



### ***What is Multiple Sclerosis?***

Multiple sclerosis (MS) is a chronic, neurodegenerative disorder that affects the brain, optic nerves, and spinal cord. It often results in progressive neurological impairment and severe disability. Multiple sclerosis has an unpredictable course with variable severity and progression. Symptoms can include pain, disturbance to muscle tone, including weakness or spasticity, chronic fatigue, unsteady gait, speech problems, incontinence, visual disturbance and cognitive impairment.

Relapsing-remitting multiple sclerosis (RRMS) is the most common clinical form of MS, characterised by periods of remission followed by relapse (which may or may not result in residual disability). Many people with RRMS will develop secondary progressive multiple sclerosis (SPMS), which is characterised by more persistent or gradually increasing disability with fewer or no relapses.<sup>1</sup>

Primary progressive MS (PPMS) affects approximately 10-15% of those with MS, it is called progressive MS as there tends to be little if any recovery after symptoms worsen. There are currently NO NICE approved treatments available on the NHS for these patients.

### ***What affect does that have on the patient?***

It can increase anxiety and stress, leading to depression and many patients believing they have nothing to offer society.

Ocrelizumab (Ocrevus) is a Disease Modifying Therapy that has proven to slow down the disability for people with primary progressive MS by 24%; compared to that of a placebo. This disability included keeping arm movements, allowing the person with MS to continue with self care and continuing to work.

Over a 120 week period it was proven that there was a 3% in T2 lesion reduction; against an increase of 7% against the placebo.

On the 2<sup>nd</sup> August 2018 NICE came to the conclusion to not make Ocrelizimab available on the NHS despite recognising that it slows the worsening of the MS disability.

### ***What are the costs?***

Ocrelizimab is £4790 for each 300mls apart from the first dosage; this is £9580 every 6 months.

The NHS spends approximately £8 on average to answer a 999 call

Dispatching an ambulance to an address costs £ 155

Taking a patient to hospital costs £250

A hospital admission cost is approximately £400 per day.

If a person was an inpatient for 1 week, to symptom manage their MS, this would cost the NHS £3,213; not including any take home drug or specialist treatment. This does not include out of hour calls or GP appointments.

The MS trust did a study from 2013-2014 which showed that £5.4 million was spent treating people with respiratory issue emergencies resulting from MS. Many of these could be avoided if Ocrelizimab was available on the NHS.<sup>2</sup>

With emergency hospital admissions on the rise, for people with MS, prevention must be the priority. Early intervention, prompt diagnosis and prescribing disease modifying treatments show that Ocrelizimab is a cost effective, smart medication.<sup>3</sup>

### ***What are the positive outcomes of making treatments available for PPMS?***

People with MS will have choice, hope and options. Rather than symptom managing these people, as nurses, we hope to be able to manage their disease. This treatment will reduce the likelihood of a person with MS needing to access their GPs and hospitals. The quality of life for patients suffering from PWMS will improve affording them the opportunity to play a full part in society, enabling them to work longer, look after their children and most importantly, reduce their perception of being a burden on those around them.

### ***How are we currently supporting our most vulnerable?***

The majority of specialist MS Consultants and nurses' time is taken up monitoring the patients with Relapsing Remitting MS and prescribing disease-modifying therapies leaving very limited time for those who are most vulnerable and potentially alone.

The MS Trust has implemented 6 pilot job opportunities (with the hope for more) for Advanced MS Champions. This role will lead MS specialists to concentrate on patients with the progressive form of MS. 6 pilot sites will provide evidence for the need for specialist services. It is hoped that these crucial roles will reduce the need for hospital admission, out of hours GP calls and emergency visits by providing co-ordinated care, timely referrals and specialist individualised care plans. The aim is to help people live independently and improve their quality of life.<sup>5</sup>

Personal Independent Payment (PIP), has recently changed from Disability Living Allowance (DLA). The change in the systems has led to many people with MS feeling greater levels of stress and anxiety negatively impacting upon them and their families. Every patient has to re-apply for their entitlement, even if they were granted lifetime guarantee under DLA.

### ***How can the situation be improved?***

#### *Welfare Re-application*

Primary Progressive and Secondary progressive patients will not get better with their diagnosis as it is a progressive degenerative illness. It is recommended this application process is reviewed so that patients do not need to re-apply again. The forms are lengthy and complicated and given the disease negatively impacts upon cognition, physical ability and dexterity, the application process significantly disadvantages the most vulnerable patients.

#### *Functional Electrical Simulation*

Functional Electrical Simulation (FES) is a non-invasive device that helps many people with MS continue to walk by preventing ulcers and improving circulation, allowing those suffering from PWMS to have an improved Quality of life. 75% of people diagnosed with MS will face mobility problems including drop foot. NICE clinical guidelines on MS support treatment such as FES however, not all health authorities provide, or have sufficient funding to provide, this treatment. It is a relatively cheap intervention compared to that of a drug<sup>4</sup> and provision of wider availability should be explored.

#### *Wheelchairs*

The current system of issuing wheelchairs is clunky and ineffective leading to significant waiting times which leaves patients without the correct wheelchairs, causing contractures pressure ulcers and referred pain. It is recommended that this system be reviewed to reduce the chances of aggravating existing conditions.

### *Cannibis/Sativex*

There is evidence to suggest that Cannibis/ Sativex helps with spasticity, mobility and pain and it is now available on the NHS, however the patients most in need of this medication are those with PPMS or SPMS. Consultant appointments are limited and the majority of patients seen are those on DMTs. Many people with advanced MS who would need this medication do not have a consultant due to pressures on the neurologists. It is recommended that greater consultant access is afforded to PPMS and SPMS patients.

### *Palliative care*

With limited time set aside to work with our progressive patients, it is more difficult to approach, discuss and action palliative care. which is an essential part of the treatment requirement for seriously ill patients. Building a rapport with the patient is vital and, as MS nurses, we are currently unable to give the necessary care, time and support to those with the aggressive and progressive life limiting form of the disease when they are coming to the end months, weeks and days of their life. Greater funding for the treatment of MS would provide more staff and release more time for specialist carers to attend to this vital area of treatment in addition to addressing the other challenges outlined in this document.

Thank you for taking the time to read this. If I can provide you with any further information please contact us on the details below.

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## References

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(FES) [http://www.odstockmedical.com/sites/default/files/how\\_to\\_access\\_fes\\_ms\\_society.pdf](http://www.odstockmedical.com/sites/default/files/how_to_access_fes_ms_society.pdf). Accessed November 2018

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