

Managing Post COVID-19 Condition Therapeutic Education Program

The Self-Advocacy Strategy



Objectives

- Define Self-Advocacy, its importance, and its challenges*
- Discuss Accommodations and Accessibility*
- Identify strategies in communication with yourself and with others*
- Discuss the Self-Determination model*



Definition

- ❑ *“An individual’s ability to effectively communicate, convey, negotiate or assert their own interests, desires, needs and rights[...]* (Van Reusen et al., 1994).
- ❑ *“Self-advocacy is the ability to identify your strengths and weaknesses, the ability to make personal goals, be assertive, and make decisions.”* (Canadian Hearing Services)
- ❑ *To speak or act on behalf of one’s own needs, views, or interests* (Singer & Mogensen, 2021)



Why is it important?

"The number one reason is that I'm the only person who has to live my life. Nobody else can know what I really need. Other people can look at me and say what they think, but it is very important for me to ask for what I want."

Mary Ellen Copeland, mental health advocate and person with lived experience



Accommodations & Accessibility

- Under the Ontario Human Rights Code there is a duty to accommodate the needs of people with disabilities to ensure equal opportunities and access to services, housing, employment, including legal services and health care
- Employers have a duty to adjust conditions, if it does not cause undue hardship, so that someone who can work is able to do so
- With family, friends and co-workers, it should also be acceptable to ask for reasonable accommodations that allow you to participate



Why is it challenging?

- Limited knowledge of the Post-COVID Condition
- Invisible symptoms
- Power imbalances and systemic barriers
- Social and cultural influences
- Finite energy level



The internal dialogue

- Why is it important?
 - Above all, self advocacy requires developing a belief in yourself!

- Why is it difficult?
 - Comparisons of the past and present self
 - Internal expectations and pressures
 - Distinguishing between my voice vs their voice





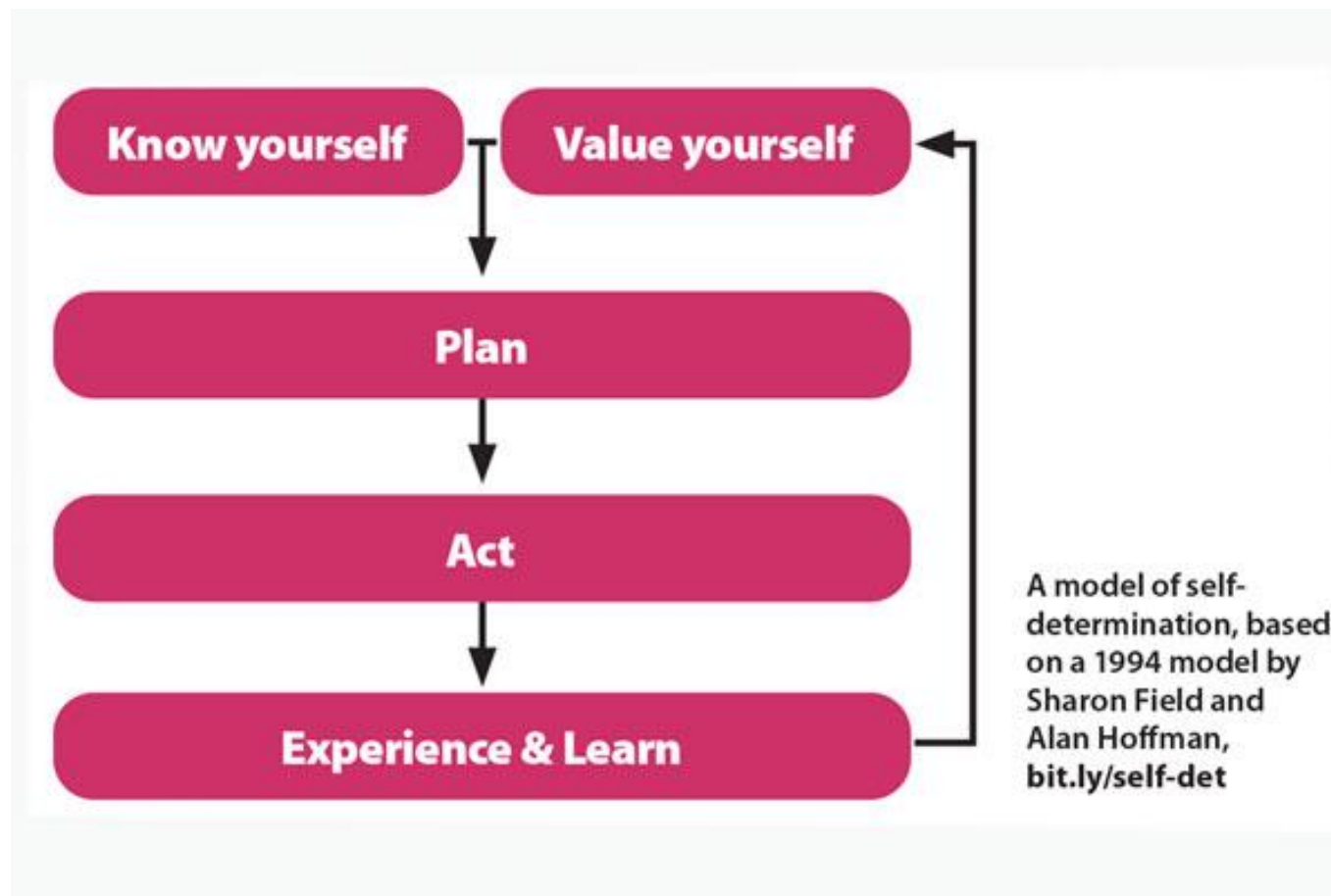
Communication strategies

- Who are my allies?
 - How can they help me?
- What do I want to advocate?
 - Choosing the 5 W's
 - Creating boundaries
 - Prepare, practice, plan
- Correcting the power balance



Communication strategies

- Time (e.g. length of conversation, breaks during an event, time of day)
- Memory (e.g. plan what you want to say, take your notes with you, record an appointment; electronic appointment confirmation; ask family to text anything that needs follow-through)
- Attention (e.g. quiet environment, undivided attention, someone else to take notes),
- Comprehension (e.g. ask MD to slow down; make sure you have my attention)
- Expression (e.g. delay conversation to allow preparation; manage environment and position)



From Singer & Mogensen, 2021

Resources and links

Ontario College of Family Physicians resources for family physicians

<https://www.ontariofamilyphysicians.ca/tools-resources/covid-19-resources/long-covid>

Information sheets on Long COVID, Fatigue and PEM/PESE, Pacing and Breathing

<https://longcovid.physio/quick-access>

Long COVID Symptom Self-Management Sheets

<https://santemonteregie.qc.ca/en/west/long-covid-symptom-self-management-sheets>

Letter to family, caregivers, or friends

http://www.phsa.ca/health-info-site/Documents/PC-ICCN_Letter_to_support_person.pdf

Long COVID as an Episodic Disability: Implications for Workplace Communication, Disclosure and Accommodation Planning

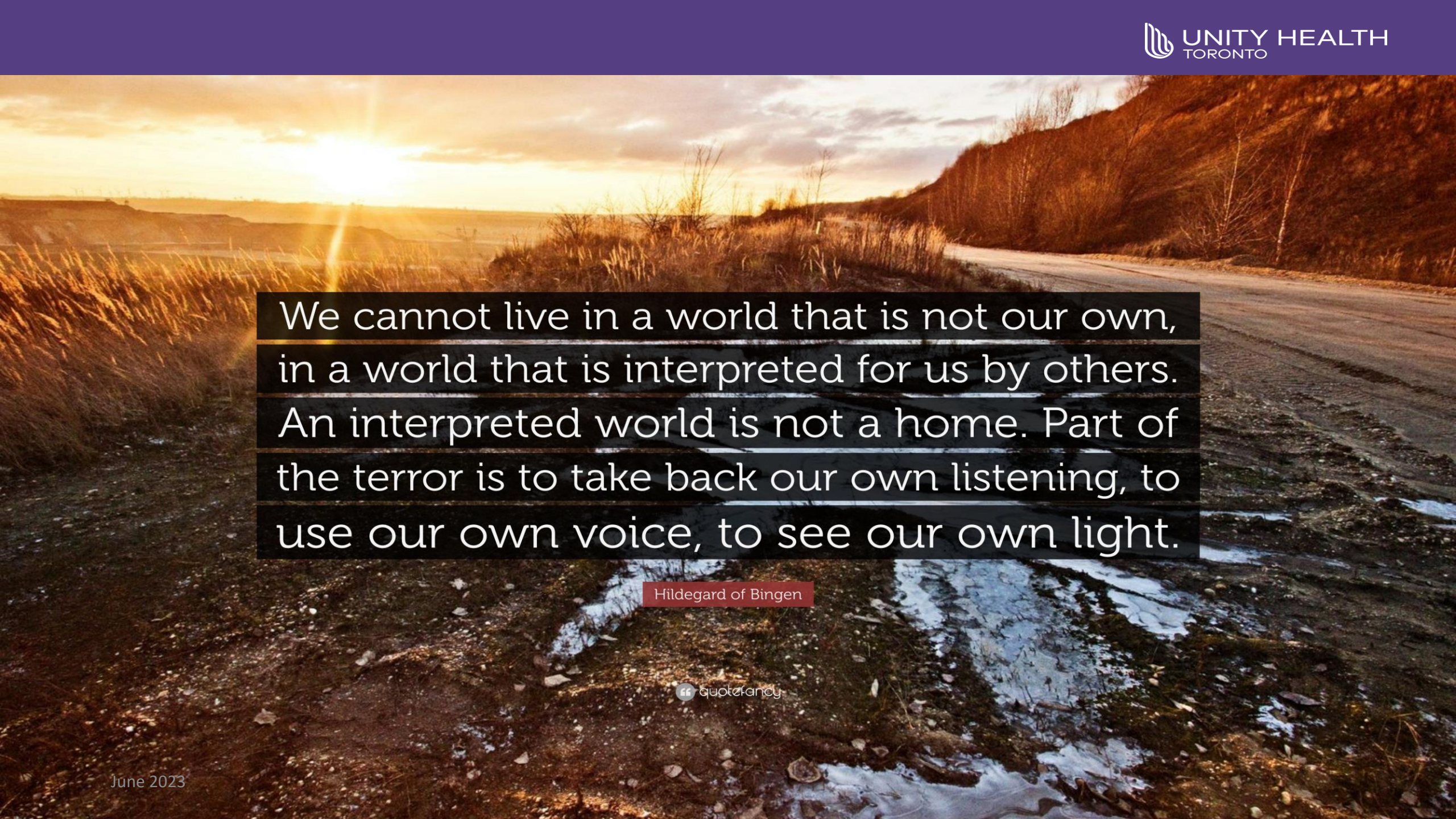
https://aced.iwh.on.ca/sites/aced/files/presentations/Gignac_Presentation_EARN_Conference_Nov2022.pdf

Recommendations for Employers, Insurers, Human Resource Personnel and Rehabilitation Professionals

<https://www.realizecanada.org/wp-content/uploads/Recommendations-for-RtW-doc-final.pdf>

Reduce Long-COVID impacts in your workplace

<https://www.sunlife.ca/workplace/en/group-benefits/insights/bright-papers/long-covid/>



We cannot live in a world that is not our own,
in a world that is interpreted for us by others.
An interpreted world is not a home. Part of
the terror is to take back our own listening, to
use our own voice, to see our own light.

Hildegard of Bingen

“ quote fancy



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