

# Living with IBM, a full time job

How to live a meaningful life





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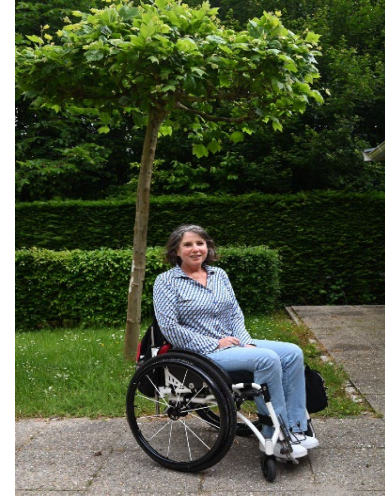
# Living with IBM, a full time job

## How to live a meaningful life

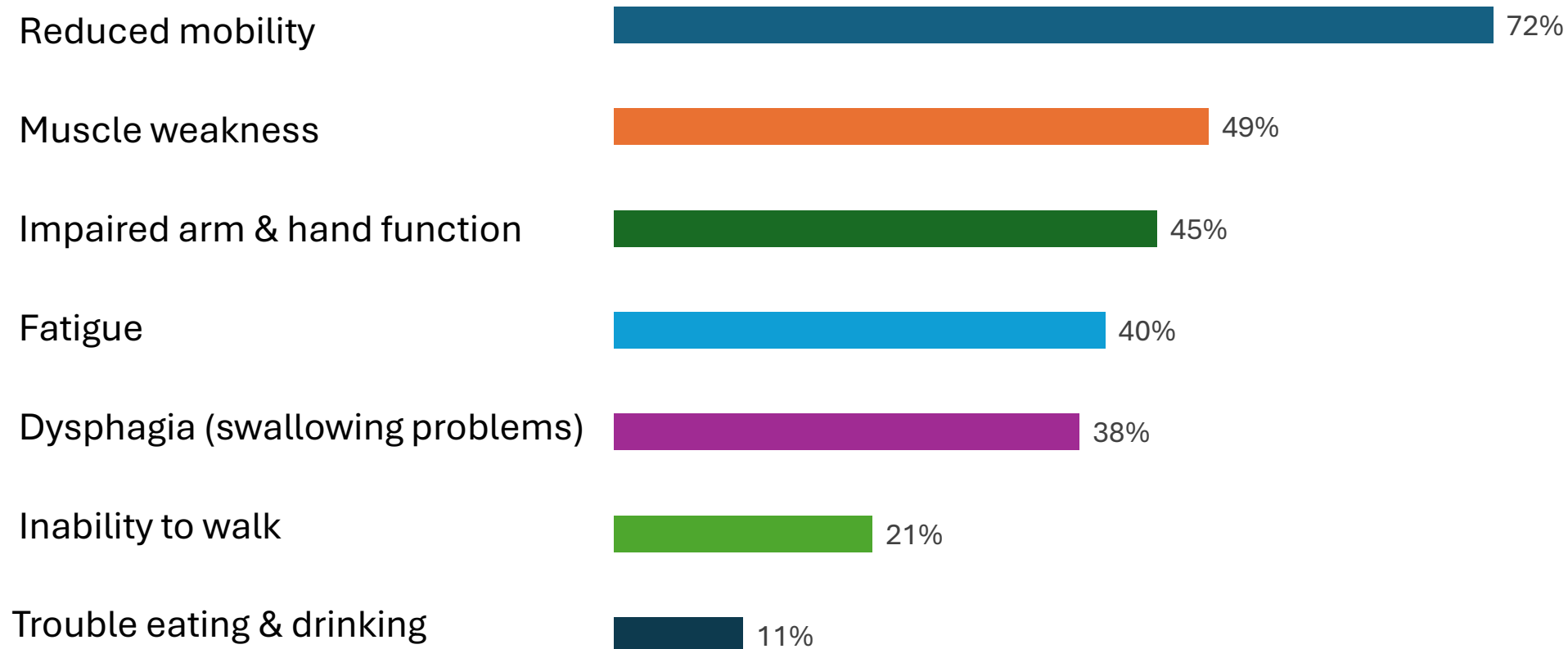
- A personal story
- What is a meaningful life?
- Strategies that might be helpful
- Key messages
- Q & A

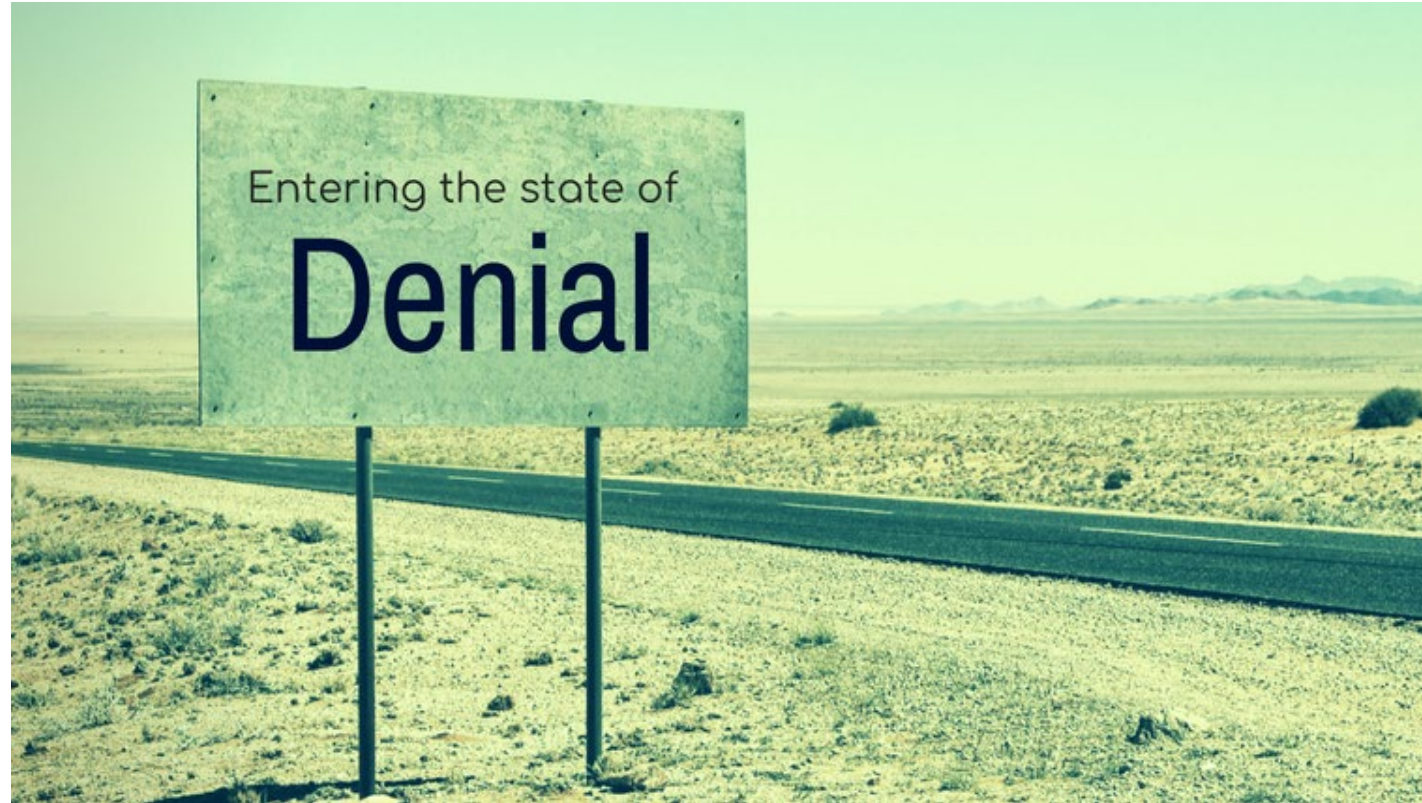


# Dermatomyositis over the years



# IBM: difficulties & challenges in daily life





“This is about living well, not about pretending the illness doesn’t exist.”

# What is a meaningful life?

A meaningful life is a construct having to do with the purpose, significance, fulfillment, and satisfaction of life. While specific theories vary, there are two common aspects: a global pattern of thoughts and behavior to understand one's life and the belief that life itself is meaningful.

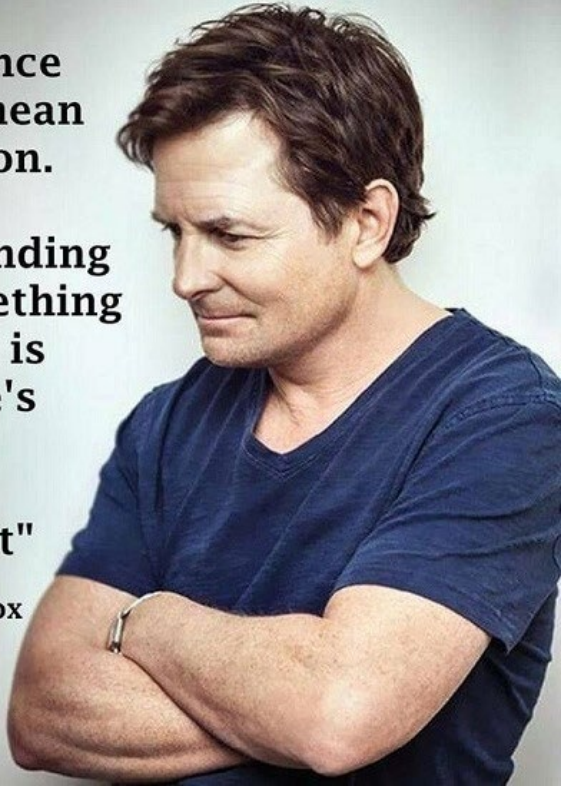
(Wikipedia)

# Strategies for building a meaningful life (some suggestions to start with)



# Strategy #1: acceptance vs resignation

- Acceptance means acknowledging the reality without giving up
- It also means letting go of the 'old normal' and creating a 'new possible'.
- Meaning is not what you do, but how you live with what you have
- Differentiate between what you can and cannot control

A photograph of Michael J. Fox, a man with dark hair, wearing a blue t-shirt, with his arms crossed and looking slightly to the left. The photo is positioned on the right side of the slide, partially overlapping the text.

"Acceptance doesn't mean resignation. It means understanding that something is what it is and there's got to be a way through it"

- Michael J. Fox

# Strategy #2: find daily meaning

What is your why?

- Small joys e.g. music, nature, pets, art, hobbies, religion
- Acts of kindness, helping others in small ways
- Keeping a journal, gratitude practice, spiritual reflection



# Strategy #3: connection and community

- The power of being understood
- Seek out support groups or trusted relationships
- Advocate or educate
- Turning “pain into purpose”

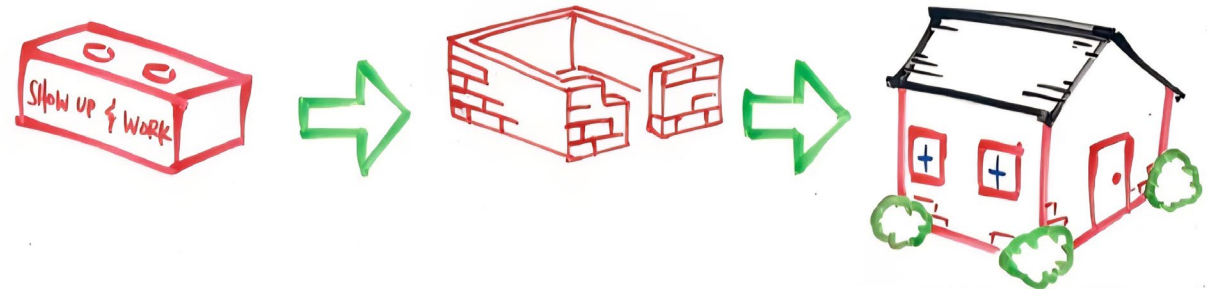


# Strategy #4: energy and pacing

- Budgeting energy:
- Say yes selectively without feeling guilty (and/ or learn to say no)
- Alternate (types of ) activities
- Value rest as part of purposeful living (not a limitation/hindrance)



# Strategy # 5: setting micro goals



- Find out what lights you up/ brings you joy or energy
- Micro goals increase chances of success and accomplishment
- Which means a boost for sense of meaning and self esteem

“Micro goals are small steps to big wins”

# Strategy # 6: emotional and mental health tools:

-Mindfulness and breathing exercise

-Therapy e.g. CBT or ACT (evidence in IBM and IIM)

-Keeping a journal to explore purpose, identity and emotions

“resilience is not about being strong all the time- it is about bouncing back in your own way”.



## Review

# Mental health in paediatric and adult myositis-related diseases: current state of research, interventions, and future steps from the MIHRA Psychological Impact Scientific Working Group

A. Lanis<sup>1</sup>, H. Alexanderson<sup>2</sup>, K. Ardalan<sup>3</sup>, S. Edison<sup>4</sup>, C.D. Graham<sup>5</sup>, I. de Groot<sup>6</sup>, L. Gupta<sup>7,8</sup>, S. Kim<sup>9</sup>, A.M. Knight<sup>10,11</sup>, L. Kobert<sup>12</sup>, P. Livermore<sup>13</sup>, C. Lood<sup>14</sup>, C. Pilkington<sup>13</sup>, M. Regardt<sup>15,16</sup>, T.B. Rubinstein<sup>17,18</sup>, S. Shenoi<sup>1</sup>, L. Turnier<sup>19</sup>, N.B.M. Voet<sup>20,21</sup>, D.M. Wahezi<sup>17,18</sup>, L.A. Saketkoo<sup>22-25</sup>

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### ABSTRACT

Psychological and emotional well-being are critical aspects of overall health for individuals with chronic rheumatologic conditions. Mental health-related literature, however, predominantly focuses on systemic lupus erythematosus

who experience depression and anxiety. Currently, knowledge and resources are limited around mental health burden and potential intervention for those living with IIMs. The Myositis International Health & Research Collaborative Alliance (MIHRA) Psychological

### Mental health in paediatric and adult myositis-related diseases / A. Lanis et al.

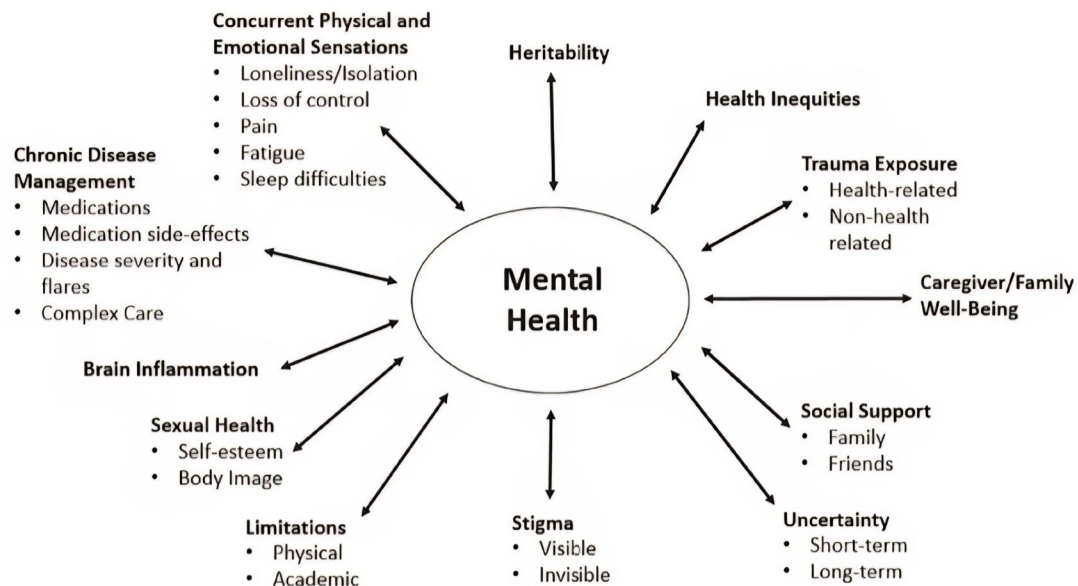


Fig. 1. Conceptual model of measurable and relevant psychological factors.

**Table II.** Potential methods to address mental health burden among those living with myositis.

### Potential resources

#### Psychological interventions

ACT\*  
CBT\* and Cognitive behavioural self-help\*  
Disease education and psychoeducation  
Talk and family therapy\*

#### Pharmacologic interventions

Biologics  
SNRIs\*  
SSRIs\*

#### Additional therapeutic interventions

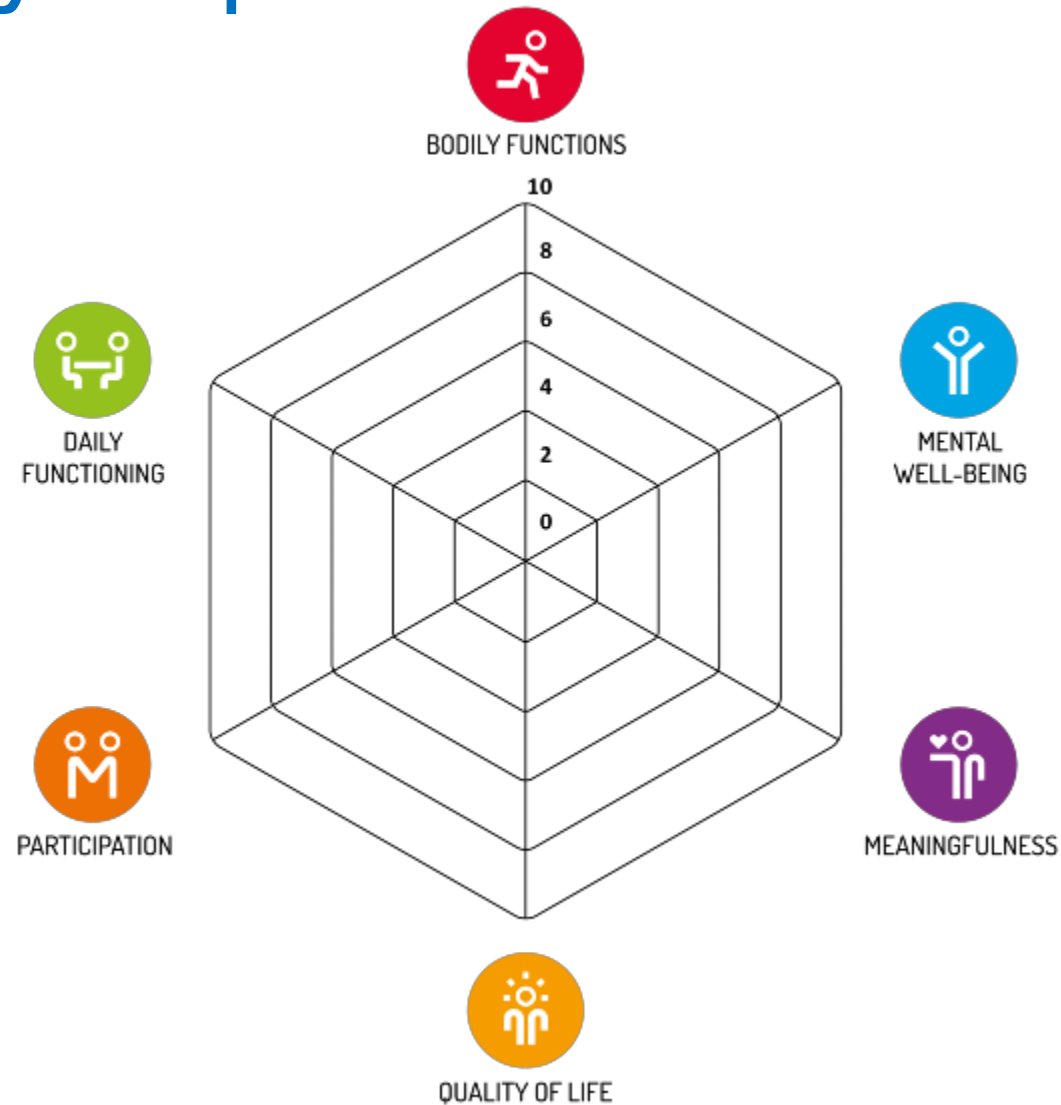
Animal-assisted intervention\*  
Art, play, music and dance therapy\*  
Embodiment practices  
Mindfulness\*  
Narrative medicine and poetry  
Occupational balance\*  
Patient associations  
Physical activity and exercise\*  
Resistance strength building\*  
Singing, humming, chanting  
Spirituality  
Yoga\*

\*Supported literature for intervention among those with IIM.

\*Supported literature for intervention among those with mental health burden.

ACT: Acceptance and Commitment Therapy; CBT: Cognitive Behavioural Therapy; SSRI: Selective serotonin reuptake inhibitors; SNRI: Serotonin and noradrenaline reuptake inhibitors.

# Strategy #7 positive health: a framework





## BODILY FUNCTIONS

Feeling healthy  
Feeling fit  
Physical symptoms  
Pain  
Sleeping  
Diet and nutrition  
Endurance  
Exercise/ physical activity



## MENTAL WELL-BEING

Recollection/ memory  
Concentration  
Communication  
Feeling happy/ content  
Self- acceptance  
Dealing with change  
Feeling in control



## MEANINGFULNESS

Finding meaning in life  
Zest for life  
Pursuing ideals  
Feeling confident  
Accepting life  
Being grateful  
Lifelong learning



## QUALITY OF LIFE

Enjoy life  
Felling happy, content  
Balance  
Feeling safe  
Living conditions  
Financial situation



## PARTICIPATION

Social contacts  
Being taken seriously  
Engage in activities with  
others  
Belonging, feeling included  
Having support from others  
Doing meaningfull things  
Interest in society



## DAILY FUNCTIONING

Taken care of yourself  
Knowing your limitations  
Knowledge of health / disease  
Managing time  
Managing money  
Being able to work  
Being able to ask for & accept  
help

# Take home messages:

- Illness may change your path, not your worth.
- Focus on mindset: you cannot change the fact that you have IBM, but you can change your response to it.
- Acceptance = acknowledge reality without giving up
- Find out “what is your why”; what brings meaning to your life?
- Stay connected
- Pace yourself
- Practice gratitude
- Ask for help when in need for it
- Use the strategies we discussed and find what works for you to live a more meaningful life





Questions and answers