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Cold Weather Payment – are you eligible?

Many people on low incomes are set to get extra help to pay bills during the freezing weather after a number of local weather stations have recorded or predicted seven consecutive days of sub-zero temperatures.

Anyone in receipt of disability related Income Support will automatically receive a £25 Cold Weather Payment if they live in an affected area, but the MS Society would like to see the payment extended to a wider group of people.

Dan Berry, Head of Policy and Campaigns, said: "Living with any disability can be expensive but it's especially true of MS. Symptoms made worse by the cold can include muscle stiffness and spasms - it's simply not an option for people to turn off the heating.

"People with MS spend longer at home because they're less likely to work, less likely to get out and about and as a result they're much more susceptible to higher fuel costs."

For more information on whether you are eligible, have a look at [the job centre online](#).

Many disabled people will also receive an additional payment of £60 on top of the usual £10 Christmas Bonus. Anyone receiving Disability Living Allowance, Carer's Allowance, or Long term Incapacity Benefit (among others) will be eligible for the payment, which they will receive between January and March 2009.

You don't need to claim Christmas Bonus or the £60 payment - you'll get it automatically. For more information see more on the government's [online information](#).

www.mstrust.org.uk 15 January 2009

Trauma of teenage years tougher for those coping with multiple sclerosis

It started when Levi Barron's right hand curled into a claw shortly after his 13th birthday. Always laid-back, he told his mom that he'd just learn to write with the other hand and not to worry.

But the debilitating stiffness crept to his other hand, and soon the athletic hockey player was having trouble walking and even fell a few times.

It took four doctors and a stint in hospital, paralyzed from the waist down and so dizzy he couldn't open his eyes without vomiting, for Levi to finally get a diagnosis of multiple sclerosis.

"I remember just being so frightened and upset that I didn't know that kids got MS," says Karen Barron, Levi's mom.

Once thought of as a young adult disease striking people in their 20s or 30s, it is increasingly being recognized that multiple sclerosis can actually emerge much earlier, says Jon Temme, vice-president of client services and research for the Multiple Sclerosis Society of Canada.

"Certainly the likelihood of a child being diagnosed accurately is much greater now than it would have been a decade ago."

Dr. Brenda Banwell, who runs the country's only pediatric MS clinic in Toronto, says it's not new that children get MS. But she says that more sophisticated medical imaging combined with research into a condition called acute disseminated encephalomyelitis (ADEM) has made it a much more common diagnosis over the past decade.

The disease has now been recognized in children as young as toddlers, and is fairly frequently diagnosed in children under the age of 10, says Temme. Most commonly, though, it emerges in puberty and beyond, leaving teens to cope with a chronic disease with varied and debilitating symptoms.

The disease attacks the protective myelin that covers the brain and spinal cord, causing inflammation that can lead to extreme fatigue, vision problems, memory difficulty, and even paralysis.

Levi's case was exceptionally severe. Traditional treatments didn't stem the frequent relapses that left him in a wheelchair and hospitalized for months on end. Lesions in his brain left him feeling boiling hot despite a normal body temperature.

It took a series of chemotherapy treatments to shock him out of the constant attacks his body had launched on itself.

"That whole period of time was just so - I don't even know how to explain it. Just so terrifying and so full of uncertainty because (with) MS, you don't know," says Barron.

It's hard for teens to come to grips with the diagnosis of a chronic disease, says Jennifer Thannhauser, who helps run a support group in Calgary and was herself diagnosed with MS at the age of 12. At that time, she was the youngest person ever diagnosed in Saskatchewan, and found herself thrust into support groups with people over the age of 40 who bore no resemblance to her reality.

"I felt like the only one around who knew anything about it or had to experience it."

Thannhauser, who is doing her PhD in counselling psychology working with teens with MS, says teens don't want to feel different from their peers.

"It's wanting to feel normal and wanting to fit in with a group. And so having MS for a teenager can challenge that sense of being normal."

Ten years ago, no clinical research across Canada focused on the childhood occurrence of MS, says Temme. Now, several large-scale projects are being conducted through a research network that spans the country, something that puts Canada at the forefront of pediatric MS research around the globe.

Studies on young people with MS hold great promise in helping to discover what causes MS, something that has so far proven elusive. Since children have experienced fewer things than adults, it's a lot easier to figure out what viruses or environmental exposures could be relevant.

"One of the things about children is they have the onset of their disease so close to what we think is the beginning. So looking for triggers or targets that start the disease process is a particularly appropriate thing to do in pediatrics," says Banwell.

"Excitingly, if you find something that's present very early, the big push would be, is it something we could modify and therefore either reduce the risk of MS in other people, or alter the course of the disease by picking up on a particular trigger early on."

After recognizing the need over the last decade, the MS society began focusing more of its energy on funding programs for children and teens. For the last two years, youths have been able to attend a summer camp in Ontario, providing what is for some the first chance to connect with others with the disease, says Temme.

Levi is now 16, and bears very little resemblance to the sickly boy who couldn't stir from his hospital bed. Outside his house, his wheelchair lift now sits abandoned, covered in snow.

After treatment began to work, he had to relearn how to walk because he'd lost all sensation in his legs.

"I just can't feel my legs that much from my knee down. Temperature's a problem. Pretty much in my feet I can only feel pain if I'm going to feel temperature, if it's too hot or it's too cold, it's all I can feel," he says.

While he attends the support group and also went to the first year of the MS camp, Levi says he and other kids with MS don't really discuss its impact on their lives when they get together.

"We usually don't talk about MS that much, we just talk about how it's going, then we just do something together."

As awareness grows, so does acceptance, says Thannhauser.

"There are now more services available for teens, there's more resources, and because there's greater awareness that teens can have MS, it doesn't seem so strange," she says of how both teens and those around them react to a diagnosis.

"The teenager isn't left out on their own, rather they have sources of support to go to, they're not criticized or questioned as much for the symptoms they report or for the illness that they have."

It was my deepest darkest secret

Erika North had come to terms with her debilitating dizzy spells. She had grown accustomed to being constantly exhausted and even the prospect of a wheelchair-bound future rarely woke her up in a cold sweat any longer.

It was, instead, a feeling of taking part in a deception that finally forced her to tell her employer and colleagues that she had multiple sclerosis; a nagging sense that, as someone who made a career out of her unflinching honesty and ability to bare her soul, she had, in fact, been living a lie.

To her immense relief, their reaction was of support and concern rather than the prejudice or patronising dismissal she had feared. But unfortunately, it was not simply a case of 'coming clean' to them, or indeed, the many friends from whom she had kept her illness for four years. As a national radio DJ, Erika was also concerned about her million loyal listeners.

Whether she was interviewing Hollywood stars or travelling the world for stories, they had shared her every high and low, and the irony that she was hiding from them the one aspect of her lifestyle that really mattered did not escape her.

So Erika, 35, who presents the breakfast show on classic hits station Gold with fellow DJ James Cannon, has now decided to speak out about her devastating diagnosis, and explain why she is no longer prepared to cover it up.

'I am someone who wears their heart on their sleeve and I talk about everything that happens to me on air,' she says.

'I'm certainly not a slick, word-perfect presenter and I hope people like me more because I am real.

'This was my deepest, darkest secret. After I was diagnosed I felt like damaged goods. I was worried people would view me differently. But hiding it made me feel as if I was living a lie.

'It has taken me this long to accept that I have MS, but now I have, I would rather be honest about what and who I am.

'There is a tiny part of me that is still scared I will be judged. Maybe I will lose friends or colleagues. But I hope that more will respect me.

'I think coming out in the open will be cathartic. I've finally found the confidence to say, "This is me. Take it or leave it."'

Erika, who became a DJ at 21 after working at Capital Radio as a guest-booker, suffered the symptoms of MS for four years before finally being diagnosed in January 2005.

'For months afterwards I was shocked. It was so out of the blue, even though I had felt there was something seriously wrong. I felt isolated and depressed and, in the beginning, I thought I'd end up in a wheelchair.

'But I've realised having MS isn't the end of the world. It's not a death sentence. Without meaning to sound twee, I'm a happier person now than I was before I had it because I don't take life for granted any more.'

An only child from Hillingdon in Middlesex, she first felt the symptoms of MS eight years ago when she was co-presenting a breakfast show with Jono Coleman on London station Heart.

'I started having dizzy spells, as if I was drunk,' she recalls. 'I'd have to hold on to the wall in the shower, or fall when there was nothing to trip over. I'd tell my doctor, but by the time I arrived for my appointment I felt fine. Then it would happen again, a few months later.'

Her GP said she had an ear infection and referred her to an ear, nose and throat clinic, where she was told she had hay fever. 'Because they didn't seem worried, I wasn't,' she says simply. But by 2004 the gap between her dizzy spells was getting shorter, and the consequences ranged from frightening to funny. On one occasion, she recalls, she fell ill going down a spiral staircase at a Tube station.

'I was violently sick at the bottom,' she says. 'People were asking me if I was pregnant.'

On another, she was travelling in a taxi from an appearance on GMTV with her Heart co-presenter at the time, Greg Burns, to their Central London studios, when she felt so ill from its movement she had to get out of the vehicle two miles before their destination. 'He had to hold me up on the pavement,' she says.

At work, Erika gained a reputation for being clumsy. She says: 'It became a part of my personality. Within minutes of going skiing I fell over and broke my wrist. Nobody was remotely surprised when I came back with it in plaster.

'I grew increasingly frustrated that my doctor couldn't find any reason for my behaviour. I felt as if I was going mad.'

So she went to a private specialist for a second opinion. It was only then that it was suggested she should have an MRI scan to rule out MS, a brain disorder that affects the ability of nerve cells to communicate with each other.

When the results came back positive she refused to believe them. 'I laughed when the doctor told me,' she says. 'One of my friends has MS. I'd seen him lose the use of his hands and feet. I knew how damaging the illness could be and was convinced I didn't have it.'

Yet further tests to analyse her body's nervous system confirmed the MS, which can progress from tingling and numbness in the limbs to blindness, hearing impairment and paralysis.

It is a non-hereditary condition that affects 85,000 people in Britain, and twice as many women as men. Drugs are available to reduce the frequency of the attacks and most sufferers live as long as anyone else, but there is no cure.

A staunch pragmatist, Erika was determined to tackle the shocking news with a cool head, so she called the MS Society that evening for advice and support. 'An old lady answered the phone and said, "Don't worry, dear, not everyone ends up in a wheelchair nowadays."

'I'm sure that she didn't mean to upset me, and the society has been great ever since, but it was the worst thing she could have said. That's when it hit me. I hung up in floods of tears.'

To compound her misery, she had been made redundant from Heart two weeks earlier.

'Obviously, that paled into insignificance next to the MS but it meant that I was looking for work,' she says.

'I knew that if I was an employer, I would choose a healthy employee over an ill one. It is a competitive industry and I was too nervous and paranoid to admit any weakness.'

Within a couple of months, she had been offered the morning slot on Gold, co-presenting with Tony Blackburn. Yet as her professional life resumed momentum, she spiralled into depression. 'Every time I got a headache or lost sensation in my hand, I was convinced it was the beginning of the end,' she says.

'When the page of the book I was reading grew fuzzy I thought I was going blind. My parents were brilliantly supportive and I put on a brave face at work but really I just wanted to hide away.'

Erika grew increasingly tired. 'I was constantly missing friends' birthday parties and dinners out because I was so exhausted,' she says.

'I became known as unreliable. Some days I couldn't get out of bed. I didn't know how much this was due to getting up at 4am to go to work, and how much was the MS.

'At work, I was still teased for being clumsy but I couldn't laugh at myself any more. I don't think anyone suspected. People were more concerned about themselves.'

She concedes, however, that hers is not an ideal working environment in which to fall ill.

'As a freelance employee on a temporary contract, which most DJs are, I'm not entitled to sick pay,' she says. 'So I'll always make sure I'm there. I have had only one day off sick in the past year.'

Erika, who, through her line of work, has flirted with Jack Nicholson and in real life dated former Big Brother contestant Nick Bateman, made a conscious decision to remain single.

'I didn't want to be a burden on anyone else and I wasn't sure how to tell those I was attracted to,' she says. 'I would have felt too vulnerable.'

Eventually, she confided in Tony Blackburn. 'We were spending so much time together that it felt dishonest not to,' she says. 'He was warm and almost fatherly in his concern. I knew he wouldn't tell anyone.'

But unfortunately, others weren't quite as empathetic. 'One of my non-media friends acted as if I had told her I had a cold,' she says. 'She couldn't understand why I was traumatised. I was hurt that she wouldn't take the time to listen.'

'Others looked awkward and changed the subject. Their reaction confirmed my belief that it was too much of a risk to speak out.'

Erika was referred to a neurologist at Charing Cross Hospital where brain scans have shown that she has approximately 18 lesions on her brain that are affecting her balance.

For the past three years she has been injecting-Avonex, a beta interferon drug. It works by reducing both inflammation and the body's autoimmune reaction that is responsible for the destruction of myelin, so reducing the amount of attacks she suffers.

Side effects include crippling flu-like symptoms, from which she sometimes suffered for 36 hours afterwards.

Hospital visits were explained away to colleagues as dental appointments.

'I felt I was constantly deceiving people,' she says. 'And I missed out on the fun stuff. I had to turn down invitations to film premieres and showbusiness parties.'

'When Gordon Ramsay - whom I had interviewed on our show - invited me to the opening of his Claridge's restaurant I was heartbroken to be too ill to go.'

Nevertheless, she was determined to honour her work commitments which have, over the years, included meeting celebrities from the Blairs to the Beckhams, and broadcasting live from the Sydney Olympics.

'Before I was due to interview Tom Jones recently I had a very bad dizzy spell,' she says. 'But I came in anyway. I knew I couldn't miss out.'

'I didn't tell any celebrities I interviewed about my illness, although I was often introduced by my colleagues as the clumsy one.'

'The confidence that has helped in my career is also helping me cope with my illness.'

Which is why, last summer, she finally found the courage to tell her boss at Gold, based in London's Leicester Square, about her illness.

'I was fed up with having to hide the niggly aspects of my illness, such as the injecting,' she says. 'To my great relief, he didn't treat me any differently afterwards.'

The Avonex was so successful that, earlier this year, she had gone six months without suffering anything other than the side effects of the drug. But in August her beloved father Eric died of a brain tumour. The stress triggered a crippling relapse.

'Although seeing what happened to Dad was a brutal reminder there were less kind illnesses, I suddenly felt dizzy all the time,' she says.

Last October, she read about a new drug, alemtuzumab. It is an antibody treatment that temporarily shuts down the immune system, meaning it can no longer attack the nervous system.

It is not without its controversy. After one man in early clinical trials in America died of internal bleeding, its development was temporarily suspended. It can cause thyroid problems and leaves users vulnerable to infection.

Yet a recent Cambridge University trial showed it can halt and even repair the damage of MS. Erika has put herself forward for a three-year UK trial, to begin next month.

'If it could halt my symptoms it would be like winning the Lottery,' she says. 'I had to stop injecting Avonex two weeks ago in preparation, which has petrified me.'

'I keep waiting for my symptoms to worsen. The drug has been tested by only a few people before but if I don't try it I will always wonder what could have happened.'

'I want my life back. It would be brilliant to be able to go out with friends again and drink until 3am.'

'I try to eat a healthy, balanced diet and take care of my health but I would rather have five years of being able to treat myself than ten years of being boring.'

'I've been lucky so far that my MS hasn't progressed further, and it is very rarely now that I wake up in a cold sweat in the middle of the night wondering what the future holds.'

Instead, Erika is determined to make the most of every minute.

'The uncertainty is quite stressful. But before, I used to worry about the most stupid things, such as my hair or fluffing my lines on air,' she says. 'How ridiculous. None of that matters. Now I don't waste time worrying and I'm much more understanding of other people's weaknesses. Most importantly, I've realised that MS sufferers can still enjoy life.'

MS: facts you may not know

Multiple sclerosis is an autoimmune condition that attacks the central nervous system which is made up of the brain and spinal cord. While the brain controls bodily functions such as movement and thought, the spinal cord relays messages from the brain to the rest of the body, controlling both conscious and unconscious actions.

The nerve fibres of the central nervous system are surrounded by myelin, a protective sheath that helps these messages move quickly between the brain and the rest of the body.

In MS, the immune system attacks myelin, stripping it off the nerve fibres, either partially or completely, leaving scars known as lesions or plaques. The signals are then disrupted between brain and body, causing unpredictable symptoms. These include nerve pain, muscle spasms, speech difficulties, severe fatigue, loss of balance, movement and sight, depression, incontinence and sexual dysfunction.

- The word sclerosis comes from the Greek 'skleros' meaning hard, referring to the plaques around the nerves. 'Multiple' refers to the many different areas of the central nervous system that may have damaged myelin.
- MS is the most common disabling neurological disease among young adults, affecting more than 85,000 people in the UK.
- The cause of MS has yet to be identified.
- MS is usually diagnosed in those aged between 20 and 40.
- An MRI scan confirms the diagnosis in 90 per cent of MS cases.
- Women are almost twice as likely to develop it as men.
- Life expectancy is near normal but there is no cure.
- MS affects sufferers in different ways and varies between benign and relapsing / remitting MS where, attacks are rare with long remission periods and progressive MS, where there is no remission.
- Research shows that 65 per cent of those with relapsing/remitting MS develop the progressive form within 15 years of diagnosis.
- Modifying drugs - brand names Avonex, Betaferon, Copaxone and Rebif - can reduce the number and severity of MS relapses.

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MS Society welcomes personal budgets in healthcare

The MS Society has welcomed today's formal announcement by the Department of Health of the extension of personal budgets to healthcare for people with long term conditions such as multiple sclerosis (MS).

The extension has been announced as part of the new Health Bill, previewed in December's Queen's speech, and formally announced today.

It means that people with MS will have greater control and choice when it comes to their healthcare.

Simon Gillespie, Chief Executive of the MS Society, said extending direct payments into health was a welcome step.

He added: "MS is a fluctuating and complex condition and people's needs can change from week to week, which is why it's so important to give people with MS as much choice and control as possible in how they access the healthcare they need."

Little Johnny's at it again..... A new teacher was trying to make use of her psychology courses. She started her class by saying, 'Everyone who thinks they're stupid, stand up!' After a few seconds, Little Johnny stood up. The teacher said, 'Do you think you're stupid, Little Johnny?' 'No, ma'am, but I hate to see you standing there all by yourself!'

Little Johnny watched, fascinated, as his mother smoothed cold cream on her face. 'Why do you do that, mommy?' he asked. 'To make myself beautiful,' said his mother, who then began removing the cream with a tissue. 'What's the matter?' asked Little Johnny. 'Giving up?'

The math teacher saw that little Johnny wasn't paying attention in class. She called on him and said,

'Johnny! What are 2 and 4 and 28 and 44?' Little Johnny quickly replied, 'NBC, FOX, ESPN and the Cartoon Network!'

Little Johnny's kindergarten class was on a field trip to their local police station where they saw pictures tacked to a bulletin board of the 10 most wanted criminals. One of the youngsters pointed to a picture and asked if it really was the photo of a wanted person. 'Yes,' said the policeman. 'The detectives want very badly to capture him.'

'Little Johnny asked, 'Why didn't you keep him when you took his picture ?'

A man is stumbling through the woods totally drunk when he comes upon a preacher baptizing people in the river.

The drunk walks into the water and subsequently bumps into the preacher. The preacher turns around and is almost overcome by the smell of booze.

Where upon he asks the drunk, 'Are you ready to find Jesus?'

'Yes I am' replies the drunk, so the preacher grabs him and dunks him in the river.

He pulls him up and asks the drunk,

'Brother have you found Jesus?'

The drunk replies, 'No, I haven't.'

The preacher, shocked at the answer, dunks him into the water again, but for a bit longer this time. He pulls him out of the water and asks again, 'Have you found Jesus, my brother?'

The drunk again answers, 'No, I have not found Jesus..'

By this time the preacher is at his wits end so he dunks the drunk in the water again, but this time he holds him down for about 30seconds.

When the drunk begins kicking his arms and legs, the preacher pulls him up. The preacher asks the drunk again,

'For the love of God, have you found Jesus?'

The drunk wipes his eyes and catches his breath and says to the preacher,

'Are you sure this is where he fell in?'

After a hardy rainstorm filled all the potholes in the streets and alleys, a young mother watched her two little boys playing in the puddle through her kitchen window.

The older of the two, a five year old lad, grabbed his sibling by the back of his head and shoved his face into the water hole. As the boy recovered and stood laughing and dripping, the mother runs to the yard in a panic.

' Why on earth did you do that to your little brother?!' she asks as she shook the older boy in anger.

'We were just playing 'church' mommy,' he said.

'And I was just baptizing him.....in the name of the *Father*, the *Son* and in...the *hole-he-goes*.'

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you can't answer all the questions, send in those you have answered – you could still win!

USING ONE OF THE INITIAL LETTERS FROM EACH ANSWER WILL GIVE YOU THE NAME OF A LOCAL TOWN OR VILLAGE

- 1/ Birthstone for November
- 2/ One of the rooms in Cluedo
- 3/ Another name for Snow Leopard
- 4/ The first US President to resign
- 5/ In Greek Mythology who was the first woman
- 6/ Lighthouse south of Plymouth
- 7/ Who wrote the virgin soldiers
- 8/ The largest artery in the human body
- 9/ Which family founded standard oil
- 10/ General Custer's horse
- 11/ Who played Eliza Doolittle in the Film 'My Fair Lady'
- 12/ A planet of the solar system
- 13/ Which Indian tribe did Sitting Bull head

Name:

Address:

Send Completed Forms To:

Mr D Henderson
74 Windermere Road
Stockton-On-Tees
TS18 4 LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

1/ Pawn 2/ Epiglottis 3/ Tin 4/ Etna 5/ Rockall 6/ Libra 7/ Excalibur 8/ Emerald 9/ Erie
10/ Apache 11/ Sir Walter Scott 12/ Bashful 13/ Yellow