



‘From the eyebrows down I’m perfect’

Meet Peter Berry, cyclist, author, inspirational speaker... oh, and he has dementia

WORDS: Julie Lucas

The last time we talked to Peter Berry in 2019 he was embarking on a five-day bike ride – 300 miles across four counties, on a penny-farthing bicycle, to raise awareness for his condition, early onset dementia. Four years on he’s still riding his bike, raising money for charity, plus he’s appeared in a Channel 4 television series, written a book and is continuing to inspire people.

Peter, 57, describes himself as a normal guy. At 50, he was living in Friston, near Aldeburgh, and had his “finger on the pulse of life”. “I was running a timber company; I was the hub of the family earning a living, organising everything and had a very good memory for my work, in fact an exceptional memory for everything,” he says. But then his wife, Teresa, noticed he would lose the thread of conversations. “We didn’t think it was anything to do with dementia because our idea of dementia was elderly

people. I put it down to stress at work and lots going on.”

It took 10 minutes for Peter’s life to change. He was diagnosed with early onset Alzheimer’s. He describes the journey as a rollercoaster ride, but has used his experience to educate people about the condition. “I want to show people that you can live with the condition. Life is not over, it’s just a bit different,” he explains. For Peter, this has included appearing in Channel 4’s ground-breaking series *The Restaurant that Makes Mistakes*, about a restaurant staffed by people living with dementia.

“We all learned so much and most of us have remained good friends. Personally, I wanted to show that people with dementia could still achieve things, we weren’t on the scrap heap. The plumber could still plumb something, the organiser could still organise. There were still things that we could achieve and that we had to give to the world.”

Photo: Sarah Lucy Brown

LEFT: Peter Berry has early onset dementia and uses his time to raise awareness of the condition as well as raising money for research into Alzheimer’s

Peter has an incredibly positive and practical approach to his condition. His advice to others diagnosed with Alzheimer's is to get the practical things, like power of attorney, out the way and then to find a sense of purpose. "Don't waste your time being depressed about it, even though it's quite a difficult place to be. Get out there and start doing the things you can do – gardening, cycling, walking, or maybe just a cup of tea of with friends.

"Cycling has always been a passion of mine ever since I was a teenager. I've rekindled that and used it to get away from my dementia monster, as I call it. When I go cycling, I become 'Peter the cyclist', as opposed to 'Peter with dementia'. It doesn't create a memory, but it does create a feeling. Sometimes when I'm cycling in the lanes in the sunshine, I think how much better can this get."

He also recognises that dementia is a diagnosis not just for the individual, but for the whole family. Teresa advises families to research the condition. "Learn about dementia – don't assume that you know. Make an effort and you can help your partner more," she says. "Don't undermine people, just prompt them and carry on as normal."

Peter admits he and Teresa wished they had told friends sooner, and believes talking about it is key. When he stopped driving, some people made the assumption that Peter had lost his driver's licence as a result of drink driving. "Support comes in many



Photo: Charlotte Bond

Deb provides support and friendship for Peter, and peace of mind for Peter's wife, Teresa, who knows that Peter is with someone when he's out cycling

different ways – rather than ask people direct questions ask them simpler questions. Sometimes, if I go out with Debs (his cycling partner, Deb Bunt), Teresa won't ask me where I've been, she asks me if I've had a good cycle ride. The rest might follow as time goes on," he says. "When my father had dementia and he didn't know who I was, I didn't worry about that, I just became a friend of his who made him laugh that day."

Deb Bunt has proved an invaluable support to both Peter and Teresa. Peter met her in Saxmundham's cycle shop, Sax Velo. Deb had just moved to the town with her husband, Martin, to take up early retirement. She and Peter struck up a friendship that has been life-changing for both of them.

"I helped Peter because he was just beginning to get nervous about solo cycling, so he offered

to take me out to show me the Suffolk countryside," explains Deb. "My presence meant he could continue to cycle, and Teresa, who was at work, didn't have to worry. I now help him by promoting his story, being his external memory. He calls me his 'plug in and save device'. He's helped me by showing me the countryside, maintaining my bike – I am clueless! – navigating – I am equally clueless – and showing me that life is for living. It is truly a reciprocal helping and supportive relationship, but I am aware that might change."

For Peter, the friendship has given him the chance to be with somebody one step removed from the condition. "It also gives my wife time on her own away from dementia. I go out with Debs and she (Teresa) knows that I'm safe and with somebody. Friendship gives me something that is so valuable nowadays. I've known

Photo: Charlotte Bond



Photo: Jayne Lindell

Key to coping with early onset Alzheimer's is dealing with the practical matters, then finding a purpose to your life, says Peter



Photo: Charnian Berry @berryphotographic

Peter's penny-farthing bike ride raised more than £15,000



Debs for three or four years and it actually seems like we have known her all our lives.”

Peter aims to destigmatise early onset Alzheimer’s through his website, talks and books, including *Slow Puncture: Living Well With Dementia*, written with Deb. It’s humorous, sensitive and thought-provoking. “I had this idea that if we could just help a few people get over the first few months of diagnosis, and help people stop going to the places that we went to in life, post diagnosis, that’s got to be something positive,” he says.

Has it made him stronger? “I’m definitely fitter,” he laughs. “I tend to live in the here and now instead of worrying about the future. My short-term memory is very poor now,

ABOVE: Deb Bunt, Peter Berry and wife Teresa Berry. Peter, from Friston, has early onset dementia and together with his cycling friend Deb, has written a book

RIGHT: Peter and his wife, Teresa

but physically I am okay. I always say to people, from the eyebrows down I’m perfect. Things are changing, but I’m still a great believer in a positive attitude – being able to laugh at ourselves and what our failings are because of the condition, it is so important. What is life without a bit of a laugh?”

Peter has raised over £20,000 for charity through his cycle challenges. But his next challenge is a little different. “I’m going to be pushed off a tall building,” he says. The abseil is being organised through Alzheimer’s Research UK. The work towards prevention, treatment and a possible cure goes on.

“I have a dream that one day somebody will get a diagnosis



Photo: Permission Peter Berry

and the doctor will say take this tablet and you will be absolutely fine, go away and forget about it,” says Peter. “Wouldn’t that be wonderful?” ♦
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