Living with dementia
Our story
We are the UK’s leading support and research charity for people with dementia, their families and carers.

alzheimers.org.uk
We launched our four-year User Involvement Plan – supported by over 50 staff members who have volunteered to be user involvement champions. This plan will help ensure that all our work is truly informed by people affected by dementia.

Beyond our own direct service provision, the first year of the Prime Minister’s Challenge on Dementia in England has enabled us to be more ambitious in pushing for much-needed improvements in health and social care. The dementia strategies in Wales and Northern Ireland have likewise started to bring about better care for people with dementia, in the NHS and in the wider community. But many challenges remain – not least the separation of health and social care, and the chronic underfunding of the latter leaving so many facing the disproportionate costs not inflicted on those with other diseases; a cost we have termed the ‘dementia tax’.

Progress on creating dementia-friendly communities has been remarkable. From an ambition of 20 towns and cities on the path to becoming dementia friendly by 2015, we already have over 50 in the first year. Alongside this, we launched our Dementia Friends programme, recruiting and training volunteers who will run awareness sessions in their local communities, reaching one million people by 2015.

Finally, to return to research, we achieve maximum impact with our funding through working in partnership, including a total of £1.775 million committed over the next three years to the Brains for Dementia Research donor bank programme and £1.1 million for a world-leading study on vascular dementia. As in our other work, the engagement of volunteers, in this case through the Research Network, is the envy of many.

Over the following pages you will meet Derek, Yvonne, Kim and Josh – a family from Romford living with dementia. Their story demonstrates not only how vital good and trustworthy information and support is, but what an enormous difference it makes when the people around you understand dementia.

As Kim says: ‘I want people to see the person, rather than the label. Instead of seeing an Alzheimer’s patient, I want people to see my dad, Derek, who happens to have Alzheimer’s.

We are grateful to Derek, Yvonne, Kim and Josh for sharing their story.

Jeremy Hughes
Chief Executive

Alastair Balls CB DL
Chair

This has been the first year of our five-year strategy, Delivering on Dementia, and our four strategic ambitions set out to mobilise thousands of people. Our volunteers and staff will change the face of dementia research, demonstrate best practice in dementia care and support, provide the best advice to anyone seeking support, and bring about improvements in the care and support provided by others. All this is only made possible thanks to the generosity of our supporters who raised an amazing £38 million in a hard economic climate, making our total income for the year £71 million.

Our face-to-face services, delivered across England, Wales and Northern Ireland, have grown significantly in the past year. Over 100 new Dementia Cafés and over 80 new Singing for the Brain Groups are just two highlights. At the same time, we reached 33,000 people concerned about dementia through the Dementia Community Roadshow, and responded to 27,512 enquirers to our Helpline, which is now open seven days a week. There were six million visits to our website – that’s two million more than the previous year – and our online community, Talking Point, now has 26,554 members – a rise of 36% over the year.

Our vision is a world without dementia. With a record £5.3 million spent on new high-quality research in the last year, we are moving forward towards that goal. But there are 800,000 people in the UK living with dementia who need our help now.

Jeremy Hughes
Chief Executive

Alastair Balls CB DL
Chair

Over the following pages you will meet Derek, Yvonne, Kim and Josh – a family from Romford living with dementia. Their story demonstrates not only how vital good and trustworthy information and support is, but what an enormous difference it makes when the people around you understand dementia.

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Jeremy Hughes
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Introducing our family

This annual review tells you about our work through the eyes of Derek, Yvonne, Kim and Josh, from Essex. They talk about the impact of dementia on their lives, how Alzheimer’s Society is making a lasting difference, and their hopes for the future.

Derek
Living with dementia
Derek, 81, lives with his wife Yvonne in Romford, Essex. He trained as a toolmaker when he left school, spent four years in the Royal Air Force and then worked as a long distance lorry driver. Since retiring, Derek enjoys meeting friends at the British Legion and playing bowls. He was diagnosed with Alzheimer’s disease five years ago.

Yvonne
Yvonne is Derek’s wife and main carer
Yvonne, 77, grew up in Brighton, where she met Derek at the Brighton and Hove Greyhound Stadium. They’ve been married 59 years and have two sons and a daughter. Since retiring from her job as a shop manager, Yvonne spends time looking after her family and helping out at her local Alzheimer’s Society group.

Kim
Mother to Josh and daughter of Derek and Yvonne
Yvonne and Derek’s daughter Kim is 47. She lives round the corner from her parents with her son Josh and they visit them most days. After many years working in London schools, supporting children with autism and other special educational needs, she is now a home-school support worker in the London Borough of Havering.

Josh
Son of Kim and grandson to Derek and Yvonne
Ten-year-old Josh loves playing football and going to Cubs. His favourite Sunday involves having dinner with his Grandad and Nana, and going to the park or playing board games together afterwards. Josh is always there to help his Grandad out if he needs him.
Meeting needs
Care and support

‘It’s really important to have somewhere to go where you can talk to other people in the same situation. Somewhere people understand you.’

Yvonne
Ambition 1: Demonstrate the way in dementia care and support

We use our extensive experience and expertise to provide high quality, inclusive and innovative services – either directly or in partnership – that people with dementia and their carers want and need. We lead the way, and help encourage others to improve and develop services.

Derek: I’d known something wasn’t right for a while. My mother had Alzheimer’s and I recognised I was doing similar things to her. I was getting confused, sometimes just walking from one place to another – which is why I knew I had to give up driving. I’m perfectly all right with some things like shopping, but it’s best not left to me to remember what we need. It can be frustrating because I know I’m capable of doing things better. I sometimes wonder if people understand what it’s like for me.

Yvonne: When you have dementia, or if you’re caring for someone who does, it’s really important to have somewhere to go where you can talk to other people in the same situation. Somewhere people understand you.

Derek: We’re both very fortunate because we have each other, as well as family and friends – particularly our daughter Kim, who helps us out with so much. Not everyone has that.

Yvonne: I go to several Alzheimer’s Society groups: a peer support group, the Dementia Café and social events. There’s a mix of people with dementia and their partners or carers that go along. When we’re there, we can pick each other’s brains about issues we’re having. Sometimes we just relax and play cards. It’s good to see people enjoying themselves rather than stuck away indoors. Whenever we have a meeting, there’s always literature around on different topics relating to dementia, services, or practical information. If something’s not clear or I have a question, there’s always someone there to ask.

Derek: The people are friendly and the staff and volunteers are very good. You don’t feel you’re one of a number. I do feel listened to.

Yvonne: Singing really helps with the memory too. There are people there who might not remember what happened 10 minutes ago, but when someone starts humming a song, they can sing all the words to it.

Derek: The health professionals we’ve come across do seem to have good knowledge of dementia now, and they try to do what they can. When Derek told the doctors he didn’t want to take any more tablets, they didn’t try to persuade him to. They took the next step and referred him on to another part of the mental health clinic. So they are listening to what he wants.

Yvonne: The health professionals we’ve come across do seem to have good knowledge of dementia now, and they try to do what they can. When Derek told the doctors he didn’t want to take any more tablets, they didn’t try to persuade him to. They took the next step and referred him on to another part of the mental health clinic. So they are listening to what he wants.

Derek: We reviewed all our face-to-face services to make sure that, wherever they live, people affected by dementia receive a consistent and high quality service that truly meets their needs.

We launched our User Involvement Plan – a four-year programme of work to develop a robust and sustainable culture of involving people with dementia across the Society.

We established an Innovation Fund to encourage new and creative ideas for initiatives that will benefit people affected by dementia.

‘You don’t feel you’re one of a number. I do feel listened to.’
Derek
‘It’s made a big difference to have the right kind of information, that I know I can trust, as well as people I can turn to.’

Yvonne
Ambition 2: Be the foremost point of contact for anyone dealing with dementia

We aim to make sure everyone dealing with dementia knows we’re here for them, with information, advice and support they can trust – whether they have dementia themselves, are a family member, carer or a health or social care professional, and wherever they live.

Yvonne: When Derek was first diagnosed I thought, “What do I do next?”

Yvonne: It’s good to feel you can be honest and open about your concerns – with people at the Alzheimer’s Society groups, and with other friends. More people know about dementia than they did several years ago. But they don’t always want to go and find out if that’s what’s wrong with them. I always advise people to go to their doctor if they’re worried about their memory, or their partner’s. It might not be dementia, but you need to find out. There is support out there if you need it.

Kim: I’m so proud of Dad and the way he’s been. If you weren’t told he had Alzheimer’s, you wouldn’t know. He’s still very articulate and leads a purposeful life. To have that, you need support.

Kim: When I first heard about Dad’s Alzheimer’s, I was scared. My son Josh was quite young, and I worried how I’d cope with Dad’s illness and looking after him, as well as how mum would cope. My Grandma had Alzheimer’s and she lived in a care home, and I remember thinking that would have to happen to Dad.

Yvonne: When Derek was first diagnosed I thought, ‘What do I do next?’ I didn’t know much about the condition. I wanted to find out more, so I went to my local Alzheimer’s Society office. They told me about different support and social groups, which I’m now very involved with. I’ve been to lots of their talks about a range of practical, useful things you need to know about, like making a Will or getting the right life insurance.

There was also a talk from the fire brigade about safety at home. Derek and I have talked about what might happen in the future – we’ve made our Wills and other plans. It’s made a big difference to have the right kind of information, that I know I can trust, as well as people I can turn to.

Kim: When you’re given your diagnosis, you do need information. But some people need time to come to terms with things themselves first. It’s helpful to be able to go home and have some time to digest what you’ve been told. After that, you want information that you can look at in your own time. You don’t always want to hear straight away what might happen in the future. But knowing where you can go for information – when you’re ready for it – is really important.
‘If scientists are working at it now, with a bit of effort, they should be able to change things for the future.’

Josh
Ambition 3: Lead partnerships and investments in research to improve care, advance prevention, and move closer to a cure

We continue to develop, publish and contribute to pioneering research into the cause, cure, care and prevention of dementia. Through research, we can improve the quality of life for all people affected by dementia and ultimately find better ways to treat or prevent it.

**Josh:** I think scientists need to be out there now, finding cures for Alzheimer’s. It isn’t people’s fault that they’re diagnosed with it, and they should get the drugs they need to help them.

**Kim:** I often say that I’d rather Dad had an illness like cancer, where, because of research and drugs, he could have got better from it. It’s so much harder with what he has, because he’s not ‘ill’. Things have changed though. When my Grandma had Alzheimer’s, I remember her deteriorating very quickly. But it’s not the same for Dad. The drug he takes seems to make a difference. He’s getting on and doing the things he’s always done, even if some things take him much longer.

**Derek:** I’d like to see more research going on—to find more drugs and a cure. You can see the difference taking Aricept has made to me. It’s been five years since I was first diagnosed and I can still do things. I’ll tell people I’ve got dementia. Lots of people say, ‘If you hadn’t told us we wouldn’t know’.

**Kim:** I do worry about Alzheimer’s because of my genes. I’m always told I’m like my Grandma, so I think, ‘One day will I get it?’ The family hasn’t been involved in any research, but we definitely would do. The more people with dementia and their families get involved, the better.

**Josh:** If scientists are working at it now, with a bit of effort, they should be able to change things for the future. I think the government needs to make changes. If they leave it, things could get worse by the time I’m ‘Grandad’’s age.

**Kim:** I often say that I’d rather Dad had an illness like cancer, where, because of research and drugs, he could have got better from it.

‘I often say that I’d rather Dad had an illness like cancer, where, because of research and drugs, he could have got better from it.’

**Kim**
I want people to see the person, rather than the label. Instead of seeing an Alzheimer’s patient, I want people to see my dad.’

Kim
Ambition 4: Campaign for people affected by dementia to be able to live the lives they want

We’re an authority on dementia issues, and we use this position to campaign for change that will improve all aspects of care and support. From influencing health and social care commissioners to improving public understanding of dementia, we help people to live well in their own homes, residential care or hospital.

Derek: When I first went to the doctor to express my concerns, he said there was nothing wrong. It took a year to get my official diagnosis. And another six months to get prescribed the Aricept that I was told I should take. It’s down to Yvonne’s efforts that I got the diagnosis and the drug I needed, and not everyone has the tenacity to fight like she did.

Kim: It really helped to get Dad’s diagnosis when we did. We finally knew that he wasn’t just being forgetful, and it meant we had something to work with. You might not want to hear it, but once you know what it is, you can then find the support you need.

Yvonne: I would shout it from the rooftops: a diagnosis is essential. And you need it as soon as possible.

Yvonne: You do hear couples where one partner has dementia saying that they don’t go out much anymore because of people’s reactions. No one has ever said anything to us though.

Derek: We still do the things we’ve always done, like go and play bowls every week.

Kim: It would be good to see that sort of thing becoming more common. It really is the little things that help, like giving people one instruction at a time and using simple language. We need to educate people in the community about dementia and then let people with dementia know ‘we understand you’. That’s where the Alzheimer’s Society’s dementia-friendly communities work will hopefully make a big difference.

Josh: I think they should tell all the shopkeepers about dementia. Just to let them know there could be people like Grandad who will come in and might need a bit more help. They need to encourage those people who’ve got dementia, who are quite shy about it, to be open and just try to not think about it.

Yvonne: You do hear couples where one partner has dementia saying that they don’t go out much anymore because of people’s reactions. No one has ever said anything to us though.

Derek: We still do the things we’ve always done, like go and play bowls every week.

Kim: I want people to see the person, rather than the label. Instead of seeing an Alzheimer’s patient, I want people to see my dad, Derek, who happens to have Alzheimer’s. We need to make sure more people with dementia are out and functioning in the community, like he is. I’m really proud of what my parents do. They’re proving that you can cope with dementia. If you’ve got the support and services there, you can live your life.

‘I would shout it from the rooftops: a diagnosis is essential.’

Yvonne

Highlights

We continued to highlight the importance of an early diagnosis, and to push for improved diagnosis rates. Thanks to our campaigning, the Government in England announced its ambition for two-thirds of people with dementia to receive a diagnosis by 2015 – an increase of 20%.

We published Dementia 2013: The hidden voice of loneliness – our second state-of-the-nation reports looking at the quality of life for people with dementia – and Low expectations – giving authoritative evidence on the number of people with dementia in care homes and their quality of life.

We continued to shape and direct the Dementia Friendly Communities Programme in England, including launching Dementia Friends – a large-scale volunteering initiative to transform dementia awareness in local communities.
The year in review

Talking Point, our online community for anyone affected by dementia, celebrated its 10th birthday.

Visits to our website increased by 45% over the year – from four million to nearly six million.

We delivered 135 Carers’ Information and Support Programmes to over 1,000 carers.

An estimated 20,000 people with dementia, carers and professionals used our Dementia Adviser Service.

We launched a major volunteering initiative called Dementia Friends, which aims to recruit one million Dementia Friends in local communities by 2015.

We reached over 33,000 people through our Tesco-funded Community Roadshow, which takes dementia information and advice into the heart of communities.

We established a network of 50 involvement champions among our staff, to help create a robust and sustainable culture of involving people with dementia in our work.

Memory Walk – our flagship fundraising event in local communities – raised over £1.28 million in 2012 – an increase of 45% on 2011.

We invested a record £5.3 million in high quality research into the cause, cure, care and prevention of dementia.

We had 215 Singing for the Brain® services across England, Wales and Northern Ireland.

Our twitter followers increased to 35,223 – that’s a year-on-year increase of 136%.

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Society money

Despite the continuing sluggishness of the economy, we are pleased that our income has remained stable at £71 million. This enabled the Society to increase its charitable expenditure by 3%. The Society’s reserves increased by £3 million.

Income

Income was stable at £71 million (2012: £71.1 million). Contract income amounted to £27.5 million (2012: £24.3 million). Credit for this belongs to the Society’s success in keeping attention focused on the needs of people with dementia and their carers. Income specifically given for research increased to £5.7 million (2012: £3.5 million).

Expenditure

During 2012/13, 88 pence in every pound of total expenditure was spent on direct costs towards improving the lives of people with dementia (2012: 88 pence in the pound). The remaining 12 pence in every £1 was spent to support our frontline activity including premises and IT around the country. Charitable expenditure increased during the year by £1.9 million to £57.9 million (2012: £56 million).

In line with the Society’s strategy to increase commitment to research, grant expenditure increased to £5.3 million (2012: £3.1 million). Expenditure on fundraising fell to £10.3 million (2012: £12 million) after investment last year.

Funds

Total funds at 31 March 2013 were £32.2 million (2012: £29.1 million) of which £23.8 million (2012: £22.2 million) were unrestricted. It is the Society’s policy to hold free reserves equivalent to at least three months of charitable expenditure. At 31 March 2013 the Society held free reserves equivalent to 4.3 months (2012: 4.3 months) of charitable expenditure.

In light of continuing economic uncertainty and the pressures on public spending at the present time, the Board of Trustees feels that the above reserves cover is prudent and allows for future growth.

Summarised financial statements

For the year ended 31 March 2013

<table>
<thead>
<tr>
<th>Income and expenditure</th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
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<tr>
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<td>Legacies</td>
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<td>Subscriptions, donations and fundraising</td>
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<td>Other income including trading</td>
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<td>Total income</td>
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<tr>
<td>Expenditure</td>
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<td>Care services: improving quality</td>
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<td>46,254</td>
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<td>Case services: extending reach</td>
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<td>Trading costs</td>
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<td>Total expenditure</td>
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Balance sheet

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<th></th>
<th>2013 £’000</th>
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<td>Fixed assets</td>
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<tr>
<td>Current assets</td>
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<td>24,294</td>
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<tr>
<td>Creditors – falling due within one year</td>
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<td>(13,951)</td>
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<tr>
<td>Creditors – falling due after one year</td>
<td>(4,798)</td>
<td>(3,623)</td>
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<tr>
<td>Provisions for liabilities and charges</td>
<td>(355)</td>
<td>(866)</td>
</tr>
<tr>
<td>Net assets</td>
<td>32,160</td>
<td>29,096</td>
</tr>
</tbody>
</table>

Funds

Restricted | 8,327 | 6,898 |
Unrestricted | 23,833 | 22,198 |
Total Funds | 32,160 | 29,096 |

The information on this page is extracted from the Trustees’ report and annual accounts 2012/13 which has been audited by Crowe Clark Whitehill who gave an unqualified audit opinion on 19 September 2013. The auditors have confirmed to the Trustees that these summarised financial statements are consistent with the full financial statements contained in the Trustees’ report and annual accounts 2012/13. The Trustees’ report and annual accounts 2012/13 was approved by the Trustees and signed on their behalf on 10 September 2013. The Trustees’ report and annual accounts 2012/13 will subsequently be submitted to the Charity Commission and the Registrar of Companies. These summarised financial statements may not contain sufficient information to gain a complete understanding of the financial affairs of the charity. The Trustees’ report and annual accounts 2012/13 may be downloaded from alzheimers.org.uk

Alastair Balls CB DL
Chair

John Grosvenor
Treasurer
A big thank you

To all our supporters who helped us continue to fight against dementia in 2012/13, including:

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- Ageas UK
- Airbus
- Anchor Care Homes
- Ascot Underwriters
- Barchester Care Homes
- Begbies Traynor
- Britian Group
- Bural Healthcare Ltd
- Bupa Care Homes plc
- Capita
- Capsiari
- Centric Commercial Finance
- Deans Garden Centre
- DLA Piper Leeds
- DLA Piper Liverpool
- Dulux Decorator Centres
- Dundas and Wilson
- Field Fisher Waterhouse
- GCA (United Utilities)
- Gelder
- Hays plc
- Home Retail Group

**Northern Rock Foundation**
- Peacock Charitable Trust
- People’s Health Trust
- P F Charitable Trust

**Trusts and Statutory**
- 29th May 1961 Charitable Trust
- Bill Brown’s Charitable Settlement of 1989
- CHK Charities Limited
- City Bridge Trust
- Cohen, John S, Foundation
- Comic Relief
- Community Foundation serving Tyne & Wear and Northumberland
- February Foundation
- Frieda Scott Charitable Trust
- Lord and Lady Lurgan Trust
- Margaret Giffen Charitable Trust
- Nominet Trust

**Ambassadors**
- Jo Brand and Meera Syal MBE become Dementia Friends
Society people
During the year 2012/13

Royal Patron
HRH Princess Alexandra GCVO

President Emeritus
Sir Jonathan Miller CBE

Board of Trustees
Honorary Officers
Chair
Alastair Balls CB DL +* Re-elected 17 September 2010
Eileen Winston * Re-elected 18 September 2009
Resigned 16 October 2012
Ann Beasley CBE +*# Re-elected 16 October 2012
John Grossenbocher +*# Elected 18 September 2009
Appointed 16 October 2012
Treasurer
Richard Ford * Elected 16 October 2012
Pippa Gough Elected 17 September 2010
Thomas Haverty Appointed 16 September 2011
Professor Robin Jacoby Re-elected 16 October 2012
Dr Linda Patterson OBE Elected 17 September 2010
Sir Chris Powell Appointed 1 August 2012
David Richardson # Re-elected 17 September 2010
Jan Sherriff # Elected 17 September 2010
Annette Southcott Resigned 16 October 2012
Alan Wells OBE * Resigned 16 October 2012

Chief Executive
Jeremy Hughes

Strategic Leadership Team as at 31 March 2013
Director of Corporate Resources
Matthew Sellen *
Director of External Affairs
Andrew Chidgey
Director of Fundraising
Liz Monks
Director of Operations
Kathryn Smith
Director of People and Organisational Development
Brett Terry
Director of Research and Development
Doug Brown
Company Secretary
Deirdre Watson

All Trustees are elected by the Society’s membership, or co-opted, in accordance with the Society’s Articles of Association.
1 Elected by the Board as Vice Chair 13 November 2012

Committee Memberships during the year (all or part of):
# Finance and Audit Committee Member
+ Nominations and Appointments Committee Member
* Remuneration Committee Member
#* Investment Committee Member

Professional advisers
Auditors
Crowe Clark Whitehill LLP
Chartered Accountants and Registered Auditors
St Bride’s House
10 Salisbury Square
London EC4Y 8EH
Bankers
HSBC Bank Plc
London Corporate Banking Centre
60 Queen Victoria Street
London EC4N 4TR
Insurance brokers
Lockton Companies LLP
The St Bdalph Building
138 Houndsditch
London EC3A 7AG
Investment managers
JP Morgan Private Bank
1 Knightsbridge
London SW1X 7LX
Legal advisers
Charles Russell LLP
5 Fleet Place
London EC4M 7RD
To 28 February 2013
Stone King LLP
16 St John’s Lane
London EC1M 4BS
From 1 March 2013
Registered charity number
296645
Company registration number
2115499