

BULLETIN



EVENTS

Drop-In:-

Greens Lane Methodist Church, Hartburn. We meet here 1pm to 4pm on a Tuesday. Alternative therapy is available for those who enjoy or would like to try Shiatsu.

Social Evenings:

These are held at the Orthoptic Supplies, 176 Belasis Avenue, Billingham, TS23 1EY, on the last Wednesday of every month at 7pm.

Shopping Online????

Buy items or book holidays through the Stockton MS Group web site and we will receive a donation. There are over 100 top retailers to choose from. It all helps raise funds for the group.

Monthly Bulletin

"If you would like to receive this bulletin by email, then just send a request to news@stocktonmsgroup.org.uk.

Remember if you change your email address to let us know by sending a message to news@stocktonmsgroup.org.uk"

Group Contacts

Carol 617864

Web address:- www.stocktonmsgroup.org.uk
e-mail: info@stocktonmsgroup.org.uk

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Christmas Social Evening

The Christmas Social Evening will be held on Wednesday 13th December 2017.

www.independent.co.uk 30 August 2017

People with MS lose more than £6m of benefits a year after PIP is introduced, show figures

A third of MS sufferers who previously received the highest rate of Disability Living Allowance have had their payments downgraded since 2013

Thousands of people living with multiple sclerosis (MS) have lost millions of pounds in benefits since disability benefits system was changed four years ago, new figures show. More than £6m a year has been taken away from people with the condition since the introduction of Personal Independent Payment (PIP), as despite previously qualifying for the highest rates of government support, sufferers have been told they are no longer eligible for it, according to responses to a Freedom of Information request by charity MS Society. The figures show that almost one in three people – or 2,600 – who received the highest rate mobility component of Disability Living Allowance, which PIP has replaced, had their payments downgraded after being reassessed in the three years up to October 2016. Of those receiving the highest rate for the care component of DLA, nearly a quarter (800 people) faced cuts under PIP's equivalent "daily living" component. The findings amount to a loss of almost £5m a year from all those receiving the highest rate of the mobility component, and £1,141,920 a year from those on the highest rate of care. There are at least 38,000 people with MS yet to be reassessed for PIP, indicating that in line with the current trend, an estimated minimum of 11,000 more could still lose out on the mobility component alone. This would mean a further £20m per year could be taken away from them by the time PIP is fully rolled out. The Department of Work and Pensions has not provided any evidence to show that those people losing out have less need for support. In light of the findings, MS Society warned that mobility assessments were failing to reflect the barriers faced by people with MS, such as the unpredictable and fluctuating nature of the condition. It highlighted that the new eligibility criteria to qualify for the higher rate mobility component did not accurately reflect people's needs, having "arbitrarily" changed from 50 metres to 20. Genevieve Edwards, director of External Affairs at the MS Society, said: "These staggering figures show how PIP is failing some of the most vulnerable people with MS who need the highest level of support."

“It doesn’t make sense that people are losing money they once qualified for, when they are living with a progressive condition that will never improve.”

“Significant numbers are getting the wrong decisions about what they’re entitled to, having a potentially drastic impact on their living situation. Their only options are to face a lengthy and stressful appeal process, or attempt to get by with inadequate support.

“The Government urgently needs to fix this broken system so that PIP assessments reflect the realities of living with MS. Having MS is hard enough; it shouldn’t be made harder by a welfare system that doesn’t make sense.”

IN response to the findings, a DWP Spokesperson said: “Under PIP 36 per cent more Multiple Sclerosis claimants receive the highest rate of support than under DLA. We recognise symptoms of Multiple Sclerosis can fluctuate over time, and regular reassessments mean we can ensure people with degenerative conditions get the help they need as their condition changes.

“Assessments consider illnesses which affect sufferers during the majority of days in a year, rather than just on someone’s ‘best days’ or assessing ability on a single day.”

However, MS Society described the 36 per cent figure as “very disingenuous”, saying: “The majority of that “increase” is due to the fact that the categories have changed rather than because the system has become more generous.

“It also only focuses on the care element of awards; there’s no mention of the fact that, for the mobility element, a third of people have had their benefit reduced after moving from DLA to PIP.”

‘My symptoms worsened, as did my depression’

Yolanda Barker, 45, has lived with MS for over 20 years and received the higher rates of care and mobility under DLA for around a decade, but following her PIP assessment last year she was downgraded to the standard rate for care.

The mother-of-two from Kent, who appealed this decision but was unable to get it overturned, said the change has caused her “a great deal of stress” and caused her symptoms to worsen. “The financial impact on me and my family has been huge. The whole process took around a year and it caused me a great deal of stress. My symptoms worsened, as did my depression,” she said.

“There were so many things the assessor got wrong or didn’t mention in my report. I tried my best to explain how my symptoms affect me differently every day, but I don’t think he understood this. If your problems don’t fit in their boxes, they’re not taken into account.

“The worst thing is that I’ll face another assessment next year. It constantly plays on mind whether I’ll lose more money or my Motability car, and if I’ll be able to manage.

“Life isn’t going to get any easier for me, yet I feel like I’m being targeted. The system has made me feel like I’m dishonest and that I’m continually being judged. There’s just no let up from it.”

DISCLAIMER

Articles in this Bulletin are meant for the sole purpose of information only and do not necessarily reflect the views of the committee.

Record numbers of disabled people win tribunals against Tory government to get benefit PIP

Judges ruled 14,077 people should get Personal Independence Payments (PIP) against the government's will between April and June - 65% of all cases

Record numbers of disabled people are winning appeals against a cruel new Tory benefits regime.

Judges ruled 14,077 people should be given Personal Independence Payments (PIP) against the government's will between April and June - 65% of all cases.

The previous highest total in any three month period was 12,661.

James Taylor of disability charity Scope said: "The PIP assessment is clearly not working.

"Thousands of disabled people are being forced to go through the appeals process just to get the support they are entitled to."

PIP hands 1.5million people with conditions like multiple sclerosis, cancer and dementia £22 to £83 a week to help pay for everyday costs.

But hundreds of thousands of people have been denied the benefit as it replaces the previous Disability Living Allowance.

Before they can appeal to a tribunal, claimants must launch a lengthy internal review called a Mandatory Reconsideration.

Success rates for those internal reviews are much lower at 17% and campaigners say they should be scrapped because they leave people in limbo.

Today's official figures also showed the proportion of people winning appeals to get sickness benefit Employment and Support Allowance (ESA) was 68%.

Benefit appeals, Apr-Jun 2017

Overall judges processed 46,058 benefit appeals of all types in the three-month period, the most for three years.

They ruled in favour of claimants 63% of the time.

Mr Taylor added: "Without an urgent overhaul of the assessment process by the Government, the system will continue to work against disabled people, instead of for them."

A DWP spokeswoman said: "Only a small proportion of all decisions are overturned at appeal - just 4% of both ESA work capability assessments and PIP assessments."

www.multiplesclerosisnewstoday.com

Swedish Study Suggests Stem Cell Transplants as Possible Treatment for Aggressive RRMS

Autologous hematopoietic stem cell transplants for relapsing-remitting multiple sclerosis (RRMS) are superior to currently approved disease-modifying drugs, according to a Swedish study published in the *Journal of Neurology, Neurosurgery & Psychiatry*.

In addition, says the review, the procedure's safety profile has improved in the last decade, and is now just as good as approved medications.

This data supports the idea that bone marrow stem cell transplants could be recommended for RRMS patients who don't respond to treatment with disease-modifying drugs if the procedure is performed at experienced centers, argued researchers at Sweden's Uppsala University.

Yet they said the benefits of stem cell transplants for patients with progressive disease is moderate at best — meaning any attempts to treat these patients with a stem cell transplant should be limited to clinical trials.

A mishmash of studies

In reviewing data of stem cell procedures in MS, the report, "Autologous haematopoietic stem cell transplantation for neurological diseases," noted that available studies vary considerably in the type of patients recruited, as well as procedures used for the transplant. They all have serious limitations, it said.

Many such studies are based on patient registries, yet they suffer the serious flaw of unvalidated data. In a clinical trial, data is always verified in numerous ways, but in a registry study, information on, for instance, disease stage is not double-checked.

Physicians scoring patients are not certified — as is the case in clinical trials — and have varying levels of experience. Moreover, since patients are not selected according to inclusion criteria, participants vary widely in their characteristics.

They are also treated according to varying protocols and in centers with varying experience levels. In fact, studies have shown that inexperienced treatment centers increase the risk of death after stem cell transplants in MS. In addition, many uncontrolled studies contribute with data.

The team identified four studies that included at least 10 RRMS patients. In total, the studies analyzed had 188 RRMS patients, but again, treatment protocols and data reporting varied among the studies. All this makes interpreting their findings difficult, researchers said, as it is often impossible to directly compare study outcomes.

So far, one published randomized controlled clinical trial of stem cell transplants in MS exists: the Autologous Haematopoietic Stem Cell Transplantation trial in MS (ASTIMS) study (EUDRACT No. 2007-000064-24).

Indications of efficiency

Despite the variability among the uncontrolled studies, researchers concluded that clinical and imaging outcomes are rather consistent between studies.

The ASTIMS clinical trial reported that new inflammatory lesions, assessed by magnetic resonance imaging (MRI), fell by 79 percent, and by 64 percent in annualized relapse rates compared to mitoxantrone — an immunosuppressive treatment used in highly active disease states. But the results were reported as a combined measure for RRMS and secondary progressive MS (SPMS) patients, of which only seven had relapsing disease.

Two of the uncontrolled studies reported no MRI activity of any sort in 85 percent and 86 percent of participants at five years. A study that had used a harsh conditioning regimen reported that none of the patients had imaging signs of the disease up to 10 years after the treatment.

Studies also reported a halted progression of disability of 70 to 91 percent at five years.

Researchers observed that the lowest numbers were found in groups with a higher proportion of patients with SPMS.

No evidence of disease activity (NEDA) has lately emerged as a robust outcome measure in studies of MS therapies. This comprehensive measure takes into account disease activity in MRI scans, the presence of relapses and disability progression.

A number of studies showed that 68 to 70 percent of patients maintained NEDA four to five years after a transplant. In comparison, in a group of patients treated at Boston's Brigham and Women's Hospital, only 7.9 percent had NEDA at seven years, even though most of them had been treated with disease-modifying drugs.

Meanwhile, in clinical trials of newer drugs such as Tysabri (natalizumab) or Lemtrada (alemtuzumab), only 32 to 39 percent of patients maintained NEDA at two years.

Finally, researchers noted that clinical trials or other studies of Tysabri or Tecfidera(dimethyl fumarate) found no improvements in patients' health-related quality of life. In contrast, one study of transplanted MS patients showed an improvement of nearly four times what is considered as a clinically meaningful improvement at two years. Improvements were seen in both physical and mental health.

A second study that used a different analysis tool reported a 15-point increase among transplanted patients. Researchers consider eight points to be clinically relevant.

Safety

Although it's becoming increasingly clear that stem cell transplants offer profound benefits for RRMS patients, the procedure's safety concerns limit its endorsement.

For a stem cell transplant to have an impact, doctors must first get rid of a patient's faulty immune system. They do this with the help of a so-called conditioning regimen. These can be of high, medium or low intensity, and the safety issues of a transplant are usually related to acute or long-term toxic effects of this pretreatment, rather than the transplanted cells.

The amount of acute toxicity is directly linked to the intensity of the conditioning regimen. High-intensity regimens use chemotherapy or radiation to completely wipe out the immune system, while milder protocols stick to immunosuppressive treatments.

Acute toxic effects include hair loss, reduction of blood cell counts and the presence of bacteria in the bloodstream — side effects that are often manageable. Far less is known about long-term side effects, though. These can come in the form of viral reactivations including shingles, development of other autoimmune conditions, impaired fertility and a higher potential risk of cancer — all of which make for a serious knowledge gap, researchers said.

In fact, acute effects have been linked with deaths among MS patients undergoing stem cell transplants. But researchers showed that while early studies showed unacceptably high death rates — 5.3 percent in a 2006 report and 3.8 percent in a 2010 report — studies of newly transplanted patients show far better outcomes.

One study that looked only at patients transplanted after 2005 found a treatment-related mortality rate of 0.3 percent, which is on par with that reported in clinical trials of Lemtrada. The same study found no deaths among patients who had a mild-intensity pretreatment.

The improved numbers might be related to the wider use of mild-intensity conditioning regimens, but also to more experience among treatment centers, researchers said.

www.dailymail.co.uk 16 September 2017

Breakthrough study offers new hope for multiple sclerosis patients as research finds a way to stop condition worsening through stem cell therapy

For patients with the incurable nerve condition multiple sclerosis (MS), there is often little hope. In the early stages, symptoms such as muscle weakness, fatigue, pain and even depression come and go.

As the disease progresses, patients lose their ability to walk and are often consigned to a wheelchair, facing an early death.

Medication can ease discomfort and improve physical problems but at present there is nothing that will stop the march of the illness.

But now, remarkable results from an NHS study into groundbreaking stem cell therapy has led experts to cautiously suggest it may halt MS from worsening, and in some cases lead to long-lasting remission.

The disease, which affects 100,000 Britons, occurs when the immune system turns on the body, attacking healthy nerve tissue. The stem cell procedure effectively resets the body and stops this process from occurring, experts claim.

About 60 patients have now been treated as part of the ongoing study at London's King's College Hospital and Imperial College Healthcare and doctors say that the effect has been dramatic for some.

At a cost of £35,000 per patient, the price is comparable to a single year of MS drugs.

One of the first patients to benefit, former pilot Sarah Brown, has revealed how the therapy has transformed her health. Once a keen marathon runner, Sarah was diagnosed in 2009, and her condition deteriorated rapidly. Two years ago the pain in her legs and hips was making walking for more than a few yards impossible.

The 42-year-old from Cheltenham said: 'If it wasn't for stem cell therapy, I may well have been in a wheelchair by now.

'I've recovered sufficiently to go back to work, which is something I thought I would never be able to do. I won't run marathons again but I've regained my independence. It has turned my life around.'

The procedure, hematopoietic stem cell transplantation (HSCT), is similar to the one used to treat leukaemia, and was once known as a bone marrow transplant.

After Sarah's husband Bob, 47, came across the UK study while researching treatments online, her neurologist in Bristol agreed to refer her to haematologist Dr Majid Kazmi at King's College Hospital, an expert in the field.

Dr Kazmi said: 'We have known for some time that patients with multiple sclerosis who also develop leukaemia seem to experience remission from their MS symptoms after HSCT. Treating the cancer meant the MS got better too.

'Immune system cells are made in the bone marrow, and during HSCT the patient's existing bone marrow is killed off with powerful drugs then replaced with a transfusion of stem cells.

'After the procedure, we have seen the immune system return to a more normal state.

'One of our first patients was treated in 2009. His MS was so bad that he would not have been expected to live more than a few years, but he is still alive today.'

HSCT is carried out in stages. First, patients are given low-dose chemotherapy drugs and medication to stimulate the bone marrow to secrete stem cells into the blood.

About six ounces of blood is taken and then processed in a laboratory machine to extract the stem cells, which are frozen and stored. Once this has happened, the patient is given more powerful chemotherapy, which kills off existing bone marrow, over a week.

As this knocks out the immune system, the patient must be kept in isolation as even a minor infection can be fatal.

Finally, the stem cells are defrosted and reintroduced via a blood transfusion.

These cells find their way through the circulation back into the bone marrow, where they reproduce and create new, healthy tissue.

'We aim to give patients about two to three million stem cells per kilogram of body weight,' explained Dr Kazmi. 'In most cases, the small amount of blood we take gives us far more than we need.'

The patient remains in isolation for a further two to three weeks as their bone marrow begins to create immune system cells. 'The main aim of this treatment is to halt further damage caused by MS,' added Dr Kazmi. 'For those with significant disability, we don't expect a dramatic transformation.

'If they are in wheelchair, they are likely to stay in one. But they may not get worse. And there have been very good results with patients with earlier-stage MS.'

Researchers from Imperial College London published results last year from HSCT trials in 25 centres in 13 countries. Out of 281 people who had the treatment, nearly half benefited for as long as five years, according to their paper in the Journal Of The American Medical Association.

Roy Palmer, 43, is about to embark on the second stage of his HSCT treatment after having his first round of chemotherapy. Next week he will have more chemotherapy, followed by his stem cell infusion and five weeks' isolation.

The father-of-two from Quedgeley, Gloucestershire, has spent a decade in a wheelchair and has a form of the disease that will get steadily worse.

He said: 'My daughter Aby, who is 12, was just a toddler when I went into my chair and she doesn't remember her dad when he could walk. To be able to walk out of my front door would mean the world.'

www.nationalmssociety.org September 20 2017

Falls are Common and a Matter of Concern in Small Study of People with MS who Use Wheelchairs/Scooters

Background: Research suggests that about half of people with MS fall at least once during any given 6-month period. Falls can cause injuries, and fear of falling can prevent people from participating in social activities. Although some research has been done on ways to prevent falls in people with MS who can walk, little is known about preventing falls in people with MS who use wheelchairs or scooters.

This Study: Investigators recruited 44 people with MS who used a wheelchair or scooter as their primary means of mobility from centers in the United States and Israel. Participants completed a survey that included questions about the frequency of falls, frequency of injuries caused by falls, the circumstances of the falls, and how quality of life was affected by falls.

Results: Of this group, 75% (33) reported falling at least once in 6 months and 48% (12) of those who fell experienced an injury. Most of the falls happened inside the person's home. Many participants (75%) reported concerns about falling and 66% (29) limited their activities because of these concerns.

The team (Drs. Laura Rice, Jacob Sosnoff, University of Illinois at Urbana-Champaign, and colleagues) report their findings in *Medicine* ([2017 Sep;96\(35\):e7860](#)).

Next Steps: Now, with a new research grant from the National MS Society, Dr. Rice and her collaborators are developing a comprehensive therapeutic program designed to educate people with MS who use wheelchairs about how to prevent and recover (get up) from falls. Such a program could be implemented widely to improve quality of life and reduce injuries.

About Multiple Sclerosis

Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. MS affects more than 2.3 million people worldwide.

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!

- 1/ Arachnophobia is the fear of what?
- 2/ What is the collective name for a group of Crows?
- 3/ The Orang-utan is native to only 2 islands, one is Borneo, which is the other?
- 4/ What type of animal is a Booby?
- 5/ The Arctic hare is found in the northern regions of the Arctic Circle, but how heavy does it grow? a) 1kg b) 2-3kg c) 4-5kg
- 6/ The armadillo is native to which continent?
- 7/ For what do butterflies use the 'proboscis' for?
- 8/ Which is the fastest moving snake in the world?
- 9/ Which animal is believed to be the largest animal to have ever lived?
- 10/ An Addax is a type of what?

Name:

Address:

Send Completed Forms To:
Mr D Henderson
74 Windermere Road
Stockton-on-Tees
Cleveland 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.

Answers to last quiz:

1/ Guys and Dolls 2/ Egypt 3/ Uganda 4/ B5 5/ Chico 6/ Alaska 7/ 1509 8/ Joseph Heller
9/ Ho Chi Min 10/ Passion Fruit