



SESSION 1  
COMMON CHALLENGES IN FAMILY CAREGIVING



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## INTRODUCTIONS



**Erin Emery-Tiburcio, PhD, ABPP** is the Co-Director of the E4 Center and a nationally recognized leader in aging, behavioral health, and improving care across all communities. She serves as Professor of Psychiatry & Behavioral Sciences and Geriatric Medicine, Director of Geropsychology, and Co-Director of the RUSH Center for Excellence in Aging.



**Caryn Blanton, LCSW, ASW-G** is the Program Manager for the E4 Center, bringing extensive clinical social work experience with adults and older adults, as well as years of experience with program management at RUSH. She also incorporates mind-body practices into her work as a certified yoga teacher with training in yoga-informed psychotherapy.

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## Program Overview

	Date	Title
Session 1	Feb 24	Common Challenges in Caregiving
Session 2	Mar 4	Compassion Fatigue
Session 3	Mar 11	Grief and Loss
Session 4	Mar 18	Cultural and Language Considerations
Session 5	Mar 25	Managing Caregiver Needs in the Room

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## CAREGIVER STORY

Diane Drago

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**Help Wanted:** Untrained family member or friend to act as advocate, researcher, care manager, and emotional support for a parent or spouse, sibling or friend, who has been diagnosed with a serious illness or chronic disability. **Duties:** Make medical decisions, negotiate with insurance companies or Medicare, pay bills, legal work, personal care and entertainment in hospital and rehab. **Aftercare at home:** Substitute for skilled nurse if injections, IV, oxygen, wound care or tube feedings are required. **Long-term care:** Medication management, showering, toileting, lifting, transporting, etc. **Hours:** On demand. **Salary and benefits:** 0

*Passages in Caregiving, 2010*  
Gail Sheehy

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## Common Challenges in Family Caregiving

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## Learning Objectives

- Recognize the importance of identifying a family caregiver when working with older adults
- Identify the challenging aspects of caregiving
- Describe the role of the caregiver as part of the care team
- Explain how to connect caregivers to resources

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## Defining “Family Caregiver”

- Caregivers are people who assist another person with activities of daily living, treatment, life needs
- Highly varied family structures
- “Family” caregivers may include
  - Blood relatives
  - Families of choice
  - Friends
  - Neighbors
- Some family caregivers are paid, but most are not



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## Caregiver Facts

- ~ 38 million caregivers in the US provide unpaid care to an adult each year<sup>1</sup>
  - Worth an estimated \$600 billion<sup>1</sup>
- Cancer caregivers alone provide equivalent of \$2000/month in care per person<sup>2</sup>

<sup>1</sup>Reinhardt et al., 2023; <sup>2</sup>Coumoundouros et al., 2019

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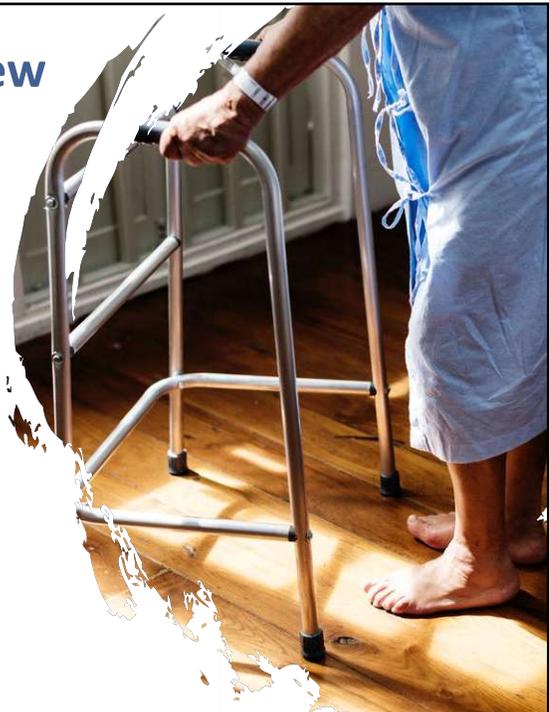


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## Caregiver Roles – to name a few

- Caregivers are often tasked with managing technical medical procedures and equipment
- Caregivers are often responsible for monitoring mobility, cognition, symptoms, and side effects
- Provide emotional support
- Often serve as gatekeeper regarding cancer diagnosis and treatment information
- Fundraising for medical bills
- Take on roles or duties of the patient
- Maintain cancer surveillance in survivorship

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## Additional Caregiving Roles

- Raising children and/or grandchildren
- Maintaining a job, household, and other relationships
- Roles that previously belonged to the person they now care for
- Learning and taking on these new roles can create mental and emotional strain



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## Advocates & Coordinators

- Providing transportation to appointments, addressing financial issues, and communicating with medical team
- Caregivers with the fewest resources are the ones who face the biggest caregiving challenges
- Caregivers can find communication with providers challenging
  - Low health literacy
  - Not speaking the same language



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## Caregiver Stress

- Caregivers tend to neglect their own health
- Most caregivers put their own needs on the back burner
- Increased social isolation, financial distress, alcohol use
- These issues can be made worse by lack of access to resources if living in resource-poor communities

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## Caregiving Decisions

- Caregivers are often faced with helping to make challenging decisions
  - May have to make decisions for the person they are caring for if they are unable to do so
- Caregivers often have to make these decisions with little support, and sometimes conflict



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## Caregiver Anxiety

- Worry about the cancer trajectory, treatment, prognosis, care recipient wellbeing
- Anxiety may increase as the care recipient's care needs increase, leaving the caregiver feeling less in control
- As cancer progresses, caregivers get more experienced but need more support from oncology team

Molassiotis & Wang, 2022

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## Caregiver Depression

- Depression is a major risk for caregivers
- 40% to 70% of family caregivers report clinically significant symptoms of depression
- Caregiving may serve as a protective factor against suicide, but thoughts or wishes may still be there
- Caregivers are also at increased risk for abusing alcohol and drugs
- Depressive contagion to care recipient



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## Caregiver Guilt

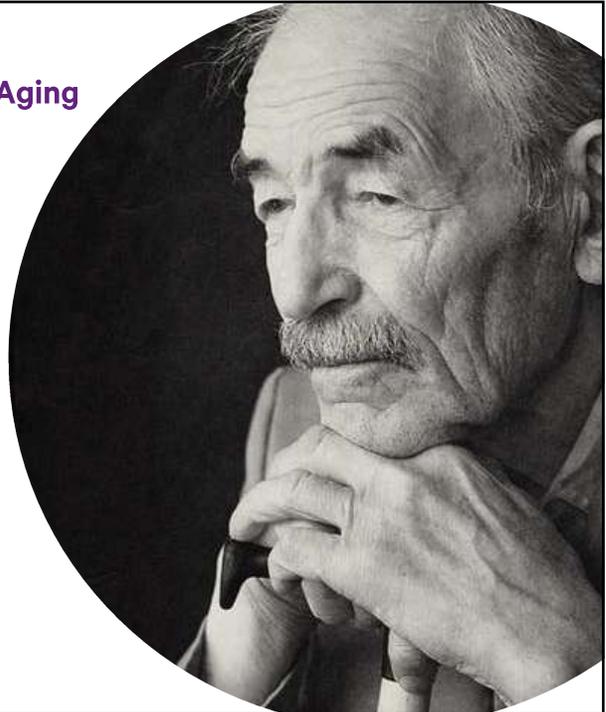
- Guilt increases as care needs test the caregiver's ability to meet them
- Stress of care provision can leave caregivers with thoughts about the relief that will come when the person for whom they provide care dies

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## Caregiver Grief

- Caregivers frequently experience anticipatory grief as their care recipient loses functional status over time
- These changes can result in experiencing a feeling of loss
- Ambiguous loss refers to a loss that does not have closure and is not fully understood by society



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## Rewards of Caregiving

- Caregiving can be fulfilling
- A healing quality to do what fits with the caregiver's values
- Caregivers and care recipients may also spend free time together doing things that they both enjoy
- Can be gratifying for a caregiver to know that they are directly helping the care recipient achieve what matters most to them



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## CARES framework for cancer caregivers

- Considering caregivers as part of the unit of care
- Assessing the caregiver's situation and needs
- Referring to appropriate services and resources
- Educating about practical aspects of caregiving
- Supporting caregivers through every stage, including bereavement

Alam et al., 2020

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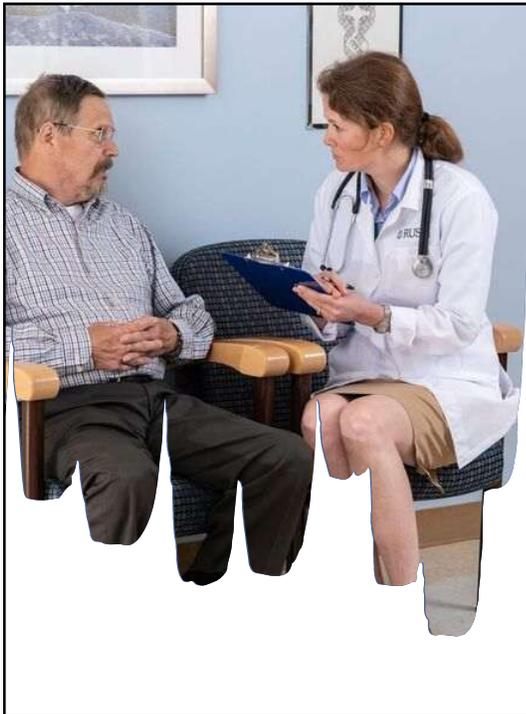


## Identifying Caregivers

- Federal law mandates family caregiver information is included in the electronic medical record
  - Michigan adopted the CARE Act in 2016<sup>1</sup>
- Many people may not understand the term “caregiver” as it applies to them
- Ask about who performs certain tasks rather than using the label “caregiver”

<sup>1</sup> <https://www.legislature.mi.gov/documents/mcl/pdf/mcl-Act-85-of-2016.pdf>

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## Caregiver Assessment

- Assess the caregiver’s confidence and knowledge about providing needed care for the older adult along with their own health needs
- Plan for the caregiver to be able to provide optimal care while addressing and maintaining their own health and well-being
- Caregiver evaluations should include caregiver risks, needs, strengths, and preferences

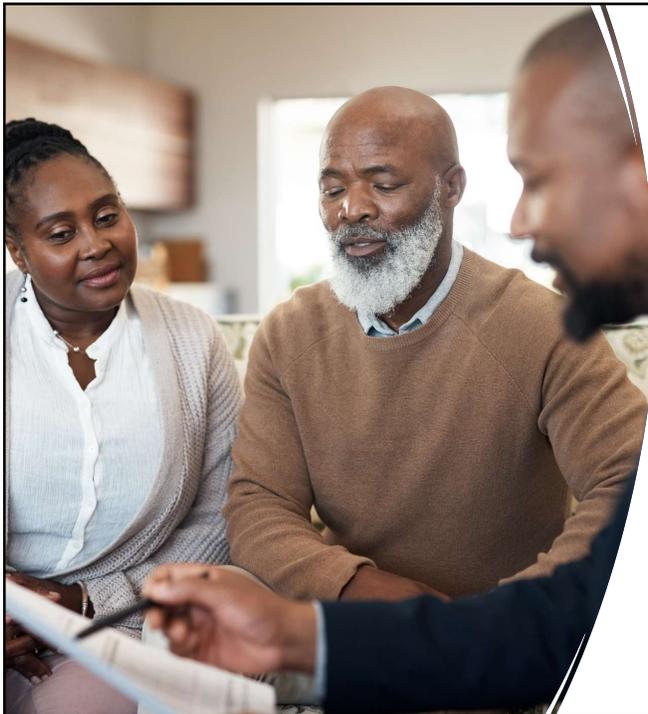
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## Caregiver Health

- Caregivers should be encouraged to see their health care providers and undergo careful screening using standardized measures
- Caregivers may benefit from speaking with their primary care physician about mental health services to treat depression and anxiety
- It can also be helpful to refer caregivers to caregiver support groups

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## Caregiver Support

- Getting caregiving support can be challenging for the care recipient, who may have specific ideas about the kind of care they want from whom
- For care recipients with significant cognitive deficits, it may also be confusing to receive care from someone else, or go to a new setting for assistance
- Navigating the needs of both caregivers and care recipients can be a balance of autonomy for both

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## Care Coordination

- Less than 1/4 of family caregivers have been asked by the care recipient's care team about the support they need
- Both care recipients and caregivers benefit from hands-on training on the health care tasks that will be needed at home
- Educate caregivers on the importance of receiving this training from medical providers so that they can ask for it

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## Communication

- Communication barriers can impact the caregiver and care recipient understanding of information
- Use the "teach-back method"
  - Professional gives information to care recipient and caregiver, and they teach it back to professional
- Ask for written instructions and contact information for follow-up questions
- Ask as many questions as needed



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## Interpreter Services

- Those who do not speak English as their primary language should request interpreter services whenever they have a conversation with a medical professional
- Caregivers should avoid interpreting for the care recipient or the medical team



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## Care Planning

- Have conversations early so that both can participate fully, understand each other's needs, and develop a plan that meets the needs of both
- Recognize the autonomy and wishes of the care recipient just as much as the needs of the family caregiver
- Communicate with both caregiver and care recipient
- Caregivers may become hostile if prognosis and treatment not fully discussed



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## Advanced Directives

- Creating advance directives assures that the patient's wishes are followed
- A healthcare power of attorney is a legal document with which an adult legally appoints someone to make decisions for them if they are unable to make decisions about health care
  - Important when the caregiver is not an immediate family member
  - Can only be signed by an adult while they have the capacity to make such decisions
  - In MI, agent must also sign form



<https://www.michigan.gov/orsstatedb/after-retirement/power-of-attorney-and-advance-directive-resources>

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## RUSH Caring for Caregivers

**Caring for Caregivers** aims to support family or friends that are providing care for adults 60 and older. Focusing on What Matters to the caregiver, we assist in developing a plan for the caregivers' health and well-being that incorporates the care needs of the older adult.

1. **Skill Building Meetings** can include occupational therapists, nurses, pharmacists, or nutritionists in teaching skills to caregivers, such as transferring patients without injuring themselves or performing basic medical care.
2. **Planning for What Matters Sessions** with our social worker to discuss what matters most to both caregiver and care recipient and develop health and life plans that reflect your preferences.
3. **Care Team Planning Meetings** involve learning to create and work with care teams most effectively, focusing on communicating effectively and ensuring that older adults and their caregivers are included in planning for care.

**Initial session is provided at no cost.** Additional services are covered by most insurances. Support for Rush Caring for Caregivers is made available through a generous grant from the RRF Foundation for Aging.

For more information, call 312.563.0350 or email us at [caregivers@rush.edu](mailto:caregivers@rush.edu)

**Tower Resource Center**  
1620 W. Harrison St.  
4th Floor, Suite 04527

Services can be provided by phone, virtual or in-person.

Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets.

From the 4th floor, follow the signs to the Tower.

Valet parking is also available in front 1620 W. Harrison Street. Parking at both locations will be validated in full.



Excellence is just the beginning.

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## Summary

- Family caregivers have a variety of roles and responsibilities
- Providing care can take a toll, leaving caregivers little time or energy to take care of themselves
- Caregivers are at increased risk for physical and mental health conditions
- Caregivers need support to help them advocate for their care recipients and themselves

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## Contact Us

To join our mailing list or learn more about upcoming opportunities, please email

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MOQC RESOURCES



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## MOQC PATIENT & CAREGIVER RESOURCES SEARCH ENGINE

CATEGORY	EXAMPLE RESOURCES
<b>Social/Emotional Support</b>	Support groups, distress resources
<b>Financial Assistance</b>	Insurance guidance, cost-of-care tools
<b>Palliative/Hospice Care</b>	Education sheets, caregiver guidance
<b>Transportation</b>	Local and statewide transport programs



[CancerHelp.moqc.org](https://CancerHelp.moqc.org)

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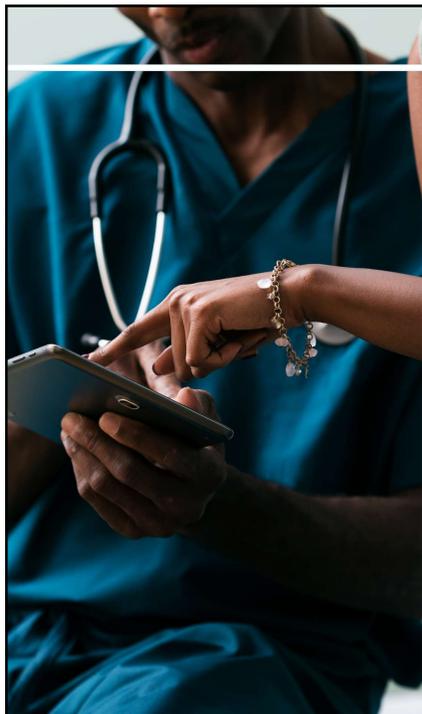
# FREE MOQC PRINTED RESOURCES

Available in multiple languages!

RESOURCE TYPE	EXAMPLES
Palliative & Hospice	Hospice myths, palliative care guides
Advance Care Planning	Five Wishes, medical POA
Nutrition	Meal ideas, food support lists
Treatment Education	Antiemetics, medication guidance
Financial	Understanding insurance, navigation



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## HOW TO ORDER AND DISTRIBUTE MOQC PRINTED MATERIALS

### Accessing MOQC Resources

- ✓ Printed Resources portal on the MOQC website
- ✓ Browse and select by category or catalog

### Customizing Orders

- ✓ Select preferred languages and quantities

### Printing and Shipping

- ✓ MOQC ships full-color materials directly to practices
- ✓ **No cost** to practices

### Flexible Distribution Options

- ✓ Resources are available as printed copies and downloadable PDFs

<https://moqc.org/resources/printed-resources/>

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## PATIENT & CAREGIVER ONCOLOGY QUALITY COUNCIL (POQC)



### Elevating Caregiver Voices

- ♥ Lived experience improves cancer care

### Meaningful Participation

- ♥ Members review resources and join projects and meetings

### Impact on Healthcare Teams

- ♥ POQC ensures oncology resources are accessible and responsive

### Community and Support

- ♥ Caregivers are connected to community and purpose

For more information on POQC, visit <https://moqc.org/moqc/poqc/> or email [moqc@moqc.org](mailto:moqc@moqc.org)

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Q&A



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