

*Illness and identity:
redefining who you are*

a TMA empowerment clinic

Ingrid de Groot
LCSW
The Netherlands

*53 year old woman with myositis
and Patient Research Partner*

Chair Dutch myositis working group
TMA - Medical Advisory Board
IMACS – ICERS
OMERACT – myositis working group



Identity : “being who or what a person or thing is.”

Elements of identity include: gender, race, professional identity, values, personality, religious beliefs etc.

Chronic illness: “a long lasting condition which requires ongoing medical care and which may consistently limit the scope of a person's daily activities”.

Typically requires lifestyle changes (medications, diet, exercise), possibly causing limitations on personal, social and professional life.

Illness identity: “ the degree to which a chronic health condition, such as a heart disease, is integrated into someone’s identity”

People describing ‘pre- illness identity’ and ‘post-illness identity’.

Illness, body image and identity

Physical symptoms

Bodily changes

Use of visible aids and tools

Social stigma

Illness identity states

Rejection: refusal to accept illness, is incompatible with one's self

Engulfment: opposite of rejection > illness becomes preoccupation
depression and anxiety may increase

Acceptance: *illness accepted as part of one's identity*
depression and anxiety may decrease

Enrichment: recognition that positive changes have occurred as result of illness

Illness identity states: a mental work-out

- Different states keep coming and going
- This means that even after experiencing an enrichment state, you may fall back into earlier states of rejection or engulfment
- Try and find out what your predominant state is
- In case of predominantly rejection or engulfment states, try and find out what is causing this (and seek help if needed)

Your personal journey

And what might help you to reach your destination

- Allow yourself time to grieve
- Allow all the emotions that come and go with this process
- Find ways to express or let go of those emotions
- Try to open up to new experiences and opportunities
- Try to find distraction
- Look for support
- Accept offers of help and generosity
- Ask for help if needed (family, friends, colleagues or professional help)
- Take time to find out what works for you
- 3 important elements in coping with illness: resilience, gratitude and intimacy
- Prepare for unpredictability :The only certainty is that there is no certainty

Messages of hope and empowerment

- You are NOT ALONE!
- Opportunity to discover new parts of yourself
- A new lens from which to gain perspective
- A chance to re-evaluate *what* is meaningful in life
- A chance to re-evaluate *who* are meaningful to you
- Disability paradox: gap between what people without serious and persistent disabilities believe and what people with these disabilities actually experience.
- There is no right or wrong way to deal with this situation!