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Mobility allowance cuts will leave disabled people trapped at home, charities warn

In a letter published in *The Sunday Telegraph*, 25 organisations said the decision to cut the £140 million mobility allowance paid to 80,000 disabled people who need residential care would be disastrous.

The charities, including Sense, Mencap, Mind, RNID, RNIB, Parkinson's UK, Leonard Cheshire Disability and the National Autistic Society, said it would prevent people from taking trips, or running electric wheelchairs or adapted cars, meaning they could no longer do "those things that others expect and take for granted".

Currently disabled adults and children in residential care or schools are given a £49.85 or £18.95 a week mobility payment, depending on their needs.

The only other money most receive is a £22 weekly personal expenses allowance designed to pay for costs such as clothes, toiletries and phone bills.

Christine Markham, a former English and special needs teacher, said she was extremely concerned for her 35-year-old daughter, Zoe, who has suffered from cerebral palsy since birth and lives at St Bridget's, a Leonard Cheshire Disability run care home in Rustington, West Sussex

"Zoe loves to go out and do the normal things, she loves to go shopping and she's particularly keen on garden centres or the local wetlands centre," said Mrs Markham, 62.

"I don't think the government fully understands what it's like for people who live in residential care. They would love not to need the money, but to have any independence they need to be able to get about, pay for trips and transport.

"Although Zoe's severely disabled she's a bright, happy human being who likes living life."

Mrs Markham, who moved to Rustington with her husband, Howard, a retired maths teacher, to be near her daughter, said the mobility allowance helped pay for the upkeep of Zoe's second-hand wheelchair-adapted vehicle.

"She can drive her wheelchair in and we, or her brother, can then drive her. The money pays for the insurance and petrol and the MOT and servicing. That's the main part of how she uses it," she said.

"We as her family have always fought for Zoe, like so many families with disabled children, and now we're having to do it again."

Tim Williamson, 64, a former recruitment consultant who suffers from Multiple Sclerosis and lives in the same care home, said he was worried he would not have the same quality of life if he lost the mobility allowance.

"Recently I went to see Australia play England at Twickenham. That cost £38 for the transport," said the married father of two.

"At Christmas I went to be with my family and the taxi back cost about £90, so the money goes very easily. Without it I wouldn't be able to get out.

"It is a dramatic cut, it takes away our independence."

Peter Bottomley, the Conservative MP for Rustington, who has visited St Bridget's to listen to the concerns, said: "All they would be left with is £22 a week, and that cannot meet their mobility needs as well as their personal needs.

"They will run out of money and their homes can then become a prison. They deserve mobility just as much as I do."

Mr Bottomley added that he expected the government's proposals would be changed to resolve any "unintended problems". However a spokesman for the Department of Work and Pensions (DWP) insisted there would be no changes.

The cut will form part of the Welfare Reform Bill, which is due before parliament imminently and aims to reduce the £12 billion yearly spend on disability living allowance (DLA), through which the mobility allowance is paid.

Rebecca Rennison, senior policy officer at Leonard Cheshire Disability, which has organised a week of campaigning against the cut, starting today, said: "If the Government cuts this mobility payment for people living in residential care it will deny thousands of disabled people their independence and leave many trapped at home.

"While the money saved will be a fraction of the Government's overall spending cuts, the impact on individual lives will be devastating and we are calling on the Government to rethink its decision."

A spokesman for the DWP said: "The Government is committed to protecting DLA for the future and ensuring that the £12 billion spent on it every year goes where it is needed the most.

"We know that there can be varying levels of support in care homes and we will be working with disability organisations about this change to ensure that disabled people have their individual mobility needs met."

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Ten more infections, four more deaths in Tysabri patients

Source - Nasdaq

Biogen Idec Inc disclosed 10 more cases of a rare brain infection among multiple sclerosis patients taking Tysabri, a medication it sells with Elan Corp, bringing the total number of affected patients to 95 as of Feb 2.

The Weston, Mass, biotech company reported that four more of those patients have died, bringing the total to 20.

The cases of the infection - known as progressive multifocal leukoencephalopathy, or PML - are closely watched as the MS market becomes increasingly competitive.

The drug is generally regarded as highly effective, but mostly used for patients that have stopped responding to other drugs or have aggressive cases of the disease. Sales rose 16% in 2010 to \$1.2 billion and 56,600 patients were on the drug at the end of December.

Regulators have said that they watch the cases of PML, but have concluded that the benefits of the medicine to MS patients outweigh the risks. Tysabri was withdrawn from the market in 2005 and relaunched in 2006 with a strict access plan that monitors patients.

There is hope that the development of a blood test may better determine the chances of patients contracting PML. Although the overall risk of the infection remains small, it can have devastating and permanent effects, so a test may make patients and physicians more comfortable with using the drug. Biogen and Elan have filed with the Food and Drug Administration to update the label of Tysabri to include information about certain antibodies in the blood being a PML risk factor.

The overall global PML rate is now at 1.16 per 1,000 patients. Although that is above the typical one-in-1,000 rate commonly cited from clinical trials of the drug, a Biogen spokeswoman said the current PML figure falls within that seen in the trials' confidence interval, a statistical tool that helps show the precision of a measurement.

The rate is about 1.64 cases per 1,000 patients on the drug for between two and three years. The incidence is about 0.41 case per 1,000 patients in those using it for one to two years, and it is essentially nonexistent in patients using it for less than a year. The rate drops to 1.06 per 1,000 patients for those on the drug between three and four years.

Warm weather may hurt thinking skills in people with MS

Source - Newswise

People with multiple sclerosis (MS) may find it harder to learn, remember or process information on warmer days of the year, according to new research.

The research released today will be presented at the American Academy of Neurology's 63rd Annual Meeting in Honolulu April 9 to April 16, 2011.

"Studies have linked warmer weather to increased disease activity and lesions in people with MS, but this is the first research to show a possible link between warm weather and cognition, or thinking skills, in people with the disease," said study author Victoria Leavitt, PhD, with the Kessler Foundation in West Orange, New Jersey.

For the study, 40 people with MS and 40 people without MS were given tests that measured learning, memory and the speed at which they processed information. Those people with MS also underwent brain scans. The daily temperature on the days the tests were taken was also recorded.

The study found that people with MS scored 70 percent better on thinking tests during cooler days compared to warmer days of the year. There was no link between thinking test scores and temperature for those without MS.

"With more research, this information might help guide people with MS in life decisions and their doctors with clinical treatment. Scientists may also consider the effect of warmer weather on cognition when conducting clinical trials," said Leavitt.

Cerebrospinal drainage not tied to multiple sclerosis

Source - HealthDay News

There does not appear to be a cause-effect relationship between chronic cerebrospinal venous insufficiency (CCSVI) and the onset of multiple sclerosis (MS), according to a study published in the January issue of the *Annals of Neurology*

Claudio Baracchini, MD, from the University of Padua School of Medicine in Italy, and colleagues examined whether CCSVI was a possible cause of MS. Fifty patients who presented with clinically isolated syndromes and dissemination in space of the inflammatory lesions, suggestive of MS, underwent diagnostic tests, including extracranial and transcranial venous echo-color Doppler sonography (ECDS-TCDS). Patients with CCSVI also had selective venography.

The researchers found that the TCDS was normal in all of the possible MS patients, but 52 percent had one or more abnormal ECDS finding. Sixteen percent of patients fulfilled the diagnosis of CCSVI. Seven of these patients underwent selective phlebography but did not show any venous abnormalities.

"In conclusion, CCSVI is an infrequent condition in pMS [possible MS]; indeed, 84 percent of the patients with pMS did not have it. Moreover, a perfectly normal venous TCDS in all our pMS patients strongly indicates that even in those few patients with a CCSVI pattern the extracranial venous anomalies do not influence cerebral venous hemodynamics," the authors write.

Several of the researchers on this study disclosed financial relationships with pharmaceutical companies, including Pfizer, Sanofi-Aventis, and Merck-Serono.

MS Society funds second stage of myelin repair research

In December, we announced great news that scientists at the University of Cambridge had found a way of reversing damage to myelin using stem cells. The work was funded by the MS Society.

Today we're delighted to announce we've committed more than £2 million over the next five years to fund the second stage of this research.

Professor Robin Franklin and his team at the MS Society Cambridge Centre for Myelin Repair will work collaboratively with world leading experts in MS (like those based at the MS Society Edinburgh Centre for Translational Research and the MRI unit at the Institute of Neurology) to carry out the next stage.

In the first stage of the study researchers found a drug that could potentially repair myelin; in stage two they'll:

1. test this treatment for how effective it is in people with MS, and at what dose
2. trial it for safety in people with MS
3. build on recent advances in myelin repair research, so it's possible to identify more potential MS treatments in the future

This next phase of the study will start in April 2011 and finish in 2016. If the work proves successful, further clinical trials in larger numbers of people will take place to reveal whether the potential treatment is safe and effective for people to use. Then it'll then need to go through the necessary regulatory hurdles before it's licensed and available. We're still some way off a drug coming through, but these are positive steps.

Simon Gillespie, Chief Executive of the MS Society, said: "We've been consistently impressed with the world class work of the Cambridge Centre for Myelin Repair and we're delighted that the generosity of our supporters enables us to continue funding this outstanding research centre."

Primary progressive MS exposed

Author: MS Trust

The MS Trust is delighted to announce that their book on primary progressive MS is now available. The new book explores both the physical and emotional aspects of a diagnosis of primary progressive MS.

The book looks at how primary progressive MS differs from other forms of the condition and the types of symptom management available. The state of research into treatments and the challenges of studying this type of MS are also explored. The book also discusses some of the psychological and emotional issues associated with living with primary progressive MS and is illustrated by comments from people who have primary progressive MS.

Helping disabled travellers

Disability insurance specialist Fish has launched a policy designed specifically to protect disabled travellers who may be unable to get cover or receive poor service from mainstream insurers. The company says the move is in direct response to feedback from disgruntled travellers among over 70,000 disabled customers to whom it already provides a range of bespoke policies.

"Our policyholders have expressed increasing frustration with the attitudes and practices of many insurers when they try to secure insurance. Existing conditions can often prove an insurmountable obstacle, while a number of people have said they've found the whole quoting process quite intrusive," says Fish Insurance's head of business development, John Garrard.

"We looked into it, found those complaints justified and so designed a policy which would meet the quite specific needs of disabled travellers."

The new policy not only covers existing conditions such as heart problems, strokes, diabetes and cancers, but also provides other benefits specific to disabled travellers. These include provision of a replacement carer, emergency replacement of prescribed medicines and cover for mobility and disability equipment, including manual wheelchairs.

The launch has been welcomed by Helen Dolphin, director of policy and campaigns at Mobilise, the charity which campaigns for better transport and mobility for disabled people.

Helen, who lost her hands and legs through meningitis, says: "I have always found getting travel insurance a headache. It's so complicated and off-putting. When you're trying to get a quote they want to know all about your problems and make the whole process an uncomfortable experience.

"I like the way this policy is geared up to meeting disabled people's needs, that it makes things easier and that it's available online so you need not be giving personal details to someone over the phone unless you want to."

The new policy is being offered via *fishinsurance.co.uk* and through Fish's UK call centre (0800-046-9862), which is hosted by staff trained and experienced in disability issues.

Following the recent disruption in foreign countries such as Tunisia and Egypt, an independent online travel agent has conducted research to find which destinations British holidaymakers feel the safest in.

A new poll by *sunshine.co.uk* has revealed that Spain was thought as the safest destination, while Mexico was voted as the least safe holiday destination.

The study was conducted as part of ongoing research into Britons' views on destinations around the world. Respondents were asked to specify which destinations they had visited on holiday in the past three years and to rate how safe they felt in those destinations on a scale of one to ten. These are the results:

TOP 5 SAFEST COUNTRIES

- 1.Spain
- 2.France
- 3.Cyprus
- 4.New Zealand
- 5.Denmark

TOP 5 LEAST SAFE COUNTRIES

- 1.Mexico
- 2.South Africa
- 3.Bulgaria
- 4.Jamaica
- 5.Dubai

YOUR JOKES

Two Mexicans are stuck in the desert after crossing into the United States , wandering aimlessly and starving. They are about to just lie down and wait for death, when all of a sudden Luis says.....

"Hey Pepe, do you smell what I smell. Ees bacon, I theenk."

"Si, Luis, eet sure smells like bacon. "

With renewed hope they struggle up the next sand dune, & there, in the distance, is a tree loaded with bacon.

There's raw bacon, there's fried bacon, back bacon, double smoked bacon Every imaginable kind of cured pork.

"Pepe, Pepe, we ees saved. Ees a bacon tree."

"Luis, maybe ees a meerage? We ees in the desert don't forget."

"Pepe, since when deed you ever hear of a meerage that smell like bacon...ees no meerage, ees a bacon tree."

And with that, Luis staggers towards the tree. He gets to within 5 metres, Pepe crawling close behind, when suddenly a machine gun opens up, and Luis drops like a wet sock. Mortally wounded, he warns Pepe with his dying breath,

"Pepe... Go back man, you was right, ees not a bacon tree!"

"Luis, Luis MI amigo... What ees it? "

"Pepe.. Ees not a bacon tree. Ees

Ees

Ees

Ees

Ees a ham bush....."

A little paper bag was feeling unwell, so he took himself off to the doctors.

'Doctor, I don't feel too good,' said the little Paper bag.

'Hmm, you look OK to me,' said the Doctor, 'but I'll do a blood test and see what that shows, come back and see me in a couple of days.'

The little paper bag felt no better when he got back for the results. 'What's wrong with me?' asked the little paper bag.

'I'm afraid you are HIV positive!' said the doctor.

'No, I can't be - I'm just a little paper bag!' Said the little paper bag.

'Have you been having unprotected sex?' asked the doctor.

'NO, I can't do things like that - I'm just a little paper bag!'

'Well have you been sharing needles with other Intravenous drug users?' asked the doctor.

'NO, I can't do things like that - I'm just a little paper bag!'

'Perhaps you've been abroad recently and required a Jab or a blood transfusion?' queried the doctor.

'NO, I don't have a passport - I'm just a little paper bag!'

'Well', said the doctor, 'are you in a homosexual Relationship?'

'NO! I told you I can't do things like that, I'm Just a little paper bag!'

'Then there can be only one explanation.' said the doctor

'Your mother must have been a carrier'

I wondered why the baseball was getting bigger. Then it hit me.

The roundest knight at King Arthur's round table was Sir Cumference.

A thief fell and broke his leg in wet cement. He became a hardened criminal.

A thief who stole a calendar got twelve months.

A chicken crossing the road: poultry in motion.

Show me a piano falling down a mine shaft and I'll show you A-flat miner.

The dead batteries were given out free of charge.

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you do not 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/ Which county is the most southern point of the Pennine Way?
- 2/ Virgo is the zodiac sign for part of this month.
- 3/ Capital of Peru?
- 4/ Which American cruise missile shares the same name as an Indian weapon?
- 5/ Street on a Monopoly board?
- 6/ Number of Derby's won by Lester Piggott?
- 7/ A chess piece?
- 8/ Rainbow colour?
- 9/ Rod Hulls temperamental puppet friend?
- 10/ Author of the Just So Stories?
- 11/ Who played Bernado in the Magnificent Seven?
- 12/ What colour jersey is worn by the leader of the Tour De France?

Name

Address:

Send Completed Forms To:
Mr D Henderson
74 Windermere Road
Stockton-On-Tees
TS18 4LY

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