

The Psychosocial Impact of Multiple Sclerosis

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The Illness Narratives

“Illness is not simply a personal experience: it is transactional, communicative, profoundly social.”

The study of illness meanings is not only about one particular individual’s experience, it is also very much about social networks, social situations and different forms of social reality.”

The Illness Narratives

“Illness meanings are an integral dimension of lives lived together; deeply embedded in the social world and consequently inseparable from the structures and processes that constitute that world.

An inquiry into the meanings of illness is a journey into relationships.”

Kleinman



“When a severe chronic illness comes crashing into someone’s life, it cannot help but separate the person of the present from the person of the past and affect or even shatter any images of self held for the future.”

“Who I was in the past and hope to be in the future are rendered discontinuous with who I am in the present.

New conceptions of who and what I am – past, present and future – must arise out of what remains.”

Corbin and Strauss

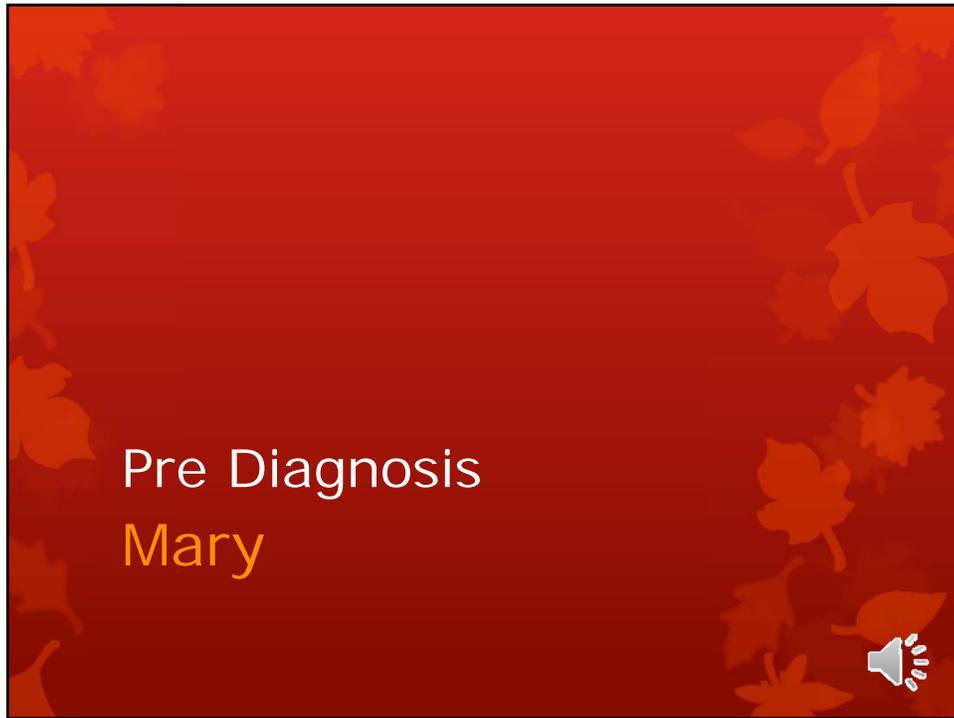
The Journey of Clinician and Patient

- Psychosocial Risk Assessment
- Psychosocial Tasks towards adaptation

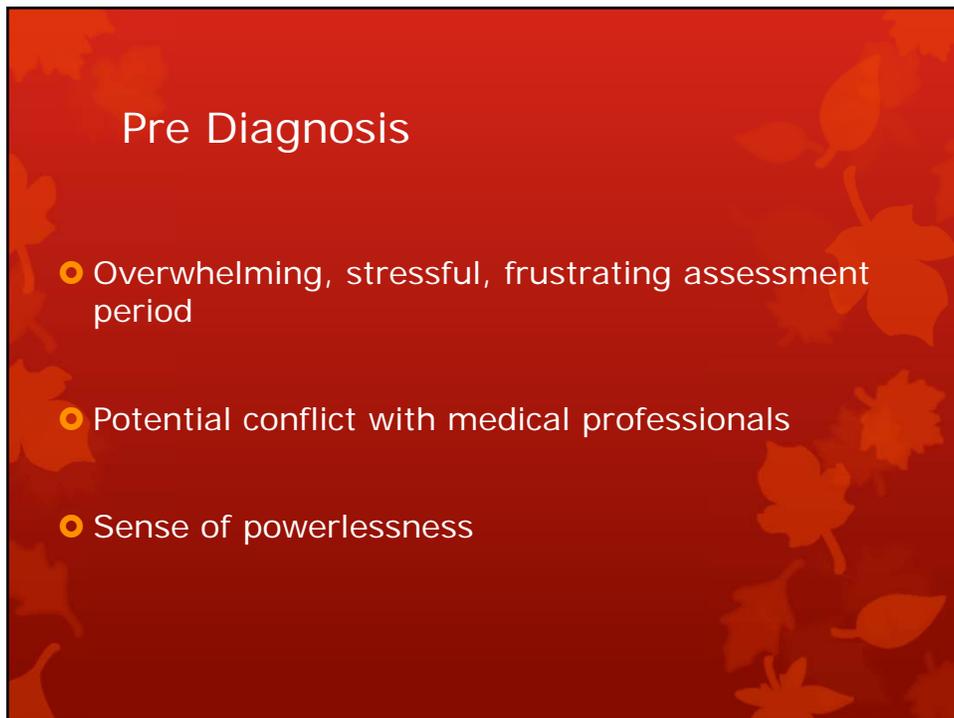
With thanks to Mary and Deb for sharing their journey.

Psychosocial Risk Assessment

- Pre Diagnosis
- Diagnosis
- Exacerbation
- Progression



Pre Diagnosis
Mary



Pre Diagnosis

- Overwhelming, stressful, frustrating assessment period
- Potential conflict with medical professionals
- Sense of powerlessness

Pre Diagnosis

- Issues of uncertainty
- Reliance on maladaptive coping mechanisms
- Potential risk to family stability
- Employer's reaction

Psychosocial Tasks to Facilitate Adjustment at Pre Diagnosis

- Access current accurate information
- Access validation of symptoms
- Access validation of their concerns and feelings

Psychosocial Tasks: Pre Diagnosis

- Begin to develop strategies for dealing with uncertainty
- Access the support of family and friends
- Access support within the workplace
- Quickly access supportive medical services within which a trusting reciprocal relationship can begin to develop

Diagnosis

Mary



Diagnosis

- Crisis and grief reactions
- Issues of uncertainty
- Compromised self image
- Emotional reaction of significant others

Diagnosis

- Issues of control
- Who to tell?
- Varying information needs

Psychosocial Tasks to Facilitate Adjustment at Diagnosis

- Access current accurate information
- Access validation of the emotional impact of this diagnosis
- Develop strategies for dealing with the emotional impact of the diagnosis and the uncertainties

Psychosocial Tasks: Diagnosis

- Maintain Hope
- Access support of family and friends
- Connect with others in similar situations
- Establish a supportive trusting relationship with the health care provider



Psychosocial Tasks to Facilitate Adjustment at Exacerbation

- Access medical support to manage symptoms
- Access concrete services within the community as required
- Access validation of the emotional impact of the exacerbation

Psychosocial Tasks: Exacerbation

- Access assistance in adjusting to change - to learn strategies for coping and for realigning roles and relationships
- Maintain hope
- Access support from family and friends
- Access support in the workplace



Themes

- Uncertainty
- Loss of Control
- Grief/Depression
- Redefinition of Self

Psychosocial Adaptation

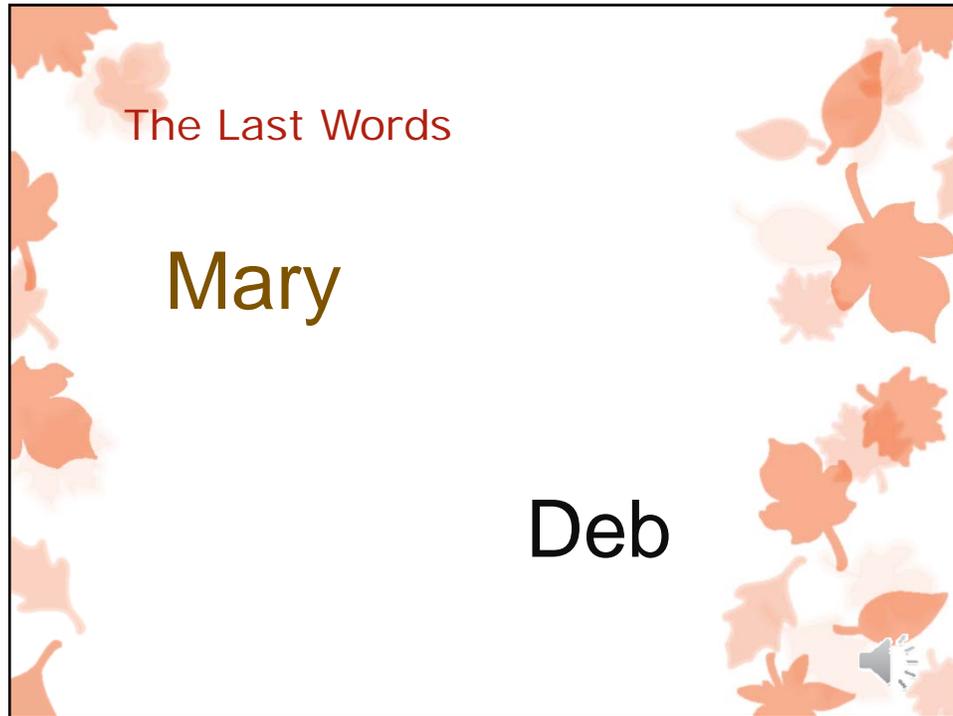
The process through which persons perceive, assess, cope with, and gradually assimilate various changes in body, self, and person-environment interactions.

In Conclusion

- The Psychosocial Implications of MS are significant and encompass all areas of life
- As health care professionals we hold a key role in assisting people and families living with MS to negotiate the psychosocial challenges posed by this illness

In Conclusion

- Through our understanding of the psychosocial risks associated with life with MS throughout the continuum of the illness, we can assist patients and their families to develop skills and strategies that will help them to mitigate the psychosocial impact of Multiple Sclerosis.



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Thank you!