SPECIAL CASE: Jenny Rowbory, aged 20, of Martlesham, who is suffering from ME Photos: OWEN HINES

REASON TO BE HOPEFUL: The new drug from the USA as used by Jenny, and, below, Jenny with her book of poetry

Drug's helping Jenny get back on her feet

HEALTH

Young ME sufferer Jenny Rowbory tells Sheena Grant about a drug she hopes will change her life and the poetry anthology she has published to help fund her treatment.

In almost 20 years as a journalist I've never interviewed anyone who was in bed – until now. But Jenny Rowbory is a special case. She suffers from ME, or chronic fatigue syndrome, and bed is where she has to spend a lot of her time.

She was expecting a phone call rather than a face-to-face interview, but when her mother went up to see if she was well enough to come downstairs and speak to me she declined.

So instead, I perched on the end of her bed in her little room, full of books and with a quotation from the Bible on a plaque hanging by her side.

Twenty-year-old Jenny of Harvesters Way, Martlesham Heath, fell ill almost two years ago when she was in her first term at Bristol University, where she was studying Classics.

"It started with a virus at the beginning of December in 2004," she said. "It was flu-like symptoms but then it developed into ME. Officially I had to stop my studies in April 2005 but, in fact, I did not go back to university after Christmas 2004.

"I had severe headaches, muscle pain, exhaustion and dizziness. Gradually the condition got worse and I developed chest and heart problems."

Jenny was diagnosed with ME in February 2005 and since then, she has been waiting to get better, with little or no medical treatment. She used to try and get outside for a very short walk each day, but just recently even that has been impossible because of the pain she is in and severe headaches and dizziness she suffers.

"I find even washing really difficult because of the pain," she said. "My day is mainly resting. I can read for a few minutes and do things in short bursts but I spend a lot of the time sleeping."

Looking at this pretty and intelligent young woman who is too ill to move from her bed much of the time it's hard to believe she doesn't feel bitter and angry at being robbed of so much.

But Jenny's attitude is remarkable.

"I have great friends and family who keep me going," she said. "Obviously I get frustrated sometimes but I keep positive – there is always hope of getting better.

> "You always hope you are going to get better"
>
> Jenny Rowbory

"Most of my friends are at university. When they come back for weekends they come and see me. They are getting on with their lives but you can't be jealous or resentful. You just have to accept it. I want to hear about all they are doing. I don't want them not to tell me because they feel sorry for me.

"You always hope you are going to get better. It takes a while at first to accept you have got ME – I didn't know anything about it at first, it took me totally by surprise, especially as before I was ill I was really sporty and took part in drama productions. It was such a shock to suddenly be immobilised."

In the last few weeks Jenny has a new reason to be hopeful. She has started taking a drug from America, that is not available in this country, after consulting a medical specialist who advises the US and Canadian governments on ME.

Professor Kenny De Meirleir is based in Brussels and his laboratories carry out comprehensive blood tests to identify which specific type of three ME illnesses a person is suffering from.

"My mum had been doing lots of research on ME and found out about these six tests you could have done," said Jenny. "She managed to get in contact with the professor, who said he was coming to London for a conference and invited my parents to meet him. We had some blood tests done before that."

The tests found that Jenny had type three ME, which carries symptoms similar to rheumatoid arthritis, and showed she had excessive amounts of a molecule that compromises her immune system and is indicative of ME.

"In normal people the count of this molecule is 2 to 10," said Jenny. "The first blood test showed mine was 53, which is high even for ME. Another blood test put it at 150-something. It was wreaking havoc in me. It means you haven't got an ininune system."

The professor suggested a drug called Nexavir, which Jenny says has helped many people get better in the US.

"It's an anti-viral drug. It is not a cure but gives the body a chance to recover its immune system," she added.

Unfortunately, the only way to get the drug in Britain is to buy it from the States at a cost of around £360 a month. Jenny has been taking it in daily injections given by her mother for almost six weeks and is hopeful that it will start to have an effect in the next month or so, as the doctor predicts.

She will probably have to take Nexavir for around a year – at a total cost of more than £4,000. But if it is successful it will allow Jenny to regain her life and a take up an unconditional place at Cambridge University to study theology next autumn (2007).

"There are thousands of people in the US recovering because of it (Nexavir)," said Jenny. "The doctor is very confident it will help me.

"Before that I had not really had any treatment at all, apart from about a week's worth of antibiotics. I was told there was nothing they could do. I was referred to a consultant at the James Paget Hospital (in Gorleston) but he just told me to pace myself and said I would be feeling better soon."

However, Jenny says her GP has been supportive of her new treatment and has provided needles for her injections.

Her main incentive for getting better is to take up her university place next year but Jenny also wants to help others with ME, who are perhaps not even aware of the drug she is taking.

"If I get better I feel I can't leave other people who have ME," she said. "I want to help. I want to tell people about the drug. There are so many people suffering – something needs to be done."

In order to help fund her treatment in the only way she can at the moment, Jenny has self-published an anthology of her poetry which she is selling for £6.99 a copy.

She seems embarrassed to be talking about her work and admits she would never have shown it to anyone else, let alone wanted it published, were it not for the desire to help with the cost of her drugs.

She has been writing poetry for the last four years and of those included in the anthology, about half have been written since she became ill.

"There is a huge mixture of poems," said Jenny. "I don't think there is a general theme. There are some silly ones and some serious. They are just things that have influenced me."

So far, she has sold 122 copies, raising a valuable contribution towards her treatment, but she is keen to sell more.

"I am proud to see my poems together although I never before showed my poems to anyone and never intended to. I wrote them for myself," she said. "I just wanted to help with the money situation.

The poems deal with a huge range of issues from homesickness to illness, religion to injustice. There is also a poem about Crocodile Hunter Steve Irwin, who died earlier this year when a stingray barb pierced his heart.

Jenny writes:

"You've been part of my everyday life.
At a time in my life when I've been housebound,
Mostly lying in bed in pain,
Chronically ill.
You always brought a smile to my face,
Entertaining and educating.
And though I laughed at your funny ways
I admired you deeply.
The things you did!
You made me remember I was alive"

● For more information or to buy Jenny's anthology, *Anchors Away*, visit or send a cheque for £8.99 (including postage) made payable to Jenny Rowbory Medical Fund Society to 35 Harvesters Way, Martlesham Heath, Ipswich, Suffolk, IP5 3UR.

ME FACTFILE

ME (Myalgic Encephalomyelitis/ Encephalopathy) is a chronic, fluctuating illness. It is also known Chronic Fatigue Syndrome (CFS). Sometimes it is diagnosed as Post Viral Fatigue Syndrome (PVFS). The illness affects many parts of the bo such as the nervous and immune systems.

The most common symptoms are severe fatigue or exhaustion, problems with memory and concentration and muscle pain.

It is estimated that there are up to 240,000 people with ME in the UK.

It can affect men, women and child of all ages and from all social and ethnic groups.

It seems to be more common to develop the illness between your early twenties and mid-forties.