Founder Trustee Jean takes a break

As one of the four Founders of our charity, then called The Clive Project, Jean Ware-Morphy has spent more than two decades, through both good and challenging times, working tirelessly to help improve services and support for people with young onset dementia. Having now completed the permitted three terms on the Board, Jean is taking a well-earned break.

Jean is far too modest to want a fuss about her wonderful work for us over the years, both on the board and behind the scenes. However, charities simply cannot function without people like Jean giving freely of their time, expertise and experience, so join us in a huge thank you to Jean for all her years of dedication.

New Trustees Wanted

At an important and interesting time in the development of YoungDementia UK, we are looking for three motivated people to join our active Board particularly if you have experience of campaigning at a national level; IT strategy development and implementation, or member engagement. If you would like to learn more, please email for a detailed role description or to arrange an initial conversation.

alisonkenny@youngdementiauk.org

Blenheim Palace generosity

Blenheim Palace has kindly donated a batch of free park and garden passes to us, valid for one-year, for use by support workers and members.

Inside this newsletter you’ll see we’re at Blenheim Palace for our ‘Walk For...’ fundraising event on 28 Sept and the October Walk & Talk so thank you to Blenheim Palace for their very kind support.
Out & About

Walk & Talk
This is a happy band of Walk & Talkers from our June walk. The next couple of outings, under the guidance of our brilliant volunteer Roger, are 18 September on Old Boars Hill 9 October at Blenheim Palace

Please note - the September walk is on the third Wednesday, not the usual second Wednesday. If you’d like to go along, contact Roger Stammers rogerstammersx987@gmail.com

Des shares his thoughts on Turtle Song
I didn’t expect to like Turtle Song. Not really my cup of tea, I thought, but I was wrong, completely wrong. The whole experience was an absolute privilege, and most importantly, great fun. It gave me a new sense of freedom, creativity and confidence. Everything was an option, nothing was off limits.

A dementia diagnosis can make the future look bleak but Turtle Song put the colour back in my life: new skills, new friends, new possibilities, just the boost I needed.

I was so touched by my first Turtle Song course with Jon and Carolyn over a year ago that I enrolled for this year’s course at the earliest opportunity. It has been brilliant – again. The thing is, if you’ve been diagnosed with a progressive, life-limiting disease, who cares if you make a bit of a fool of yourself on stage? You are surrounded by friends and supported by people who love you: what can go wrong? Remember life is for living – to the full.

So, to Carolyn and Jon, without whom there would be no Turtle Song: thank you both. Between you and the awesome band – you made us great! So thank you all. Now, where do I sign up for Turtle Song 3?

Des O’Sullivan

As another participant said, ‘The experience has been unforgettable, and for people who forget things, nothing could be more important.’

Turtle Song is a collaboration between YoungDementia UK, Turtle Key Arts and music students from Oxford University.
Jen Marks is back!
As some of you will already be aware, we’re thrilled to have Jenny Marks back on the team, bringing her special blend of warmth, sensitivity and creativity to her support work.

Jana joins the team
A warm welcome to Jana Khamis who was recently appointed as our Support Service Manager. Jana brings experience from the health and voluntary sector plus she has worked for a dementia charity before. Jana will be joining us on 2 Sept and will be attending groups and meetings during her induction to allow her the opportunity to meet with as many people as she can.

Mandy Blair, who has been the interim service manager will be starting her new role as Young Onset Dementia Advisor, supporting people in south Oxfordshire, and will be in post from 16 September.

Planning ahead
Our support has grown since we started individual support over 20 years ago and we now offer a range of groups and activities across Oxfordshire. We are spending some time looking at how we can improve our support to ensure we offer valuable, flexible and affordable support which meets your needs now and in the future and which reaches everyone with a diagnosis of young onset dementia.

Sheffield group takes off
The wide range of activities we run for younger people with dementia and their families in Oxfordshire are starting to be replicated by us in other parts of the country. Pictured here are some members of the Sheffield group who have tried Tai Chi, flower arranging and archery in recent months.
YoungDementia UK Garden Party 2019

Were you there? Did you enjoy it? In case you missed it, here are some lovely photos which, thanks to Peter Kavanagh, Phil Wakefield and Simon Hutchens, tell the story of the day with almost no need for words.

As you can see, we picked another perfect day to enjoy our annual Garden Party in the grounds of the Abbey at Sutton Courtenay.

Obviously there was a good joke doing the rounds!
The team who made the day go so well included John on drinks, Suzy and Tim (volunteers from John Lewis), our wonderful band, Michelle and Sean, the fundraising ladies, the craft group, etc, etc - too many to mention here. Oh, and of course, all of you who turned up to share the day. Thank you to one and all!
If we missed your picture, we’re sorry - there were so many superb photos we just couldn’t fit them all in. Maybe next year? Hope to see you all again then.
More food with friends

Supper Club
If you enjoyed the Garden Party and would like some more opportunities to share food and fun don’t forget the monthly Supper Club gatherings at Cassington Village Hall.

We can’t promise al fresco eating and glorious sunshine but there is always a tasty meal and entertainment - often a live performance - with plenty of time to dance or just sit and chat over supper.

The next Supper Club will be on Thursday 26 September, 7.30-9.30pm.

Further Supper Club dates and lots of other groups are listed on our events flyer that accompanies this newsletter.

Family Members group
A group has been set up for family members supporting people with young onset dementia living in residential care homes or at home with advanced dementia. The group meets monthly. For details email Deborah. deborahcrawshaw@youngdementiaku.org

Christmas Party - save the date!
Following on from the fun of the Garden Party, we’d love you to save the date of our Christmas Party. It is taking place on Thursday 12 December at Cassington Village Hall at 7.30pm.
Diagnosed with dementia - what’s next?
Our second Adapt course finished recently. Eleven participants spent five weeks covering various topics to do with young onset dementia and diagnosis. These included adapting to life with dementia, staying active and involved, sharing information and signposting to different organisations, and practical pointers for legal and financial matters.

Sessions were supported by some of our PACE members talking about their experiences and knowledge of living with dementia. They shared practical tips and coping strategies for everyday life, and gave a valuable personal perspective. One of the members attending said, 'It’s encouraging to know that there are other people in the same position as me'. Another said, 'Just listening to others has helped'.

This course aims to help people adapt to their diagnosis by meeting others in a similar situation and gives pointers to further advice and support.

YoungDementia UK has two more courses planned this year to help and support more people in understanding their diagnosis. For info contact lizrose@youngdementiak.org

Liz Rose
Adapt Project Worker
Remembering life
- then & now

Remember the 1970s?
Here Phil recalls his wonderful memories from the 1970s. Was it like this for you too?

Home and homelife
- House - end terrace, indoor bathroom, no central heating, coal fire in the front room that I liked to light to send burning paper up the chimney.
- We knew our neighbours - could say ‘hello’ to about 10 or 12 families who lived on our long street.
- One television set. Twin tub washing machine, filled from the kitchen tap with a special hose. Stereo radiogram - a big piece of furniture housing a joint record player/radio.
- Ambition - to be an actor or maybe a vicar because they seemed to work only on Sundays!

Spending Money
- 1971 - Decimalisation!
- My weekly pocket money - about 10-20p. A chocolate bar was 4p or 5p but I preferred penny chews and Flying Saucers.
- We bought groceries at the small local Co-op supermarket but we also had a corner shop on our street.

Transport
- We had a car but I walked

the 10-15 minutes to school.
- Holidays were often at family in London or Whitstable in Kent, taking about seven hours by coach.

Pop Culture
- We listened to the Top 20 on Radio 1 on Sunday nights and recorded our favourite hits on a cassette recorder using a microphone next to the radio. I didn’t buy records until I was about 15, when me and my sister bought second-hand Juke Box singles.
- I persuaded mum to buy me a denim jacket - I thought it looked cool, she thought it looked scruffy!

‘Living a new life’
Back in March, three Brookes University media studies students spent a fortnight following Des O’Sullivan around Oxford, recording his daily activities. The footage was edited into a fantastic six-minute film, titled ‘Living a new life’ which mixes footage of Des discussing his life since his diagnosis, with volunteering at The Oxford Food Bank and family life. You can view the film on our YouTube channel https://youtu.be/MFvSX19I9I8

We hope you like it!

9
9-15 September is Remember a Charity Week. It’s a campaign by over 200 charities to raise awareness of the importance of making a Will.

Making a Will is one of the most important things each of us will ever do. Your Will is your chance to take care of everything that’s important to you, starting with your family and friends. Many people believe that writing a Will is complicated, or only for the rich and famous, but in fact it’s valuable for all of us and relatively straightforward.

Why make a Will?
• Reduce the burden on the loved ones you leave behind.
• Protect your assets and help reduce the impact that inheritance tax and residential care fees can have on your estate; protecting your assets for loved ones.
• Ensure all your assets are dealt with correctly, with debts paid and items going to the people you wish to receive them.

When making or updating your Will the recommendation is that you should always seek professional advice. Our website has a guide to the different ways you can get started making or amending your Will.

www.youngdementiauk.org/legacies

Remember a Charity week is also a chance to talk about the amazing work that charities like ours can do, thanks to gifts left in Wills. We are very grateful to our supporters who consider remembering us in this way. YoungDementia UK is on a mission to ensure that no-one faces young onset dementia alone. By leaving a gift in your Will you can be part of that mission beyond your lifetime.

To discuss leaving a legacy in your Will to YoungDementia UK please contact Anne on tel 07591 220446 or email annebajorek@youngdementiauk.org
Sahara Trek
For the more adventurous, another way to help ensure no one faces dementia alone is by taking part in an epic challenge of a lifetime. For the Sahara Trek you will join a team of YoungDementia UK supporters, UK based leaders and doctor along with a charity representative on a four day trek in the Sahara.

The team will trek through ever-changing landscapes, climb to the top of dunes, witness the stunning Sahara sunrise and sleep under the stars. Help us to raise vital awareness and funds so we can continue supporting people living with young onset dementia to adapt and live life well.

This trek is ideal for people who are short of time because it’s just a short haul flight to Morocco and the whole challenge is six days in total, with four days trekking. Visit www.youngdementiauk.org/sahara-trek for more information or contact Claire, her details are above.

Walk For...
Join us on the 28 September 2019 for our first Walk For... at the beautiful Blenheim Palace. Walk For...yourself, for a loved one, for everyone who is or has been affected by young onset dementia.

Join us to celebrate living life or to remember a relative or friend. Enjoy the stunning park and gardens of Blenheim Palace and then celebrate your achievements with other YoungDementia UK supporters at our celebratory picnic.

By being sponsored to take part you can help us ensure no one has to face young onset dementia alone. Register your place today at www.youngdementiauk.org/walk-for

Email Claire Smith clairesmith@youngdementiauk.org or tel 07840 744559
Parkinson’s disease study needs volunteers
If you are 50-75, diagnosed with Parkinson’s disease in the last six years and would be interested in taking part in a study on the effects of Parkinson’s medication on learning memory, the Department of Psychiatry at the Warneford Hospital would like to hear from you. To find out more phone 01865 618245 or email pdcognition@psych.ox.ac.uk

Moving Music Concerts
Monday 21 October at 11.30am and 2pm at Radley College, near Abingdon. People with dementia welcome, tickets £5 payable in cash on the day, carers free, lots of parking, accessible venue. For info or to reserve your place places, email their new email address movingmusicconcerts@gmail.com

Talking Space Plus CBT course
Talking Space Plus will be running Cognitive Behavioural Therapy group sessions for family carers of people with dementia for 12 weeks from Thursday 12 September to Thursday 28 November, 2pm-3.30pm at Abingdon Mental Health Centre, Abingdon Community Hospital, Marcham Rd, Abingdon OX14 1AG. For more details, or to self-refer, phone 01865 901222, email talkingspaceplus@nhs.net or complete the online form on the website www.talkingspaceplus.org.uk

Contact us
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