Linda has devoted herself to caring for David

The forgotten cancer

Some 16,000 people are diagnosed with a brain tumour every year in the UK, yet still very little is known about this devastating illness

We all know how to look for signs of breast cancer, that smoking causes lung cancer and about protecting ourselves from skin cancer. But there is still one kind of cancer that goes largely unchecked, devastating thousands of families every year: brain tumours.

Unless you know someone with the illness, or have suffered personally, you probably know very little about this life-shattering disease. But of the 16,000 people in the UK who are diagnosed with a brain tumour every year, 86 per cent will die within five years, and experts say that this could be a contributing factor as to why the outlook for sufferers hasn't improved in the last 30 years.

'Unfortunately, the fact that so many people are so extremely ill means they are less able to campaign for more funding and research,' says Sue Farrington Smith, director of the charity Brain Tumour Research, which is campaigning for a cure and trying to raise £7 million to fund seven specialist treatment centres.

Even less aggressive tumours can be devastating, changing a person's personality and affecting their ability to lead a normal life – so it falls to relatives, plunged into a world of caring for their loved one, to speak up on their behalf.

LINDA RICKFORD, 64, from Coulsdon, Surrey, found her world turned upside down when her son was diagnosed with a brain tumour three years ago. Since then, she has become a full-time carer and campaigner to raise public awareness with the support group, Astrofund

'If you look at brain-tumour symptoms nausea and vomiting are right up there with headaches, yet my son David's sickness was put down to gastritis - an inflamed stomach - by nine different doctors.

For months, David had been so tired that he fell asleep every time we saw him. He was so worn down by his constant sickness that he didn't question the doctors. But I did. You never stop being a mum, even though David was 28 and the father of a three year old. Four years earlier David had had cancer (Hodgkin's lymphoma) and I was concerned that his tiredness and vomiting could be a sign of recurrence or even a new cancer.

David loves having his son Andrew to stay

In desperation we took him to a private hospital, where the doctor looked into David's eyes (something none of the other doctors had done) and then, clearly concerned, booked MRI and CT scans for the following morning. Immediately the results were through, he called us to say there was "an abnormality" on David's brain. My husband Barry and I were shocked to the core, but David's dry sense of humour kicked in as he phoned round his friends. "I know it's a poor excuse not to come to your wedding, mate, but I've got a brain tumour," he managed to laugh.

The tumour – which was nothing to do with his previous cancer – was the size of a walnut. Although technically benign, it was blocking the drainage of spinal fluid from his brain and had the potential to seed into his spine setting up new tumours. It needed to be removed

➔

straightaway, but the emergency surgery left David unable to see as well as he had before, eat or talk properly, sit up, stand or walk as his balance was severely compromised.

Because David had separated from his son Andrew's mum a couple of years earlier, he was discharged from hospital and came back home to Barry and me. We became his full-time carers, helping him in and out of bed, taking him to the loo, feeding him, and counting every little milestone in his recovery.

Fortunately, as we'd recently retired we were in a position to do it – or I don't know how we, or he, would have coped. There was no support offered at home – we just had to get on with it.

Despite needing more than a year off work, David's wonderful employers at Ikea held his management job open, and gave him a temporary lower-level-job as he gradually built up his hours. He is now working four days a week and is a great dad to Andrew who comes for sleepovers every other weekend. But the tumour wasn't entirely removed, and although he is in remission, David doesn't want to know what the prognosis is – apathy and depression can be a symptom of any brain tumour, brain surgery and radiotherapy. The average life expectancy for this kind of tumour is ten years so he is luckier than most, but not as lucky as we would like. What can we do except hope that much needed research comes up with some answers soon, and that David will still have many decades with us and his lovely little son.'

> "I was shocked to the core, but David's dry humour kicked in"


David can now enjoy time with Andrew

BRAIN TUMOURS – THE FACTS

- Every year, there is a four per cent increase in incidence of brain tumours. Currently, there is no evidence to show that chemicals in the environment, electricity power lines or mobile phones can cause brain tumours, but research is ongoing. There are more than 100 types – most commonly they develop from the cells that support the brain's nerve cells
- Brain tumours are the biggest cancer killer of UK children
- One in four people with another cancer will go on to develop a brain tumour
- The average GP sees just one patient with a primary brain tumour in their career.
- 'If you have two or more symptoms, including headaches, nausea, sickness, muscle weakness and poor speech and vision, or you've had a seizure for the first time in your life, it is crucial that you are referred for an MRI scan,' says Sue Farrington Smith of Brain Tumour Research
- Take part in Wear a Hat day on 30 March to raise awareness of brain tumours
- **For more information on brain tumours, visit www.braintumourresearch.org and www.astrofund.org.uk**

IN MY CASE

'I've learnt to live in the present'

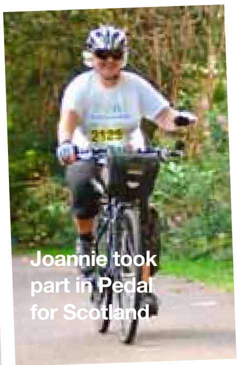
JOANNIE MCCUTCHEON, 60, is an IT consultant from Edinburgh

'Before my diagnosis in 2005, I was living a whirlwind life, with a hectic job in IT that involved travelling worldwide. I was getting terrible headaches and for nine months doctors were convinced these were caused by work stress. But then one night I had a seizure in my sleep and woke up with blood in my mouth where I'd bitten through my tongue. I was finally given an MRI scan that revealed not just one but two "lesions" on my brain. When I realised these were tumours, I thought my life was over…it was, but not in the way I'd feared.

Without discovering the tumours (both low-grade gliomas), I would never have managed to turn my life around. And it has changed hugely, for the better.

People find this hard to believe since I've lost some of my peripheral vision, and also have problems with brain-to-eye coordination, which means it can take me a long time to recognise something I'm looking for – even when it's right in front of me. I had to give up my job and my marriage broke down under the strain of my illness. Yet, my life is richer as a result.

I took up voluntary work, creating websites for cancer charities, through whom I met some wonderful people I never would have known if I hadn't become ill. I started writing poetry and taking on challenges to raise money for Edinburgh Centre for Neuro Oncology and Maggie's Cancer Caring Centres. I've cycled across Spain, and abseiled off the Forth rail bridge. My tumours are slow growing and stable, in fact the less serious of the two could have been there since I was a baby. Either tumour could become aggressive at any time, but while to some people, that is a terrifying thought, to me, it is a simple motive to live in the present and love this life while I have it. And I really do!'


Joannie took part in Pedal for Scotland

Feature: Karen Evennett