



# Knowledge Is Power, but Is Ignorance Bliss? Optimising Conversations About Disease Progression in Multiple Sclerosis

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**Abstract:** Communication about multiple sclerosis (MS) disease progression between healthcare professionals (HCPs) and people with MS (PwMS) has historically been considered difficult, and attention to improving it has been neglected. However, a growing number of studies have shown that this is a key area to get

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right, since negative experiences can affect patient satisfaction, treatment adherence, and clinical outcomes. This article reports on a symposium at the European Charcot Foundation, 2018, led by a panel of leading clinicians and patient experts from MS in the 21st Century, who debated the benefits, drawbacks, and challenges of communicating about disease progression, for both HCPs and PwMS, and potential ways to optimise these discussions. PwMS' preferences and priorities regarding conversations about disease progression vary widely. While the majority want to have these conversations, some will be reluctant and/or emotionally unready. Communication therefore needs to be personalised, and HCPs should always be prepared to have such conversations in an appropriate and sensitive manner. Clinical information can be opaque for PwMS, so HCPs also need to use language that is clear, easily understandable, and patient-friendly. MS in the 21st Century is in the process of developing several resources and programmes to help improve disease progression communication between HCPs and PwMS.

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### Key Summary Points

A growing number of studies have shown that communication about, and understanding of, disease progression in MS play a key role in improving patient satisfaction, treatment adherence, and therefore clinical outcomes.

However, the stigma associated with progression, and communication challenges surrounding a complex and uncertain disease course, may prevent HCPs and patients from having these discussions.

A panel of leading clinicians and patient experts from MS in the 21st Century debated the benefits, drawbacks, and challenges of communicating about disease progression, and potential ways to improve these conversations, with an international audience at the European Charcot Foundation Annual Meeting 2018.

The debate highlighted that PwMS' preferences and priorities regarding conversations about disease progression vary widely. HCPs should therefore try to personalise their communication as much as possible to the needs and preferences of their patients, by communicating in clear and understandable language, and acknowledging and discussing the role that invisible symptoms play in patients' experience and understanding of progression.

It is important to support both HCPs and PwMS by providing them with the skills and tools needed to facilitate open and effective communication.

especially true for people with multiple sclerosis (PwMS), who face an uncertain disease course and are required to make various key decisions as their disease progresses. However, many PwMS report never having discussed disease progression with their HCPs. With this in mind, members of MS in the 21st Century recently held a debate between HCPs and PwMS to explore how HCPs currently communicate with their patients regarding MS disease progression and how this communication could be improved.

Challenges experienced by HCPs in the communication of disease progression included concerns that their relationship with the patient could be undermined because they are unable to predict exactly how their patient's MS will progress in the future. Conversely, it was felt that acknowledging these limitations in honest and open conversations about disease progression might help to foster trust in the relationship. It is important to carefully consider the timing of these conversations, as some patients might find information about disease progression overwhelming or may not be emotionally ready, which could negatively affect their engagement with their care. However, overall, the audience of HCPs, PwMS, and carers considered that clear education about, and understanding of, disease progression is predominantly beneficial for PwMS, as it can help to inform decision-making, set realistic treatment and care expectations, motivate lifestyle changes, and increase adherence to treatment.

To improve conversations about disease progression, HCPs should try to personalise their communication to the needs and preferences of their patients. Information needs to be communicated in clear and understandable language, and HCPs should be mindful of the ways in which negative language can adversely influence the responses of PwMS to the topic. HCPs should also understand that their interpretation of 'progression' may be different from that of their patients, and there should be greater acknowledgement and discussion of invisible symptoms. In recognising the importance of these conversations, but also the challenges associated with them, it is important to support HCPs and PwMS with the skills and

## PLAIN LANGUAGE SUMMARY

Good communication between patients and healthcare professionals (HCPs) is vital in the management of chronic conditions. This is

tools needed to facilitate open and effective communication.

## INTRODUCTION

Effective communication between healthcare professionals (HCPs) and patients with chronic conditions such as multiple sclerosis (MS) is well known to improve a range of outcomes, including patient engagement, treatment compliance, and patient satisfaction [1]. Good HCP–patient communication has been shown to improve treatment adherence in people with MS (PwMS) [2], enhance the ability of patients to cope and adapt to their condition [3], and enable successful disease management [4]. Such communication may be especially important for PwMS, who face an uncertain future due to the high variability of the disease course and difficulties in determining an accurate prognosis [5, 6].

PwMS and their caregivers are confronted with multiple uncertainties over the course of their disease and must make many decisions as the disease progresses, including decisions on lifestyle changes and treatment [7, 8]. Good communication and strong relationships with their key HCPs can enable patients to feel more actively involved in such decision-making [9]. Patients inevitably feel more included in this process when they sense that their doctor is listening to them and providing the right amount of information according to their needs and preferences [10]. Indeed, involving patients in shared decision-making has been shown to be a key factor in successful disease management [6, 11–13].

Despite the demonstrable benefits of good HCP–patient communication for PwMS, 25–50% of PwMS report never having discussed disease progression or long-term prognosis with their HCPs [14] (MS in the 21st Century data on file). The MS in the 21st Century initiative—in which these authors are involved—comprises a steering group of MS specialists and patient experts from 14 countries. This group recognises the importance of effective communication between PwMS and HCPs in optimising the patient journey and overall MS care, and is

committed to improving communication through awareness-raising activities and educational resource development.

This report summarises a debate between a panel of MS in the 21st Century members and an audience of HCPs, PwMS, and carers, with a goal of exploring how HCPs currently communicate about MS disease progression with PwMS. The debate was held at the European Charcot Foundation Annual Conference in Baveno, Italy on 15 November 2018. The panel comprised Prof Dawn Langdon and Prof Patrick Vermersch, and patient experts David Yeandle and Jane Shanahan, and was chaired by Prof Sven Schippling, with additional support and input provided by Dr Nektaria Alexandri. In the light of current evidence, opinions, and experiences among HCPs and PwMS regarding disease progression in MS, the panel discussed whether, and how much, PwMS should be told about the future progression of their disease. Key points for consideration included the need for HCPs to communicate disease progression with PwMS, the challenges in doing so, and ways to overcome these in order to improve patients' experience and care outcomes. The discussions and opinions presented in the debate form the basis of this paper, and supporting literature for these perspectives are included.

## HOW OPENLY SHOULD HEALTHCARE PROFESSIONALS DISCUSS DISEASE PROGRESSION WITH PATIENTS?

### Risks of Open Communication About Disease Progression

MS disease progression is a controversial topic within the healthcare community. There are ongoing debates around the accuracy of existing disease classifications, and prognosis varies substantially between individual patients, with accurate long-term prognostic forecasting often impossible [15–17]. HCPs can therefore be reluctant to communicate prognostic uncertainty to patients for a variety of reasons, in particular the fear that it would undermine

patient trust in the relationship [18, 19]. Full understanding of the complexity of disease progression is reliant on long-term specialist training. Particularly in MS, given the potential impact of cognitive impairment, there is a risk that too much information may overwhelm patients and raise the risk of misunderstandings that could negatively impact both treatment adherence and patient well-being, for example by increasing the likelihood of depression [20].

Added to this, many patients will comment that the word ‘progression’ produces an almost visceral reaction. A sense of the inevitability of neurodegeneration can leave patients feeling hopeless and can increase the risk of treatment non-adherence [21, 22]. A more patient-oriented care approach, which looks at symptom management, quality of life, and things that patients can control, can be more motivating than focusing on a negative future [5, 23]. Further, many PwMS may not be emotionally ready to hear about MS disease progression—in which case an insensitive or premature discussion of the topic may damage the relationship with their healthcare team and adversely affect future care utilisation [5, 20].

Arguably the greatest challenge for both HCPs and patients in discussing disease progression is that they inherently have different perspectives and priorities. MS disease progression means different things to patients and HCPs. HCPs generally define progression clinically in terms of measurable change either radiologically or through common metrics of physical impairment. By contrast, patients are more likely to see the worsening of invisible symptoms, for example extreme fatigue or a bad mood episode, as signifying progression. Since these changes are not picked up via magnetic resonance imaging (MRI) or the expanded disability status scale (EDSS), the HCP may not consider or discuss them as signs of progression [24], yet failure to recognise changes in these invisible symptoms causes significant problems with regard to both mutual understanding of progression and patient satisfaction [24, 25]. In addition, the use of clinical terminology, coupled with the complexity and variability of MS progression, can make conversations around

the topic difficult for patients to fully understand [26].

### **Benefits of Open Communication About Disease Progression**

Despite the risks, there are also considerable benefits to open communication regarding MS disease progression. Slowing disease progression is the primary aim of HCPs treating MS [27]; however, real-world studies show treatment discontinuation and non-adherence rates of around 30% [28–31]. Indeed, the actual rates of non-adherence may be even higher than reported [32]. There is evidence to suggest that a common misunderstanding amongst PwMS is that progression is the same as treatment failure, and this perceived lack of treatment efficacy is one of the driving factors behind cessation of adherence [33, 34]. This concern could be allayed through open communication, as there is also evidence that treatment adherence rates are positively linked to patients’ levels of education about—and understanding of—MS [2].

Disease progression discussions can also help patients to understand the need for certain clinical tests which they might otherwise feel are invasive and unnecessary, and can contribute to the development of a trusting relationship in which patients do not feel that their HCP is withholding information from them [20, 26, 28]. These discussions are important for creating realistic treatment expectations, leading to improved patient satisfaction and engagement, and enabling shared decision-making [5, 28, 35–39]. In addition, they can help to motivate patients to take responsibility for managing their disease [40], as they begin to better understand the importance of actions like regular physiotherapy appointments, eating healthy, exercising frequently, and staying mentally active. Allowing for practical planning for the future can also help to mitigate the impact of disease progression at the point of disease worsening, by temporally separating the decision-making process from the situational stress at the time of additional disease burden. Examples of this include patients installing a

walk-in shower in their house or adapting their car to use hand controls before these adaptations are needed, allowing continued independence, without interruption, at the point where these become necessary.

Furthermore, PwMS learn about the disease from a whole variety of sources, including other patients, the internet, news, and social media [41]. Discussions with HCPs regarding disease progression can thus be valuable opportunities to counter any misinformation and allay anxieties resulting from online research [42]. Among patients with chronic illness, PwMS are some of the highest-frequency users of the internet [43]. They are often less optimistic about their prognosis than HCPs; for example, believing that their MS means they will inevitably become wheelchair-bound [23], fuelled by negative depictions of the disease via television, films, and print media. HCPs can therefore play a helpful role in countering such depictions or misinformation and provide a trusted sounding board for patients [28], as despite their comparatively high reliance on online information, many patients still place greater trust in their physician [44]. However, while studies have shown that the majority of MS patients do in fact want to talk about progression, many find that this need goes unmet [14, 45].

### Optimising Conversations About Disease Progression

Since negative communication can impact both patient well-being and engagement, the importance of effective and transparent communication cannot be overstated. Achieving it requires a move from present-focused discussions of clinical findings to addressing patients' priorities regarding their present and future well-being, quality of life, and the day-to-day challenges of living with MS. Clinical information needs to be translated into easily understandable language, couched in patient-friendly terminology, and adjustments made for individual patients [17]. It may be helpful for HCPs to use more neutral terms; for example, 'progression' can have negative connotations that

may be avoided by the use of alternatives such as 'evolution' or 'spectrum', or referring to varying levels of ability rather than increased disability. Discussions also need to be personalised with regard to timing, patient circumstances, and cultural considerations in order to provide tailored, personalised care [20, 24, 46].

Given the multidisciplinary nature of MS care, it is also important to consider who is best placed to provide information on the topic of disease progression to patients. While neurologists are typically the primary source of patient information, MS nurses often have more regular interaction with patients, which may make them better suited to having conversations on associated sensitive topics such as sexual dysfunction or urinary disturbances, and answering questions regarding the day-to-day management of the disease [20, 21, 28, 32]. The timing of these conversations is also important to consider, as patients will probably have different views about when they want to receive information on disease progression, with some wanting the information as early as possible. HCPs should therefore be ready to raise the topic early after diagnosis, but keep in mind that others may prefer to receive information only when it becomes relevant, for instance when making important life decisions such as having a child or changing their employment.

For HCPs, the point at which a patient transitions to secondary progressive MS (SPMS) would historically have been a particularly challenging time to try to discuss disease progression, due to potential treatment limitations and the fears of a subsequent breakdown of trust [17, 26, 47]. However, clinical management of MS today is on the cusp of a transformation of treatment paradigms regarding progressive disease [48]. There is now clinical trial data on the use of siponimod for SPMS [49] and the established use of ocrelizumab in primary progressive MS [50], and promising treatments are in development for reducing nerve cell loss [51] and alleviating disability [52]—all making it easier to discuss disease progression more openly and positively. All of this combined should help to alleviate some of the previous concerns about having these conversations.

In light of this, it is important therefore that HCPs are supported as much as possible through access to appropriate communication skills training. Frameworks such as ‘ask-tell-ask’ and the SPIKES tool may help HCPs to deliver information in a way that reduces the chances of overwhelming patients [53]. In addition, understanding the patient’s priorities and psychological state are essential steps before approaching any discussions about disease progression [24]. MS in the 21st Century have developed two communication tools, myMS priorities and myMS commitments, specifically designed to support better mutual understanding of priorities and responsibilities in MS care [54]. Focused and effective disease progression conversations will enable the HCP and patient to set personalised and achievable goals for the future, acknowledge the possibility of future decline but demonstrate opportunities for action and prevention, and empower patient agency. Shared decision-making provides a framework within which it is easier to raise conversations on disease progression over time [6, 43].

Patient empowerment involves educating patients to make informed decisions about their care [35]. Therefore, supplementary educational initiatives are important aspects of fostering good communication and building a shared decision-making framework [28]. The role of educational initiatives in encouraging patient self-management in chronic conditions such as MS has also been widely acknowledged for decades [55]. ‘Newly diagnosed patient days’ are one type of these sorts of patient education initiatives. An example of this is the ‘Ecole de sclerose en plaques’ (School of MS) in France, which is run by the APF France handicap (<http://www.sclerose-en-plaques.apf.asso.fr/spip.php?article427>). The purpose of these initiatives is to provide those attending with a better understanding of MS and, crucially, an open opportunity to ask questions to the multidisciplinary team. These days may also include peer support, with more experienced PwMS able to present discussions about their own experiences and how they have learned to cope with MS and its symptoms.

One of the biggest barriers to optimal communication around disease progression is the lack of a reliable measure for progression, with the most common clinical scoring system, the EDSS, referred to as MS’s ‘tarnished’ gold standard [56]. Clinical measures such as EDSS and radiological findings often do not take into account the patient’s perspective [28]. A potential solution to this may be to combine clinical assessment scales with parallel feed-in from subjective patient evaluations [57]. From the patient side, it is also helpful for discussions to focus on disability progression rather than disease progression—and for physicians to differentiate the subjective experience of MS from the concept of disease activity and MRI changes, which may not be synonymous [15, 25, 58]. These changes may help to alleviate difficulties for HCPs in distinguishing secondary progression from silent progression—which could, at times, represent an ageing effect [59]—and help PwMS to understand the difference between ‘disease progression’ and ‘progressive MS’, preventing distress that can arise from conflating these concepts.

## SHARING KNOWLEDGE, MOVING FORWARD

Conversations about MS disease progression do not necessarily need to be difficult. An increasing understanding of MS coupled with recent developments in disease modifying therapies mean that such conversations can be much more positive than they were even 10 years ago. However, there remains substantial need and room for improvement, not least since negative experiences are known to adversely affect treatment adherence and patient satisfaction. Information needs to be clear and easily understandable and, when discussing sensitive topics, personalisation is essential and timing is key; conversations need to happen early enough to avoid patients resorting to unreliable information sources, but with consideration for their emotional readiness. It should also be considered whether the multidisciplinary team could be engaged more actively to support with providing this information to PwMS as,

depending on the healthcare system, they may have more frequent or less time-constrained interactions. Finally, educational initiatives and communication tools such as those developed by MS in the 21st Century have an important role to play in supporting both PwMS and HCPs to optimise these conversations.

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