

Alzheimer's Society Campaigners' Network

Alzheimer's Society [campaigners](#) change the lives of people living with dementia and their families.

Why we need your help

- 60% of people living with the symptoms of dementia never receive a [diagnosis](#)
- More than half of people with dementia leave hospital with worse symptoms than when they arrive
- [People with dementia](#) often have to pay huge amounts for their essential care



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How you can make a difference

We need you to help us make the case for people with dementia and their families. Join us in the fight against dementia by signing up to our [Campaigners' Network](#) and you will receive regular updates on our campaigns and details of easy ways to get involved. By signing up to the network, you will join a movement of thousands of people dedicated to improving the lives of people living with dementia.

Meet some of the Alzheimer's Society campaigners [here](#).

Getting involved couldn't be easier - there's something for everyone.

- [Campaigners' Network e-bulletin](#) - our supporters receive no more than 12 emails each year, each with a quick and easy action that is aimed at influencing key decision makers and opinion formers
- [Campaigners' Network local groups](#) - our local groups play a vital role in influencing the care that people receive at a local level. From working with hospitals on the way they deliver care, to campaigning to protect local services, our groups are right at the heart of the campaigning work that we do



Every action you take will play a vital role in raising awareness of dementia and pushing it to the top of the political agenda. Please [join Alzheimer's Society's Campaigners' Network](#) and help us change lives.

Contact the Campaigners' Network

You can contact us via email campaignersnetwork@alzheimers.org.uk or phone 020 7423 5128.

Meet the Campaigners

There is something for everyone at Alzheimer's Society. In order to make advances in dementia we need a range of volunteers with different interests and skill sets. Meet some of the people who are campaigning for a better future for people with dementia.

- [Anne: Campaign Group Lead](#)
- [Christine: Campaign Group member](#)
- [Jane: Media volunteer](#)
- [Kash: Campaign and media admin support](#)
- [Margaret: Campaign Group Lead](#)
- [Matt: Campaign Group coordinator](#)
- [Sue: Campaign Group Lead](#)
- [Tony: Campaign Group Volunteer](#)

Anne Williamson

Campaign Group Lead, Norfolk

Why do I campaign for Alzheimer's Society?

When my working life stopped at the end of 2011 there was no way I could spend every day at home, however much gardening, decorating and dog walking beckoned. I decided to do something different from my paid work - most recently in business support and previously as a careers advisor. Alzheimer's Society fitted my criteria - a national organisation, with good training and back-up and, of course, a cause I could support wholeheartedly. Campaigning is a win win role for me. I am helping ensure that many vital issues are addressed. At the same time I am busy, feel useful, am meeting new people and on a learning curve which is a challenge I love.



What does my role involve?

I currently represent Alzheimer's Society on campaigns to [put care right in hospitals](#) and to enhance [early diagnosis](#) by ensuring that literature is available in places accessible to people with memory problems. I plan to get involved ensuring that [care homes](#) are of a high standard. In just five months I have attended three training days, an away day, three conferences and staffed stands in a hospital and a Tesco car park. Local office staff have assisted with recruiting a second campaigner and advised on ways to make local contacts. I spend a couple of days a week doing something for Alzheimer's Society, but volunteering is very flexible. It fits really well around my other interests.

What skills and qualities does a campaigner need to have?

A friend's wife recently died with [Alzheimer's disease](#) so I knew a little about its [progression](#), concerns of [carers](#) and the need for support. Campaigning uses lots of transferrable skills and qualities - organising, presenting, advising, communicating verbally and in writing, and reasonable IT skills. Great training is available to update skills. I have written a press release and my first ever (but probably first of many) letter to my MP. For volunteers from a non-health background it can be daunting at first but I

have found health and care professionals keen to involve Alzheimer's Society in discussions and I am acquiring confidence and learning rapidly.

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Christine Gunby

Campaign Group Member, Sheffield

Why do you campaign for Alzheimer's Society?

When my mother died it fell to me to look after my father, who had more severe [vascular dementia](#) than I had realised. Like many partners, my mother had hidden the problems from other people, even their [GP](#) and her own family. I was completely at sea. I appealed to the [GP](#), who had my Dad seen by a psychogeriatrician, who confirmed the [diagnosis](#). After that we were on our own. Social Services tried to fob us off onto the NHS. The NHS batted us back to Social Services. The [GP](#) did his best, but he was not an expert. In desperation I [rang](#) Alzheimer's Society. In the almost three years that I cared for my Dad they were the only people who seemed to understand the problems and were able to give me advice. When my father died I decided I needed to put something back and campaigning to get a better deal for people like my Dad and their carers seemed a good route to take. I have now been involved for about two years.

What does your role involve?

I am a member of Sheffield's Campaigns group. The group meets once a month and we have, so far, piggy backed on other campaigns, making them more relevant locally, e.g. [Worried about your Memory](#). The time we spend depends very much on what is needed at any particular time. Personally, I would like to see our group talking to people with [dementia](#) and their [carers](#) on a regular basis to try to establish what exactly is needed locally to make their lives better. Having established the needs our group could then try to make some real impact locally.

What skills and qualities does a campaigner need to have?

To campaign I would say you need to have a real belief in what you are doing, dogged determination and endless energy. There will be setbacks, but, if you are passionate in your aims, you'll overcome those, in fact they will strengthen your resolve.

If you have been affected by [dementia](#) and want to help, then go for it. Sometimes bureaucracy gets in the way, and communications could be better but, with an ageing population, we are all going to be touched by dementia at some time in our lives, so getting the government to recognise they need to act is really important. Alzheimer's Society have provided me with media training (how to avoid pitfalls whilst using the media to its full advantage), but probably the best training I have had was the dementia awareness training, something I feel should be mandatory for everyone. Maybe, if we all realised the impact it has on people's lives, we would all treat dementia patients and their carers differently.

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Jane Driver

Media volunteer, Sheffield

Why do you campaign for Alzheimer's Society?

I decided to become involved in campaigning for Alzheimer's Society due to personal circumstances (my mother was 'officially' [diagnosed](#) with [vascular dementia](#) and [Alzheimer's](#) two years ago). When I began to ask for help from Social Services and the NHS, it soon became clear that I was dealing with a shambolic system which consisted of 'year long' [waiting lists for diagnosis](#), inconsistent information and total lack of care or consideration for people with dementia and their carers. I was determined for my story to be heard in an attempt to ensure that others did not endure the same treatment that I had received during an extremely difficult time.

I chose to become a member of Alzheimer's Society as it was clearly the only organisation which provided me with immense support and extensive [information](#) which was current and correct. After attending only one '[Dementia Cafe](#)', I felt included, supported and informed. I was also provided with points of contact who followed up on my questions and 'kept me in the loop'. It was also a great opportunity to meet and speak to people who were experiencing the same difficulties as myself.

What does your role involve?

Although I have only been a volunteer for only six months, I have been involved in the [Dementia Community Roadshow](#) and have taken part in interviews with the local radio and press. This was an ideal opportunity to raise awareness of the condition, its devastating affects along with the shortage of support which [carers](#) are currently provided with.

What skills and qualities does a campaigner need to have?

As a campaign volunteer, I feel that a potential volunteer should have a deep understanding of [dementia](#) and the impact it has on family members. The person should be a good communicator, assertive and willing to 'stand up' for those who cannot speak for themselves. Additionally, they should have empathy and understanding in all situations - and probably most importantly - a good listener. For anyone thinking of becoming a volunteer, I would assure them that it is a greatly satisfying role. You will be operating with the knowledge that, through campaigning, you are helping and representing thousands of people either unwilling or unable to speak up for themselves. You will be there to 'make a difference'.

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Kash Velagala

Campaign and Media Admin Support Volunteer, Preston / North West

Why do you campaign for Alzheimer's Society?

As a self-employed person working from home I have the flexibility of organising my time. Having some free time I decided to utilise my skills and experience for a good cause by volunteering at a local charity. After noticing the recent coverage of [dementia](#) in the [national media](#), I visited Alzheimer's Society website and read through their activities and was drawn towards the organisation to offer my spare time as a volunteer. I have been volunteering as a Campaign and Media admin support volunteer at my local Preston office for the past five months.



What does your role involve?

My main responsibilities include supporting the External Affairs representative with volunteer administration, which involves keeping volunteer records up-to-date, writing for references, and contacting volunteers for relevant information. As the role develops I am hoping to take on more responsibility, such as supporting the current campaign volunteers and distributing campaign materials. Day-to-day I am in contact with other volunteers, staff from the local offices and I am supported by Amy, the regional External Affairs rep.

As an admin support volunteer I have agreed to work around eight hours a month - but I am very keen to offer more time whenever possible as I enjoy volunteering at Alzheimer's Society.

What skills and qualities does a campaigner need to have?

I would definitely encourage and recommend others who have time and are willing to volunteer to contact this organisation. There are many good reasons to volunteer - whether you want to give something back to the community or to develop your interpersonal skills. This is a good opportunity to add another dimension to your life as you get involved in a diverse range of activities and can meet different people and share others' experiences. There is always help and support from your team as well as various online training programmes available to develop your skills and to progress further.

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Margaret Morgan-Owen

Campaign Group Lead, Buckinghamshire

Why do I campaign for Alzheimer's Society?

I was for many years a local politician representing my village on the district council and got involved in quite a lot of campaigns. Prior to that I worked for an engineering company as a steel buyer.

I am a [carer](#) for my husband who has [Alzheimer's](#) and [Vascular Dementia](#) and as the disease has [progressed](#) I have had to cut down on my outside activities to dedicate more and more time to [caring](#) for my husband.

The realisation of how little help is available shocked us both profoundly, and from hearing stories from fellow carers with similar problems, I decided to get involved in the Alzheimer's Society Campaign and Media Group to use all the skills I had learnt on the district council to raise awareness and campaign to improve the lives of people with dementia, their families and carers.

The Campaign and Media Group uses the skills I already have and working as a volunteer for the Alzheimer Society allows me to have an outside activity that I care passionately about that fits in with caring for my husband. The highlights for me are when I get a story in the local press and someone says they read it and as a result they have come to a local group activity. Strangely I enjoy going to meetings and getting people to see things from the point of view of a carer or a person with dementia. For me it is all about raising the profile and getting more support for relatives, friends, and family to enable people to live well with [dementia](#).



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Matt Brewis

Campaign Group Coordinator, Manchester

Why do you campaign for Alzheimer's Society?

I support Alzheimer's Society because I have friends and relatives affected by [dementia](#). I initially started by collecting sponsorship and then decided to get more involved. The Campaign Group is a great way to do this - a year in and I feel we've really been able to make a difference.



What does your role involve?

The group works with the local Alzheimer's Society team, building on their work and relationships, looking at specific campaigns that perhaps need extra focus or time. Recently our team supported a local hospital trust during [Dementia Awareness Week](#). We organised a stand with a 'Memory Tree' that enabled visitors and hospital staff to share memories of those they know living with dementia, as well as providing information for people to find out more about dementia. Team members contribute what they can when they can.

What skills and qualities does a campaigner need to have?

In my opinion all you need is the time and desire to get involved - everyone can bring something. I'm part of a great team- small but growing. We pool our experience, expertise and enthusiasm and I've enjoyed meeting people from different backgrounds. If you've thought about volunteering why not give your [local Alzheimer's Society team](#) a call?

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Sue Vincent

Campaign Group Lead, Suffolk

Why do I campaign?

Following my mother's admission to a [dementia](#) assessment unit after we had reached a crisis point I came into contact with other family carers. They encouraged me to become involved with the East Suffolk branch following which I was recruited to the then 'branch development committee'. The branch were then discussing various issues around gaps in services and how to raise awareness of these to the right people and decided to set up a local campaign group in 2008 to take this forward. In 2010 we became the Suffolk Campaign Group with myself as Campaign Lead.

I was not previously aware of the work of Alzheimer's Society and if I had been I would have been more aware of the support and services available and more able to improve my mother's quality of life. I became involved in campaigning to help make a difference so that others are better informed and supported to help them get the best care and support available tailored to the needs of the person with dementia and their families.

What does my role involve?

As well as ongoing work related to 'Worried about your Memory' (encouraging [early diagnosis](#)) and 'Counting the Cost/This is Me' campaigns (hospitals), myself and the group are also following up on some problems relating to 'Care at Home' services and some specific local issues relating to the National Dementia Strategy and cuts in local services. We regularly liaise with GPs, local authorities, Primary Care Trusts, Mental Health Trusts, Acute Hospital Trusts, libraries, local media and politicians.

What skills and qualities does a campaigner need to have?

Enthusiasm, passion, good communication and the ability to be a diplomatic 'pain in the neck' - like a dripping tap that keeps going until someone pays attention!



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Tony Robinson

Campaign Group lead, Warwickshire

Why do you campaign for Alzheimer's Society?

Having [cared](#) for my wife Isobel through the whole "dementia journey", most of it 24/7, I want to pass on that experience to the thousands of others following us, to make their lives easier. I have been an active member of this group since Oct 2010 after Isobel went into residential care, having been approached nine months earlier by a lady from Alzheimer's Society. She suggested I would make a good volunteer after I gave a presentation on my experiences as a [carer](#). This seemed an ideal opportunity to fill some of the void created when the caring role finished.



What does your role involve?

To me it is like going back to work part time, but striking the right balance with the rest of my life. I am involved with annual campaigns like [Dementia Awareness Week](#), helping on the [Dementia Roadshow](#), radio interviews, attending conferences and Parliamentary Delegations, including regular contact with my MP. I also give talks to social groups, and help at a [dementia café](#) once a month. Our group is now engaged in possibly our biggest challenge undertaking a pilot project aimed at improving [early diagnosis](#) rates.

What skills and qualities does a campaigner need to have?

Perhaps I have been fortunate that most of my working life was being a team member, and ultimately being in charge. I can reuse those skills I acquired then as a volunteer. As with any team, all members have different talents, and the trick is to use those talents to full advantage. Any prospective volunteer would be most welcome, as there can never be enough of us. We are encouraged to expand our range of skills; previously I had never written a press release, and dare I say, my greatest challenge has been to adapt to a female dominated environment.

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Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

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