



Essential Caregivers

**Susan Mills and
Donna Thomson**

**Caregivers'
Perspective on Being
#notjustavisitor**

DONNA'S Story – Before COVID-19



Partly Who She Was Incompatible with COVID-19



ADULTS WITH CP EXPERIENCE PREMATURE AGING

“Between about 20-40 years old, most adults with cerebral palsy will experience some form of premature aging.” - CerebralPalsyGuide.com

- Increased Pain
- Decreased Mobility
- Increased Fatigue
- Increased Dysphagia, Osteoporosis and Arthritis

SUSAN'S Story



Prior to COVID-19 - An Active Participant



Visitor vs ESSENTIAL CAREGIVER

Visitor

- Social Interaction
- Does not participate in Care/Care Plans

Essential Caregiver

- Designated by Resident or POA
- Participates in Care (Physical, Psychological, Emotional etc.)
- Improves Resident Safety and Reduces Harm
- Ensures Continuity of Care
- And much more...

Essential Caregiver – What Susan Does

- Assist with Feeding (takes an hour)
- Help feel better by washing/curling hair and dressing well
- Help with Personal Care
- Emotional Support
- Physical Exercises
- Mental Stimulation (Counting, spelling, cards etc.)
- Take Outdoors Regularly
- Facilitate window and video visits with family

Essential Caregiver – What Donna Does

- Act as POA for medical decision-making
- Translator and trainer on communication and positioning for newer staff
- Liaise with nursing supervisors and MDs
- Arrange social schedule with extended family (distance)
- Ensure continuity of care for physical, emotion and social care including reminders of important events (sports)
- Bedside presence during illness or medical emergencies

What happened During COVID-19 with no Essential Caregivers allowed to support?



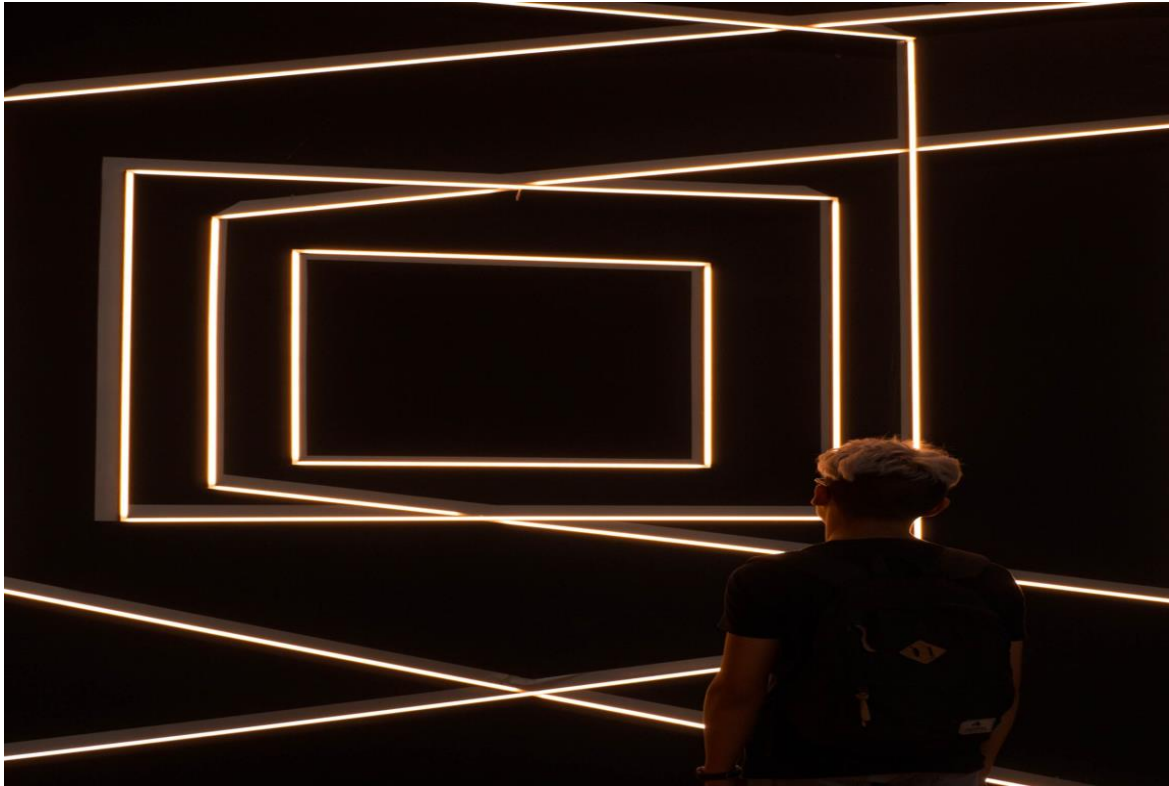
COVID-19 Visits through the window



The Effects of Isolation: On Him, On Us



What it meant when residents were allowed Essential Caregivers



SUPPORT AND LOVE



SUPPORT AND LOVE (and a PS5 😊)



WHAT IS STILL MISSING AND WHAT DO WE
NEED GOING FORWARD?



Thank You! Questions?

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