BUILDING COMMUNITY& RELATIONSHIPS WITHIN CAREGIVER SOCIAL ISOLATION & LONELINESS

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WELCOME!

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AGENDA

01. **DEFINE SOCIAL ISOLATION & LONELINESS**
For the Masses & Caregivers

02. **SOCIAL BARRIERS**
Why are we here?

03. **COMMUNITY & RELATIONSHIPS**
Challenging Assumptions

04. **SOCIAL AWARENESS**
What can we do?

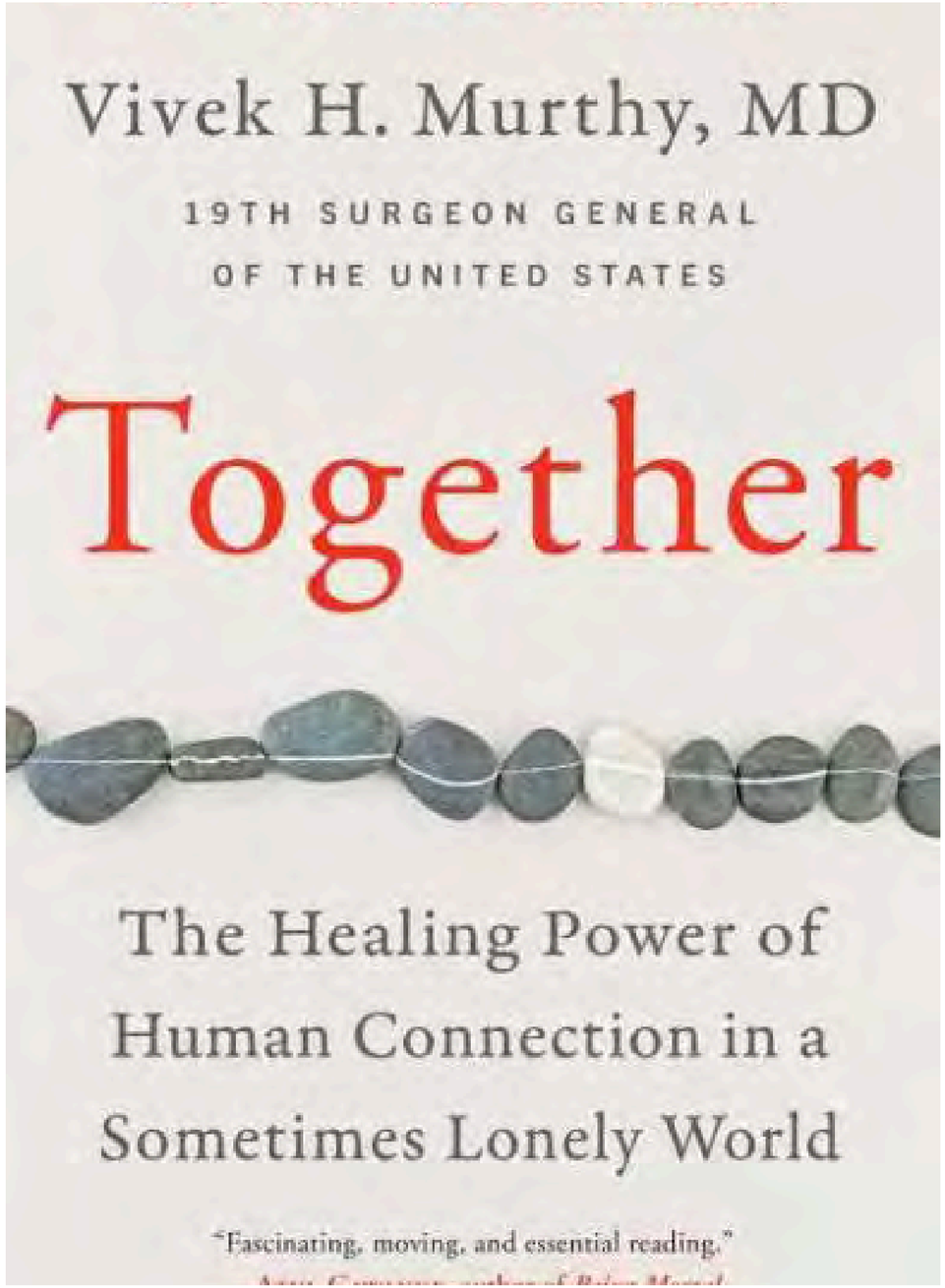
INTRODUCTION

Dr. Vivek Murthy
U.S. Surgeon General

Current Priorities

- **Social Connection**
  - *National Strategy to Advance Social Connection*

https://www.hhs.gov/surgeongeneral/priorities/index.html



DEFINITIONS

National Strategy to Advance Social Connection

Social Isolation– objectively having few social relationships, social roles, group memberships, and infrequent social interaction.

Loneliness– *a* subjective distressing experience that results from **perceived** isolation or inadequate meaningful connections; unmet need between an individual's preferred and actual experience.

https://www.hhs.gov/surgeongeneral/priorities/index.html

NATIONAL STRATEGY TO ADVANCE SOCIAL CONNECTION

- ***Seek out opportunities to serve and support others. Try helping your family, friends, and community members or participating in community service.***
- ***Actively engage with people of different backgrounds and experiences to expand your understanding of and relationships with others.***
- ***Participate in social and community groups such as fitness, religious, hobby, professional, and community service organizations.***
- ***Reduce practices that lead to feelings of disconnection from others.***

https://www.hhs.gov/surgeongeneral/priorities/index.html

QUESTION

Does these strategies apply to family caregivers and care partners?

Why or why not?

CAREGIVER ISOLATION & LONELINESS

Between 40% to 70% of the 56 million caregivers in the U.S. exhibit symptoms of depression.

https://www.wellnesseveryday.org/

THE PICTURE

THE STORIES

“I can’t leave my husband alone. But he doesn’t need skilled nursing. He doesn’t belong in a facility. And it would be devastating to him.”–59-year-old Barbara Gruenwald, a San Francisco financial consultant who struggled to find all-day care for her husband, John, who suffers from Lewy body dementia

“I’ve heard of families who are considering signing over their parental rights for their children in order to remain the caregiver,” –Kate Barrow, Indiana Governor’s Council for People With Disabilities

Sources:
https://www.mercurynews.com/2012/11/30/cost-of-dying-at-home-caregivers-face-challenges-sacrifice/
https://www.marketplace.org/2024/04/01/some-states-consider-slashing-payments-to-parents-who-care-for-disabled-kids/

SOCIAL STRUCTURE

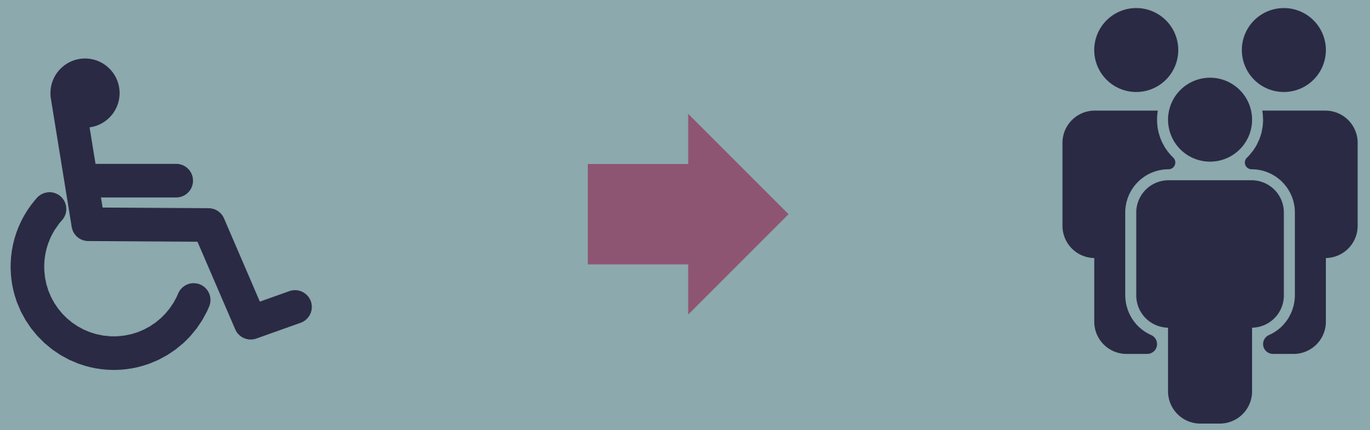
- Paid Leave
- Caregiver Pay
- 40+ hour work week
- Cost of care
- Low staffing
- Gender dominate roles

WHAT CAN WE DO?

IS CHANGE *REALLY* POSSIBLE?

MEDICAL MODEL OF DISABILITY

- Frames the body of a person with a disability as something that needs to be “fixed,” suggesting that “typical abilities” are superior and that physical or mental impairments should be “cured” with the help of an outside force



Social negativity, Infrastructure, participation, norms & reciprocity

https://www.lovedisabledlife.com/blog/the-four-most-recognized-models-of-disability-in-disability-studies

SOCIAL MODEL OF DISABILITY

AS OPPOSED TO THE MEDICAL MODEL

- Views the origins of disability as the mental attitudes and physical structures of society, rather than a medical condition faced by an individual.

Social positivity, infrastructure, participation, norms, reciprocity

https://www.lovedisabledlife.com/blog/the-four-most-recognized-models-of-disability-in-disability-studies

I don’t know what to do.

SELF AWARENESS

- Asking ourselves how we feel about chronic illness, disability, and pain/suffering, and death.
- What are our biases and social schemas?

https://www.yourcpf.org/blogs/hidden-bias-quiz/

https://implicit.harvard.edu/implicit/takeatest.html

ADVOCACY

Ensure our care partners maintain valued roles and are included in community life as much as possible to counteract **“courtesy stigma”** or **“associative stigma.”**

SELF COMPASSION

No matter how hard we try, sometimes **suffering is suffering.** *Self-Compassion* can help cope with difficult realities.

- Boundaries and clarity
- Designate “leaders” on your care team and/or rely on community-based organizations.
- Small practices are better than none. Be patient.

Dr. Kristen Neff, 2021

MOVING FORWARD

- Representation and visibility **matters**.
- Small acts of kindness and curiosity **matters**.
- Vulnerability **matters**.
- Family focus rather than just the individual.
- Focus on what we DO have common rather than what we DO NOT.
- Valued roles and unpaid relationships.

THANK YOU!

QUESTIONS?

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