

Specialist Support Services

A Lifeline for Younger People with
Dementia and their Families

Annual Review



'I am proud to be associated with
YoungDementia UK and the work
they do to enrich the lives of people
affected by young onset dementia'

Patron • Baroness Susan Greenfield

Chair's Message

From small beginnings, three Support Workers in our One to One Service, we have blossomed. One of the main reasons for this is that we listened to members and followed their lead.

This has resulted in a unique, award winning charity that has developed a very special and consistent relationship with its members. Our new name will help us influence the development of services regionally and nationally.

Over the years many people - members, staff, trustees and volunteers – have shared responsibility for the achievements of YoungDementia UK. I hope we will continue to be as fortunate with those who support us in the future because the needs of younger people with dementia will be just as important in the years to come no matter what financial, political or health changes may occur.

Jean

Living Well with Young Onset Dementia

Life with dementia can feel like a life without choices, without opportunities. With our **One to One Service** alongside, together with our team's knowledge of dementia and its impact on everyday life, our members in Oxfordshire and borders make the most of the present, adapt to the changes and prepare better for the future.

We create long-term partnerships between our trained support worker and the person with dementia. Ten new people have started with us this year. Regular active sessions focusing on their needs and wishes ensure enjoyment and stimulation, as well as a reliable break for the family.

Confidence and self-esteem are boosted, and the positive approach taken by the support worker provides a model for family members.

I feel so much better with Kay's support and I love the way that Isobel delightedly sets off for a morning out. Kay is giving her more variety in her life. Roger, husband of Isobel who has fronto-temporal dementia.

Wendy with Sarah

We lay down on the grass looking up at the skies to see house martins, swallows and those wonderful mercurial kites and then Wendy started giggling – a sunny afternoon spent with Wendy who has Huntington's Disease – her zest for life and positive attitude is amazing. That rosy tinge from the sunshine made her look positively radiant.



Norm with Jo

We have had wonderful adventures together visiting the Brecon Beacons, rowing down the Avon and exploring local Roman ruins – Norm diagnosed at 56 with CADASIL, has been supported by us for seven years. As time passes and Norm's condition progresses it is harder for him to do many of the things he loves but we still enjoy our time together and adapt our adventures to suit him.



Eileen with Kaija

When I first started working with Eileen she was nervous about leaving the house but now she is waiting for me at the gate – Eileen, diagnosed with fronto-temporal dementia, aged 56, heads a large family, but with me she has time and space for herself where she feels no pressure from anyone. *This support is my lifeline – I feel safe and comfortable.* Eileen



Facts

- 6,500 hours provide over the past year to 54 younger people
- Nearly 69,000 person-centred active support hours since 1998

- Achievements**
- Promoting a feeling of well-being
 - An improvement in self-esteem and confidence
 - Nurturing a welcoming community for all
 - Providing a specialist resource for professionals

They help me live the life I want to live

Sandy, journalist and author, living with Huntington's Disease

A Lifeline for the Family

A diagnosis of young onset dementia of a family member or partner brings about huge challenges.

Our **Family Service** offers advice, information, signposting and emotional support, directly in person in Oxfordshire and by phone regionally. A dedicated, trained worker is partnered with the family to provide continuous and responsive support over the long-term.

The Service is then used flexibly to meet the unique needs and wishes of the family – focussing on practical aspects such as finances, legal issues or navigating the social and health system at one time, moving to working through difficult decisions as the person with dementia loses capacity, and then coming to terms with the gradual loss of the person and a shared future.

Our new Coffee 'n' Chat mornings and Walk 'n' Talk events enable families to meet in local community venues, share experiences and gain strength from one another.



Marissa with Emeline

Every time I fall apart you hold me together and set me back on the right path. Marissa

Dave had symptoms of fronto-temporal lobe dementia for three years before he was finally diagnosed at the age of 55, which was when I first met Marissa.

Together since she was 19, it was difficult to cope without her best friend, the boys' father, her husband.



Marissa and Dave

Dave, formerly a bomb disposal expert, needed occupation so we set about finding activities for him. Marissa, being an army wife, is very capable but emotionally she was finding life tough going and worrying. She needed to understand the finances and future plans. I am always there for Marissa.

Mandy with Sue

Accepting Nigel's diagnosis was very difficult for Mandy. He was just 55 when we first met. Nigel had been a keen sailor and rugby coach. Mandy had to cope with his Alzheimer's disease, the impact on their teenage sons, and her increasing sense of isolation.

Our talks reassured Mandy that our support was available for Nigel, when necessary, and the Family Service would help her with advice on benefits and legal issues, as well as strategies for reducing Nigel's frustration and volatility.

When living at home was too challenging, and Nigel moved to a care home, we were able to help during that time. Our support continues. Mandy joins our Coffee 'n' Chat mornings to enjoy some lively conversation and relax. We are here for her.

Café and Club

This illness can be lonely. Friends and family can drop away. The cafés are wonderful – something to really look forward to. Family member

Now in its fourth year, our monthly evening **Café**, with live music, dancing and a tasty supper are increasingly popular. They are an excellent place for younger people with dementia and their families to meet together for companionship and to share experiences.

Friendships made there sustain people during the years of living life with young onset dementia. Our team are always present to offer support and advice. And professionals are welcome too.



Stephanie West • Guest Harpist at our Garden Party

Facts

- This year we partnered 70 family members for support
- 2,100 personal contacts - including home visits

This year we recruited more Café volunteers from the local community. They play a vital role in making the evening go with a swing.

The Founders' Garden Party in summer and the Christmas party at the end of the year are fun fixtures in our calendar too.

Younger people with dementia experience a double blow

They have a terminal progressive condition that is incurable and rare
It affects them in their prime of life

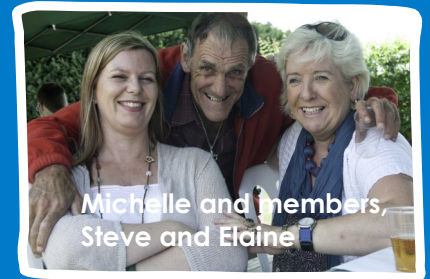
Life is very challenging and the need for specialist support essential

Life with Dementia

People experience a progressive decline in their ability to think, reason, communicate, remember and carry out everyday activities. Changes occur in personality, behaviour and mood - common symptoms are depression, aggression and disinhibition.

Life for a Person aged 30 to 65 with Dementia includes

- dependent children, and older parents too
- work - a career, a fulfilling vocation
- social and leisure, friends
- physical fitness, energy
- financial responsibilities - a mortgage, pension
- planning for retirement, a future



Working with Others

As our focus is on the person and family, and their lives, we aim to provide a continuum of care and support from early diagnosis, through the changes, to bereavement and beyond.

To do this well, we work hard to develop strong relationships with organisations which also form part of the person's network. This has been a challenge this year as the statutory health and social care services and the local branches of national charities have undergone major changes, whilst at the same time increasing the activity related to the national dementia implementation and receiving less funding.

We have selectively pursued opportunities to raise the profile of young onset dementia with Oxford Health NHS Foundation Trust, Oxfordshire Social Services and Oxfordshire Primary Care Trust. And we are carefully monitoring the new services for Carers and Dementia Advice to ensure that our own support complements others.

Our links with Huntington's Disease Association continue well and we have worked together to improve the support of our shared members.

Oxfordshire Dementia Forum brings together key representatives from the voluntary and statutory sectors to ensure people with dementia are well served. For us, as a small specialist team, maintaining our focus whilst working with others and keeping contact has been valuable. The lifeline for the person and family is stronger too.

Tessa

Linking Lives

Our **Newsletter** enables us to keep in regular contact with everyone in Oxfordshire and regionally. We plan to extend our **YoungDementia UK Website** to create a wider community for people affected by young onset dementia.

Winner of National Awards from GlaxoSmithKline & Kings Fund and the Department of Health for Promoting Independence • Improving the Quality of Human Life • Making a Real Difference to our Community

YoungDementia UK Homes

Our younger people and their families have for many years identified their wish to have an alternative to home for a break or long term that suits them better than a care home for older people. We set up YoungDementia UK Homes in mid-2009 with the help of Bray D'Oily Housing Association.

Finding a site for a new-build small home or suitable property to adapt, developing a business case and considering the best way to finance and fundraise is a real challenge for our Homes team in the current climate. However we are as committed to fulfilling this particular wish as ever.

Weboffice Working

So that we can centre our work on the person with dementia, their home and their locality, the team work from home-offices with links to a weboffice for shared information. This means that most of our resources are spent just where they should be, on enabling younger people with dementia and their families to live well.

Statement of Financial Activities for the year ended 31 March 2011

	Unrestricted Funds £	Restricted Funds £	2011 Total £	2010 Total £
Incoming resources				
Incoming resources from generated funds				
Voluntary income				
General donations and events	16,695	-	16,695	28,859
Investment income	1,256	-	1,256	345
Incoming resources from charitable activities				
One to One Service	46,547	95,777	142,324	167,027
Family Service	531	47,491	48,022	87,567
Development and other services	-	37,272	37,272	41,768
Total incoming resources	<u>65,029</u>	<u>180,540</u>	<u>245,569</u>	<u>325,566</u>
Resources used				
Cost of generating funds				
	22,507	-	22,507	15,840
Charitable activities				
One to One Service	75,251	106,811	182,062	163,833
Family Service	37,233	41,901	79,134	83,338
Development and other services	18,886	22,705	41,591	44,166
Governance costs	9,662	-	9,662	9,511
Total resources expended	<u>163,539</u>	<u>171,417</u>	<u>334,956</u>	<u>316,688</u>
Net movement in funds	(98,510)	9,123	(89,387)	8,878
Total funds at 1 April 2010	147,229	37,214	184,443	175,565
Total funds at 31 March 2011	<u>48,719</u>	<u>46,337</u>	<u>95,056</u>	<u>184,443</u>

This summary of our income and expenditure account is taken from our Annual Accounts for the year ending 31 March 2011. For more information about the charity's financial affairs, the full *Report and Financial Statement* is available from www.youngdementiauk.org

Our reserve policy is to maintain funding, excluding restricted funds, which are not committed to or invested in tangible assets amounting to at least six months of total resources expended. At 31 March 2011 the free reserves were £48,719 which amounts to 1.7 months of expenditure. Following over a decade of good steady funding, this year the fundraising was disappointing. However, we have since reviewed our fundraising plan and resources, and our income is now significantly improving.

Reporting Accountants Wenn Townsend 30 St. Giles' Oxford OX1 3LE
Bank CAF Bank Limited 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ

Balance Sheet as at 31 March 2011

	£	2011 £	£	2010 £
Fixed assets				
Tangible assets		1		1
Current assets				
Debtors	19,192		22,868	
Cash at bank and in hand	77,051	-	162,679	
	<u>96,243</u>		<u>185,547</u>	
Creditors: amounts falling due within one year	(1,188)		(1,105)	
Net current assets		95,055		184,442
Net assets		<u>95,056</u>		<u>184,443</u>
Funds				
Restricted funds		46,337		37,214
Unrestricted funds		48,719		147,229
Total funds		<u>95,056</u>		<u>184,443</u>

Thank You To All Our Friends, Donors and Funders

YoungDementia UK members and team would like to thank everyone who has supported us in our work this year:

- Alzheimer's Society Banbury & District
- Banbury Society of Friends
- Chapman Trust
- Chipping Norton Golf Club Seniors
- Esmée Fairbairn Foundation
- Forte Charitable Trust
- Garfield Weston Foundation
- Helianthus Charitable Trust
- Henry Smith Charity
- Lord Faringdon Charitable Trust
- Lynn Foundation
- Marchday Charitable Trust
- Odin Charitable Trust
- Our Lady's Junior School Abingdon
- Oxford Health NHS Foundation Trust
- Oxford Private Care
- Oxfordshire Community Foundation
- Oxfordshire County Council
- Research Sites Restoration
- Royal Army Ordnance Corps Assn
- Sandford Trust
- Sobell Foundation
- St. Michael & All Saints Charities
- Thomas Wall Trust
- YoungDementia UK Homes

We especially appreciate our café volunteers and entertainers, and companies such as C D Alive and API Computing. They give their time, skills and energy to help YoungDementia UK in our quest to enable younger people with dementia and their families live life to the full. Details on how to donate or support the work of YoungDementia UK are available on www.youngdementiauk.org