

Lots of Existential Fear and Spiritual Distress Needing a “Soft Place to Land”

- ❖ Loneliness: Missing friends, family, community connections, regular staff.
- ❖ Uncertainty: Why this is happening? Why all the changes? What is it? Why are you doing this?
- ❖ Anxiety: Loss of connections, grounding rituals, and fear of end of life, death, hospitals, etc.

(Chat: What have you seen and felt in your caring?)

Loneliness

Not only loss of current relationships, but potential feelings of being forgotten or left out, as in the past, or of losing family or friends in the near future. Hard to stay virtual in a world where touch is so important.

Strategies:

- ❖ Who are the key supporters and relationships in someone's life?
“Who's important to you?” Work with and through them as needed.
- Keep connected however possible: Facetime, calls, letters, cards, one minute videos sent to cell phones, photographs, yard to porch visits, chalk on driveways or sidewalks, picture pillows, Zoom calls through programs, self advocacy groups,
- **Voice Quilt.** <http://www.voicequilt.com/> A website that helps creates personalized keepsakes of friends' and family voices.
- Relationships, relationships, relationships.

(Chat: Other strategies you have seen or used?)

Uncertainty

So much unknown. What is, may be hard to understand. Health staff will now know my child or adult family member. Hard to sit in and with the uncertainty. All behavior is communication.

Strategies:

- ❖ Clear, simple communication. Words, pictures, video. Lots of good ones.
- ❖ Welcome questions and feelings. Who's the person or persons someone trusts most? Have my voice heard.
- ❖ Recognize behavioral acting out goes both ways.
- ❖ Creative tools to let health care staff know about a person, e.g., Health Care Passport,
- ❖ Advocacy to change policies to allow family or staff care support.

Anxiety

Confusion about daily living changes, loss of connection with key support personnel, friends or family, new behaviors to learn, possible boredom, depressed “feelings” with no place to go.

Strategies:

- ❖ Keep as many normal rituals as possible.
- ❖ Enlist individuals in establishing new ones. (Nothing about me/us without me/us.) Maximum involvement by individuals in adaptations.
- ❖ Build on interests, strengths, gifts as well as history of resilience.
- ❖ Rituals of faith, music, comfort, i.e. very person centered.
- ❖ Connections, connections: Zoom dance parties, Facetime, etc., etc.
- ❖ Recognize learning and irony: Some people are preferring the “new ways,” i.e., more focus on individual interests, fewer mandated activities, more choices.

Openness to Talking about Grief, Loss, and End of Life Issues (and Planning)

- ❖ First, recognize it and welcome it. “Grief delayed is grief denied and grief denied is grief delayed.” (Same for anger, fear, questions, etc.) Huge teachable moments for agencies, carers, individuals, families.
- ❖ Create a safe place for it. A sanctuary. Key relationships, spaces, rituals. Professional willingness to be vulnerable.
- ❖ Be alert for behavioral expressions and the fact it is a two way street. People with IDD and carers.
- ❖ Assist in individualized and cultural ways of sharing feelings, supports, , e.g., cards, photos, letters, talking about feelings and memories, grief and loss rituals. “Loss assessments,” i.e., what family and cultural habits, rituals, and traditions are there. Plan with people for what they want.