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Living Under the Umbrella of Dementia

Who are we?
Why are we here?
How did we come to be under this umbrella?
What can we do to live well under this umbrella?
How can we create an inclusive community?
Why do we choose to be inclusive and diverse?

Who are We - Living Under the Umbrella of Dementia?
- People who are aware they are living with various types, variations, and combinations of neurodegeneration
- People who are unaware they are living with neurodegeneration
- People who have known a PLwD from before and recognize changes
- People who have known the PLwD from before and do not notice significant changes
- People who have jobs or careers that serve the public and find value in serving well
- People who provide services to PLwD who are embracing change to provide better support and care
- People who provide services who are not aware of the need to change
- And more.....

Why are Each of Us Here - Under this Umbrella of Brain Change?
- Each of us thought or felt there was some value in coming together
- Each of us is interested, to some extent in the others me might find here
- Each of us experiences our time together in a unique way, and yet we have some similar or common experiences
- Some of us did not choose to live under the umbrella
- Some of us did choose to be part of life under the umbrella
- Some of us have only been under one specific rain drop or have only had one experience of living with neurodegeneration, others have experienced many variations and combinations
- We are each hoping to have experiences of value while we are together or take something of value away with us when part
How Did We Get Here - Under the Umbrella of Changing Brains?
- Some were searching for this space
- Some were involuntarily placed under the umbrella
- Some were drawn here by relationships that made a difference
- Others came in order to guide their own brain development or change
- Many came with the intent to offer something in return
- Some came hoping for new awareness or knowledge
- Some came for the fellowship and community
- Others came to begin something new

What Role or Responsibility Do We Have to Make Life Go Well - Living Under this Umbrella?
- All have potential to share space, time, and opportunity
- Each may need time away from one another, because spending time apart rather than together is one of five strategies we might use to cope with our own needs
- We each try our best to seek permission to connect, interact, support rather than expect or assume it is OK
- Whenever we can, we will notice our own brain state, notice the brain state of others, and seek to offer support and options that benefit all, if possible
- Each person has some responsibility to offer the respect they would want from another
- Each person has a responsibility to be curious about others and possibly seek to connect, yet respect another’s choice to want or need something different
- We each determine our ability to be among people who think, act, react, and respond differently than we do

How Do We Combine Diversity with Inclusion as We are Gathering Under this Umbrella?
- We use the four Fs and the four Ss for increasing comfort
- We keep it friendly, familiar, functional, and forgiving
- We seek to provide for variable social, space, sensory, and surface preferences
- We seek to build relationships that are based on four principles:
  - We try to stay curious, regardless of the intensity, frequency, or volume of the message
  - We find a sense of compassion when seeking to appreciate the other’s perspective although it may be very different
  - We act and respond authentically, wanting to know more, understand better, and offering support or space
  - We seek to empower others through our words and actions
- We use PAC knowledge and techniques and skills to approach, connect, interact, and respond
- We seek to learn from our errors and one another as we seek to keep and celebrate what is valued, and change what is not working well
Why is it Essential that We Develop this Diverse, yet Inclusive Community as the Umbrella Expands?

- We all live here, whether we are aware of it or not
- We will find ourselves in a variety of roles as time passes, abilities change, and relationships change
- Each of us has the potential to help or harm ourselves and others, so we choose to try to help when we can and ask forgiveness when we make mistakes
- We believe in the strength, value, and inherent good in forming a community that cares wisely and well for all of its members
- We ultimately believe that life under the umbrella is well worth living