PROMOTING PERSONHOOD AND DIGNITY DURING HEALTH CARE VISITS:

Tips for You and Your Loved One

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Promoting Personhood

Why?

When?

How?
Why?

◦ 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*

*From Dr Al Power, Dementia Beyond Disease

Photo by Johann Siemens
Why?

- 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
How?

- Body language
- Advocacy
- Words
- Actions
How?

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

- [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
How?

- [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