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### ReachMD

www.reachmd.com

info@reachmd.com

(866) 423-7849

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## Addressing Employment Issues with MS Patients: Updates from the Ready for Work Project

Narrator:

Welcome to ReachMD, and this is On the Frontlines of Multiple Sclerosis, brought to you by an independent educational grant from Merck KGaA Darmstadt, Germany.

Dr. Birnholz:

This is ReachMD, and I'm Dr. Matt Birnholz. Joining me today is Antonella Cardone, Executive Director of the Fit For Work Global Alliance at the Work Foundation. She joins me to discuss the Ready for Work Project which aims to promote positive work outcomes in clinical care with particular focus on improving access to treatment and employment support for all people living with MS.

Antonella, welcome to the program.

Dr. Cardone:

Thank you.

Dr. Birnholz:

It's great to have you with us. So, to start, can you share some more details about the Ready for Work

Project, such as, how it came about and what its main objectives are?

Dr. Cardone:

Sure. We started the project, the Ready for Work Project, in 2015 to promote positive work outcomes, so for people with multiple sclerosis. Our vision on the project is that the work ability, which refers to supporting people into employment, should become a priority outcome of the clinical care. This will lead to maximizing work productivity, inclusiveness and the therapeutic benefits for the patient. The concept of work ability, although becoming more prominent, is far from being a mainstream concept in clinical settings. This is why a multi-stakeholder engagement and collaboration is key to our success.

Dr. Birnholz:

That's excellent, and on that subject of the multiple stakeholders, maybe you can help run us through both the population, and populations, that this project serves and the organization's members in terms of who is part of this collaboration. What can you tell us about that?

Dr. Cardone:

The Ready for Work Project is addressed primarily to people with MS, to healthcare professionals and to employers. And it is a collaboration between the Work Foundation, the European Multiple Sclerosis Platform, Novartis and Merck. The Work Foundation is a semi-independent department of Lancaster University in the UK, campaigning to improve the quality of working life. We take the position that good work is beneficial to all, including individuals, employers and the community. And we develop evidence and translate it into a language that is accessible for policymakers and other stakeholders. The European MS Platform is the umbrella organization of the main national MS societies from 35 European countries, and represents more than 700,000 people with MS and 1.5 million people affected daily by MS, including family and other caregivers.

Dr. Birnholz:

And Antonella, you had mentioned one of the primary stakeholders here are medical professionals, and the main objective is translating this message of work ability. So, I understand that there is a guide that was created specifically to help medical professionals initiate the conversation about the value of work. What can you tell us about this guide?

Dr. Cardone:

The guide we have developed for healthcare professionals to start the conversation about work with people with MS was produced to reflect the current wide range of evidence about the interrelationship between health and work. In many cases, work has been found to have a positive effect on the health and wellbeing of people with a range of chronic health conditions, including MS. Bad health has a negative effect on employability, work and associated income, while bad work or unemployment has a

negative impact on the health of the individual. So good health enables people to be productive workers and good work has been shown to improve health outcomes. Many people with MS would like to work and see work as a valuable part of their recovery, but they face a number of health and social barriers to achieving this ambition. So, our guide is for neurologists and other healthcare professionals to help them hold effective conversations regarding work with people with MS. The guide contains information and practical guidance on why, how, and when to conduct such conversations, as neurologists and other healthcare professionals have a relevant role in addressing the interrelationship between health and work.

Dr. Birnholz:

And how was this guide developed, specifically, to be able to address that how, why, and when of work?

Dr. Cardone:

We started the project with a literature review and the policymaking to set the scene and use as a sort of baseline for our activities. Then, as we planned to reach out to neurologists and other healthcare professionals as a priority target group, we decided that the best way was to facilitate, to initiate the conversation about work with people with MS to developing a guide for them to use. So, the guide is based on the strong academic evidence and has been developed in consultation with an expert panel including neurologists, MS nurses, patients and advocates.

Another important fact about this guide is that it has already been endorsed by the European Committee for Treatment and Research in MS,ECTRIMS, and by the Rehabilitation in MS, RIMS.

Dr. Birnholz:

Interesting. So, given everything that went into developing this guide, the expert panels, the endorsements by these institutions, maybe you can run us through what aspects of multiple sclerosis are most relevant for healthcare-directed conversations about work.

Dr. Cardone:

We have identified 4 main aspects of MS relevant for the work discussion. So, the first is the loss of working years, the second is economic and social costs, the third is the MS symptoms, comorbidity and work, and the fourth is employment and health outcomes.

So, on the loss of working years, around 700,000 people in Europe have MS. In 70% of the cases, MS is diagnosed between 20 and 40 years of age, so during their primary working years. Overall, only 37% of people with mild MS work. And 10 years after the onset of MS, only 50% of people are still in work, and this figure decreases to 20 to 40% after 15 years. An estimated 17% of people with MS are

dismissed by their employer and approximately one-third retire early. So, the evidence is clear, people with MS are at an increased risk of becoming unemployed and economically inactive during their prime working years, with the potentially dramatic influence on their life course and opportunities.

On the second aspect identified, MS has a large economic impact on society. The total cost of MS across Europe is 15 billion Euros per year. This cost affects not only healthcare systems; it is estimated that 50% of the total disease costs are indirect costs related to informal care, welfare systems and work productivity, with the early retirement accounting for 36% of the total cost. We also have to consider that the longer someone with the chronic illness is away from work, the less likely it is that he or she will return to work.

On the third aspect, many symptoms associated with MS create challenges for work. Fatigue is often reported as the most challenging symptom when it comes to finding and retaining work. There are also mobility and dexterity related symptoms, pain and heat intolerance, and cognitive issues. People with MS face an increased risk of developing other health problems which may form a further barrier to work. Such comorbidities include obesity, hypertension, arthritis, irritable bowel syndrome, and chronic lung disease. Moreover, a very relevant factor is that the rate of incidence of depression and anxiety among people with MS is 2 to 3 times higher than that of the general population.

When looking at employment and health outcomes, a large body of evidence indicates that unemployed people have lower physical and psychological wellbeing than their employed counterparts. Those who are unemployed are more likely to have a chronic illness and poorer mental health and to require more frequent medical consultations. For people with MS, unemployment is correlated with negative psychological and physical health effects, to such an extent that it is a contributing factor to higher mortality rate. On the other end, employment has a proven positive effect on health and wellbeing, especially in relation to mental health outcomes.

Dr. Birnholz:

Thank you Antonella, that was a great thorough review of the burden of the disease on society and on these patients as far as how that affects their ability to work. I want to tie this back to the clinical office, the healthcare professional settings. You have already given us a really good sense of why, then, it is important for healthcare professionals to talk about work with their patients and their caregivers, and maybe you can comment on that a little bit, but I am also, then, interested in how they should go about doing this? How do they assist their patients in talking about this and even helping to manage workplace disclosure?

Dr. Cardone:

Let me emphasize that healthcare professionals do have a role to play to keep people with MS at

work. Many people with MS can work, and would like to work, however, along with their symptoms, a culture of low expectations, stigma and discrimination, all present barriers to realizing such ambitions. So, the support that healthcare professionals can provide is on the adherence through conversation, return to work, work as a clinical outcome, symptom management at work, recovery goals, opportunity for independence, early and effective intervention and problematic treatment.

On the adherence through conversation, we know that effective communication has positive effects on adherence. It also contributes to patients' likelihood to returning to work. This guide has been designed to facilitate such high quality conversations about work.

On the return to work and the benefits obtained from this, we need a partnership approach between the clinicians, the persons with MS and employers. Employers need to understand what is being asked of them, by way of making reasonable accommodations, allowing time for treatment within a working week and maintaining a healthy regular conversation with their employee regarding their changing needs.

An extensive body of research suggests returning to or staying in work should be considered as a clinical outcome due to the role work can have in improving health and wellbeing, promoting recovery and rehabilitation and, ultimately, improving quality of life. Good quality of work has been found to be protective of health. This is why healthcare professionals should view work as a clinical outcome and recognize it as a topic within their sphere of influence.

On the symptom management at work, evidence shows that poor symptom management in the workplace has a significant role in causing people with MS to drop out of employment. An improvement in this area could lead to a rise in employment rates. Healthcare professionals have a vital role in helping people with MS understand and manage their condition. This places them at a unique vantage point from which they are able to support their MS patients to become or remain a fully active part of society.

On the recovery goals, we all know that work is an important part of our life, as well as an income, it provides social networks, status and a sense of purpose. It is important that the healthcare professionals work with patients to identify what patients believe would improve their health and wellbeing. This may be broader than symptom management. Healthcare professionals could also strive to determine the goals of treatment for each individual patient and what the barriers are to achieving them.

On the early and effective intervention, by integrating conversations about work as a routine part of clinical consultations with the healthcare professionals, we can identify potential work difficulties and

take action to address them early. Much as early diagnosis and early intervention are important in a clinical setting to reduce or even hinder some elements of disability, preventing people falling out of work in the first place is also crucial in reducing longer term harms.

On the problematic treatment, we need further consideration that some medications used in the treatment of MS, may cause symptoms which are problematic for certain jobs. It is important that people with MS working in occupations where they may be automatically banned due to taking symptomatic drugs, such as train drivers or pilots, are encouraged and facilitated to seek expert employment advice. Further, this may be a consideration when making decisions about appropriate treatment for an individual patient.

Dr. Birnholz:

So, Antonella, there are a number of great takeaway messages there through everything that you had just said. One of the most important messages being for healthcare professionals to remember, to really consider making work a clinical outcome, and considering it that way, thinking of it that way, defining it that way, and maybe that that will change their approach to counseling patients with MS.

Now, before we wrap up, are there any additional takeaway messages you'd like to share with our listening audience?

Dr. Cardone:

I would stress that healthcare professionals have a fundamental role to play in maintaining people with MS at work or allowing them to return to work as soon as possible. So, they should exercise this role more and more. I also encourage them to check our guide, and possibly use it, because we believe it is a very useful tool, and I would also recommend them to stay tuned and check regularly our website as we will publish soon a checklist which will complement the guide to help them having an effective conversation about work with people with MS, and it will also be the basis for followup and keep track of any improvement.

Dr. Birnholz:

Antonella, with that, I very much want to thank you for joining us and sharing these updates on the Ready for Work Project, and how clinicians globally can better serve their MS patients when it comes to employment and career opportunities. It was great having you with us today.

Dr. Cardone:

Thank you for organizing this session.

Narrator:

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