

[Home](#) | [About](#) | [Newsletters](#) | [INvoice](#)

Margaret Brew's story

Back to: [Newsletter 19](#)

Margaret came close to death - now life looks good again.

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Margaret of Berwick knows only too well the trauma of being desperately ill after being struck down by Guillain-Barré syndrome (GBS).

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GBS/CIDP Awareness Day - 1st May

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People who have been close to death and completely recovered have been on a very sobering journey. Margaret Brew of Berwick knows only too well the trauma of being desperately ill after being struck down by Guillain-Barré Syndrome (GBS). The disease is a rare paralysing and potentially catastrophic disorder of the peripheral nerves. Its cause is unknown and the length of illness is unpredictable, often leading to months in hospital. GBS has a compatible disease, Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).



All's well, now, for Margaret and Len Brew.

to move my limbs while in bed, but I was experiencing extreme tiredness and many times I just told the physiotherapist to go away and leave me alone," she said.

However, the medical staff did not leave her alone and she gradually found she was able to take normal food and to regain her strength.

"I had to learn to fend for myself again, to sit up, to feed myself, to stand, walk, and to take myself to the toilet and shower.

"As my mobility increased so did my confidence and then all I wanted after six weeks was to go home.

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GBS has a compatible disease, Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

Thursday 1 May is GBS/CIDP Awareness Day and Margaret said now was a good time to tell people about the need to support people suffering from the disease.

Margaret has fully recovered, but was left with a desire to support those looking for prevention, and a cure of the syndrome.

She is a member of The Inflammatory Neuropathy Support Group of Victoria ("The IN Group") which supports GBS and CIDP sufferers.

Margaret said the Group provided educational material, supported patients and their families and funded medical research.

She said 100 Australians contracted GBS each year and about the same number contracted CIDP.

"It can strike suddenly and it is considered that it is usually preceded by some intrusion into the body such as flu or gastro-enteritis," she said.

Margaret said she was fit and well in January 1992 when she started to feel she had the flu.

"I thought I had a bad dose of the flu but after a week there was no improvement.

"I was living on the Peninsula and went to a local doctor who gave me antibiotics but I became worse," she said.

Margaret said she was suffering from aches and pains all over and was becoming weak. She suffered from double vision and then when she wanted to go to the bathroom during one night she was unable to stand.

"We became alarmed and called the doctor who was upset at receiving a 2am call.

"We insisted he came and he made the effort but after regular checks he was unable to give a diagnosis and suggested I take some Panadol and try to sleep.

"He said he consult with his colleagues next day.

"By 11am I was having trouble breathing, speaking and swallowing.

"My daughter who is a nursing sister and my husband decided I should go to hospital and insisted that the doctor have me admitted.

"I was admitted to the Monash Medical Centre at 1pm where I was soon diagnosed as having GBS and that was the start of months in hospital," she said.

"The stay in hospital was usually followed by a long rehabilitation period but she was too ill to fully comprehend what was happening.

"It was the worst kind of nightmare for us all and at that time there was no specific treatment and no support group," she said.

By evening of her first day in hospital Margaret was placed on a ventilator because she had lost the ability to breathe and she needed tubes to take over her bodily functions.

"I don't remember any great pain because I was heavily sedated, but suffered nightmares and hallucinations as a side effect of the drugs.

I will never forget the nightmares," she said.

Margaret can vaguely remember, during the first two and a half weeks, constant attention by medical staff and the trauma of having her blood washed to eliminate the virus.

"I had six treatments, injections, a spinal tap and endless x-rays and during all this my husband and family just had to stand by and watch helplessly," she said.

Margaret's improvement started after three weeks and she has expressed thanks to Monash Medical Centre staff for their expert medical care and to her husband, family and friends for their spiritual support.

Also there was her will to survive.

"As the tubes were being removed one by one my need for sedation was reduced and I was transferred to an intermediate ward.

"Then the hard work began.

"I had regular visits from the physiotherapists who encouraged me to move my limbs while in bed but I was experiencing extreme tiredness and many times I just told the physiotherapist to go away and leave me alone," she said.

However the medical staff did not leave her alone and she gradually found she was able to take normal food and to regain her strength.

"I had to learn to fend for myself again, to sit up, to feed myself and to take myself to the toilet and shower.

"As my mobility increased so did my confidence and then all I wanted after six weeks was to go home.

"I attended a day centre three days a week for intensive physio and had the council home help once a week for two months.

"By then I was able to walk unaided, my sight was normal and I was able to carry out physical activity for longer periods," she said.

Margaret said there was no follow up from the hospital and the local doctor didn't bother to find out whether she was dead or alive.

"I began to treat myself with natural remedies which incorporated a nutritious diet, herbal remedies, massage with essential oils, regular walks and meditation.

"By mid-year I was well enough to travel to Queensland with my husband on a caravan trip for the winter months," she said.

Margaret said she became so interested in natural therapies that she completed a diploma course with the Queensland Institute of Natural Science and now counsels people in natural therapies.

She strongly supports The IN Group and says if it were not for the Monash Medical Centre she would be dead.

The In Group can be contacted (03) 9853 6443.

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