2016 in brief

Karen was fortunate, help was on hand when she needed it. There are over 42,000 people in the UK living with a diagnosis of young onset dementia and yet services for younger people are few and far between.

A diagnosis of dementia in the prime of life is devastating. People living with young onset and their families need access to someone like Emeline to provide practical and emotional support and guidance, whenever help is required.

YoungDementia UK (YDUK) believe that every person whose life is affected by young onset dementia should have support so they are able to live their lives as fully as possible.

Support that is age appropriate, enabling, consistent and tailored to their needs and wishes.

When they gave me the diagnosis, they shook my hand and left me to my own devices. Meeting people my own age in a similar situation has been very important, I have made friends and feel less isolated.

Jacqui, a YoungDementia UK member, was diagnosed with dementia at the age of 49.

The world seemed to stop moving and I watched our future disappear before my eyes.

My husband was only 45 years of age. I felt that I had been punched in the chest and I was waiting to hit the ground.

That never actually happened. Emeline stood with us, and it was as though she scooped me up just before I hit the floor.

She was fully understanding of the fact that I felt drained. She encouraged me to contact her if I needed to talk, but assured me that she would be in touch the following day.

Every time I recall that day I always think back to Emeline. She was so empathetic, professional, caring and understanding. I can honestly say I would not have got through the day without her.

Karen, speaking about YoungDementia UK’s Young Onset Dementia Adviser service

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Support alongside

The close working relationship that has developed between the Cognitive Disorders Clinic and YDUK is now a cornerstone of the clinical service for younger people with dementia throughout Oxfordshire and the surrounding counties.

It is a model of excellence for other memory clinics around the country. We are indebted to YDUK and their funders for the fantastic service they provide.

Dr Chris Butler, John Radcliffe Hospital

Regular attendance at the Cognitive Disorders Clinic in the past year enabled our Young Onset Dementia Advisers to connect with people living with dementia and their family members at the point of diagnosis.

They understand the impact of young onset dementia on the whole family and provide

- a vital source of specialist information
- help with financial and legal matters
- signposting to local groups and services
- practical and emotional support
- specific advice for people who live alone.

Adapting positively - supporting early

We are increasingly supporting people at an earlier stage and are developing this as a specific strand of our work. This early intervention has many benefits

- help to better understand the diagnosis
- enabling prompt access to treatment and support
- more time and capability to plan for the future
- reducing isolation and maintaining independence for longer.

Meeting others

Throughout the year, we offer a range of regular opportunities for younger people with dementia and family members to come together, enabling everyone to share experiences, socialise and gain mutual support.

Our group activities increased in the last year with the addition of arts group Creative Minds. Our monthly Café was renamed the Supper Club, to better reflect what the evening offers and partnerships were formed with Turtle Key Arts and the Ashmolean Museum.

Future activities

We have launched PACE (Positive Activists Consultants & Educators), a new group which aims to educate others about dementia and are looking forward to working with the Pitt Rivers Museum in the coming year.

Individual tailored support

We also offer active support sessions which are tailored to individual needs. We enable people with young onset to

- build their confidence and regain independence
- connect with friends and their local community
- be supported to take part in activities they enjoy.

We are now working with Age UK Oxfordshire and Guideposts to provide a countywide service, Dementia Oxfordshire.

In the last year in Oxfordshire we...

Supported by phone, email and face-to-face visits
172 family members and 126 individuals with 15 different types of dementia.

Provided 59 younger people with dementia
8100 hours of active, individual support.

Set up over 110 group and social opportunities attracting 1100 attendances.
Working together nationally

Dynamic and determined

Our national programme is focused on bringing about change to policies and services, so people like Karen and Jacqui don’t feel alone. We are working with partners across the UK to raise awareness and increase understanding of the condition. We are collaborating with researchers, clinicians and families to find out what support is most effective and to define a clearer route to diagnosis and beyond.

A key part of our plan is the creation of a Young Dementia Network. It will bring together those affected by young onset, as well as professionals and people who are interested in the condition, to form a focal point and opportunities to share experience and learn from each other. The Network will launch in late 2016.

For over a year, we have led a collaborative group which will guide the Network and its activities. This small group of dedicated individuals are drawing on their knowledge and connections to help steer us forwards, focusing on priorities recommended by people living with young onset at our conference in 2014.

‘It is one of the best pieces of work I’m involved in currently,’ says Keith Oliver who was diagnosed aged 55, pictured centre below with Kate Swaffer and Wendy Mitchell, both also living with young onset.

In 2015 we secured funding for a National Development Manager. As well as launching the Network and coordinating its activities, we’ll also explore how we can encourage more face to face support in other areas of the UK.

At first Liz didn’t want to meet other people with dementia, but it’s the best thing we’ve done.

We’ve got involved in giving talks and in research to help others.

Pat’s wife Liz was diagnosed with PCA aged 56.

Learning together

We set up a joint programme with EDUCATE, a dementia group from Stockport. It was funded by the European Foundations’ Initiative on Dementia.

This included a Tea & Talk afternoon which was an international gathering thanks to the presence of Kate Swaffer, a renowned dementia campaigner from Australia. The event was an opportunity for people living with young onset to share their experience of educating others, and gain confidence in public speaking. Whilst our Celebrate & EDUCATE event in March 2016 was a celebration of the creative achievements of people living with young onset.

In September 2016, we are holding our second annual conference in partnership with the Journal of Dementia Care which we hope will attract over 200 people.

Keeping in touch

‘I was feeling isolated and terrified about the future but your website and emails cheered me up. You’ve really given me hope,’ wrote Phil, after his diagnosis last year.

We continue to develop our website and use our social media pages and newsletters to share news, events and articles with a young onset focus.

- Our website has been visited over 120,000 times.
- During Dementia Awareness Week in May 2016 our posts and tweets reached over 50,000 people on both Facebook and Twitter.
- Our newsletters are sent to over 1600 people.
- In late 2015, we released a short film, ‘Make a Point About Young Onset Dementia.’
- We will create a new support-based film in 2016.

Robert was diagnosed with frontotemporal dementia in his late-30s. His sister Lucy told us, ‘Rob was too young for services for older people and too old for younger services. No one locally helped us or could advise us.

My parents had to fight to get him support.’
Thank you to all our funders, supporters and volunteers. With your support we will be able to achieve our goal of reaching out to every person with young onset dementia in the UK and together ensure excellent information and support for all.

I live in Denmark so only see Mum one weekend in three. Whenever I see her, the first thing she tells me about is her latest trip out of the care home with her support worker Paula from YoungDementia UK. It really is the highlight of her week and adds immeasurably to her quality of life.

Charlie ran the London Marathon in April 2016, raising over £1500 for YoungDementia UK.

Special thanks to the Esmée Fairbairn Foundation, the Tudor Trust and the Henry Smith Charity whose generosity has enabled us to develop our national programme and the many individuals who fundraised for us this year. For a full list of our supporters go to www.youngdementiauk.org/our-supporters

Facts & figures

Income
- Trusts & foundations - 40%
- NHS & social services contracts - 22%
- Support services - 25%
- Community fundraising - 13%

Expenditure
- Service development & delivery including staff & support activities - 83%
- Cost of raising funds - 10%
- Administration / e-office - 6.5%
- Governance - 0.5%

In the last financial year our charity’s income was £438,968; expenditure was £420,749. We have to fundraise for more than half of our income and depend on voluntary contributions.

Our team of 33 works from home offices using cloud based IT solutions, meaning we spend very little on office overheads. It makes our services professional yet flexible and enables us to invest in development and supporting younger people living with dementia.

Money awarded to us by the Oxfordshire Community Foundation’s Future-Building Fund has been invested in Raiser’s Edge software.

This software is enabling us to manage our fundraising efforts much more effectively, making it easier to communicate with our members and supporters and allowing us to efficiently connect with an increasing number of people and organisations.

Detailed accounts for 2015-2016 are available on our website.