

Mhàs

- For the sake of our persons with dementia
 - Combatting stigma
 - Truth telling that reduces suffering
 - Meeting needs of identity, connectedness, security, autonomy, meaning, growth, joy*
 - Promoting Personhood promotes well being*



Photo by Johann Siemens

^{*}From Dr Al Power, <u>Dementia Beyond Disease</u>

Mhàs

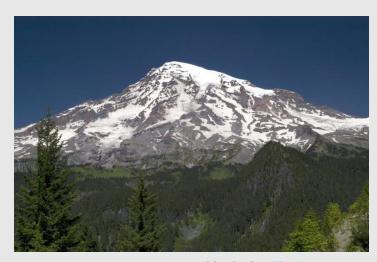
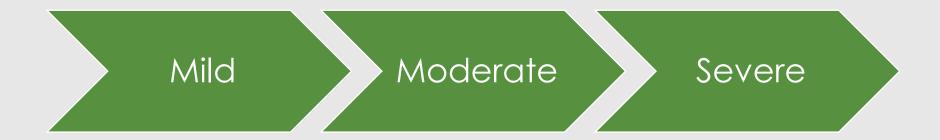


Photo by Tim Rogers

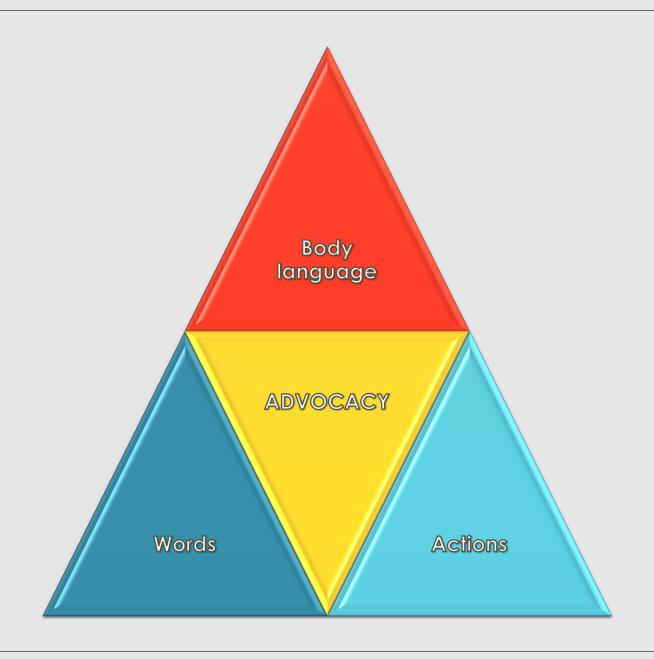
For us as carers

- To help in authentic ways
- For warmth and closeness
- To have a positive impact and not reinforce negative stereotypes
- For satisfaction and meaning in our work/efforts
- To build a legacy
- To maintain a sense of control
- To protect

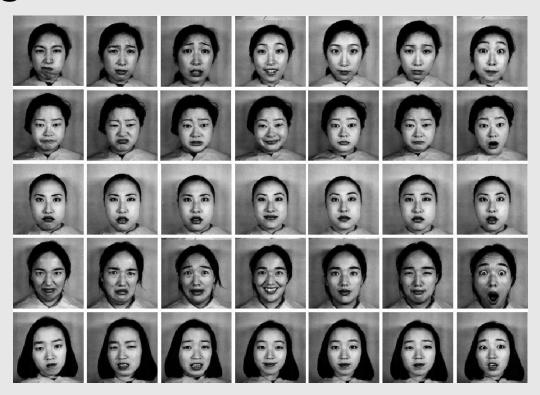
When?



 Personhood, identity, needs, and our humanity exists in us all throughout our lives

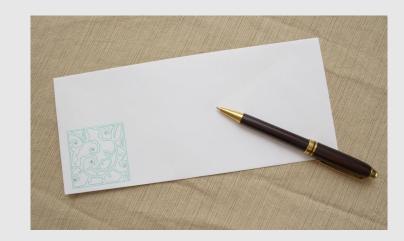


- [Deferential] Body Language:
 - Presence
 - Facial expressions
 - Positioning
 - Eye contact
 - Timing of when we answer





- [Humanizing] Words:
 - Helping health care providers get to know our loved ones with dementia
 - Even when a question is directly asked of us, inviting the person with dementia to answer first
 - Recognizing the human needs for identity, connectedness, security, autonomy, meaning, growth, joy
 - Talking about stress/distress behaviors in relationship to unmet needs



- [Supporting] Actions
 - Ask for improvements and acknowledge good practice:
 - Give feedback in person, fill out the survey, post online, write a note
 - The serious and tough option: when all else fails, it's your right to walk away, to establish care with a new provider who can align better with your values

Barriers



- Unrecognized bias
- Unconscious fears
- Uncharted territory for many health care providers
- Communication challenges
- Reduced insight
- Dynamic nature of being a carer and adapting to changing cognition and needs

Dynamic advocacy



- Personhood promotion for our persons with dementia, to meet their needs and protect them from stigma
- For our carers, to meet needs for meaning and building a legacy,
 and to protect the relationship
- For health care providers, to meet needs for growth, overcoming bias and fear