Our goal is that by 2022 everyone affected by young onset dementia has access to specialist support to adapt and live life.
Making a lasting difference

YoungDementia UK is a national charity supporting people with young onset dementia and their families to adapt and live life.

We started our work in Oxfordshire over 20 years ago, evolving a pioneering range of support services with people living with young onset dementia at the heart of what we do.

Sadly the majority of the 42,500 people affected simply do not have the support they need to make the most of their changed lives.

People with young onset dementia tell us that if they are better supported, feel well-informed, and can connect with others to share their story or drive change, this gives them the opportunity to continue a life that they value.

They say that it is possible to create new friendships, make a worthwhile contribution and enjoy both fresh and familiar experiences.

This is not to deny the stark reality of living with a progressive, incurable disability – it is to challenge all of us to make sure that we play our part in supporting people well – better than in the past.

So here we are, YoungDementia UK, striving to make a lasting difference to enable each person, wherever they live, to make the most of their lives, now and in the future.

Tessa Gutteridge, Director

Living as well as you can with dementia is all about adapting. Adapting to new ways to enable us to live better for longer with dementia.

Wendy Mitchell, dementia blogger, author and Young Dementia Network steering group member

Young onset dementia - did you know?

- Reliable incidence and prevalence numbers are not known. It is estimated that only around 40% of the expected numbers of younger people living with dementia actually have a diagnosis.

- Finding out an accurate diagnosis takes on average 4.4 years, double the time for an older person.

- There are over 120 different causes of dementia and people with younger onset are more likely than older people to have a rarer type of dementia.

- Early symptoms are often not just memory - personality, behaviour, planning and decision making, vision, balance, mobility, language and understanding can also be affected.

- There are considerable emotional, psychological, work, financial and social impacts that affect the person with young onset dementia, their partner/spouse, children, parents and other family members. This needs to shape the support that is provided.

- A recent survey of Mental Health Trusts indicated just 25% of respondents had access to age-specific support, 14% to appropriate respite and 11% to appropriate long-term care.
Our plans for 2019-2022

We know there is a great need for support across the UK for people and families living with young onset dementia and it is this need that drives us forward. Over the next three years the staff, trustees and volunteers at YoungDementia UK will build on the charity’s innovative work in Oxfordshire and Sheffield to offer support to people across the country in a way and at a time that suits them.

Amanda Stratford was appointed as our Chair of Trustees in July 2018. She is also Healthwatch Cornwall’s chief executive and has over 25 years experience in the third sector.

Over the next three years, we plan to help more people across the UK with young onset dementia and their families to adapt and live life

- By improving our digital services and by increasing local services through the creation of new regional young onset dementia hubs
- By building on our expertise to provide the national voice for the needs of people affected by dementia in mid-life
- By continuing to innovate and collaborate to improve young onset dementia services.

What’s important to us

Our vision
We want to help create a society where every person living with young onset dementia is valued and has the support they need to adapt and live life.

Our values
- Positive and enabling
- Inclusive and collaborative
- Creative and inspirational

And always centred on the person living with young onset dementia and their family.

Our mission
- to work collaboratively with people with young onset dementia and their families, professionals and organisations to extend and improve services
- to provide directly a range of specialist services for people with young onset dementia and their families from diagnosis onwards
- to promote a better understanding of young onset dementia amongst professionals and the public.
We have provided active individual support to people living with young onset dementia, as well as a busy programme of groups and social activities in Oxfordshire for over 20 years. This plays a vital part in helping people to come to terms with their diagnosis and adjust to the changes in life that it brings.

Our Young Onset Dementia Advisors connect with people at the point of diagnosis at the Cognitive Disorders Clinic and provide ongoing practical and emotional support to people with a diagnosis and their family members.

We have built on these well-established services with a new programme of support specifically designed for people who have been recently diagnosed which we call Adapt. This early stage support is offered via one to one support sessions, a five-week course which is delivered alongside people living with the condition and through our Adapt films which we have created with members to share personal experiences on subjects relevant to people who are newly diagnosed.

The progressive nature of dementia requires constant adjustments. We have set up a peer support group for people affected by behavioural-variant frontotemporal dementia and a group for family members whose spouse / partner has moved into residential care or is at a late stage of dementia to enable them to share experiences with others, to help them to cope and adjust.

In January 2019, we launched a popular monthly support group in Sheffield enabling up to 30 people to socialise, share experiences and take part in sports and crafts activities.

I feel like we’ve been caught in a safety net. This course is a life-saver. It’s been so positive to meet other people who are sharing the life journey with all its hurdles.

Ken Teasdale, family member and Adapt course participant

In the last year we have...

Provided 5,325 hours of individual support sessions to people who are living with young onset, increasing their social interaction and physical activity

Provided 1,932 hours of support to younger people with dementia and their family members via our Young Onset Dementia Advisors helping them to be better informed and more confidently plan for the future

Run a five-week Adapt course and provided 75 hours of individual support to people who are newly diagnosed to help them to adjust

Launched a group in Sheffield enabling 30 people a month to try out sports activities, socialise together and access peer support.

In the coming year, we plan to increase the number of people we support by launching a digital service, creating a model for regional young onset dementia hubs which act as catalysts for local support and starting a pilot hub in a new location or two!
When Phil stepped into the lounge with his daughter by his side to see the exhibition of his photos for the first time, he just beamed from ear to ear.

Simon Hutchens, support worker

In their weekly one to one sessions, Simon supports Phil (right) to take photographs. Phil exhibited a collection of photos titled ‘Fabulous Flowers’ at the care home where he lives in Oxfordshire. Phil was overwhelmed by the positive reaction to his photos from visitors, giving his confidence a real boost.

I’ve been going to this group since it started and have really enjoyed it. It has been a godsend. I feel safe, welcome and able to be myself without having to try and hide anything. I can’t imagine not having it now.

Dan McIntyre, 42

Dan is a member of the monthly YoungDementia UK Sheffield group. He is pictured with group coordinator, Natasha Wilson.

You can read Dan’s story on our website www.youngdementiauk.org/dans-story
Information is empowering. Being informed and having practical tools and resources makes a tremendous difference to how confident people with young onset and their families feel and how they live. With that in mind, we use a variety of platforms to share relevant information.

Our website, newsletters and social media enable us to regularly communicate news, resources and events information with our ever-growing audience.

In addition, our biennial Young Dementia conference organised in partnership with the Journal of Dementia Care, external conferences, training sessions, workshops and events all provide wonderful opportunities to connect with others and share ideas and learning.

The Young Dementia Network is a vital part our work. It is a YoungDementia UK initiative for people living and working with young onset dementia. Free to join, it has over 2500 members and is guided by a collaborative group.

During the year, with the Young Dementia Network members, we created a series of new young onset focussed resources. This includes newly-launched young onset dementia ID cards, designed to help people who are living or supporting someone with a diagnosis, to explain to others in a public situation that they may need help or understanding.

The Network has created a range of leaflets, posters and graphics for doctors’ surgeries to help raise the profile of young onset dementia and to encourage people to discuss any symptoms of concern with their GP.

Further to this, the Network has published a Personal checklist to be used to record symptoms and to aid a conversation with a GP or health professional.

In the coming year, we will connect with people with young onset dementia and their families to learn more about their needs, pressure points and what works well for them, and enhance the information and resources available to them and the professionals supporting them.

In the last year we have...

Signed up over 1,400 people via our website to keep them informed about young onset news
Welcomed over 93,500 people to our website for information, personal stories and signposting
Developed a series of new young onset dementia focussed resources.

Distributed over 2000 clinic leaflets to diagnostic services with over 86% of survey respondents rating the information provided excellent or good
Shared the highly valued Decision Making Guide for GPs with over 12,000 surgeries across the UK. One GP told us, ‘It is clear and simple with useful tips on things to consider.’
If only we had seen this earlier. It might have helped us get an earlier diagnosis for my 41 year old nephew.
Karoline, family member

This is excellent. It gives clear information on the support available nationally. I'm grateful to have it to signpost my young onset patients to sources of support.
Survey respondent

You can download these resources here www.youngdementiauk.org/young-onset-dementia-resources
To find out more about the Network email network@youngdementiauk.org
Or visit www.youngdementiauk.org/young-dementia-network
Many people tell us that young onset dementia has affected every aspect of their lives including their relationships, sense of security, well-being and futures. And every year, around 4,000 more newly diagnosed people are facing those difficult changes without adequate support, their needs hidden or neglected.

No single organisation can offer all that is needed but by working collaboratively with others who share the same passion and purpose, we are determined to improve that support.

Changing policies, standards and practice at a national level is a vital aspect of the Young Dementia Network, our collaborative initiative. We want to ensure that young onset is explicitly part of all dementia plans, that there is an expectation and an obligation to establish high quality services for all people wherever they live. This is why we created the Network in the first place. We are so appreciative of the high-profile people affected with young onset dementia and professionals who contribute their expertise tirelessly to this vibrant Network.

Our current work, and an excellent opportunity resulting from the Network, is the inclusion for the first time of young onset dementia within the Department of Health Dementia Challenge initiatives. Here, with Young Dementia Network leading, we are seeking improvements in the accuracy of the data available on numbers of people affected — this helps in strengthening the case for better services. We also want a diagnostic service for all people with suspected young onset which is timely, accurate and compassionate, and continuing support for all people and their families provided by a trained, knowledgeable team who understand young onset dementia.

Some may be surprised that this is not already available. It is not. This is why the Young Dementia Network is so important in casting a light on young onset dementia inequalities.

The Network’s research group held the second annual event to focus on priorities for research chosen by Network members — employment, health and social care education, and family support. The Network’s best practice care pathway includes a specialist worker for advice and information. Most advisors though do not have this knowledge. So, our Oxfordshire PACE group of activists and educators and Lifting the Cloud group from Derby city, funded by a DEEP grant, are using their experience to create guidance for advisors to prompt important conversations at the right time.

In the coming year, as part of the Young Dementia Network, we will drive improvements to services through promoting the adoption of our comprehensive care pathway and by developing and promoting accredited tools and standards for use by commissioners and professionals.

We will strengthen our existing relationship with key research groups such as The Angela Project to ensure our work is informed by evidence of good practice reported by younger people with dementia, family members and professionals.

In the last year we have...

- Enabled people with young onset dementia to contribute to policy recommendations including those of the Royal College of Psychiatrists for NHS Mental Health Services
- Provided consultancy in Derbyshire to develop specialist training for dementia professionals
- Further strengthened relationships needed to change national policies and practice through the collaborative Network
- Identified service needs with people with young onset dementia and professionals in south and west Yorkshire
I attended the Network’s research event. There were some very interesting talks. A group of us who live with dementia discussed where we want the research to go next. I felt we achieved a lot and I met some fabulous people.

Tracey Shorthouse, living with young onset dementia and Network member

This is what we need – a checklist designed by people with young onset dementia, for those who support them.

Lindsay, living with young onset and member of Lifting the Cloud

Lifting the Cloud, Derby city (middle left) has worked with PACE, Oxfordshire (middle right) on a year-long project to create young onset dementia advice guidance.
Fundraising update

Our year started and ended with marathon running and fundraising efforts. Congratulations to Dominique who completed the London Marathon 2018 and Zofia who took on the Reading Half Marathon 2019.

In between, three amazing supporters jumped out of aeroplanes! Thank you Wendy, Rachel and Anna.

There were no limits to the variety of ground-based challenges from Mangesh’s triathlon, to Tony, Harold and Lesley’s long distance canal walk and Peter’s epic 330 mile cycle ride. Anna and friends went carol singing and held several book sales.

Christmas was a very busy time with our first national raffle and our Christmas Appeal. Many supporters also fundraised via Facebook this year to mark special birthdays.

We would like to thank everyone who took part in our first Thames Walk in March and would love to see many of you at our March 2020 event.

There are also many people who regularly give us their support from collecting used stamps to public speaking. Larry, Sharman, Dave, Rick, Sarah and so many more - you are all amazing.

Our gratitude goes to everyone who has 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. Thank you.

My dad was diagnosed at 52 with Alzheimer’s and vascular dementia. Along with my sister, brother and five of our children, we did a sponsored walk to raise money for YoungDementia UK. We don’t want other families to face this condition alone.

Natalie Pye, fundraiser

We would like to remember our members and supporters who have passed away this year. Our condolences to their families and our grateful thanks for all the donations that have been made in memory of them.

For more information about how you can donate or raise funds for YoungDementia UK
fundraising@youngdementiauk.org
www.youngdementiauk.org/get-involved
As part of our strategy to extend our reach and support more people across the UK, the charity identified the need to make our income generation more sustainable and to strengthen our financial reserves.

In recent years, we have invested in expanding our fundraising team and this year we started to see the benefits of this when we generated a record income of £556,730 for the charity and created a small surplus. However, times remain challenging and whilst we endeavour to grow our income base, we will maintain our vigilance over costs as we continue to expand our work and seek to ensure that no one faces young onset dementia alone.

How the money is spent

**Income £556,730**
- Trusts & foundations - 40%
- NHS & social services contracts - 15%
- Members - 19%
- Community fundraising - 25%
- Others - 1%

**Expenditure £511,251**
- Staff, service development & service activities - 70.5%
- Cost of raising funds - 25%
- Administration / e-office - 4%
- Governance - 0.5%

Detailed accounts for 2018-2019 are available on our website [www.youngdementiauk.org/our-publications](http://www.youngdementiauk.org/our-publications)

Special thanks to the following organisations who made significant donations

- Adnams Southwold
- Banbury Charities
- Bartlett Taylor Charitable Trust
- Batchworth Trust
- BMW Oxford Plant
- Bothwell Charitable Trust
- Brasenose College, Oxford
- CHK Charities Limited
- Christ Church College, Oxford
- Combined Cutlers’ Company Charitable Trust
- Cotton Trust
- D’Oyly Carte Charitable Trust
- DEEP Involvement Fund
- Delphie Lakeman Memorial Trust
- DLM Charitable Trust
- Doris Field Charitable Trust
- Esmée Fairbairn Foundation
- Evan Cornish Foundation
- Five Star Events
- Garfield Weston Foundation
- George A. Moore Foundation
- Gerald Palmer Eling Trust Company
- Grey Court Trust
- HDH Wills 1965 Charitable Trust
- Helianthus Charitable Trust
- Hugh Neill Charity
- Invesco Cares Foundation
- John Ellerman Foundation
- Lloyds Bank Foundation
- Lynn Foundation
- Lunaria Trust
- Michael and Anna Wix Charitable Trust
- Miss WE Lawrence 1973 Charitable Settlement
- Oxfordshire Community Foundation
- Persula Foundation
- PF Charitable Trust
- Roger and Jean Jefcoate Charitable Trust
- Rotary Club of Romsey Test
- Sheffield Church Burgesses Trust
- Sheffield Soroptimist Housing Company Ltd
- Sir Jules Thorn Charitable Trust
- Sober Foundation
- Souter Charitable Trust
- St Michael’s and All Saints’ Charity
- Stanton Ballard Charitable Trust
- Talbot Trusts
- TCS Biosciences Ltd
- The Kirby Laing Foundation
- The Lions Club of Henley-on-Thames
- Tolkien Trust
- Tudor Trust
- Wardington House
- Woodroffe Benton Foundation

For a full list of our supporters go to [www.youngdementiauk.org/our-supporters](http://www.youngdementiauk.org/our-supporters)
We believe that people living with young onset dementia are enabled to adapt well and live life when supported within a nurturing and informed community.

In contributing to and creating such communities, including our own, we are inspired and sustained by the people within it, those with dementia, their family and friends.

YoungDementia UK team