SIGNALS OF CHANGE
RECOGNISING THE EARLY SIGNS
OF PROGRESSION TO SPMS

This article has been sponsored and written by Novartis Pharmaceuticals UK Ltd in collaboration with expert contributors.
Multiple sclerosis (MS) is a progressive autoimmune neurological condition affecting the central nervous system (CNS), leading to the development of increasingly debilitating symptoms. This long-term condition, often striking at the prime of people's lives, progressively worsens as damage and scarring to the nervous system builds. It is therefore essential to provide people with MS (PwMS) and healthcare professionals (HCPs) with the opportunity to discuss early identification of SPMS, with the goal of raising awareness and driving towards an earlier recognition of SPMS, improve consultations and keeping PwMS at the centre of their management, we suggest this may mean for their future.

Since the majority of PwMS (85%) are initially diagnosed with relapsing/remitting multiple sclerosis (RRMS) and its psychological impact, there is a gradual worsening of neurologic symptoms caused by the difficulty in recognising the subtle signs and symptoms that characterise progression, due to their gradual and variable nature. This is also combined with the lack of treatment options available for SPMS to date due to their gradual and variable nature. This is also combined with the lack of treatment options available for SPMS to date, marking the transition to secondary progressive MS and discuss attributes that parallel the current landscape of SPMS.

The updated Lublin criteria have been a great step forward for characterising SPMS and have questioned the diagnostic structure beyond RRMS. They provide criteria beyond the simple dichotomy of ‘relapsing remitting’ vs ‘secondary progressive’ MS and discuss attributes that parallel the current landscape of SPMS. They have highlighted that the definition of activity in SPMS is different from relapses – it is slow and hard to discern changes in function or a new/unequivocally enlarging T2 lesion.

Taking action in SPMS first requires addressing the challenges surrounding MS progression is different from relapses – it is slow and hard to discern changes in function or a new/unequivocally enlarging T2 lesion. This leads to an accumulation of disability over time, making the transition to secondary progressive multiple sclerosis (SPMS). Over 75% of people with RRMS transition to SPMS within 30 years of diagnosis. Both inactivity and neurodegeneration are integral components of SPMS, with immune reactions compartmentalised within the CNS being more evident in SPMS than in RRMS.

Current SPMS Diagnostic Challenges

- Lack of treatment options to date
- Stigma of formal diagnosis of SPMS and its psychological impact
- Reduced amount of time with PwMS
- Impact of comorbidities

Supplemented with the opinion of Dr David Paling

STAYING CURIOUS

The Consultant Neurologist perspective

Dr David Paling is a Consultant Neurologist at the Royal Hallamshire Hospital, Sheffield, visiting Consultant Neurologist at Doncaster Royal Infirmary, Honorary Senior Lecturer at the University of Sheffield and Clinical Lead for the MS Centre, Sheffield.

Dr David approaches his consultations for people with SPMS with curiosity, vigilance and honesty and encourages them to come prepared to maximise the short time they are able to spend in clinic. As the SPMS landscape continues to evolve, David emphasises that people recently diagnosed with SPMS should leave their consultations with “a feeling they have been listened to, an explanation of their symptoms, an understanding of what might help and an action plan of what they and their Consultant feel is the best way forward.”

CONFRONT THE STIGMA OF SPMS

“The Lublin criteria are challenging our diagnostic structure, and these fit much more intuitively with what PwMS are telling us.”

MAXIMUM TIME DURING CONSULTATIONS

“One useful thing about the waiting room was that PwMS had undisturbed time where they could think about what has changed over the past year.”

During clinical appointments, symptoms remain the focus of conversation for PwMS. David advises that to maximise their short 15-minute annual consultations, PwMS should try to spend some time thinking about what they feel has changed for them in the last year, what they are worried about, and what they want to get out of their appointment. This organisation of thoughts provides the basis for strong conversations to figure out what support PwMS need and identify any signals of progression. David also notes that the COVID 19 pandemic has sometimes made this harder for PwMS as when they have teleconsultations, rather than clinic appointments, they have not had their journey and time in the waiting room to reflect. Therefore, it is really important for PwMS to try to schedule this time of reflection in a different way.

Once in the appointment, the Consultant Neurologist should ask open questions and be attentive to signals of progression. When suspicions are aroused, investigations should promptly occur to confirm whether the signals point to progression, a relapse or another disease. Forestalling questions and be attentive to signals of progression. When suspicions are aroused, investigations should promptly occur to confirm whether the signals point to progression, a relapse or another disease. Following addressing changes means losing the opportunity to focus on the holistic treatment of SPMS with the help of the multidisciplinary care team; a benefit that could provide real support, empower PwMS to engage in their care, and alleviate some of their concerns.

“It’s important to ask open questions. I ask PwMS if anything has changed recently. I often ask about their holidays as these tend to stick in the mind.”

MS progression is different from relapses – it is slow and hard to discern on a day to day basis. PwMS may discuss urinary tract issues and cognitive impairment, yet not necessarily associate them with their MS or progression, but rather a sign of ageing. It is important that the Consultant Neurologist, as well as the multidisciplinary care team, uncover such symptoms, especially if they can be treated, and not delay in offering practical support. For example, PwMS who have balance problems can be referred to physiotherapy and bladder symptoms can be seen by a continence service. By identifying these signals early, it is possible to both provide practical support and address the topic of MS progression.

TOPICS FOR OPEN DISCUSSION DURING CONSULTATIONS FOR PWMS

- A list of anything that has changed in the past year
- Worries and/or concerns
- Review of key time points, such as holidays
- Needs from their appointment

DEFINITIONS AND TIME FRAMES

Recommended time frame for evaluation

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Annual</th>
<th>Annual</th>
<th>Annual</th>
<th>Annual</th>
</tr>
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<tbody>
<tr>
<td>Active disease</td>
<td>Clinical: relapses, acute or subacute episodes of new or increasing neurological dysfunction, followed by full or partial recovery, in the absence of fever or infection</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Imaging: gadolinium-enhancing lesions or new or unequivocally enlarging T2 lesions</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Progressing disease or disease progression</td>
<td>Accrual of disability, independent of any relapse activity, during the progressive phase of MS (PPMS or SPMS)</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Worsening disease</td>
<td>Any increase in impairment/disability irrespective of whether it has resulted from residual deficits following a relapse or (increasing) progressive disability during the progressive phase of the illness</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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FOREGROUND

By Dr David Paling

The Committee urges investigators, and regulators to consistently and fully use the 2013 phenotype:

1. Using the full definition of activity, that is, the occurrence of a relapse or new activity on an MRI scan (a gadolinium-enhancing lesion or new or unequivocally enlarging T2 lesion)
2. Framing activity and progression in time
3. Using the terms ‘worsening’ and ‘progressing’ or ‘disease progression’ more precisely when describing MS course

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**AN HONEST ASSESSMENT**

The MS Clinical Nurse Specialist perspective

Sarah White is a MS Clinical Nurse Specialist based at St George’s University Hospital in South West London. An important part of her role is establishing and building relationships with PwMS, providing them the support they need and coordinating their holistic care with other members of the multidisciplinary team.

**MS nurses tend to stay in their role for a long time, and Sarah is no exception, having spent 17 years supporting PwMS. Through this experience, Sarah believes that building trusting relationships with PwMS can lead to more honest assessments and open conversations that can help facilitate the identification of the signals that mark MS progression.**

“The nurse and the person with MS often have this trusting relationship, as we have known each other for a long time. PwMS will open up to you more, and part of our role is to do that more introspective assessment.”

**SUPPORT HONEST CONVERSATIONS**

“It’s important to go at the pace of the person with MS. I often bounce questions back at them and ask what they’re thinking, getting them to voice it first. We can then have a gentle conversation about what it then means.”

Approaching the conversation about transitioning to SPMS can be difficult, but Sarah finds honesty to be an important asset. She is keen to point out that it can be a difficult time for all the new symptoms associated with SPMS, and that PwMS may often feel frustrated and feel that they are not being taken seriously.

**MANAGING HOLISTIC CARE – A ROLE FOR AN MS CLINICAL NURSE SPECIALIST**

People with SPMS often need coordinated care, and an MS Clinical Nurse Specialist can have an important role in building relationships with the community teams (local services) and hospital teams to maximise coordinated care.

- **Know where a patient can be referred, and the capacity within those teams**
- **Provide advice on what specific services are offered to help join up care**
- **Provide tips whilst PwMS are waiting to see a Specialist to help them prepare (i.e. tips for swallowing before seeing the Speech and Language Therapist)**

**THE JOURNEY OF PEOPLE WITH SPMS**

**TRANSITION TO SPMS**

**DIAGNOSIS OF SPMS**

C H O R E O G R A P H Y

**USE DATA TO GUIDE CONVERSATIONS**

“If everyone starts to talk about progression early, it doesn’t have to be the elephant in the room. There are a lot of processes that can be put in place to support PwMS through their SPMS diagnosis. As a multidisciplinary team, it is really important to take time, listen and support PwMS.”

In a landscape where there is a drive towards drug management and ‘stopping’ MS progression, discussing SPMS and progression can be complex. As a person with MS progresses, it can be difficult for them to grasp the moment when transitioning from MS to SPMS. This is an exciting role because people with progressive MS often do not receive the dedicated attention and support that their condition demands. This role is instrumental in organising the services involved in an individual’s management, following an informed approach to care.”

**THE JOURNEY OF PEOPLE WITH SPMS**

**TRANSITION TO SPMS**

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C H O R E O G R A P H Y
PATIENT PERSPECTIVE

Patrick Burke, a retired IT Consultant from London, was diagnosed with RRMS in 1995 followed by SPMS in 2000 and has described his diagnoses as very different to current practice in which a landscape of DMTs, medicines and therapies are now available. At the time of his SPMS diagnosis, Patrick was working overseas, had a busy life and regarded it as "just an ordinary day" — it was just a different type of MS, but still the same thing. He describes it as "going downhill" from there, realising you don't go back to normal.

Patrick identifies the transition from early to late stage MS. "With RRMS, you constantly go between two kingdoms; one of the healthy and one of the ill. However, with SPMS you are permanently in the kingdom of the ill. The problems with walking, falling over, bladder symptoms etc. are always there, you build up and don't go away. To my mind, that's a very significant point that identifies the transition from early to late stage MS."

Patrick’s initial RRMS diagnosis was led by a very slow and gradual progression. He recalls the switch between working and retirement especially challenging due to the loss of motivation and support. He talks about medical benefits, support groups, adaptations to the home and work place, making sure their condition is as good as possible. This includes information about medical benefits, support groups, regular coffee mornings, or other activities where possible.

Patrick advises that for his disease course, reliable sources and a support team, especially a Consultant Neurologist, can provide perspective on what they can't see for themselves.

Outside of the direct clinical community, Patrick believes there are several trustworthy sources for PwMS which provide honest information and management tools to supplement knowledge and navigate SPMS diagnosis, such as the MS Trust or The MS Society. Not only do these reliable sources help PwMS feel like they are not alone, they can be a basis for connecting people or acting as signposting to those who can provide further information. Patrick believes that building a MS community through WhatsApp groups, regular coffee mornings, or other activities where possible, is key for PwMS to help manage their condition, share signals that may indicate change and aid in their educational outreach. Patrick emphasises that it is essential for PwMS to build a relationship with someone who can provide advice outside of consultations and act as a foundation of support, which can only develop through knowing the person with MS and the course of their condition.

THREE PILLARS OF SUPPORT

Education is about empowering PwMS with the information and tools to navigate their disease. It is important that PwMS are educated as early as possible after their initial MS diagnosis about what could happen during the course of their disease. MS can often feel a sense of anxiety, which needs to be managed as early as possible, with the right level of upfront transparent information.

"Education is key and this is missing in the MS community. You have to educate and make sure that the person that has got the illness has the tools to find a way around it."

Honesty is about arming PwMS with the right information to prepare them for their future. This includes, whenever possible, complete transparency from the Consultant Neurologist and multidisciplinary teams. When it comes to recognising MS progression, PwMS should be honest with themselves also, and it is beneficial to have someone who is honest with them, and that can provide perspective on what they can't see for themselves, such as the compensations they make on a daily basis to manage.

"The Consultant Neurologist needs to be as upfront as possible so that you can prepare yourself early on for what might happen in your future."

Relationships are about building confidence in the person with MS and providing them with knowledge about their condition through a foundation of support. It is important that PwMS find their own support group that can help them, but also to have someone to point towards useful information including SUHMS, The MS Trust, MS Society or an MS therapy centre. It is important for people to act as signposts. As MS is different for everyone, it must be recognised that there is no one size fits all approach, the template is not the same for each person.

"Sometimes you have to paddle your own canoe to find someone with whom you can work and build a relationship with, and find ways of increasing your own knowledge about MS."

While the landscape of MS is continuously changing and important conversations are happening earlier in the course of progression, Patrick advises that following these three pillars of education, honesty and relationships will provide a more complete care package to support people with SPMS. These combined factors will help raise earlier awareness and identification of the key signals of change that characterise progression, and most importantly, help PwMS prepare for their future.
REFERENCES


2. MS Trust. Relapsing Remitting MS. Available at: https://www.mstrust.org.uk/a-z/remitting (Last accessed: October 2020).


