Connie’s Colander – speaker opportunity

The Library at Carterton is hosting a thought-provoking play about young onset dementia on Tuesday 25 June at 7.30pm.

Connie’s Colander tells the story of retired domestic science teacher Connie who is facing dementia with the help of her daughter Emily. The play shows the changes in their relationship and the impact of Connie’s young onset dementia has on them.

A short Q&A will follow the play. If you’d like to be part of the expert panel and share your experience of dementia, they’d love to hear from you. Email Gaye Poole gaye@humanstorytheatre.com

Book your FREE tickets here humanstorytheatre.com/shows/ or contact Carterton Library, tel 01993 841492.

Not just any party - this is our Garden Party!

This year’s Garden Party is fast approaching so put the details in your diaries and we’ll look forward to seeing you there. Invitations will be sent via email shortly. If you get this newsletter by post, your invite is enclosed.

Friday 12 July, midday-3pm The Abbey, Sutton Courtenay Oxfordshire OX14 4AF

Walk & Talk

Meanwhile, if you want to join Roger and our regular Walk & Talk folk, seen here on their April walk, here are the next dates and locations - 12 June, Annie’s Tea Rooms, Thrupp 14 August, Port Meadow 18 September, Boar’s Hill 9 October, Blenheim Palace.

For more details, or to tell him you’re going, email Roger rogerstammersx987@gmail.com
Good Luck!
We’ll miss you Simon

Simon Warren has been a stalwart of the individual support service since 1999, when young onset dementia was just starting to be acknowledged. Since then he has built many truly wonderful support relationships, including one lasting 17 years and one 10 years! But now he’s decided to take a break and ‘retire’.

We’ve lost count of how many times he has been described as, ‘the kindest person I know.’ That kindness and compassion have been the bedrock of his support, gaining people’s trust and acceptance, and connecting with them, even in the toughest of circumstances.

Simon’s colleagues hold him in the utmost respect, but maybe those he has supported sum him up best. ‘He is one in a million’, ‘Simon is absolutely brilliant’, ‘He is so gentle – he just knows how/what to do,’ ‘A diamond geezer. He’s my friend. I look forward to Fridays as the highlight of my week.’

Here’s to you Simon - and good luck from all of us!

A fond farewell to Emeline

Emeline Keown, joined YoungDementia UK in 2010 as a Family Support Worker and later a Young Onset Dementia Advisor (YODA). For over nine years, she has listened, guided and supported family members, using her innate ability to build trust and excellent relationships.

Emeline has been instrumental in developing our connections with the clinicians at the Cognitive Disorders Clinic which has enabled us to support people from the moment of diagnosis. She has always had a special interest in bvFTD and set up a group specifically for family members which has been a tremendous support for those who attend.

Emeline’s commitment to every person she has supported has been invaluable. Over the years she has been described as ‘a lifeline,’ ‘a godsend,’ and, ‘beloved and wonderful.’

Emeline is sadly leaving us on 19 June. We send our very best wishes for the future - we’ll miss everything about you.
With summer approaching, thoughts turn to holidays and outings. Travelling with a person who is living with dementia might seem like a tall order but with thought and planning you can still enjoy a break away from home. Here’s some advice from a couple who have just been away.

Jane’s holiday tips
I’ve realised that dementia isn’t something you can get away from. It’s with you every second, of every minute, of every hour, of every day, wherever you are. There really is no escape.

That’s why, if you plan to go away, it’s important to put strategies in place which make life comfortable for everyone. We had a great few days away recently and it made us feel almost ‘normal’.

So here are my top tips.

• Be prepared to be woken in the night. One night my husband Ash woke in a panic not knowing where he was, but once I reminded him he went back to sleep.
• Don’t plan too much, and definitely not more than one thing in a day. We walked every morning then read, listened to music or napped in the afternoon.
• Organise something to keep your partner occupied whilst you are packing up. I asked Ash to walk the dog which was not only useful, it gave him a purpose and meant that everything went smoothly.

The main thing we learnt was that planning does work. Because we had planned so carefully, we knew exactly what was going to happen and when, which meant we were confident about the whole trip. This confidence was then absorbed by Ash and he was relaxed because he knew, however subconsciously, that he had nothing to worry about.

Jane’s husband Ash was diagnosed aged 58. She writes a regular blog where she shares their experiences. You can read it here www.memoryfortwo.com
The Young Dementia Network has created special cards for people living with young onset and their family members / carers that they can show to people if they are in a situation where they may need help. Printed versions of the cards will be trialled in Oxfordshire soon. If you’d like a copy of either the card for a person who has young onset, or the card for a family member, please email network@youngdementiauk.org

The Network has also recently developed a Personal Checklist, in collaboration with Oxfordshire member Des O’Sullivan. It is intended for people who have concerns about young onset dementia, to help them record the symptoms that they are experiencing for discussion with their GP. You can view the personal checklist here www.youngdementiauk.org/personal-checklist

Helping others to Adapt
Last year, we held a film day where 10 of our Oxfordshire members who are affected by young onset dementia were filmed speaking about three issues that particularly affect them. The footage has been edited into three films - ‘Being a parent,’ ‘Employment and keeping active’ and ‘Who and how to tell’ – which are now available to watch and share.

We hope the films will help to educate and inform people about young onset dementia and be of particular use to people who have been newly diagnosed and those who support them.

In the words of Judith van de Kamp, ‘The films are inspiring. It’s good to know that you are putting young onset dementia on the agenda and helping people and their relatives cope with it.’

You can watch the Adapt films here www.youngdementiauk.org/adapt-films

Jacqui - film participant
Living with bv-FTD
Elaine’s husband Steve has behavioural-variant frontotemporal dementia (bv-FTD). She reflects on their journey and on attending our dedicated FTD support group.

I enjoy going to the new group for people affected by bv-FTD at Witney. We can chat, laugh, and even cry, about our experiences. It’s the one place to feel people understand our problems.

Some of the people who go are only in the early years of this journey. From my experience, I found those early years very tough indeed. Shaping our new life to fit both of us was hard as Steve couldn’t be left. Four years in, I finished work and began 24/7 caring and being together, so money was tight, but we coped.

Lots of problems crop up but I find ways to overcome them, as do other people. Sometimes the problems are unique but some are common to others.

Now, ten years on, I know so much more than I did at the start. At the group I’m never sure if they really want to know what is to come. Would they prefer not know? I’d thought of not going to the group any more but I am told ‘yes’, they may not like the sound of the path ahead but they listen, and they support me too.

I feel the lucky one to have come this far and it feels more manageable now, although still very tough. Social Services are very much involved and now provide me with more money for care so, if at all possible, do ask for help. You cannot do this for long without help.

Elaine Biles

Monthly bv-FTD group
We now have a monthly group for family members of people living with bv-FTD. For details contact Mandy Blair.

Moving Music Concerts
The next Moving Music concert is on Friday 21 June, 11.30am and 2pm, (half an hour earlier for refreshments), at Radley College, OX14 2HR. Contact 01865 251305 for details and bookings.
Fundraising

Walk For…
Would you like to join us on the 28 September for our very first six mile ‘Walk For …’ event at beautiful Blenheim Palace?

You might choose to Walk For a loved one or even Walk For yourself. Come along to walk and remember a relative or friend, or simply to enjoy the walk, celebrate life and raise some much-needed funds. Enjoy the beautiful grounds and picnic afterwards with other YoungDementia UK supporters to celebrate and share our achievement.

By being sponsored to take part you can help us continue supporting people and families facing young onset dementia. Register for your place at www.youngdementiauk.org/walk-for

Sahara Trek
Or how about joining a team of YoungDementia UK supporters on a short-haul flight to Morocco? Then spend four days trekking through the breathtakingly beautiful Sahara Desert. Sleep under the stars, witness the stunning sunrises, sunsets and vast dunes. You will be guided by the UK trek leaders, UK doctors and a charity representative throughout, from initial preparation to the end of the trek. What a journey!

For more information visit www.youngdementiauk.org/sahara-trek

Tara Patterson
Catherine Kiely
More fundraising news
It has been a busy few months for the fundraising team here at YoungDementia UK. We watched the fantastic Wendy, Anna and Rachel (above) take to the skies and jump out of a plane at 10,000ft, raising over £5000 between them!

We are really excited about the future of the charity, so why not join us and help ensure that no one faces living with young onset dementia alone. Visit the ‘get involved’ section of our website.

We have been sad to see our Trusts Fundraiser Alex Taylor leave for his well-earned retirement. However, it’s great to welcome Tara Patterson to the team. Tara has a wealth of experience and has hit the ground running, after a short handover with Alex.

We’re also delighted to have Catherine Kiely join us to manage our database and provide support to the team!

... and thanks, as always
Thank you to all our supporters who have been out and about fundraising for us; we’re sorry we can’t mention everyone. However, retailers and customers alike have been great at supporting us recently through their various ‘green token’ schemes!

- Thank you to the staff and customers of Oxford John Lewis for raising £1268 with their green tokens.
- Another thank you for £314, raised by staff and customers at Waitrose Oxford, Botley Road through the green tokens scheme.
- Thanks to the staff and customers at ASDA Wheatley whose green tokens raised £500 for us in their store.
Phil’s ‘Fabulous Flowers’ photography exhibition wows visitors
On seeing this first-ever exhibition of his photographs, Phil beamed from ear to ear. After posing for several photographs, and seated with his first ever glass of Bucks Fizz, support worker Simon asked Phil how he thought it had gone. ‘Great!’ said Phil, a Yorkshireman of few words, summing it up absolutely perfectly.

NIHR - Clinical Research Network Thames Valley & South Midlands
Sophie Pueschel, a research nurse with this group is keen to hear from you if you’d like to take part in their NHS dementia research clinical trials. For details contact Sophie on 01865 234310 or Sophie.Pueschel@nhs.net

New Community Equipment provider for Oxfordshire.
NRS Healthcare has taken over from Millbrook Healthcare as the provider of equipment such as beds, hoists, commodes, walking frames and stair and grab rails, supplied to aid people in their own homes. They will deliver, collect and maintain the equipment. Find out more from NRS at enquiries@oxfordshire.nrs-uk.net or 01869 225420

Exciting job opportunity at YoungDementia UK
We’re seeking a full time Support Service Manager for Oxfordshire and bordering counties. For more information and application forms go to www.youngdementiauk.org/jobs
Closing date – 17 June 2019 at 9 am. Interview date – 27 June 2019

Contact us
To email any member of the YoungDementia UK team, please use the format firstname.surname@youngdementiauk.org

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