

Communication challenges at different stages of MS

MS Nurse PRO
A European community for MS professionals

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Every MS is unique!


MS – THE DISEASE WITH 1000 FACES

- Variability in phenotypes of MS
- Heterogeneity of symptoms of MS
 - Visible and invisible symptoms
 - All functions coordinated by CNS can be affected
- Unpredictable course and prognoses

Paresthesias (~ 60 %) 	Dysphagia (20–50 %) 	Ataxia, balance disorders (~ 50 %) 	Hearing disorders rare 	Visual field defects (~ 40 %) 	Dysarthria (slurred speech) (~ 30 %) 
Diplopia (~ 40 %) 	Impaired short-term / working memory (40–80 %) 	Bladder dysfunction (~ 40 %) 	Nystagmus (10–80 %) 	Language disorders a) Language comprehension  b) Language production 	Kinetic tremor (~ 30 %) 
					Spasticity (~ 60 %) 


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Different stages of Multiple Sclerosis


- **Before diagnosis**
 - Uncertainty, insecurity
- **At diagnosis and just after diagnosis**
 - Shock, Ignoring, denial, confusion, worrying, anxiety
 - Processing impressions and limitations leading to new stability
- **Living with MS**
 - Stable periods
 - Relapse
 - Progression



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The role of the MS Nurse



The diagram illustrates the various roles of an MS Nurse, arranged around a central figure. The roles are categorized into two main groups, each with a vertical stack of roles and a horizontal flow of roles.

Left Group (Vertical Stack):

- Coordinator
- Teacher
- Supporter
- Educator


Right Group (Vertical Stack):

- Facilitator
- Referee
- Mentor
- Partner


Central Roles (Horizontal Flow):

- Guider
- Advisor
- Coacher
- Informer
- Mediator
- Advocate
- Spokesman

Blue arrows indicate the flow of roles: a large arrow points from the left group to the central roles, and another large arrow points from the right group to the central roles. Smaller arrows connect the central roles to the right group.




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Possible challenges

- **I see people having problems to walk and finally end up in a wheel chair! So, MS is a muscular disorder!**
 - MS is a autoimmune disease of the CNS
- **I have a stable MRI, no symptoms and my neurologist told me that my EDSS didn't change from last year**
 - Smouldering MS
- **My MS is stable so I just go on with my life!**
 - Importance of (P)rehabilitation and working on your reserves, physical and cognitive
- **How do I tell my boss that I've MS? What will I do with my coming promotion in my job?**
 - 75% of the PlwMS stopped working 10 years after diagnosis
- **As a nurse, together with my neurologist, I know what is best for my patient!**
 - The PlwMS is the expert by experience and is your collaborating partner in therapy



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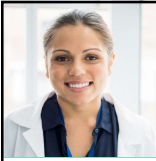


Possible challenges

- **Family planning**
 - What to do, how and when, related to DMT's?
- **Starting and monitoring Disease Modifying Therapies**
 - From burden to risks
- **Studies**
 - What to advice?
- **Symptom management**
 - When to advice about e.g. bladder disorders?



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Role of the MS Nurse

- Understand pathology of MS
- Identify general health related needs of care of the PlwMS
- Recognize MS related symptoms
- Listen to the PlwMS, be empathetic and refer if necessary
- Inform, educate, coach, support
- Support therapy adherence / Coach process of change via concept of MI
- Enhance healthy life style and guide to stop smoking
- Support physical and cognitive reserves
- Importance of Multidisciplinary approach and (P)rehabilitation
- Aim for quality of life
- Empower to self efficacy
- Humour is always important and necessary



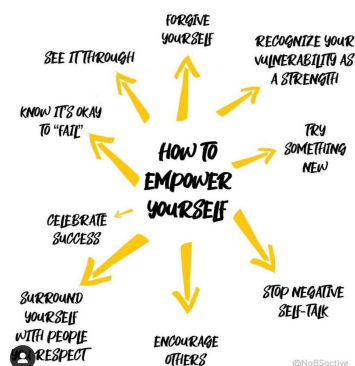
➡ Tresshold to MS-Nurse is often lower and bond of trust is often closer

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Communication challenges

- Inform
- Educate
- Coach
- Guide
- Support
- Collaborate
- Empower
- Be informed



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