trevor jumped onto a drum set and began playing. The shop owners were very accommodating and set him up with headphones as a silent drummer so that he could play to music.

‘Trevor thoroughly enjoyed it. He sang along, really in his element and so happy,’ said Kay. ‘We had such a lovely afternoon.’
Give your GP our decision-making guide
If you receive our Oxfordshire News by post, you’ll find enclosed the Young Dementia Network’s ‘Decision-making guide for GPs’. The Network created the guide to help doctors identify the most common signs and symptoms of young onset and rarer forms of dementia.

The aim is to speed up onward referrals and diagnosis, which currently averages 4.4 years for younger people. We’d be very grateful if you would pass the leaflet to your GP next time you see them.

If you receive this newsletter via email and would like a copy for your GP, please email network@youngdementiauk.org

Dance Creative
These musical dance sessions again proved popular. Tim is clearly having great fun!

Here’s what some of the participants said -
‘I enjoyed myself and the music was great.’
‘It was good fun, all of it, and good exercise.’
‘I like the way Rhonda, the workshop leader, drew people out, talked about what people liked to do and incorporated it into a dance’

The Herbert Protocol - for vulnerable missing people
A new tool to help find missing people with dementia was launched in February in partnership with search and rescue teams across the Thames Valley. The Herbert Protocol records key information about a person with dementia, completed by family members or carers, in case they go missing.

Adopting the Herbert Protocol helps ensure that the police and partner agencies have the best possible information should they need to search for a missing person with dementia. The form may include whether the person is on medication, favourite places they like to visit or key people they know. The form and details are at www.thamesvalley.police.uk/about-us/publications-and-documents/herbert-protocol/
Getting involved

Setting the PACE
PACE (Positive Activists, Consultants and Educators), is a YoungDementia UK group for people affected by young onset dementia that focusses on educating others.

The group has been consulting on the new Zipabout travel app. Our feedback was accepted and the app, now nearly complete, looks fantastic. Participation was so positive for all of us, we can’t wait to use it!

Recently we discussed joining in research – both how good and how frustrating it can be. Some of us are enrolled in major studies such as Join Dementia Research, but our experiences have been quite mixed. Answering the many questions involved made it a difficult experience – and some respondents then heard nothing more. Even if they did not fit the criteria, surely a ‘thanks but no thanks’ is due? However, reactions to smaller studies seemed more positive. Interviewers visited at home: interesting and far better to talk face to face than by phone or online.

As Des said ‘What do we want? Understanding! When do we want it? Yesterday!’

Jacqui, Jonathan, Valli, Des, Wendy and Anna

We hear of new projects via YoungDementia UK’s social media or newsletters, from DEEP, or from each other. We all felt good to be contributing to a greater understanding of young onset dementia.

Deborah’s our new YODA
Starting my new role as a Young Onset Dementia Advisor brings mixed emotions. During 4½ years as a one to one support worker, I supported many wonderful people and had great fun in so doing; I will miss those special relationships. However, the prospect of offering support and information more widely across the organisation is exciting. I’ll be working with people in central and south Oxfordshire, while Emeline focuses on those in the central and north area. I look forward to meeting you over the coming months. Contact me on 07759 328666 or deborahcrawshaw@youngdementiauk.org
Readers’ writings

Putting thoughts and ideas on paper can be an effective coping strategy for dealing with difficult situations and emotions. Several readers have shared poems with us. Here is a taste of their writings.

Friends!
You must remember John?
He’s the mate you used to drink with, the smartest man you knew.
He influenced the way you dressed and how you cut your hair.
He had a passion for music and his love for life shone through.
You must remember John, because he remembers you.
So if you see him when you’re out don’t turn and walk the other way
Just come over and say hello because it would make his day!
Jan

Dementia has arrived. It’s come to stay
Although you don’t want it, it won’t go away.
Why did it arrive? Nobody knows.
Proteins in the brain, that’s what the brain scans shows.
Mick

Remembering Ronnie Jones
Ronnie was a much-valued support worker and colleague at YoungDementia UK. She was herself sadly diagnosed with dementia. I was privileged to support her, though it never felt like ‘support work’ - we were friends. We shared such happy times walking, looking at flowers, gardens and nature.

Aside from family, Ronnie’s passions were photography and books. With a photographer’s keen eye for architecture, colours and shape, and a great interest in plants. She designed the garden where she and husband Jim lived. She enjoyed the Walk & Talks and going to the Supper Club with Jim. Her face lit up radiating gentle warmth to everyone she met.

Ronnie enriched my life, and the lives of many others who knew her as a very special lady, now sorely missed.
Nicky Henderson
Hi, I’m Anne, the charity’s new Head of Fundraising. I joined YoungDementia UK in January and have had such a warm welcome! It’s been a busy first couple of months here and I have been so inspired by the stories I have heard and the lengths so many of you go to, volunteering and fundraising. Thank you so much for all that you do.

Fundraising made easier
We now have bright blue balloons printed with our logo so if you are organising an event do get in touch so we can send you some. We have also printed some donation envelopes - suitable for funeral collections, events, weddings, parties and so on. Guests at the event can pop in their cash or cheque and, by completing the gift aid declaration on the envelope, increase the value of their gift by 25%. Please do request them for your event.

Every Step Challenge
Every Step will be back in September. Simply set your own personal step goal for the month and get sponsored for your steps to raise money for YoungDementia UK. It’s that easy - run or walk it really doesn’t matter - literally every step counts!

For more information or to sign up please visit our website www.youngdementiauk.org/ every-step-challenge

Ready to Bake?
YoungDementia UK has a charity cake stall at the Coffee Café in Summertown, Oxford, on Saturday 9 June, from 10am – 12noon. We hope it will be a busy morning so need as many cakes as possible. If the cakes are as good as the ones at the event below, we’ll make a fortune! Please get in touch if you can help us.
Thank you to everyone who has fundraised and donated over the last few months.

Particular mentions for those still working on their fundraising challenges go to -

The Dementia Help Cycle Challenge team - who will be raising money for us by taking on a 330 mile ride from Aberystwyth, on the Irish Sea coast of Wales, to Aldeburgh, on the east coast of Suffolk, between 25-30 June. The team includes Peter Berry (below), who was diagnosed with young onset dementia three years ago, aged 50.

Tony Robinson who has young onset dementia and his friend Harold Jerred are completing an Oxford Canal Charity Walk. Once a month they walk a section of the canal and warmly invite you to join them. To sponsor them, go to uk.virginmoneygiving.com/Team/TonyHaroldWalkingCompanionsandFriends

Thank you to everyone who baked and brewed for Coffee & Cake month. Brownies and Victoria sponges were the top bakes, with awareness and lots of funds raised.

And finally – 26.2 miles later Dominique Kent completed the London Marathon for us, raising over £5,500! A huge thank you and congratulations! Like the proud, happy fan in this photo, we’re delighted for you, Dominique, and for all of our epic fundraisers!

To find out more about Dementia Help or to sponsor Peter and the team please visit www.dementiahelpuk.com

For help or information for your fundraising idea contact us fundraising@youngdementiauk.org or call 07591 220446
Welcome Rachel Clayton – our new trustee
Rachel joined YoungDementia UK in 2018. She lives in Warwickshire and is currently the Quality Manager for a national advice charity. She has held roles in both the public and charitable sectors including with the Alzheimer’s Society. Rachel has experience in service development and commissioning, and a passion for service quality.

Young Dementia Network seeks a volunteer
Could you spare about an hour per week to post out resource materials for the Young Dementia Network? If so, our National Development Manager, Donna Chadwick, would love to hear from you on 07752 584523 or donnachadwick@youngdementiauk.org

Young Dementia 2018 Conference
The Journal of Dementia Care is hosting a conference in association with YoungDementia UK in Birmingham on 20 September. It will focus entirely on young onset dementia. Find out more www.careinfo.org/youngdementia/

Contact us
You can contact us via email, Facebook, Twitter, phone or post. To email any member of the team, please use the format
firstnamesurname@youngdementiauk.org

Some useful contacts are

Support Service Manager
Anna Eden
07506 597365

Support Coordinator / Adapt Project Worker
Mandy Blair
07493 790921

Young Onset Dementia Advisors
Emeline Keown
07909 060430

Support Coordinator
Michelle Francis
07932 672868

Deborah Crawshaw
07759 328666

Young Onset Dementia Advisors
Emeline Keown
07909 060430

Deborah Crawshaw
07759 328666

Young Dementia 2018 Conference
The Journal of Dementia Care is hosting a conference in association with YoungDementia UK in Birmingham on 20 September. It will focus entirely on young onset dementia. Find out more www.careinfo.org/youngdementia/