

MEDICINE » 'TALK THERAPY' TAKES ON CHRONIC FATIGUE SYNDROME » COMING SOON TO CANADA

'It was very much like being a dead person ... I could only lie there.' The victim of an exhausting, little-understood malady, this young woman spent six long years confined to a darkened room. **Zoe Cormier** describes how a new – and surprisingly simple – therapy brought her back to the light

NORWICH, ENGLAND

Anna Debbage suffers from wanderlust. At this very moment, she is backpacking in Thailand, which isn't unusual for someone her age, except that she hasn't exactly lived her 26 years to the fullest. Ms. Debbage has yet to finish high school, has never dated seriously and, until a few months ago, knew precious little about the infamous terror attacks of Sept. 11, 2001.

For almost six years, she was a prisoner in her own bedroom, consigned to a life she now characterizes as "like being dead, like being in a tomb."

The young woman from Norwich, two hours northeast of London, had fallen victim to a baffling illness that medical science for years refused to recognize and even now has yet to devise an effective treatment. At her worst, she was unable to move her arms or legs and couldn't tolerate even the tiniest sliver of light or the faintest sound. She kept her blinds drawn tight, her eyes covered and the power indicator on any electronic devices coated with foil. Even the quietest sounds were so painful that her parents added insulation to her walls and bought her industrial headphones.

Ms. Debbage had contracted a case of chronic fatigue syndrome (CFS) so extreme that she thought she would never get better. And yet, after being robbed of nearly a decade of her life, she has made a full recovery, for which she credits a strange – almost implausible – new treatment that is coming soon to Canada.

'HYSTERICAL NONSENSE'

Chronic fatigue syndrome is a true mystery. Some experts feel the affliction has always been with us, but it first came to the attention of medical science midway through the 20th century as a bizarre, debilitating condition sparked by an initial flu-like illness. Preliminary investigations suggested the fatigue was linked to inflammation in the brain and spinal cord, and the condition was dubbed "myalgic encephalomyelitis" (ME), as it is still known in England.

But no symptoms were visible. All that seemed to unite its victims was their exhaustion. (Even now, there is no diagnostic test for it.) So, in 1970 two psychiatrists writing in the British Medical Journal dismissed the condition as mere hysteria, an assessment that stuck for decades. Young doctors were taught that CFS was "hysterical nonsense, a non-disease," says Charles Shepherd, medical adviser to the ME Association in Britain. "So it became something that few people were willing to investigate," and retained its "psychosomatic" status through the 1980s when it was derided as the "yuppie flu" suffered by self-obsessed hypochondriacs.

"But now the research shows that this is undoubtedly not a psychological problem," Dr. Shepherd says.

CFS researcher Anthony Komaroff, a professor of medicine at Harvard Medical School, agrees, pointing to clear evidence of "objective, biological differences" between chronic-fatigue sufferers and the rest of the population.

"The central nervous system and the immune system are measurably different," Dr. Komaroff says. People with CFS have less grey matter in their brains and abnormal functioning of the hypothalamus, as well as elevated levels of cytokines (proteins released by the immune system), impaired white blood cells and lower adrenalin levels. And now researchers have found genetic differences, which may lead to a gene-based diagnostic test.

CFS is now taken so seriously that Statistics Canada estimates as many as 1.3 per cent of Canadians suffer from it and the U.S. Centers for Disease Control and Prevention has launched a public-awareness campaign to dispel the "psychosomatic" stigma.

Still, there is no "cure." The few drugs commonly pre-



'I love so much just being able to feel the sun on my face,' says Anna Debbage, a young Briton who has so recovered from her extreme case of chronic fatigue syndrome that she is now backpacking in Thailand. ZOE CORMIER FOR THE GLOBE AND MAIL

Faded genes

What makes a person prone to chronic fatigue syndrome?

The answer is written in our genes, researcher Anthony Komaroff says.

"The disease is a consequence of some biological vulnerability that patients are born with," explains Dr. Komaroff, a professor of medicine at Harvard Medical School, "and then something in their environment exposes that vulnerability."

Scientists now believe the sequence is something like this: First, a viral infection leads to a flu-like illness – for example, studies have linked CFS to a number of viruses (including those for Type 6 herpes and its cousin Epstein-Barr, a common cause of another exhausting illness, mononucleosis). Although in most cases, the immune system responds and the people recover, for an unfortunate few, the illness persists, and the immune response never shuts down.

It appears that the fatigue becomes chronic because of malfunctions that occur in a number of cranial control centres, but there remains a great deal that doctors don't know. For example, there is growing evidence that rather than being just one illness, "CFS" may be an umbrella term for several.

» Zoe Cormier

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» Source: Phil Parker's website www.lightningprocess.com

scribed can only address the symptoms, such as pain and sleep deprivation. And few of the many alternative remedies available offer much relief.

Most sufferers hope that by looking after themselves and pacing their activity, they can manage the illness. But for some that simply isn't enough.

EXHAUSTED BUT SLEEPLESS

Anna Debbage belongs to this select group. For a few years after she fell ill in 1998, her father, Noel, says, "I read about CFS as much as I could, and I thought, 'We are getting away lightly with this!'"

But slowly she grew increasingly tired, missed more and more school, and spent more time in bed. A devout Christian, she now says it was almost a blessing that "I had no idea how bad it would get."

The condition slowly took control. No matter what they tried – vitamins, herbs, medications, magnesium injections, oxygen supplements, gluten-free diets – nothing worked. Any activity exhausted her and, paradoxically, rest didn't help: In a cruel irony, CFS sufferers are plagued by insomnia. Ms. Debbage went weeks without proper sleep.

At first, she would feel worse in the winter and pick up in the spring, but in the third winter she went down and stayed there. In December, 2001, she lost the use of her legs, followed two months later by her arms and hands. By April, she could no longer see, and by June she could no longer hear.

"One thing that helped me cope was a sense of humour," she says. "If you try hard enough, you can see the funny side in almost anything."

But then she started to lose something that made no one laugh: the ability to breathe. She began to panic. "I really thought I might have been dying." With concentration and the help of her family, she regained control. But almost every minute for the next year was spent focusing on breathing slowly and regularly.

The mental fatigue was just as acute. "It was very much like being a dead person. I couldn't remember things, I couldn't imagine, I couldn't plan. I could only lie there."

No light. No movement. No music. No visitors. Minimal, whispered conversations with her parents. Her relatives sent her letters and tape recordings. "But nothing held any meaning any more," she says. "All I needed to hear were the words 'I love you.' But so many people just don't know to say it. Maybe it's our culture – we're very reserved in England." Most friends abandoned her.

"People who would come to see me wouldn't come back. They just couldn't take it in." Life was hell for her parents. (Mr. Debbage says Anna's mother "hated the fact that light, of all things, would make her ill – there's something so awful about that.") By 2002, "the depression broke me," Anna says. "I felt suicidal."

Yet her dark, lonely paralysis was interrupted on occasion: In 2003, she managed to listen to a few minutes of music, turned 21, taught herself to whistle, felt God's presence return and had her depression ease. By November, she says, "I was well enough to cry."

And then, in the winter of 2004, she really started to improve. She tolerated light a few minutes a day and by March she could listen to the odd track by her favourite singer, Elvis Presley. In April, her eyes were well enough to see her younger brother, now a grown man. By July, she could read *Winnie the Pooh*, feed herself with a remote-controlled arm and be taken out in a wheelchair. In August, she managed to stand for 10 seconds.

She grew so hopeful that she attended a friend's wedding in her wheelchair. But it was too much. She relapsed to square one: motionless, silent, super-sensitive to light – unable even to chew.

"But one thing that always brought me courage and hope was the metaphor of a butterfly chrysalis: They spend a lot of time alone in the dark, unable to move, while turning into something beautiful."

BOLT FROM THE BLUE

The butterfly began to emerge last May when Ms. Debbage underwent a new therapy so unusual that it's difficult to believe it could possibly work.

Known as the "lightning process," it was devised by British alternative-health practitioner Phil Parker to help people snap out of negative patterns, such as smoking, depression, anxiety – and CFS. The goal is to strike like lightning: do it all in just three days.

Available in Britain for about seven years, the program combines elements of various alternative therapies, such as osteopathy, hypnotherapy and neurolinguistic programming. The end product is essentially a blend of behavioural therapy, "positive thinking" and a few posture exercises. No injections, no pills, no ointments.

Not that CFS is a figment of the imagination, the London-based Mr. Parker says. "Just because we approach an illness from a partially emotional side doesn't make the illness purely emotional," he insists. "This is about neurologically restoring

balance from the inside rather than the outside."

Robert Fulcher, a stroke specialist at the Norfolk and Norwich University Hospital, endorses the notion that the brain can be "rewired."

"When you are bedridden," says Dr. Fulcher, who is also trained as a hypnotherapist and who introduced Ms. Debbage to the lightning process, "certain pathways in the brain can become fixed, and a lot of what we do becomes unconscious."

But those patterns can be broken. Not unlike stroke victims who must build new neural pathways to regain lost brain functions, he explains, "in order to get better, CFS sufferers need to actually establish in their mind that they are not going to be stuck in bed for their whole lives."

Still, it all sounds a little far-fetched, and critics have called the process unscientific, New Age rhetoric. Ms. Debbage was certainly not very hopeful. "I had already accepted that I wouldn't have my life back until my 30s, maybe my 40s – I was sick of false hopes."

She had good reason to be skeptical, says Dr. Shepherd of the ME Association. "Some new alternative miracle cure comes along every two months or so – such as anti-candida diets, multi-vitamin shots, co-enzyme Q-10 pills. Most hang around for a year and disappear from the scene. None has really stood up to scientific investigation."

Although he believes that CFS is a brain disorder, "I am equally skeptical of 'talking treatments.' ... They all claim incredible success rates, but they have never been subjected to a proper medical trial."

The exception, he says, is the lightning process, which is the focus of a small independent pilot study conducted by Leslie Findley, a clinical neuroscientist who has spent decades working with Parkinson's disease, CFS and other neurological disorders.

Because he feels that CFS sufferers "are vulnerable to exploitation, and there have been all sorts of quackery and bogus treatments," Dr. Findley is very skeptical. But after tracking more than 100 of his own patients who have undergone the therapy, he feels that there may be something to it.

About two-thirds of his subjects seem to have some benefit. This is quite a bit short of the success rate lightning-process practitioners claim (they say that, done properly, it should work for everybody), but there is a measurable benefit nonetheless.

"Whenever something new comes along," Dr. Findley says,

"I'm keen to see if it has anything to offer – and there's no doubt that this does." He believes the key is the way the process helps people manage stress, which accentuates any illness. For example, stress worsens the tremors in Parkinson's patients.

Does this mean that CFS really is all in the mind?

"No," Dr. Findley says. "The fact that we are changing the functioning of the stress system by a verbal technique does not imply in any way that this is psychosomatic – only a fool with a superficial understanding of the way the brain works would make this assumption."

But neither does he feel the tactic – which will reach Canada this spring when psychotherapist Maxine Henk, trained in the procedure by Mr. Parker, moves to Vancouver – is for everyone. "This is a collection of techniques packaged in a way that effectively helps some patients – but not all of them. I see it as another way of managing some patients, mainly those that haven't yet responded to much more simple approaches – the majority won't need it."

And in some cases, it could do more harm than good. "If a patient is offered this with the belief that they will get better because their recovery is entirely up to them," he says, "if it doesn't work, they could go off with more guilt and a sense of failure, which just perpetuates their stress and, therefore, their illness."

There is certainly no shortage of reports online describing how the lightning process has failed and disparaging its cost (about \$1,200), principles and claims.

"I myself was by no means convinced that this was going to work," Noel Debbage says. "But it did. The doctor talked to her, gently asked her if she would try and open her eyes – and she did."

Being a math teacher, he says, "the idea that you can use language to reach in and switch a button in your head to impact your body is still very hard to believe, even though I saw it happen." And yet his daughter seems to have made a full recovery.

"She was undoubtedly the worst case I have ever treated," Dr. Fulcher says. "This girl hadn't been out of a darkened room for years – and yet by the end of the third day of training, she went to a market with her mother and bought some chewing gum."

HAPPY TO BE ALIVE

Over the next few months, Ms. Debbage reclaimed her life. She learned to walk again. She started swimming and biking. And she moved back home from the full-time care facility where she had lived since 2004.

Someone who met her today would hardly suspect that she lost almost a decade of her life, although she looks like a teen, having seen so little sunlight for 10 years, and is overjoyed at things others her age take for granted. While warming up for her Thai adventure, she was thrilled to drink "a whole Bailey's" during her first-ever evening out.

But enormous challenges lie ahead. While she was in the dark, her friends left her behind (most are married or working now), and she has to get to know the world again.

"Anna seems to be walking free," her father says. "But she can't just live as though it never happened – it has changed her irrevocably. But as a parent I don't want to foist my own schemes on her; she has to decide what kind of person she wants to be."

She'll make that decision in time. For now, Ms. Debbage is content to bask in rekindled happiness. "I love so much just being able to feel the sun on my face. I don't know if this will fade – it may – but I think I have an appreciation for life will be with me forever."

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