

Alzheimer's  
Society

Leading the  
fight against  
dementia

# Living with dementia



No looking  
back

## In this issue

### Page 8

Friends for the  
journey

A dementia adviser talks  
about her new role in  
supporting people with  
dementia in Sheffield

### Page 16

And the  
winners are...

Read the winning poems  
from the poetry  
competition, as picked  
by Roger McGough

### Page 20

Train your  
brain

Society teams up  
with BBC to  
launch new brain  
training trial

# No looking back

**Graham Browne featured on the cover of the first Living with dementia magazine in September 2007. Two years on, we catch up with Graham, 52, and his wife Debbie, 49, to find out how life with Pick's disease has been treating them**



## **Graham**

I was diagnosed in June 2006 after several visits to the doctor. After several scans and a week in our local neurological centre seeing eight different consultants, we were

## **Graham Browne at home in Peacehaven, near Brighton**



given the news that I had Pick's disease\*, and there was no medication to stop this.

In myself, I have not noticed any significant changes. I am the same old Graham as the day I was diagnosed. If anything, I will now stand up and talk more. I want to talk to people in the right places and talk about the need for better services and recognition of dementia. If you've got dementia, people tend to listen.

Mostly, people ask me if I'm sure I've got dementia. They expect someone who has it to be gibbering. It used to annoy me, this ignorance. I still think it's ignorance but I look at it from a different angle now. That's why it's important to talk about it.

I first got involved with Alzheimer's Society when I was diagnosed, when Debbie went on the internet to find some support for me. She

found the Towner Club for younger people with dementia, based in Brighton, and I have not looked back since.

Since then, I've attended the Liberal Democrat party conference in Bournemouth, followed by the UK Dementia Congress a few weeks later at the same venue. I was at the Society's launch of the Out of the shadows report with Terry Pratchett, who also has dementia.

I've also done numerous interviews for the media and had a visit from a film crew to make a DVD for the Society. More recently, I attended a RIBA presentation to architecture students who were asked to design care homes for the future.

Locally, I've done training courses with West Sussex County Council. This allows me to talk to groups on training days such as nurses, volunteers, social workers and hopefully, schools.



**Graham and Debbie Browne with their three-year-old grandson, Kyle**

I still attend the Towner Club. We are going along nicely although we did lose our manager to retirement. This year is the club's tenth anniversary so we're going to have a party.

Earlier this year, I was invited by Neil Hunt to become an Alzheimer's Society Ambassador, which I was very proud to accept on behalf of all people with dementia. It was like receiving a gold medal to be recognised for what I've been doing, and I will always stand up and let people know what our needs are.

I'm determined to fight this disease. I'm going to have plenty of time later in life to keep thinking about it. In the back of my mind, I'm trying to defeat it.

I have bad days when not all is as it should be, but having my family around me makes all the difference.

**Debbie**

It's been fine looking after Graham. He is deteriorating very slowly, luckily, so I've had many years to adjust to his new ways. One of the symptoms of Pick's is losing your inhibitions, and at one stage Graham became obsessed with sexual stuff. I kept getting whisked off to Amsterdam!

I'm broad minded, but if you weren't I can imagine that could have finished a relationship off. That's changed now, but he still has no concept of how anyone else feels. He couldn't understand why everyone was so upset about the tsunami. That can be hard to deal with, but again, that's a symptom of the disease.

He has to concentrate really hard on how to behave when he does the conferences, but I think it does him good as it gives him

something to think about and keeps him going.

When he was first diagnosed I wouldn't let him go out by himself. I was so worried what might happen. But as soon as I relaxed, he blossomed. He's a fighter.

I do get exhausted as Graham constantly talks, but I think we're both lucky with the way it's going. Our relationship has changed, but we still laugh all the time. Even with the disease we look at the positive side, but that's what works for us. I think if you keep positive, you're half way there.

**\*What is Pick's disease?**

Pick's disease is a type of fronto-temporal dementia (FTD). It is caused by damage to the frontal lobe and/or the temporal parts of the brain. These areas are responsible for our behaviour, emotional responses and language skills.

Typically, during the initial stages of FTD, the person's memory is still intact but their personality and behaviour changes. People with FTD may:

- lack insight, and lose the ability to empathise with others
- become extrovert when they were previously introverted, or vice versa
- behave inappropriately, for example, make rude or tactless comments
- lose their inhibitions, for example exhibiting sexual behaviour in public
- become aggressive
- be easily distracted
- develop routines, for example, compulsive rituals
- experience language difficulties, such as finding the right words or lack of speech.

It is important to recognise that these symptoms have a physical cause, and cannot usually be controlled or contained by the person.