

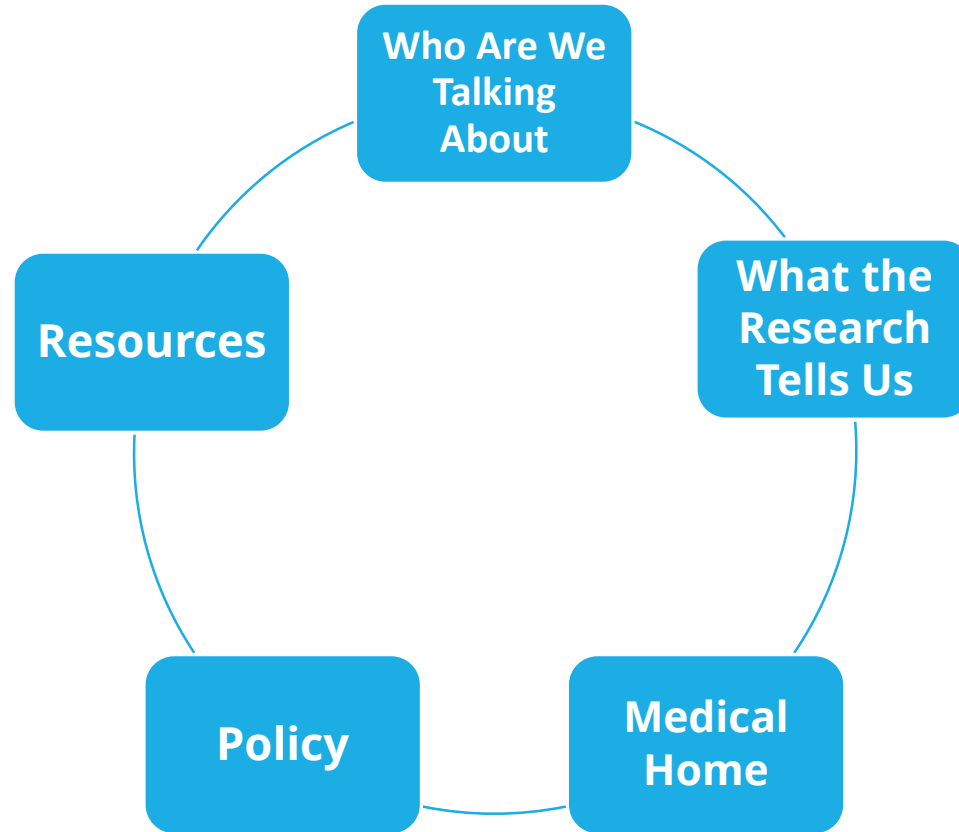
How the Medical Home and Collaborative Care Benefit Caregivers

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Agenda





Who Are We Talking About?

- Caregivers provide essential assistance to a child or adult with chronic illness or disability, or to a frail or cognitively impaired older person. Caregivers can be:
 - relatives
 - partners
 - friends
- Family caregivers can be part time or full time roles, providing or managing all or some of the care
- Females are 2/3s of all unpaid caregivers; Siblings are a growing group of caregivers
- Family caregivers have multiple roles: emotional support, surrogate decision making, financial contributions, care management, and hands-on care
- Caregiver may or may not live with the care recipient

Some of the Numbers



- Approximately 25% of U.S. adults 18 years of age and older reported providing care or assistance to a person with a long-term illness or disability in the past 30 days (2009, Behavioral Risk Factor Surveillance System)
- One year value of this unpaid caregiver activity was estimated as \$450 million dollars (2009)
- Caregivers and families often experience economic hardships through lost wages and additional medical expenses.
- 27% of caregivers of adults reported a moderate to high degree of financial hardship as a result of caregiving
- Number of people 65 years old and older is expected to double between 2000 and 2030



What The Research Tells Us

- Medical advances, shorter hospital stays, limited discharge planning, and expansion of home care technology have placed increased costs and care responsibilities on families
- Caregivers are being asked to assume greater care burdens for longer periods of time
- Most caregivers are not prepared for their role and receive little or no support
- Caregivers often focus on their role as caregiver and neglect their health
- Caregivers are more likely to lack health insurance coverage due to time out of the workforce, leading to higher health care costs and a negative impact on the quality of life of both the caregiver and care receivers



Impact on the Health of Caregivers

- 1 in 10 report that caregiving has a negative impact on their physical health
- 3/5s of caregivers reported fair or poor health status, one or more chronic conditions or a disability, compared with only 1/3 of non-caregivers
- Nearly 75% of caregivers report that they had not gone to the doctor as often as they should, and more than 50% had missed doctors appointments
- Strain of caregiving demands has been linked to poor health outcomes including depression, physical illness, anxiety, and poor sleep habits
- Caregivers in rural areas are at a greater disadvantage for having their own medical needs met due to difficulty getting to the hospital and doctor



Some of the Terminology

“Sandwich caregiving” refers to people who undertake caregiving responsibilities for one or both of their aging parents while still having parenting duties to their own children

“Compound caregiving” refers to parents who are already providing considerable caregiving responsibilities to their son/ daughter with an disability and who subsequently become a caregiver for an additional family member

Substantial # of caregivers are actually caregivers to more than one person

Benefits of Caregiving



Caregiving can be an enriching and life enhancing experience, creating a positive impact on caregiver and family

- Increased closeness to their loved one
- Sense of satisfaction in fulfilling this important role
- Extended social networks or friendship groups associated with caregiving
- Feeling needed and useful
- Learning something about one's self, others, and the meaning of life

Adaptation of families to caregiving: families first

“How do we reconcile what we want for our children, ourselves and our family with what is possible given our circumstances?”

Resilience



Families demonstrate resilience when they are competent in performing core family functions:

- membership and family formation
- economic support
- nurturance
- education and socialization
- protection of vulnerable members

Services and supports should enable family and caregiver to maintain a sense of control and manage difficult situations **AND** maintain valued social identities



Patient Centered Medical Home

- Approach to providing comprehensive primary care for children, youth and adults
- Facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient's family
- Philosophy of health care delivery that encourages providers and care teams to meet patients where they are
- Replaces episodic care with coordinated care and a long-term healing relationship
- Whole person orientation
- Care is coordinated and/or integrated across all elements of the complex health care system
- Enhanced and timely access to care

Role of Health Care Team



- Sometimes reluctant to ask questions about the kinds of help that a caregiver may need, because they are not sure how to address these needs
- Most caregivers are grateful for any suggestions and for the support provided to them
- Important for caregivers to have a chance to talk about their own lives
- Explore the individual's values, needs, and preferences about caregiving:
 - “ I promised my Mom”
 - “I’m embarrassed because we can’t cover the costs: medicines, equipment, appointments”
 - “I don’t think I can handle the lifting now”
- Engage caregivers in discussions about their health, wellness and access to healthcare:
What matters to you?
- Health care providers need to be aware that time is precious and make every effort to offer appointments at times and places caregivers find convenient and appropriate

Caregiver Assessment



Systematic process of gathering information:

- What is the caregiving situation?
- What are the specific needs, resources, concerns and strengths of the family and caregiver?
- What is the caregiver's perspective and culture?
- What assistance may the caregiver need?
- What outcome does the caregiver identify as important, critical, desired?
- How can we provide support to the caregiver so they can protect and maintain their health and well-being?

A collaborative care team (multiple healthcare professionals and systems) can conduct a caregiver assessment and develop an integrated plan of care

What can you offer: compassion, empathy, expertise, skill set, connections?



Sample Assessment Questions

Next Step in Care: Family Members and Health Care Professionals Working Together
www.nextstepincare.org

Assessment forms:

- What do you need?
- What kind of care are you providing?
- Do you need more training? More or different resources?
- What worries do you have?
- Who do you turn to for assistance? for support?

Support Strategies



- Interventions to increase caregiver competence and confidence
- Interventions to reduce caregiver burden and distress
- Respite
- Financial support to alleviate the economic stress of caregiving
- Primary care interventions that address caregiver health and social needs
- Navigation services and assistance
- Caregiver education and support programs



Tips (Rosalyn Carter Institute)

Take Care of Yourself	Allow Your Loved One Independence
Be Informed, Get Educated	Believe that Laughter is the Best Medicine
Get Connected with Others	Let Go of Situations Beyond Your Control
Receive with Grace	Plan Ahead
Nurture Your Faith and Spirituality	Be a Caregiver Advocate

National Priority



- Families are the primary caregivers and the system could not function without their contributions
- Keeping family caregivers healthy and able to provide care is key to maintaining our nation's long-term care system
- Improved recognition and treatment of physical and psychological symptoms among caregivers is a growing health concern
- Issue will only grow more important in the coming decades

Good Health



- Good health means having the energy for work, learning, relationships, recreation and caregiving
- Health shifts back and forth on a continuum during one's lifetime
- Everyone has the right to the best possible health status and quality of life
- Everyone needs to **know how to protect, preserve, and improve** their health

Key Recommendations



- Respite Care
- Creative Combination of Services and Funding Streams
- Identifying caregivers in need
- Health promotion and disease management for caregiver(s)
- Integrated Care



Public Policy

- Direct services for caregivers: National Family Caregiver Support Program, Lifespan Respite Care
- Financial Incentives and Compensation for Family Caregivers Program: direct payments and tax incentives for family caregivers
- Family Caregiving and Consumer Direction: Cash and Counseling model
- Employer-Based Mechanisms to Support Family Caregivers: Family and Medical Leave Act

North Carolina Resources



- Family Support Network of NC, www.fsnnc.org
- Sibling Leadership Network, First in Families NC, www.ncsibs.org.
- NC Respite Care Coalition, northcarolinarespitecarecoalition.org
- Area Agency on Aging, www.ncdhhs.gov/assistance/adult-services/area-agencies-on-aging

National Resources



- National Alliance for Caregiving

www.caregiving.org/resources

- Rosalyn Carter Institute for Caregiving

www.rosalynncarter.org/caregiver_resources

- AARP

www.aarp.org/caregiving/local/info-2017/resource-guides



Publications

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Thank

You

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