

Geriatric Behavioral Health Conference



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DISCLOSURE

**Lyn Hilgenberg does not have any financial relationships with
ineligible companies to disclose.**



Living at Home

With Mental Illness & Dementia

Lyn Hilgenberg
Geriatric Behavioral Health Conference
November 4, 2022



Aging Population

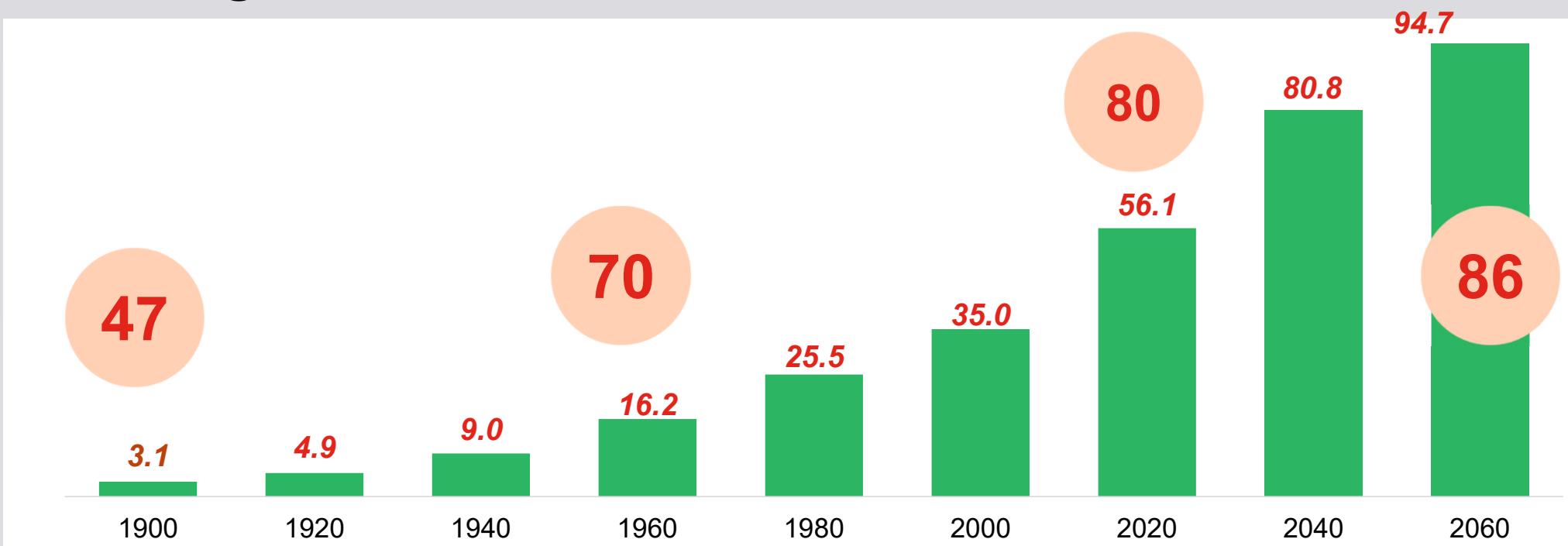
CHALLENGES AND COST
CONCERNs



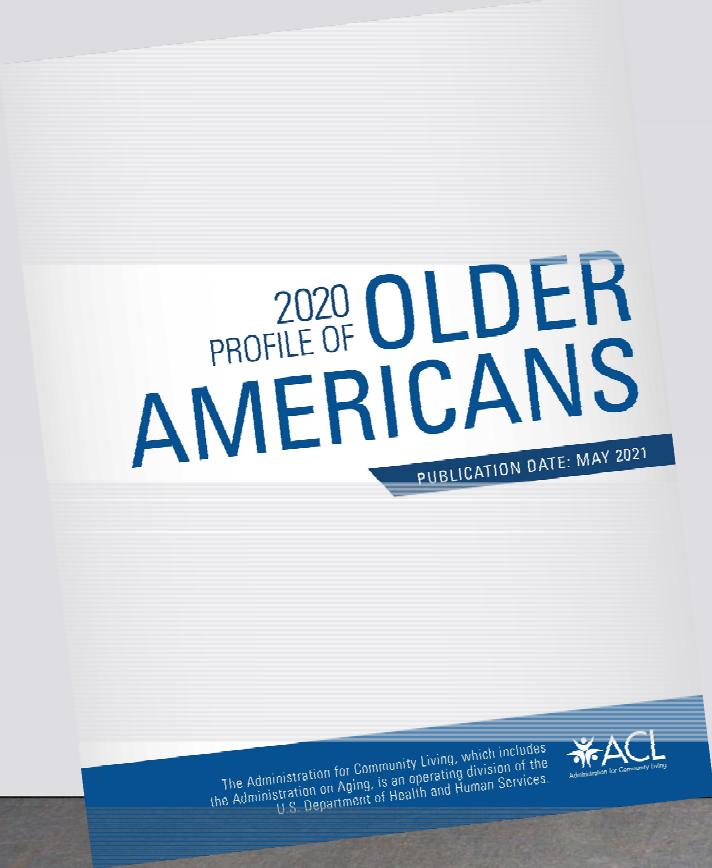
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Aging Population Challenges

People 65 and Older – In Millions & Life Expectancy



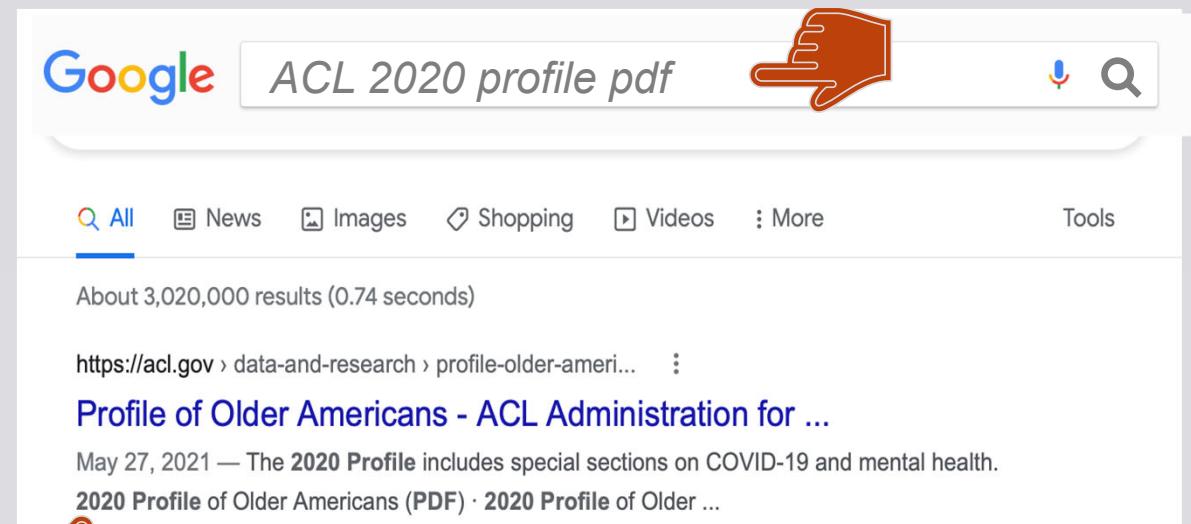
Source: U.S. Census, Demographic Turning Points for the United States: Population Projections for 2020 to 2060; revised February 2020



2020 PROFILE OF OLDER AMERICANS

PUBLICATION DATE: MAY 2021

The Administration for Community Living, which includes
the Administration on Aging, is an operating division of the
U.S. Department of Health and Human Services



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<https://acl.gov> › data-and-research › profile-older-ameri... ::

Profile of Older Americans - ACL Administration for ...

May 27, 2021 — The 2020 Profile includes special sections on COVID-19 and mental health.

2020 Profile of Older Americans (PDF) · 2020 Profile of Older ...



What is the avg life expectancy for those who reach 65? (pg. 4)

Approx. age 86/ women & 83/ men

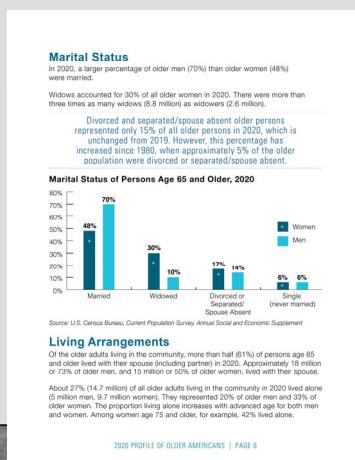
What percentage of women 75+ live alone? (pg. 6)

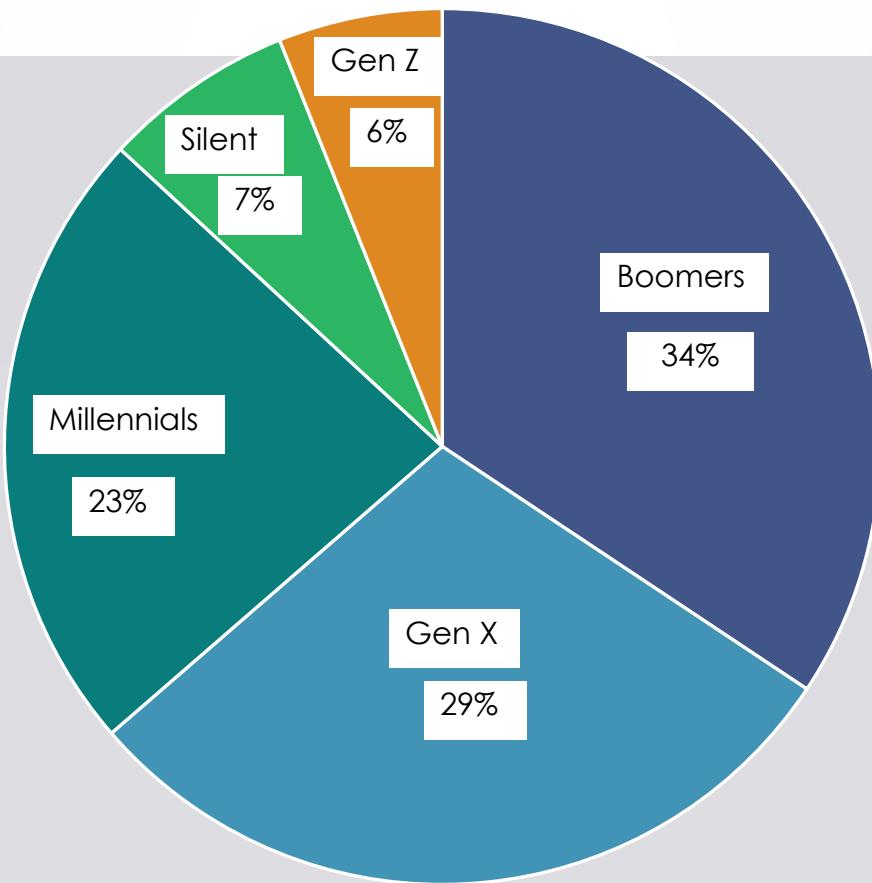
Almost half – 42%

Behind the Statistics:

How many 65+ live in nursing homes? (pg. 7)

- 1% 65-74
- 2% 75-84
- 8% 85+





Caregiving in the U.S. for 2020

National Alliance for Caregiving & AARP

AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020
<https://doi.org/10.26439/ppi.00103.001>



Common Myths about Dementia

- 1 in 4 (24%) thought that people who received a dementia diagnosis would instantly have to stop going out for a walk on their own
- almost half (45%) thought they would have to immediately stop driving a car
- 58% thought they would personally struggle to join in conversations post-diagnosis and 49% worried people would think they were ‘mad’
- Half (52%) said that if they experienced confusion or problems recalling recent events they would wait until the problem has worsened to the point of affecting work and personal life before visiting their GP
- 60% would visit their GP as soon as they notice a physical health symptom, compared with just 2% for a non-physical health symptom such as memory loss/ confusion.

YouGov Research



Mental Health Disorders Lead the Causes of Morbidity & Mortality Worldwide

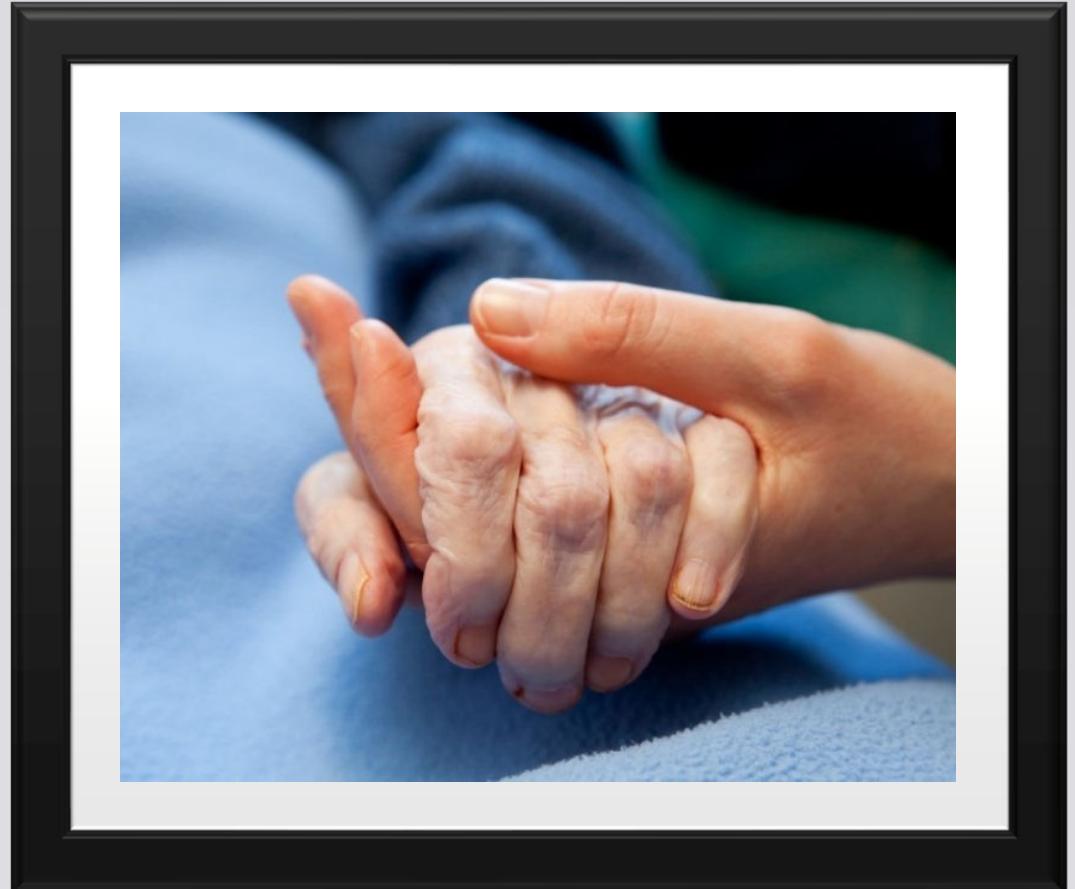
- Could cost the global economy \$16 trillion by 2030.
- Today, an estimated 300 million people worldwide suffer from depression alone.
- Suicide is the second leading cause of death among young people.
- Most mental illnesses are treatable.
- Some estimates suggest that around 2/3 of people experiencing a mental health challenge go unsupported.
- Even in wealthy nations such as the US and the UK, over 50% of people may receive no care.

*Empowering 8 Billion Minds: Enabling Better Mental Health in All via the Ethical Adoption of Technologies;
A National Academy of Medicine Discussion Paper (October 28, 2019)*



Interpreting Needs

Mental Illness & Dementia
Within the Home Environment





Components of Motivational Interviewing

- The relationship is a person-centered partnership
- The client's goals drive the change—not the facilitator
- The client weighs the pros and cons of change with guided questions from the facilitator rather than influencing what the client should do
- Explore the pros and cons of change (drivers of ambivalence)
- Direct persuasion is not an effective method for resolving ambivalence
- The role of the counselor is to probe and ask questions that help the client examine their behavior, goals for change, and direction/approach
- Ambivalence is expected; readiness to change can fluctuate

POLL Questions!

Please respond at **pollev.com/dmucme**.



Build Care Partner Team Skills

- Observation & Documentation Skills
- Problem Solving Skills
- Environmental Management Skills
- Relationship Skills
- Practical Hands-on Skills
- Planning & Time Management Skills



What Families Want From Their Team

- Good communication with any care partners
- Information about the disease, your program & resources
- Understanding their coping strategies
- To listen & consider their opinion
- Be seen as an important part of the team

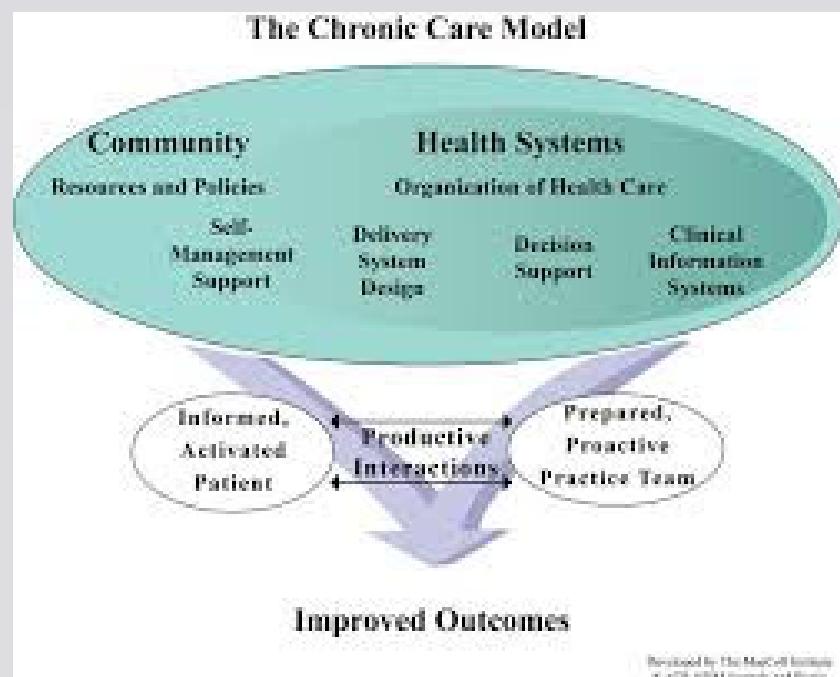


Supporting Families

- Recognize and validate emotions
- Listen
- Encourage them to focus on what they can do
- Encourage caregiver self-care
- Create a trusting partnership
- Help them understand that guilt is a normal part of grief

Chronic Care Model (Wagner et al., 1999)

- Improved functional and clinical outcomes from:
 - Self management Support
 - Informed, activated patient
 - Productive (person-centered) interaction with prepared, proactive practice team





Social Support: From where? (Insights from the Home Project--UCLA)

- A number of clients/families have fragile networks or none at all
- “The extent of social isolation observed is profound and has implications for the mental health and well-being of these individuals.”
- Vulnerable to neglect and abuse
- Good care requires a responsive delivery system AND person-centered care that nurtures the human spirit.



Care Delivery

The preparation which provides the highest well-being potential for the individual?



Defining the Problem...





How families can live with the changes

- GET SUPPORT for you
- Cry every now and then for what you have lost
- Find joy in the new relationship you are building
- Get help, if there is NO JOY
- Take time to remember...
- Take time for learning and changing

Why do roles change?



Cognitive impairment affects *everything* about the person you care about



Abilities are changing with or without awareness



Awareness varies



Your lives have been connected ... those connections are changing



What we shouldn't do:

Argue

Make up
stuff

Ignore
problem

Try a
solution only
once

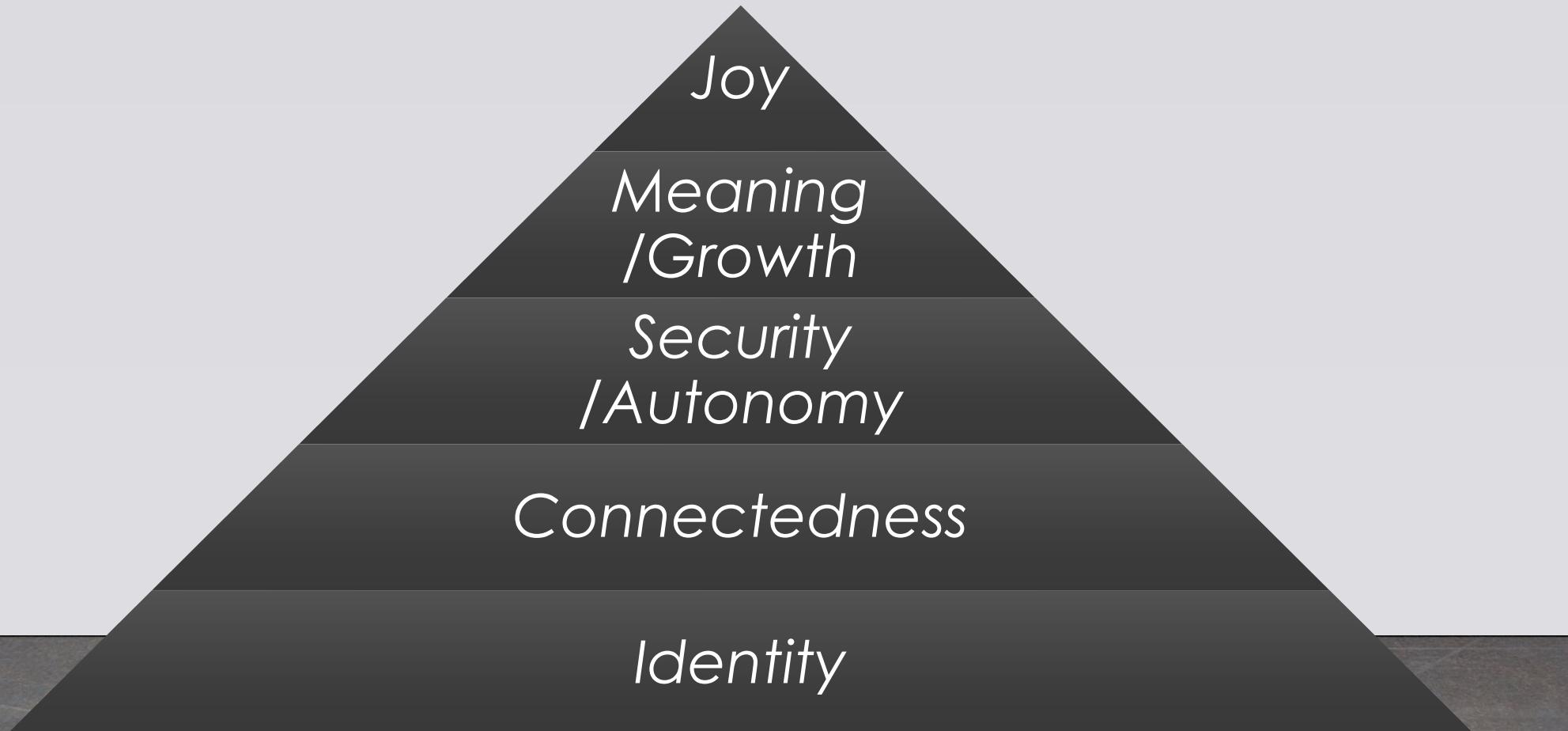
Give up

Let them do
whatever

Force them



Seven Domains of Well-Being





Life Story – Social History

See the person,
not the disease

Establish daily
living routine
around past &
present interests

Spirituality

Past roles have
great
importance



Maintaining Personal Identity Sense of Self

Quality of life is improved through maintaining...

- choice & control,
- physical & cognitive support,
- comfort & personal care,

while creating a sense of normalcy.

#####
During our lives, many connections can be lost:

We retire
Spouses and friends pass away
Children, friends, and neighbors move away
We become home-bound and don't get out



It is about being a part of
something that is BIGGER than
ourselves!



Creating Meaning...

DRIVEN PARTIALLY BY
EACH INDIVIDUAL.

ACTIVITIES THAT SPEAK
TO BACKGROUND,
VALUES, PREFERENCES,
STRENGTHS,
RELATIONSHIPS, AND
SPIRITUALITY.

CREATED IN “BEING”
AS WELL AS “DOING.”



Support Considerations

Keep the old familiar contacts

Explore volunteer opportunities

Join a support group

Make new friends & form partnerships

'Give things a try' – more than once

Time away from your partner... some



Sometimes we incorrectly define good care as doing everything possible!

Recognition that the well-meaning generosity of the care partner may be leading to learned helplessness and actually diminish individual choice.



Nurturing the Human Spirit in Chronic Care

A personal care provider on the importance of personalized touches

“She has the balcony, you know....
The flowers make her feel fresh, you
know, happy, so that’s why I help her
water her plants.”

(The HOME Project)



Vickie, 89 receives services from a home health nurse, two social workers, and has a Life Alert system.

"I still want to be independent at this stage in my life. It's just so good to feel that you can still take care of yourself at 89 years old because many people by that age can't do it at all."



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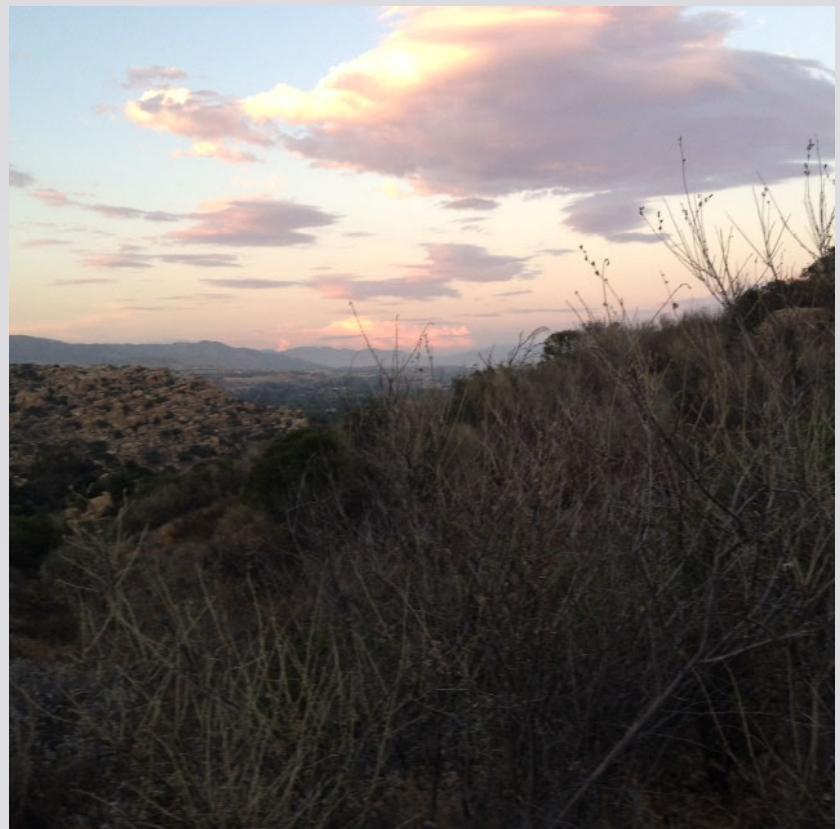
(The HOME Project)



Roy, 67 diagnosed with neurological and psychiatric conditions

“One of my greatest fears is being institutionalized...not being able to live independently and to be able to come and go... to be free, to have that freedom. I think those are ... very important aspects of life. Those are the things that give me a lot of joy”

(The HOME Project)





The Way Forward

Acknowledging the challenges while reflecting on priorities, transitions, and support.





"I'm going to take your blood pressure, so try to relax and not think about what a high reading might mean for your chances of living a long, healthy life."



"Give it to me straight, Doc. How long do I have to ignore your advice?"



Person-Centered Care is a Key Component

(One of the Institute of Medicine's six pillars of quality health care)

- Patients/clients are partners in treatment planning & disease management
- Empowers patients by shifting decision-making from the provider to an approach guided by the individual's preferences, values, and choices in health care decisions.

Looking for Positive Outcomes: Right Now...

What is happening that is OK?

What is happening that is NOT OK?

What is NOT happening that needs to?

Set some priorities – separately – THEN together

Keep what works

Decide on TOP NEEDS to CHANGE

Start on it – ONE STEP at a TIME!



Evidenced-Based Self-Management Principles

- Patient education: although necessary is not sufficient to change behavior.
- Recognize that change/doing something new or different is hard; Being stuck in ambivalence is common
- Person (or Patient) Centered Care is a collaborative partnership
- Support includes empowering people to make their own decisions (set goals), supported with skill building, problem-solving effective strategies, group support, and “norming”
- Not advising, rather focus on decision-making process leading to behavior change

Acknowledge Stress:



Physiological or biological stress is a response to a stressor. It is the body's method of reacting to a condition such as a threat, challenge, or physical and psychological barrier.

Burnout vs. Stress

Stress:

- Involves **too much**: too many pressures that demand too much of you physically and mentally
- Still imagine that if they can **just get things under control**, they'll feel better

Burnout:

- About **not enough**, feeling empty & mentally exhausted, devoid of motivation, & beyond caring
- **Don't see any hope** of positive change in their situation





Final Challenges: The Way to Create Change

What kind of community do you want to live in?

How is that different from how you see things now?

What are some of the things that need to happen to create that kind of change?