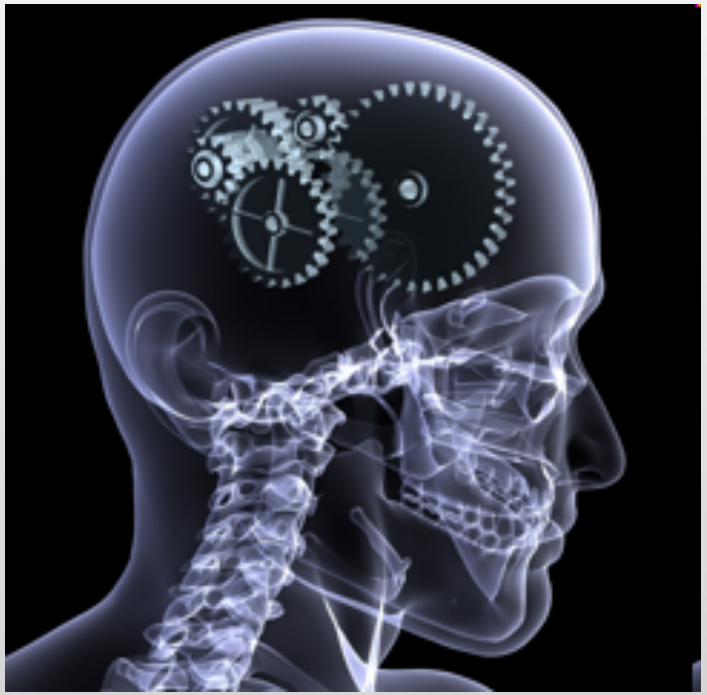
The unmet needs of people with MS

Psychosocial aspects...



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Pasquale Calabrese
Professor of clinical Neuroscience
Head of Dept. of behavioral neurology & neuropsychology

Unversity of Basel, Switzerland

Pasquale.Calabrese@unibas.ch

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Peter (aged 32, married, 2 children) has been diagnosed with MS a few months ago. When the diagnosis was disclosed to him, he was somewhat shocked; His doctors carefully explained what MS is and he was then offered a DMT before discharge. After a half year he comes to the hospital to see the doctor.

Doc: *„...well, your vision has recovered, your inflammatory parameters are satisfactory and your MRI looks great!...“*

Peter: *„...That´s wonderful doc, because my life is falling apart, I feel lousy and that medication you gave me made me sicker than my MS did“....*

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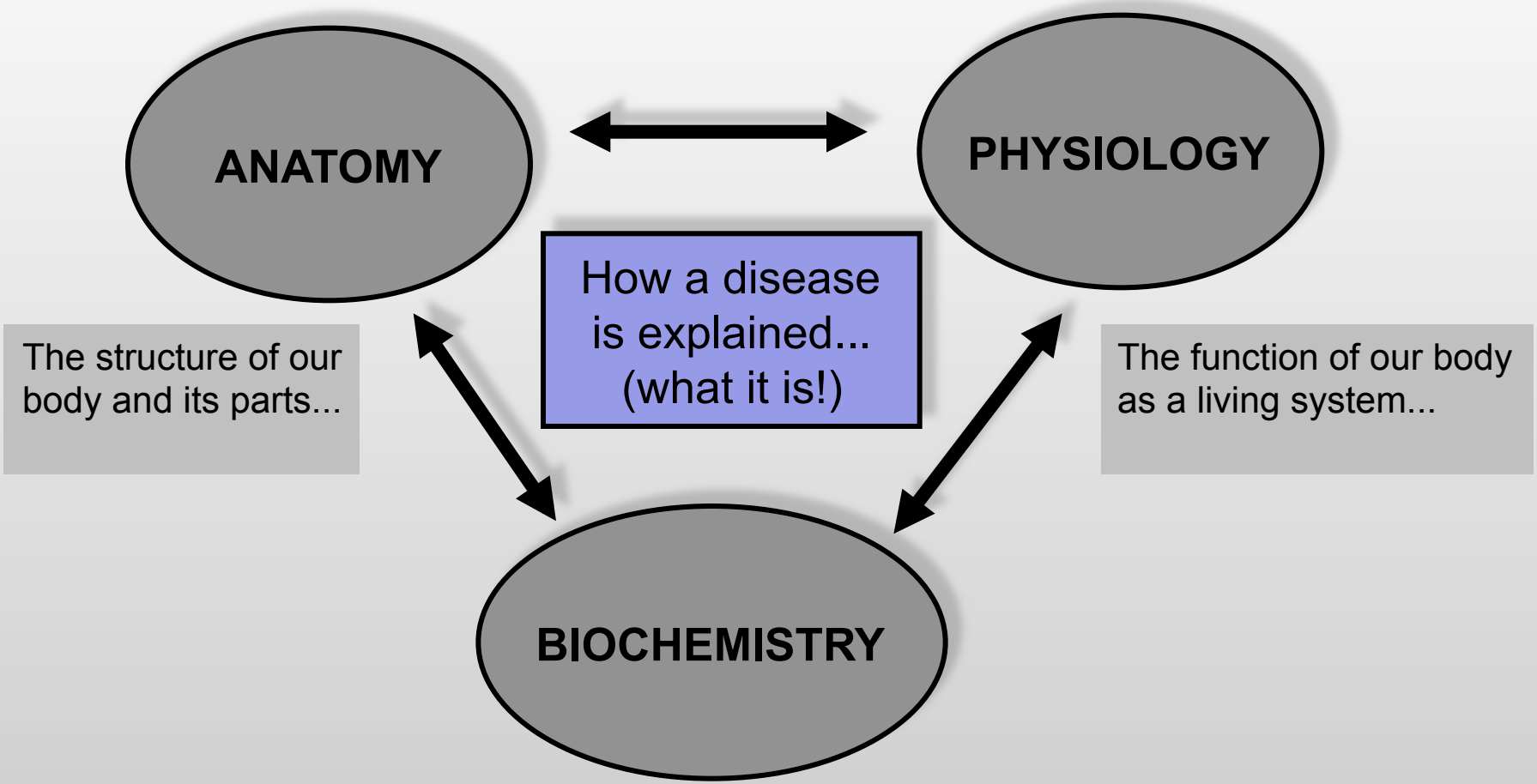
„Biological model“



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When a severe chronic organic illness crashes into someone`s life, it does not only affect someone`s body!
It separates the person of the present from the person of the past and shatters any image of self held for the future. By doing so, it tends to separate the individual from his significant others...

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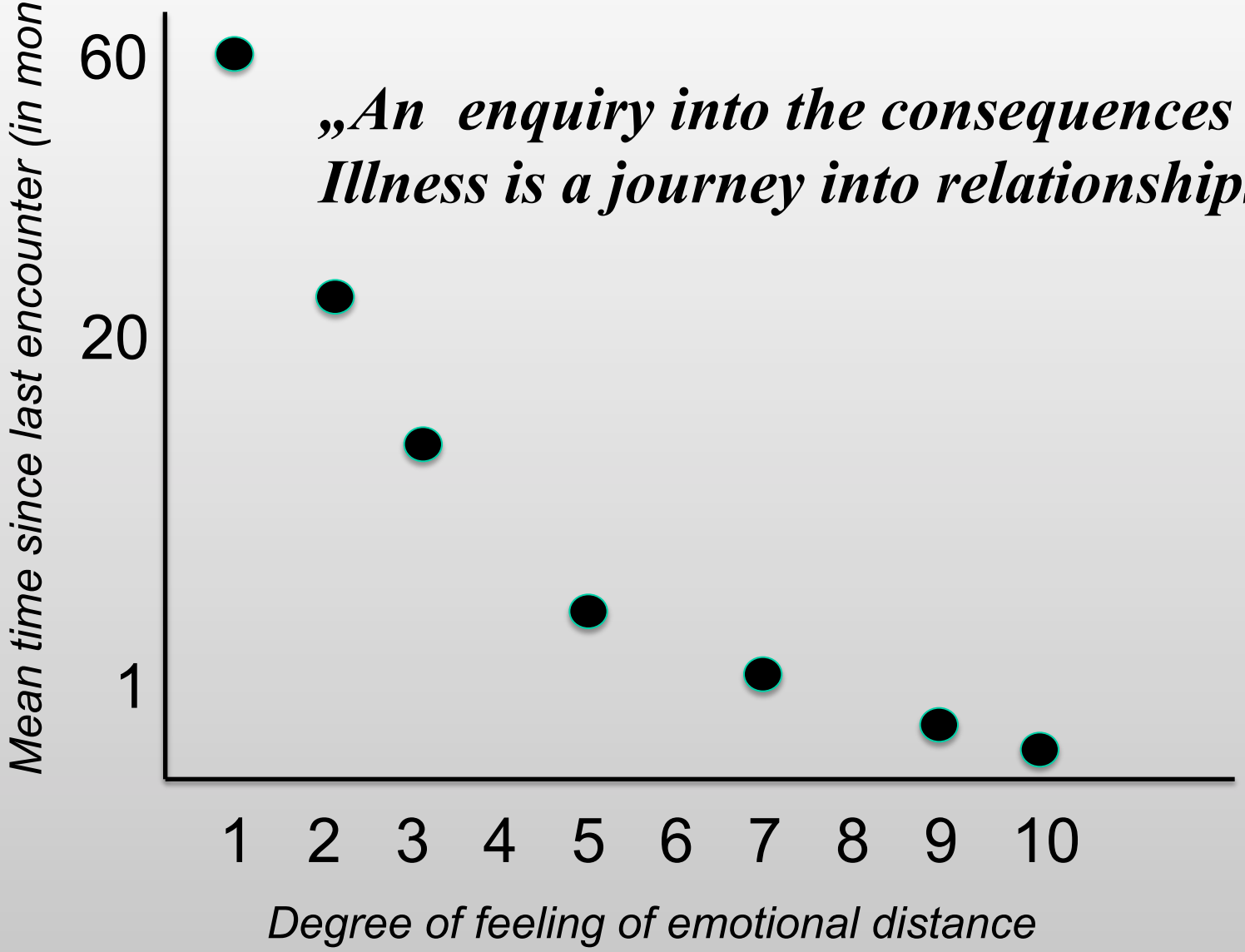
Building intimate relationships (Bonding)

The importance of meeting other people...



(adapted from: Gamble, Gowlett & Dunbar, 2016)

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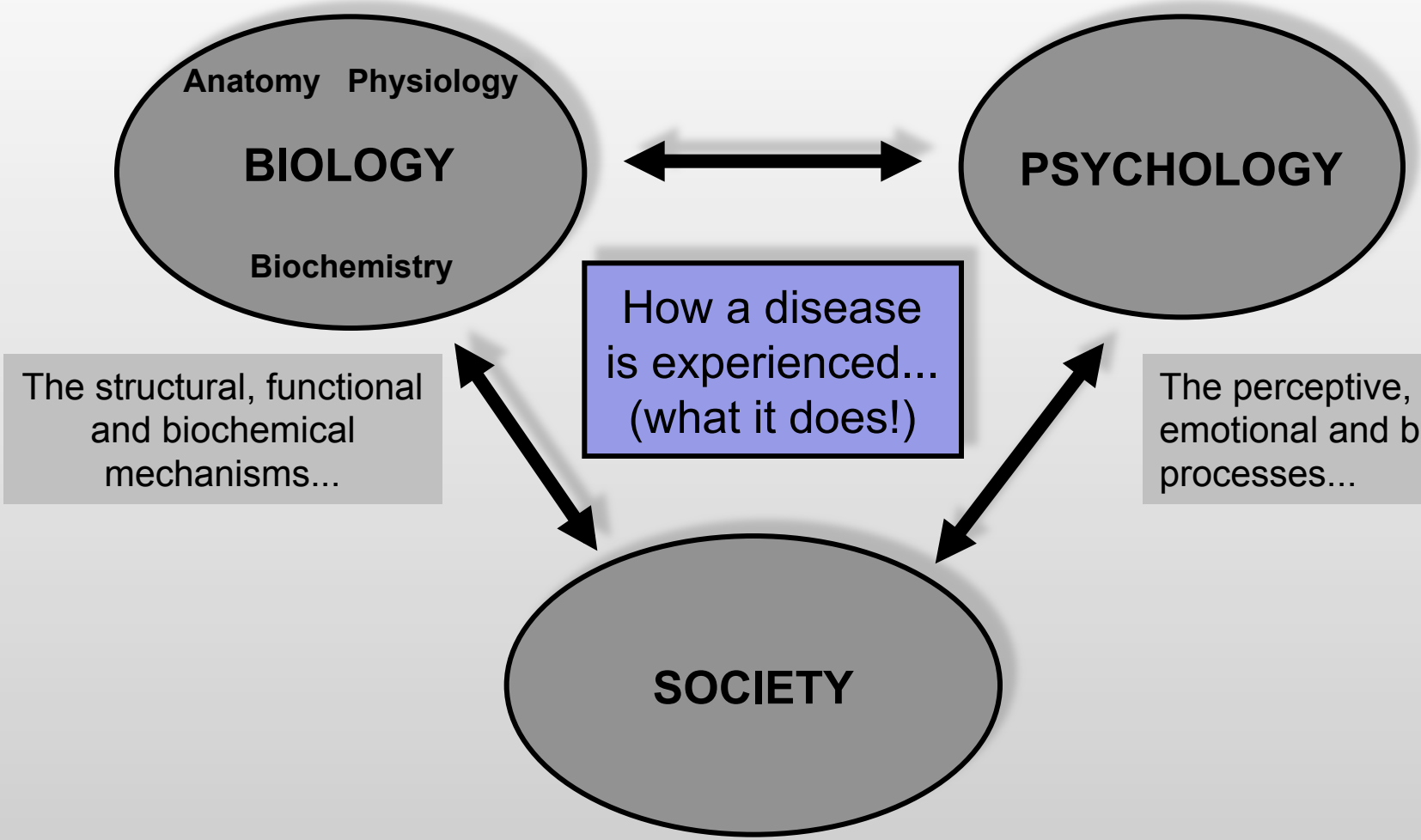
„Biopsychosocial model“



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„...what kind of life is this…“

?

„...**why me?**…“

„...will the symtoms get worse…“

„...will there be things I`ll never get to do…“

„...is there a cure for it…“

„...will I keep my friends…“

„...will I be able to maintain my job…“

„...whom should I tell…“

„...what kind of dad can I be…“

„...will she stay with me…“

„...will I be a burden to everyone…“

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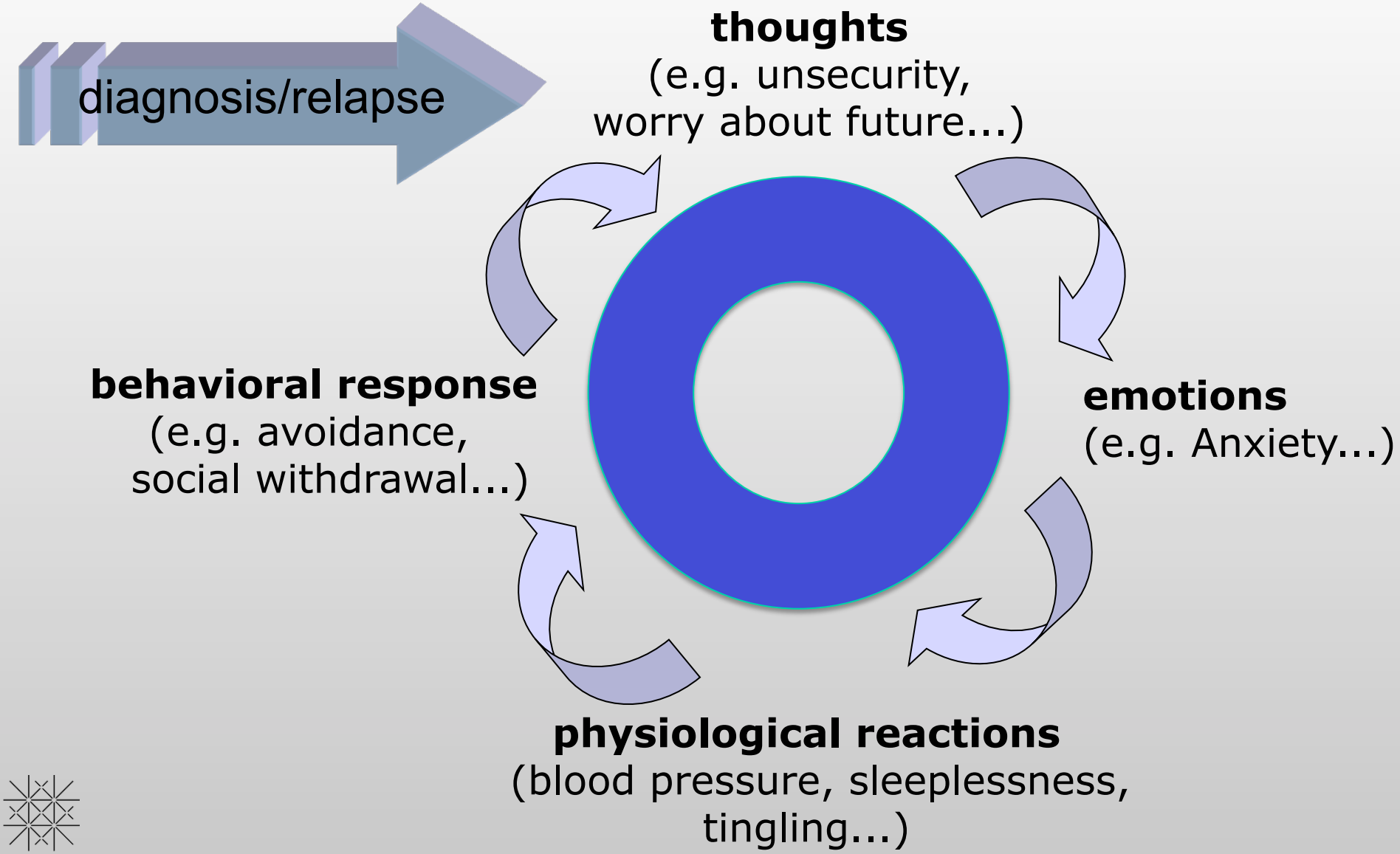
Symptoms creating symptoms…



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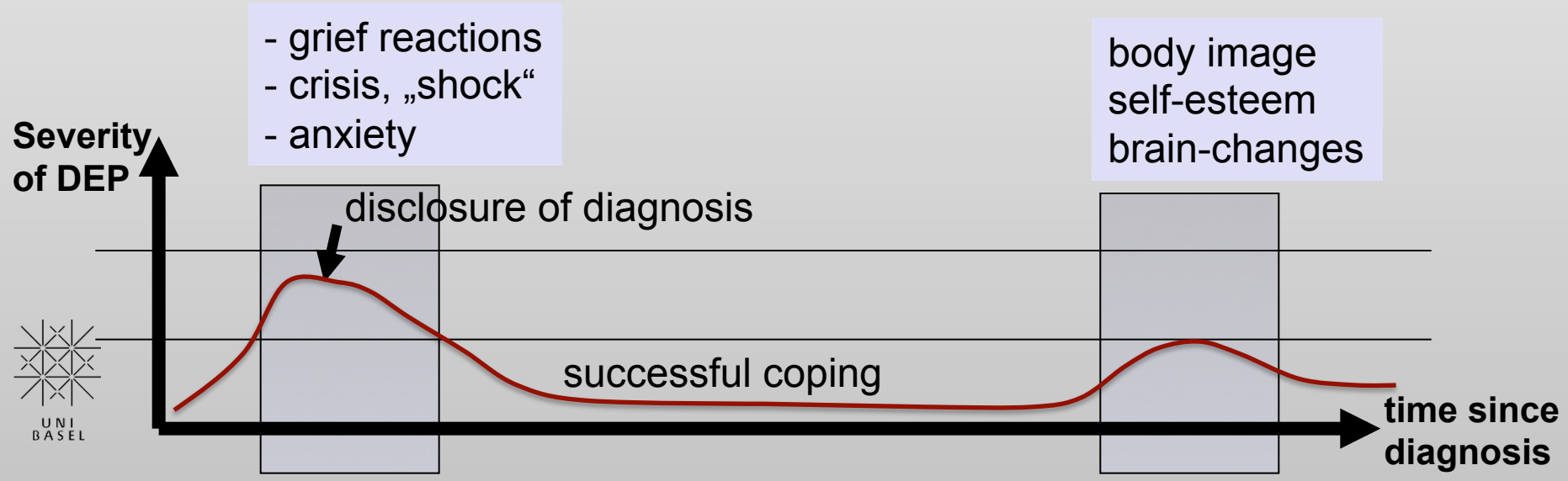
Depression in MS

- **Lifetime-prevalence of DEP in PwMS = ~ 50 %** (Sadovnik et al., 1996)
- **DEP most common psychiatric comorbidity in PwMS** (Harel et al, 2007)
- **Highly related to suicides (30% LTP for suicidal intent)** (Feinstein, 2002)
- **DEP in PwMS is 3-4 x higher than in the gen. population** (Ghaffar et al., 2007)
- **DEP more frequent in patients with cerebral lesions than in those with spinal cord affection** (Feinstein et al., 2004)

PwMS who adopt active coping strategies and who have a network of psychosocial support tend to have lower levels of depression and a better remission … (Chwastiak et al., 2002)



Different stages - different challenges

(requiring ongoing adjustment...)

(pre-)diagnosis	relapse	progression
uncertainty about symptom`s significance	emotional destabilization	ongoing loss and sorrow
stressful assessment procedures	compromised self-image	compromised body-image
misunderstandings with medical professionals	reorganization of family structure and job	compromised self-esteem
feeling of powerlessness	redefining the social role	uncertainty
crisis and grief reactions		
depression/anxiety		
emotional reactions of significant others		
provide accurate information for PwMS and sign. others	install therapeutic support to manage symptoms	provide support for change and accomodation within family and societal roles
explore helpful self-resources to deal with emotional impact of diagnosis and uncertainties	provide access to services within the community	provide constant access to Services and social networks
establish a supportive trusting relationship with professionals	focus on coping strategies for realigning social roles and relationships	**...don`t forget the person nearby...!**

CARE **ADJUSTMENT** **BONDING**

Why is there a vulnerability for psychological disturbances in PwMS?

- Disease variability and difficulty of prediction causes distress in PwMS
- Medical condition interacts with premorbid personality traits

- Immunodysregulation inherent to disease, influence neurocommunicatory pathways (e.g. HPA-Axis)
- Neuroanatomical changes due to inflammation and degeneration lead to functional disconnection of loops relevant to cognitive and psychoaffective regulation

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Take home

- MS is a Biological dysfunction, leading to **biopsychosocial** consequences
- **Cognitive processes** as well as **social relationships** have a strong influence on disease process
- MS poses **different challenges** in different periods

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