KEEPING CAREGIVERS WELL
YOU, ME, AND ALL OF US

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OBJECTIVES

• DESCRIBE CHALLENGES OF LONG-TERM CAREGIVING FOR
  PSYCHOLOGICAL AND PHYSICAL HEALTH
• IDENTIFY THREE WAYS TO SUPPORT CAREGIVERS’ HEALTH
  AND WELLBEING FOR THE LONG RUN

WHY WE CARE

“Caregiving is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers…more present and thereby more fully human.”
- Arthur Kleinman MD

“Let the more loving one be me.”
- W H Auden
WHO IS A CAREGIVER?

- SOMEONE WHO CARES FOR ANOTHER PERSON WHO...
  - Is vulnerable
  - Cannot be(come) independent
- FOCUS ON FAMILY AND FRIENDS TODAY
  - It’s personal – relationship based
  - It’s cultural – obligations differ
  - It changes – roles shift as care needs change
- MANY CAREGIVERS DON’T LIKE THE WORD
  - “I’m his WIFE! (not his caregiver)”

NAVIGATING WITHOUT A MAP

- WHAT YOU FOCUS ON
  - The person and what’s good – or the disease and hard times?
  - What is now – or what’s been lost?
- HOW OTHERS TREAT YOU
  - Feeling recognized, seen, heard, and accepted by people who count – or neglected, discounted, or judged?
- HOW OTHERS SUPPORT YOU
  - Well matched to everyday and crisis needs – or not enough, wrong, or mismatched?
- YOUR QUALITY OF LIFE
  - Bearable; meaning is possible – or unbearable, trapped by tragedy?

A MAP OF CAREGIVER WELLBEING

- Research-based
- Integrative
- Speaks to everyone
- Focuses interventions

Adapted from van Wijngaarden et al. PLOS One 2018
WHAT SUPPORTS CAREGIVER WELLBEING?

- **CARING FOR SELF — “SOMETIMES I COME FIRST”**
  - Emotional, spiritual, physical, social practices that promote resilience, respite, and joy
- **SHARING EXPERIENCE — “GOING THROUGH THIS TOGETHER”**
  - Caregiver support groups – in person, by phone, on line
  - Practical help - family, friends, and paid care workers
- **WORKING TOWARD MASTERY**
  - Of thoughts, feelings, and behaviors
  - Of knowledge about dementia
  - Of caregiving skills

**EDUCATION AND SKILLS TRAINING — “WHAT DO I NEED TO UNDERSTAND? KNOW HOW TO DO?”**

- **FORMAL DEMENTIA CAREGIVER TRAINING PROGRAMS, E.G. SAVVY CAREGIVER, REACH**
- **MANY BOOKS, YOUTUBE VIDEOS, ONLINE RESOURCES – FIND WHAT WORKS**

**HEALTH CARE PARTNERSHIPS — “I NEED YOU TO HAVE MY BACK”**

- **ENGAGED, SKILLED PROVIDER, TWO-WAY LEARNING**
- **ANTICIPATING CHANGES, COMPREHENSIVE CARE MANAGEMENT, ADVANCE CARE PLANNING, SHARED GOALS OF CARE, WORKING ON WHAT MATTERS MOST**
- **CAREGIVER ACTIVATION FOR HEALTH CARE (MANAGING YOUR LOVED ONE’S HEALTH)**

**GOALS OF CARE FOR PEOPLE WITH DEMENTIA**

5 key domains

- Brain protection
- Mental and emotional health
- Social health
- Health
- Physical health

Adapted from Borson et al. 2012, Borson and Chodosh, 2014

* Resources for Enhancing Alzheimer’s Caregiver Health
HOW THIS FRAMEWORK HELPS

- Reduces complexity
- Improves sense of control
- Helps identify who needs to be involved
- Promotes communication
- Simplifies goal setting
- Targets outcomes
- Supports continuity of care and care management

APPLYING THE MODEL: LOUISE AND MEL

- To reduce complexity
- To improve sense of control
- To help identify who needs to be involved
- To promote communication
- To simplify goal setting
- To target outcomes
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HOW TO COACH CAREGIVERS FOR DEMENTIA HEALTH MANAGEMENT

- ASSESS THE PERSON WITH DEMENTIA (5 DOMAINS); ASSESS CAREGIVER KNOWLEDGE
- IDENTIFY MANAGEMENT GOALS FOR EACH DOMAIN
- CHOOSE SPECIFIC HOME MANAGEMENT GOALS, ASSESS CAREGIVER SKILL
- EXPLAIN WHAT, WHY, AND HOW
- USE TEACH-BACK, ENCOURAGE QUESTIONS
- REVIEW AND REVISE
- ADAPT TO STAGE – CONSIDER FUTURE RISKS
- MAKE ADVANCE CARE PLANNING MEANINGFUL

CAREGIVER COACHING NEEDS

- You've met one caregiver? You've met one caregiver.
- Basics everyone needs to know
  - Causes of care recipient's problems – and what care is required
  - How to engage clinicians – and advocate for self and care recipient
  - How, when, and what to plan for the future
  - How to recognize worrisome changes in health
  - Who to call when changes those occur
  - How to get help with caregiving – day to day vs in crisis
  - Self-care - what, how, why, when

Sadaki, Wright, Borson J Appl Gerontol 2016; Borson, Mobley Fernstrom et al PLOS One 2018
THE DARK SIDE OF CAREGIVING

- Caregiver health breakdown, depression, exhaustion, burnout, death
- Mistreatment of care recipient
  - Psychological or emotional abuse 30-60%
  - Physical abuse 5-23%
  - Financial abuse
  - Sexual abuse
  - Neglect
- Intended vs unintended
  - Matters to the law
  - Interventions very different

Wiglesworth, Mosqueda, Mulnard et al. J Am Geriatr Soc 2010

ELDER MISTREATMENT: UCI EXPERT PANEL EVALUATION

- 129 people with dementia living at home + their caregivers
- Overall prevalence of mistreatment – 47.3%
  - Psychological abuse only – 27.9%
  - Neglect, no physical abuse – 10.1%
  - Physical abuse + other – 9.3%
- Unmet need for good elder mistreatment screening tools
  - What to include? How to ask?
  - How to get people to tell the truth when they’re not proud of it?
- Ask if caregiver was mistreated by person with dementia


PATHWAYS TO MISTREATMENT: WORKING MODEL

ROBERTA AND WALTER
MEETING THE NEEDS OF PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS: WHERE ARE WE HEADED?

- Workforce development
  - Providers (physicians, nurse practitioners)
  - Other key clinicians (social work, nursing, pharmacy, speech, OT, others)
  - New roles (care guides, navigators, community health workers)
- Organizing care and services – local tailoring
  - Bringing health and social care together ("integrated care" systems)
  - Creating strong linkages (e.g. clinician e-prescribes social care services for dyad)
  - Dementia care teams – within health care, and across boundaries between health and community based services

PAYING FOR THE CARE WE NEED: RIGHT NOW

- SEVERAL MEDICARE BENEFITS CAN HELP
  - Annual wellness visit – promotes early detection, preventive health (2012)
  - Cognitive assessment and care plan code – promotes systematic approach, teamwork, caregiver inclusion (2017)
  - Chronic care management – expands nurse role
- BARRIERS
  - Clinician uncertainty, workforce, organizational structure, financial incentives
  - Low consumer demand
- INADEQUATE PROVISION FOR CAREGIVER EDUCATION AND SUPPORT

PAYING FOR WHAT WE REALLY NEED: POPULATION BASED CARE WITH CAREGIVER TRAINING AND SUPPORT

RESOURCES

- WIGGLESWORTH, MOSQUEDA, MULNARD ET AL. SCREENING FOR ABUSE AND NEGLECT OF PEOPLE WITH DEMENTIA. J AM GERIATR SOC 2010; 58: 493-300.