



**Share your experience
of dementia activism**



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Kate



I work with an activist who has young onset dementia and have learned a tremendous amount from him. He has inspired me to bring in people living with dementia to assist with training our frontline staff.

I have taken a special interest in being able to provide services that promote dignity in care and support as well as being a champion to break down stigma and advocate for better resources.



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She inspired me in so many ways, and we became good friends, sharing our love of nature and photography as well as activism.

Gail

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There are so many people living with dementia that inspire us – I think everyone is an inspiration in their own way, without even realising.

I don't think of myself as an activist, I'm just me, but I'm part of the LEAP lived experience advisory panel for Dementia UK. I educate others alongside my Admiral Nurse, I share my artwork to hopefully inspire others, and I write a blog, *Don't be scared to live. Don't be scared to try something new. Life is for living with or without dementia.*

I've been supported by an Alzheimer Scotland post-diagnostic support worker, and she's been great.

I'm determined to keep making plans and living life to the full for as long as possible.

Wendy



When I was diagnosed with young onset Alzheimer's disease in 2023, I was only 61.

It was a lot to deal with, but I remember thinking – you can't sit and cry about this, you have to stay positive and make the best of things.

I've been supported by an Alzheimer Scotland post-diagnostic support worker, and she's been great. I'm no longer able to work, but I focus on keeping busy and spending time with family and friends, plus I've taken part in dementia research studies.

I have good and bad days, but I don't ever feel sorry for myself. I'm determined to keep making plans and living life to the full for as long as possible.



The FTD Brothers are a beacon of inspiration to all families living with a person with young onset dementia.

Madeleine

The FTD Brothers are inspiring and amazing! Brilliant examples of how to live life even when bad news is the centre of your universe and life.

Sarah

The FTD Brothers are a beacon of inspiration to all families living with a person with young onset dementia.

My husband was diagnosed with FTD at the age of 52, when our youngest child was only 12. Her childhood from then on has been different.

I work in the field of dementia (with older people) and personal experience has influenced my day-to-day job, mostly in my understanding of carers, the unsung heroes, who live with so much which no one really understands until they are in that position themselves.

Madeleine

Irene has been an activist in so many ways – inspiring people through her writing and delivering dementia awareness sessions.

She selflessly gives up her time to make a difference to the way people see dementia.

She is an absolute inspiration!

Ruth



Irene was diagnosed with dementia at the age of 54.

She has been an activist in so many ways – inspiring people through her writing and delivering dementia awareness sessions including in primary schools and has contributed significantly to policy discussions and the creation of the current Scottish dementia strategy.

She selflessly gives up her time to make a difference to the way people see dementia. She is an absolute inspiration!



When Des was asked if he had accepted his dementia diagnosis by the partner of someone newly diagnosed, he said no, he hadn't accepted it, he had embraced it!

This completely changed the view of the person asking and for the first time they saw a future that could be positive.

Anna

When Des was asked if he had accepted his dementia diagnosis by the partner of someone newly diagnosed, he said no, he hadn't accepted it, he had embraced it!

This completely changed the view of the person asking - and for the first time they saw a future that could be positive.

I have told this story to a number of people, and each time, it touches them, and I think changes minds about dementia. Thank you, Des.

I found a Facebook page called 'Forget me not for dementia loss' created by a special lady called Julie.

I now help Julie run the page, and together we raise awareness and fundraise for dementia charities.

It gives us a reason to wake up each morning and fight. Julie is an amazing angel with the biggest heart.

Tracey



I lost my beautiful mum Audrey to Alzheimer's disease in 2020, not young onset, but I struggled losing her.

I found a Facebook page called 'Forget me not for dementia loss' created by a special lady called Julie. The page now has over 1000 members who support each other daily.

I help Julie run the page and together we raise awareness and fundraise for dementia charities. It gives us a reason to wake up each morning and fight.

Julie is an amazing angel with the biggest heart. She lost her mum in 2019 – our motto is 'Together we'll be okay.'



Michael Booth is one of the most well-known dementia advocates in the Teesside area.

He's pushed us to get the message out that dementia isn't just a condition affecting older people.

We hope it will inspire others to recognise their symptoms and seek help and support.

Marie

Michael Booth is one of the most well-known dementia advocates in the Teesside area.

He's written a book about his personal journey and has inspired us to create a page on our website dedicated to people living with young onset dementia.

He's pushed us to get the message out that dementia isn't just a condition affecting older people. We hope it will inspire others to recognise their symptoms and seek help and support.

I chair tide's monthly online peer support group for carers of people with young onset dementia - they are amazing!

I've learned so much from them.

Ruth



I've been inspired by many people with dementia over the years, including Wendy Mitchell.

I chair a monthly online peer support group for carers of people with young onset dementia - they are amazing! Even when going through really difficult times, some are active in their local communities, others at a regional or national level.

Others have no spare time or energy beyond their caring role yet can still be a source of information and ideas – their activism is manifested in the way they support their peers, and I've learned so much from them.



Michael Andrews has inspired me to have an increasing involvement in research.

Encouraged by him, I have also become one of the University of Bradford's 'Experts By Experience' and a public speaker.

Julie

Michael Andrews has dedicated himself to educating professionals about the lived experience of posterior cortical atrophy and encourages others to find ways to live positively with their diagnosis.

He's involved in research, the development of training materials and has contributed to a number of books. He's a public speaker and a gifted photographer and musician.

Like me, he lives alone, and he has inspired me to have an increasing involvement in research. Encouraged by Michael, I have also become one of the University of Bradford's 'Experts by experience' and a public speaker.

**I'm dementia activist myself.
I'm a member of the Scottish
Dementia Working Group.**

**I also get involved in
campaigning and government
policy work.**

Ronnie



**I am a dementia activist myself
and a member of the Scottish
Dementia Working Group.**

**I'm an active member of Brain
Health Scotland, Alzheimer
Scotland's prevention initiative
and the Scottish Dementia
Research Consortium.**

**I also get involved in
campaigning and government
policy work.**



Gail supports us with our teaching sessions.

She's a real advocate showing everybody you can learn new skills and live well with dementia.

She shares her positive experiences to improve the lives of others, writing a regular blog and posting on her social media.

Maxine

Gail Gregory lives with young onset dementia. She supports us with our teaching sessions to professionals, academics and the public.

She's a real advocate showing everybody you can learn new skills and live well with dementia. She shares her positive experiences to improve the lives of others, writing a regular blog and posting on her social media.

She's keen that children learn about dementia at a young age which inspired us to create a platform to share resources which we presented to pastoral carers in local school and college and at our hospice establishment as well as in the community.

At first I was frightened by the diagnosis, but I decided to seek all the information I could to make the time we have together the best and happiest possible.

Nancy



I am experiencing young onset dementia through my husband, who was diagnosed about three years ago.

At first, I was frightened by the diagnosis, but I decided to seek all the information I could to make the time we have together the best and happiest possible.

We seek therapies such as speech therapy and physiotherapy but mainly try to keep his mind connected and positive.



The team at Royal London Hospital headed by Professor Nick Fox has inspired me.

They're a very enthusiastic group who clearly love supporting people.

They've created a genuinely unjudgmental, caring and thoughtful atmosphere.

Kenny

The team at Royal London Hospital headed by Professor Nick Fox has inspired me.

They're a very enthusiastic group who clearly love supporting people. Their passion and optimism for developing a cure for dementia is incredible and they've created a genuinely unjudgmental, caring and thoughtful atmosphere.

I've been inspired by them to get involved in medical trials to help change the future for everyone.

We go to a dementia group at Pendleside Hospice and are still active in any way we can - supporting and making newer people feel part of the group.

All the staff at the hospice are open, friendly, smiley angels.

Peter and Maria



My name is Peter; Maria is my wife. I was diagnosed with young onset Alzheimer's disease aged 62, I'm now 67.

I did an article in our local newspaper, the Burnley Express, which was well received and gave me a lot of confidence.

We go to a dementia group at Pendleside Hospice and are still active in any way we can - supporting and making newer people feel part of the group.

All the staff at the hospice are open, friendly, smiley angels. Thanks for the opportunity for us to share our experience, strength and hope.

She's become amazingly outspoken and helps me raise awareness in my role as a dementia advisor.

We've done it all together: attending groups and events, conferences, and taking up opportunities to raise awareness about dementia.

Lisa



When this lady's husband was diagnosed with posterior cortical atrophy, she felt so lost.

Now she's a vocal 'activist' trying to help people understand her husband's condition. She's become amazingly outspoken and helps me raise awareness in my role as a dementia advisor.

We've done it all together: attending groups and events, conferences, and taking up opportunities to raise awareness about dementia. She plays a very active role in our carer and young onset dementia groups, and she's supported so many other people.