

# Engaging Family Caregivers in Complex Patient Care: Strategies for Primary Care Teams

**Jasneet Parmar** MBBS, MSc, MCFP(COE)

**Charlotte Douglas** RN BScN

**Sheny Khera** MD, MPH, FCFP, CAC (COE)

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**UNIVERSITY  
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Caregiver-Centered Care Health Workforce Education is a Program of Applied Research & Innovation in Health Services Delivery in Family Caregiving, Department of Family Medicine, University of Alberta

# Faculty/Presenter Disclosure

🌸 **Faculty:** Jasneet Parmar MBBS, MSc, MCFP(COE)

🌸 **Relationships with financial sponsors:**

- **Grants/Research Support:** Alberta Health Leading the Way (Jasneet Parmar, PI), CABHI-SPARK+, Northern Alberta Family Medicine Fund
- **Speakers Bureau/Honoraria:** NA
- **Consulting Fees:** NA
- **Patents:** NA
- **Other:** NA



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🌸 **Faculty:** Sheny Khera MD, MPH, FCFP, CAC (COE)

🌸 **Relationships with financial sponsors:**

- **Grants/Research Support:** Northern Alberta Family Medicine Fund
- **Speakers Bureau/Honoraria:** NA
- **Consulting Fees:** NA
- **Patents:** NA
- **Other:** Co-founder CARM&A Health Inc.



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# Faculty/Presenter Disclosure

🌸 Faculty: Charlotte Douglas RN BScN

🌸 Relationships with financial sponsors: None

- Other: employee St. Albert Sturgeon Primary Care Network



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# Agenda and Learning Outcomes

At the end of this session, participants will be able to:



1

Recognize the roles and value of involving family caregivers as care team members.

2

Explore and practice strategies for empathic, collaborative communication with family caregivers.

3

Apply shared decision-making to partner with family caregivers in care.



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# 1. Identify the barriers and benefits of involving family caregivers as members of the care team



# Who are Family Caregivers? (Carers, Care Partners)

Any person (e.g., family, friend, neighbour, or chosen family) who takes on a generally unpaid caring role

Provide emotional, physical, or practical support in response to an illness, disability, or age-related needs

1 in 4 Canadians aged 15+ in a given year (*1 in 2 in their lifetime*) [Statistics Canada 2018](#)



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# What is Caregiver-Centered Care

a collaborative working relationship between family caregivers & health and community care providers

- highlights caregivers as vital partners in care
- supports family caregivers in their caregiving role so they can maintain their care and own wellbeing



[www.caregivercare.ca](http://www.caregivercare.ca)



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## The under-recognized workforce

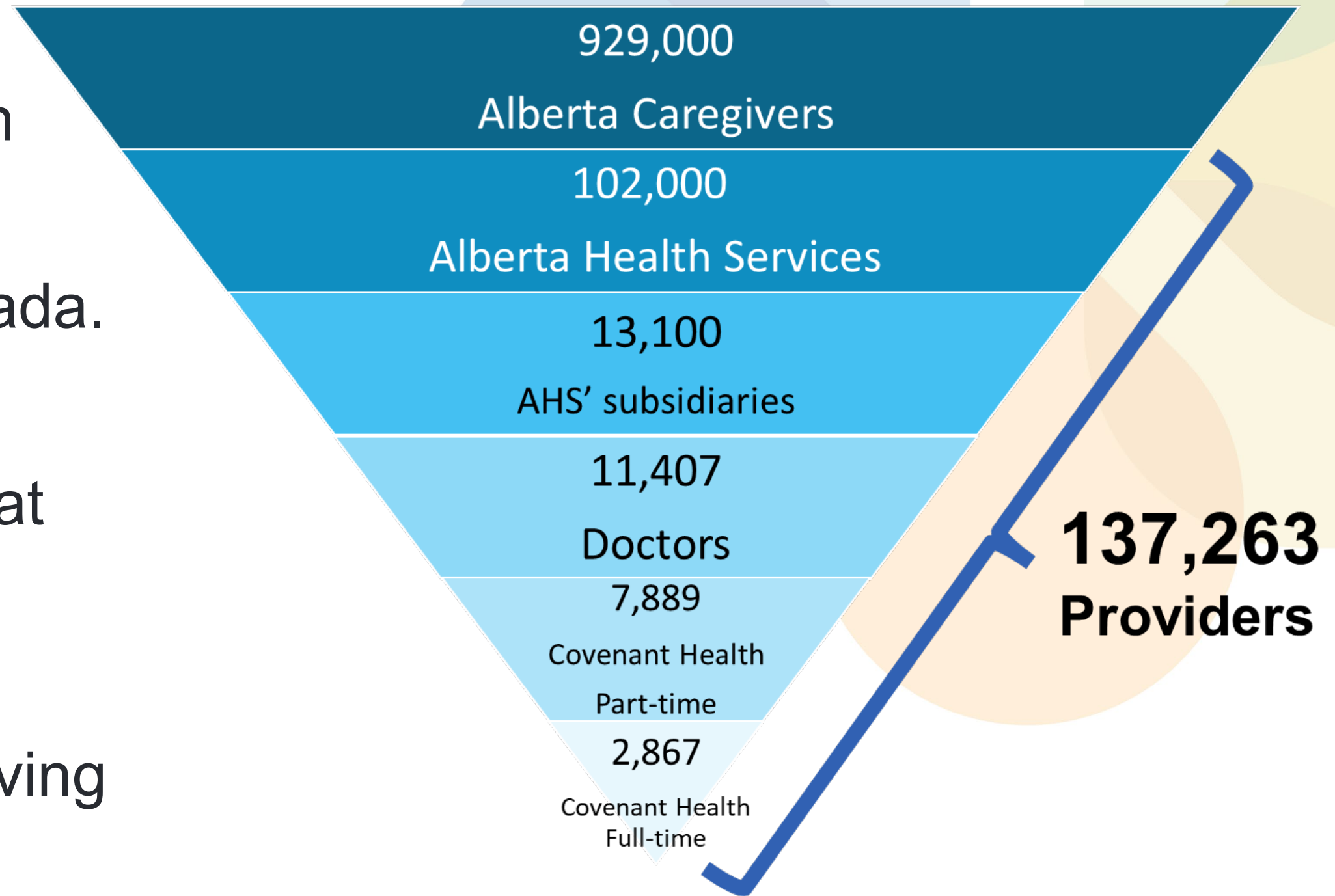
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# The Unrecognized Workforce

Advanced health workforce education to support family caregivers

# Family Caregivers: The Largest Care Workforce

- Provide 75- 90% of the care in the community & assist with 15 - 40% in continuing care
- 5.7 Billion unpaid hours/year in Canada. Equivalent of 2.8 million FTE
- Caregiver unpaid care work valued at \$97.1 Billion annually
- Caregivers play a critical role in reducing safety incidents and improving patient health outcomes and experiences



# Contributions & Challenges for Caregivers to Manage

## 1 CARE

Assistance with personal care, instrumental and extended activities of daily living tasks

## 2 Medication

Keeping track, ordering, organizing & storing, understanding dose/ side effects.

## 3 Medical Appointments/Care

Coordinating, Attending, Transporting, monitoring, crisis

## 4 Emotional burden

loss of health, personal autonomy, relationship.

## 5 Physical Burden

Lifting, carrying, bending.

## 6 Being on-call

- Most of the day & night
- Assumption FCGs are available, able, and willing to take on the burdens & responsibilities of supporting patients

## 7 Out-of-pocket costs

Medication, driving to medical appts, parking, food away from home.

## 8 Structural Burden of Care

Assuming roles of project manager & care coordinator

## 9 Setting aside one's own needs

Losing one's sense of identity  
Losing other roles

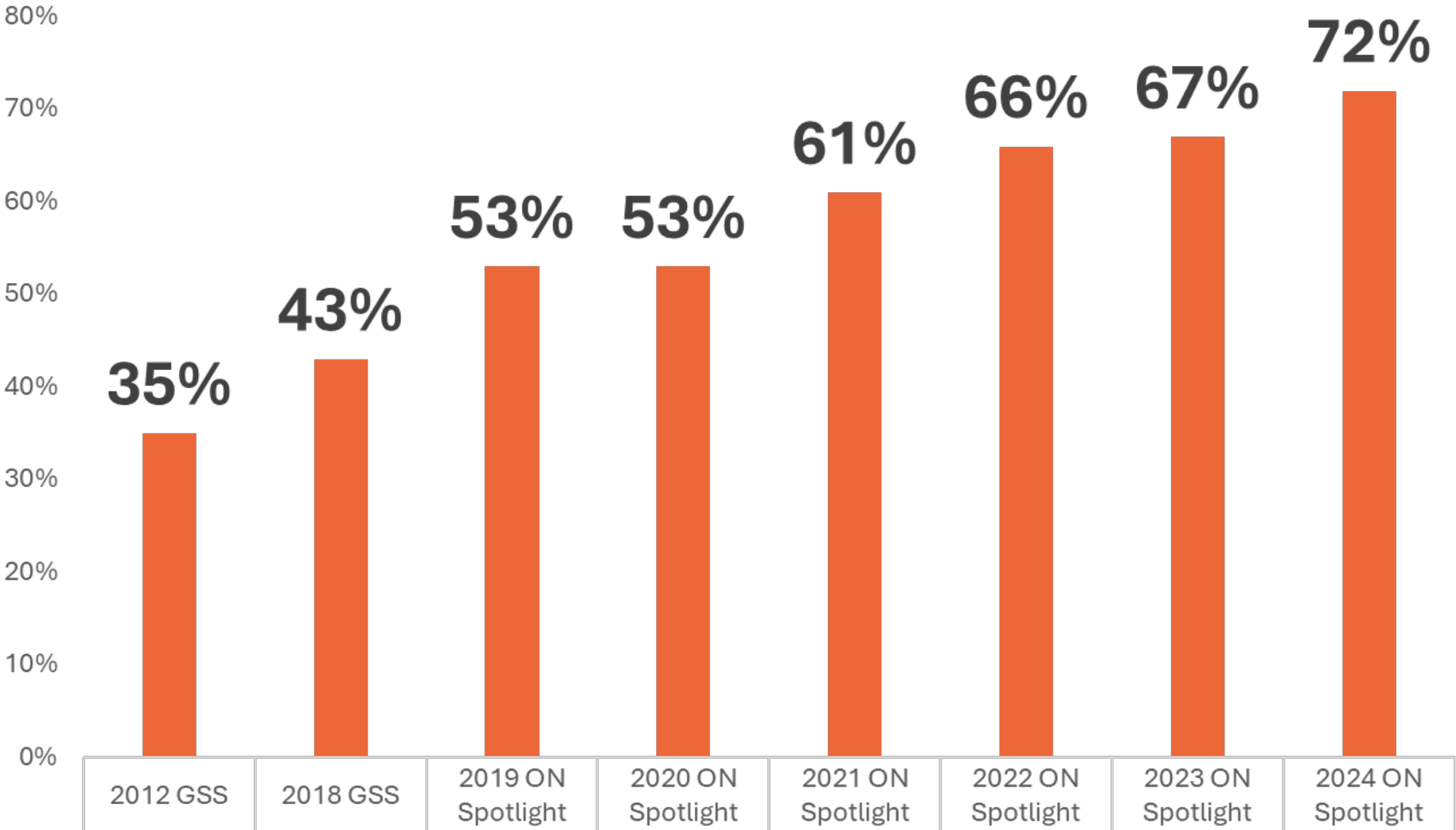
# Family caregivers are doing nursing and medical tasks

- 70% perform medical/ nursing tasks to help care receiver manage pain and/or discomfort, including opioid injections such as morphine
- 82% manage medications including for insulin, antibiotics,
- 37% deal with wound care (surgical wounds, ulcers, rashes, or sores)
  - cleaning wounds,
  - ordering wound care supplies,
  - monitoring wound conditions for infection and healing, changing dressings
- Managing respiratory equipment: oxygen therapy, (including continuous positive airway pressure [CPAP] units), spirometers,
- Managing drains and drainage bags including ostomy bags.
- 30% manage incontinence
- Managing and arranging for medical equipment,
- Half (51%) assist with canes, walkers, wheelchairs, scooters, or other mobility devices
- Coordinating care.

Caregivers who perform medical or nursing tasks worry about making a mistake and the more complex the ask, the greater the worry.

# Rising Family Caregiver Anxiety, Distress, Burnout

Family Caregivers: Feeling Overwhelmed



Anxiety most frequently occurring disorder in caregiving

- typically rises as care responsibilities increase & energy is depleted.
- Increases risk of heart disease, dementia, & premature mortality.\*\*

Fewer Family Caregivers

Longer Care Trajectories

Aging in Place

# Invisible Caregivers

*“Healthcare delivery simultaneously ignores and relies heavily on family caregivers to provide ongoing support to older adults with cognitive issues, physical impairments, and/or advancing complex conditions.”* (Schulz and Czaja 2018)



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## Paradigm Shift required:

- ✿ The work of family caregivers is NOT simply to implement the health care team's plan of care for their family member.
- ✿ The work of health care teams is to recognize, support, enrich, and augment the care that family caregivers already provide to their family members.
- ✿ **Family caregivers are the most valuable health care team member we have.**



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# Think, Pair, Share

Take a moment to think about:

- The benefits of including family caregivers for your patient care and practice.



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# Family caregivers play a pivotal role in patient care

The CanMEDS-Family Medicine Competency Framework explicitly calls for person-centered care and collaboration with family caregivers ([CanMEDS family medicine 2017](#)).

## Family caregivers playing a critical role in:

- **Identifying symptoms** to support early diagnosis, prevention, and support strategies ([Heidenreich et al., 2023](#))
- **Preventing unnecessary hospitalizations**, emergency room visits, and medical interventions ([Griffin et al 2022](#) | [Sawan et al 2021](#) | [Shultz et al 2018](#))
- **Enhancing the safety, quality, and continuity of care** ([Beach et al 2018](#) | [Griffin et al 2019](#) | [IPFCC 2017](#) | [Griffin et al 2022](#) | [Levine et al 2010](#) | [O'Hara & Canfield 2023](#) | [Shultz et al 2021](#))
- **Improving care recipients' health and well-being** ([Shultz et al 2021](#)) and quality of life ([Delgado-Guay et al., 2013](#) | [Prizer et al., 2020](#))

# Supporting Family Caregivers Improves Healthcare

- **Enhances Population Health**
  - Improves caregiver well-being ([Roberts et al 2020](#) | [Tan et al 2023](#))
  - Improves care recipients' health and well-being ([Schulz et al 2018](#))
- **Contributes to Healthcare Cost Savings**
  - Prevents unnecessary hospitalizations, emergency room visits, and medical interventions ([Griffin et al 2022](#) | [Sawan et al 2021](#) | [Schulz et al 2018](#))
  - Reduces readmissions and length of hospital stays ([Beach et al 2020](#) | [Glose 2020](#) | [Yasmeen et al 2020](#))
- **Enhances Experiences of Care**
  - Supports aging in the right place ([Holland 2022](#) | [Wagner 2021](#))
  - Enhances safety, quality, and continuity of care ([Beach et al 2018](#) | [Griffin et al 2019](#) | [Griffin et al 2022](#) | [Levine et al 2010](#) | [O'Hara & Canfield 2023](#) | [Schulz et al 2021](#))
- **Enhances Workforce Wellbeing/Joy**
  - Reduces healthcare providers' workload/stress ([Morton-Chang et al 2016](#) | [Schulz & Czaja 2018](#))
  - Increase healthcare provider satisfaction ([Brannelly et al 2019](#) | [Griffin et al 2021](#) | [Reinhard et al 2019](#))



## 2. Explore and practice strategies for empathic, collaborative communication with family caregivers.

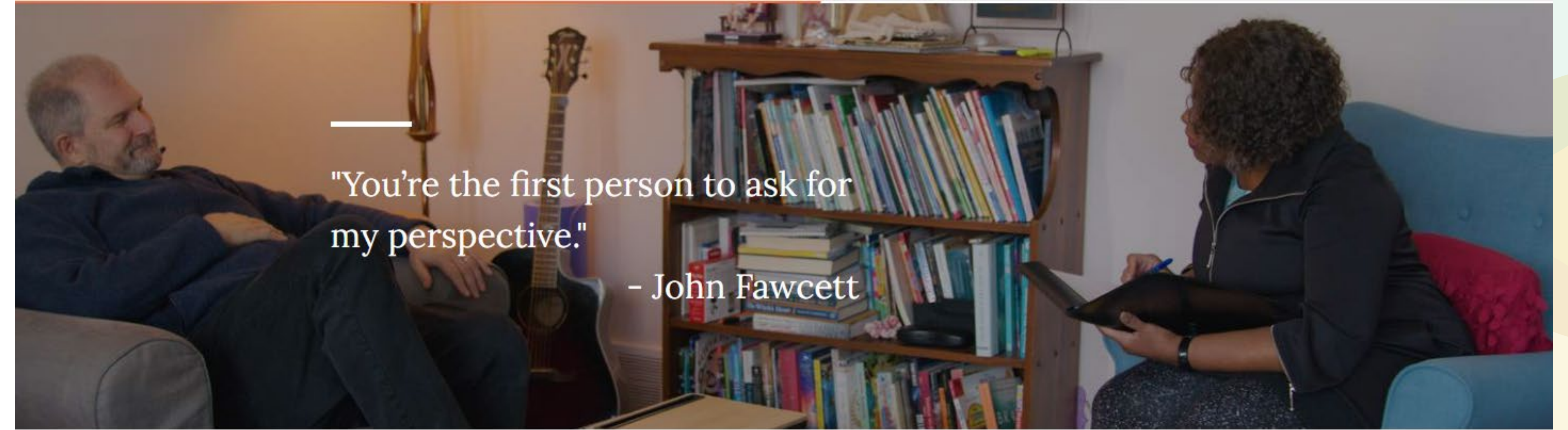


High Level Bridge / Lethbridge Viaduct



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"You're the first person to ask for  
my perspective."

– John Fawcett

## Caregiver-Centered Care Communication

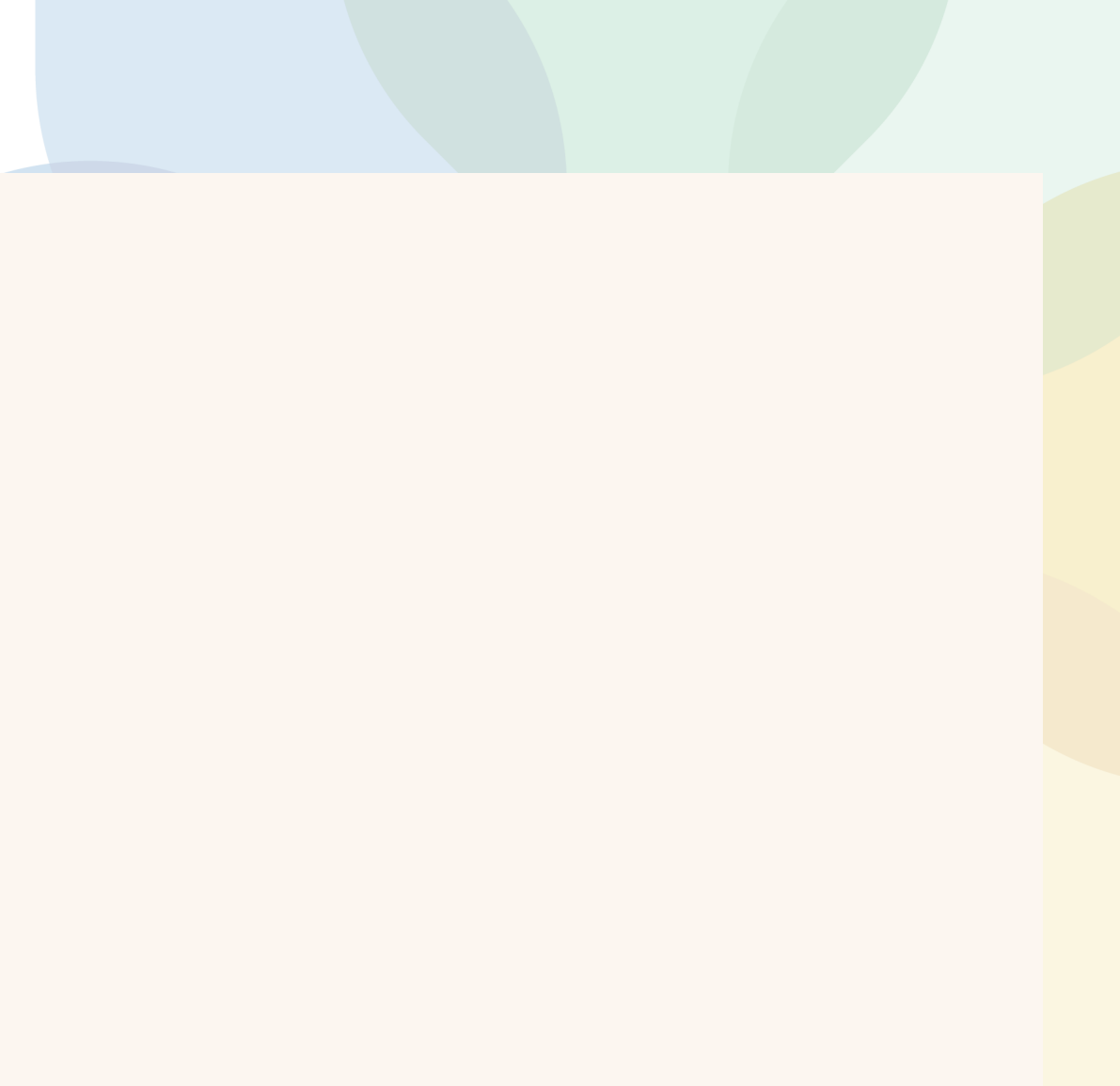
Caregiver-centered care is person-centered care for family caregivers. It is a care strategy based on the belief that overall health outcomes are a function of the views, input, and experiences of both the patient and the family caregivers. Family caregivers provide the majority of care and are key partners in improving overall health outcomes.



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# Initiating the Conversation



# Think, Pair, Share

Take a moment to think about:

- What would help collaborative conversations with family caregivers in your practice?



## What does empathic communication mean to family caregivers?

It's acknowledging that I'm an essential part of the team. It's hearing me...and seeing me.... **ask me sincere questions about** how I am, **how I am managing**, and whether I'm able to do all the things that my husband needs... whether I have any questions or concerns and **if there is something that [you] can do** to help me manage or care better.



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**Laurie Caforio**

# Establish Collaborative Partnerships

C

**Connect:** Proactively connect with family caregivers. Introduce yourself and greet caregivers with a smile and natural eye contact

A

**Ask & Acknowledge:** Ask about, actively listen to, and acknowledge caregivers' knowledge, feedback, & how they'd like to support care.

R

**Roles & Responsibilities:** Work together to review and define expectations. Be honest about what your site cannot do.

E

**Establish communication channels:** Ensure family caregivers know who to contact for what, the best communication channels, and what they can expect when they do reach out

R

**Revisit & Reassess** roles and responsibilities to ensure they are clear, realistic, and continue to meet needs.

S

**Supports:** Provide timeline and tailored support to family caregiver(s) on an ongoing basis.

Link to CARERS Handout.

[https://drive.google.com/file/d/1IUY8Sg0UMjUt3ZS9bclwGBE0qCH52OVe/view?usp=share\\_link](https://drive.google.com/file/d/1IUY8Sg0UMjUt3ZS9bclwGBE0qCH52OVe/view?usp=share_link)



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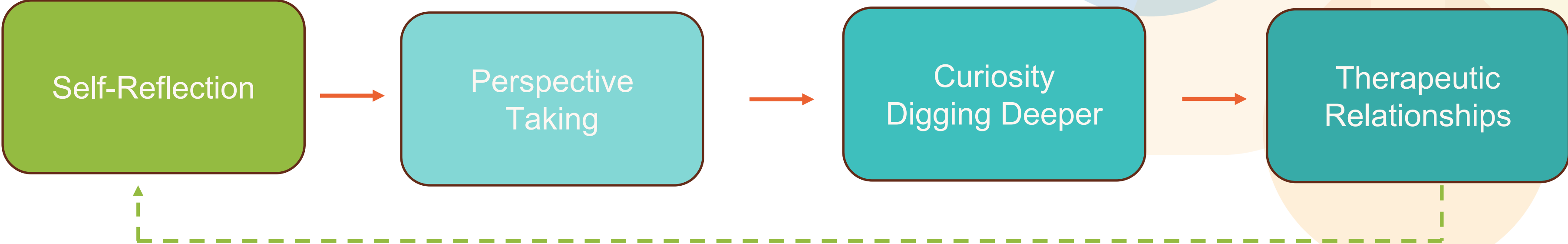
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# Foundations of Effective Communication




[www.caregivercare.ca](http://www.caregivercare.ca)

Curiosity is one of the most critical traits to develop if you want to communicate more effectively.

## Curiosity - Digging Deeper

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A photograph showing four people (three women and one man) sitting around a white table in what appears to be a meeting or collaborative work environment. They are engaged in conversation. The woman on the far left is wearing a dark blazer. The woman next to her is wearing a purple top. The woman on the right is wearing green scrubs. The man on the far right is wearing a dark blue button-down shirt. There are papers, a laptop, and some food items on the table.

Curiosity is an attitude of wanting to dig deeper, willing to admit that you don't know something.

- Michelle Lobchuk

**Curiosity is one of the most critical traits to develop if you want to communicate more effectively.**



# Benefits of Empathic Communication for Patients and Caregivers

## Improved Trust and Satisfaction

1. Patients and caregivers feel heard, understood, and valued, leading to stronger patient-provider relationships.
2. Increases adherence to treatment plans and medical advice.

## Better Health Outcomes

1. Patients are more likely to follow medical recommendations when they feel their concerns are acknowledged.
2. Reduces anxiety, distress, and pain perception in patients.

## Enhanced Caregiver Support

1. Family caregivers feel validated and included in care decisions.
2. Reduces caregiver stress by ensuring they are recognized as partners in care.



# Bridging the Gap with Empathic, Collaborative Communication.



“We need to change the focus from tasks and mechanics of care to relational care that focuses on collaboration and building relationships between family caregivers, patients, and healthcare providers”

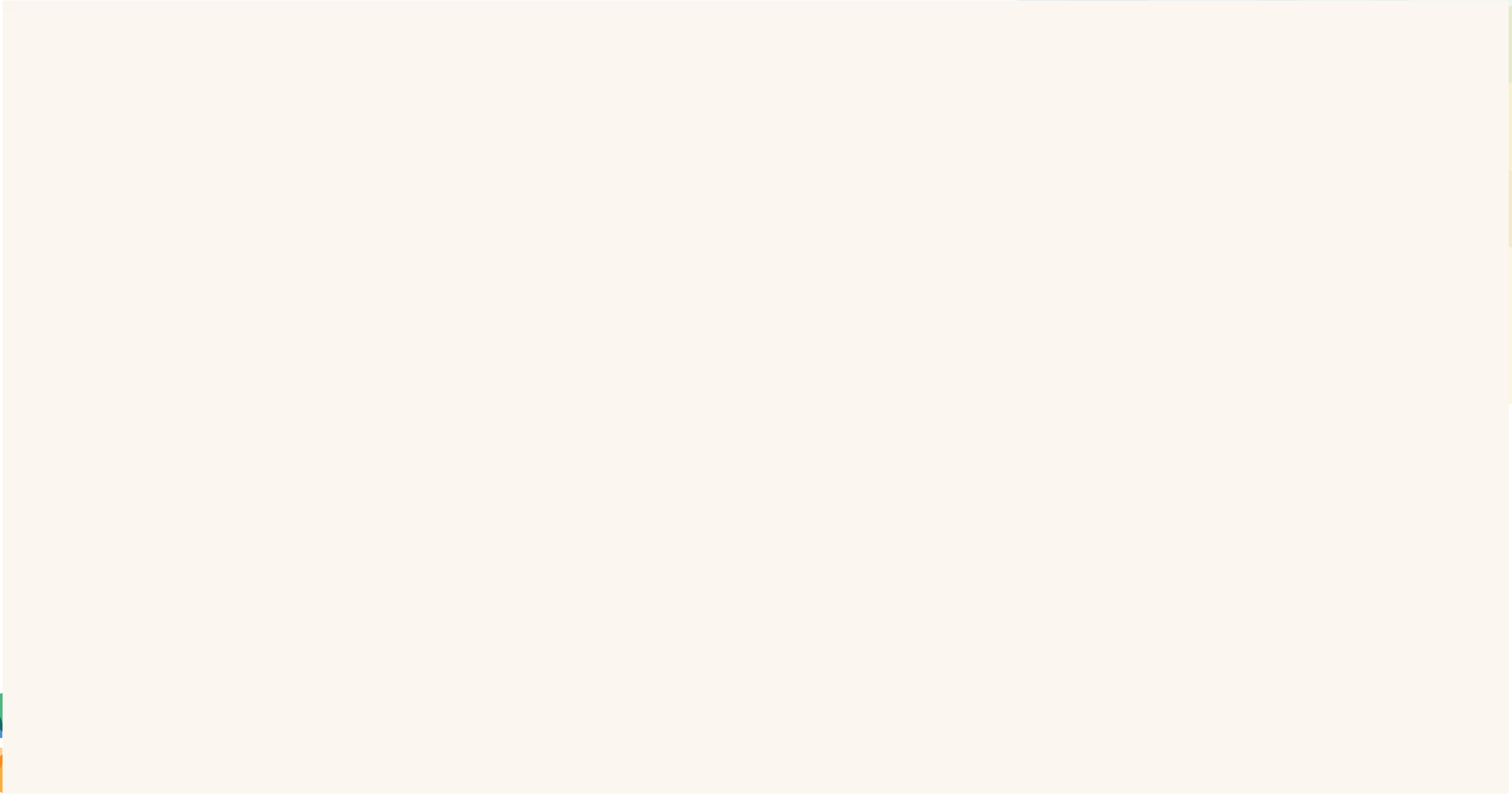
(Udod & Lobchuk, 2017)



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# Key Takeaways – Dr Treena Trustham



# #3 Apply shared decision-making to partner with family caregivers in care.



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**Shared decision making** refers to the process in which caregivers, family members, clinicians and **patients** work together to make decisions and select tests, treatments and care plans that balance risks and expected outcomes with a person's life wishes and values.

# Provider Interactions With Caregivers Is Common and Leads to Better Patient Outcomes

**97%** Nearly all US providers say caregivers play an important role in patient care.

**8 in 10** of patients with caregivers are 50+ years of age

**65%** believe they will be working more often with caregivers in the next few years.

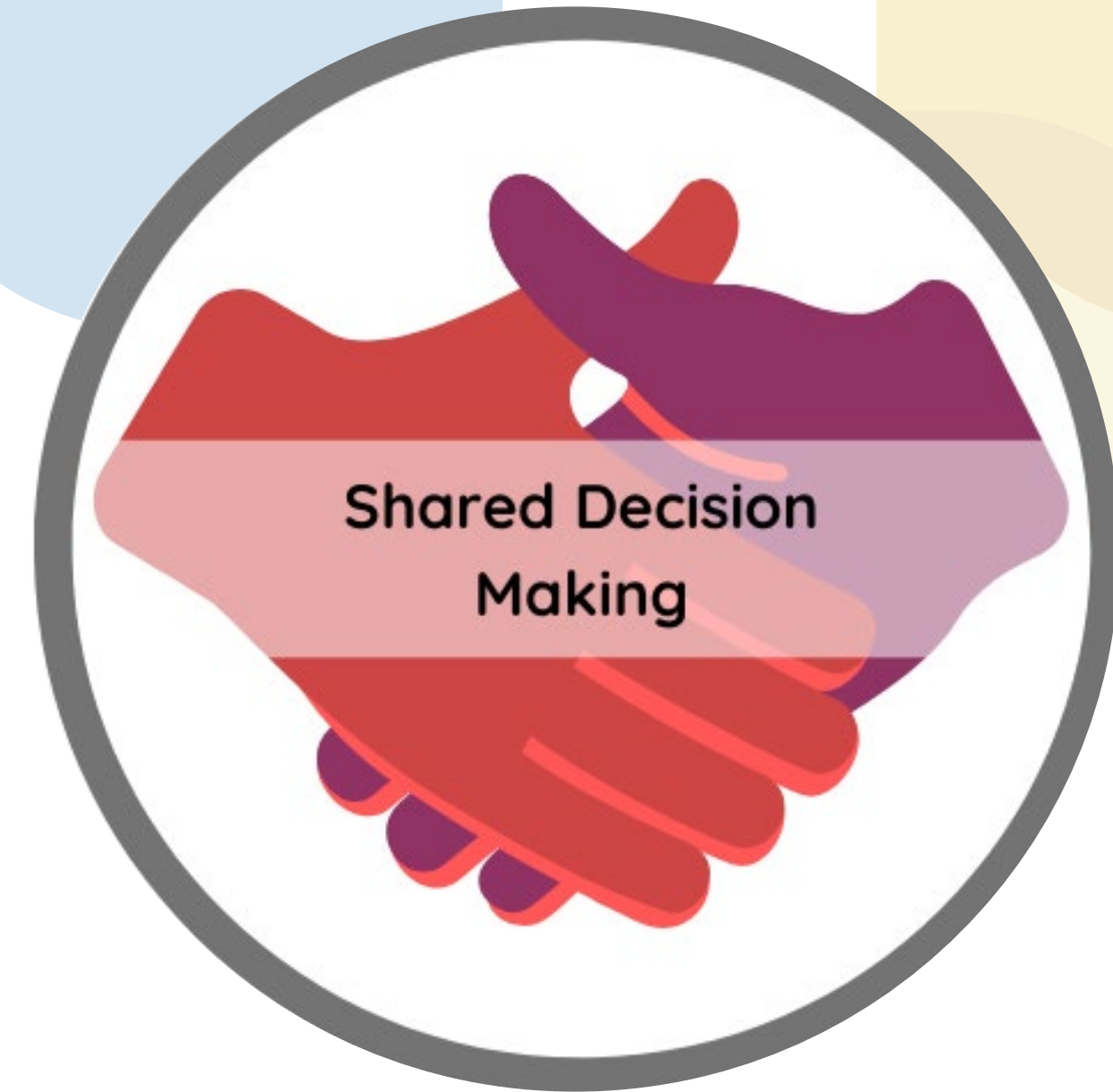


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# Involvement of Family Caregivers of People with Complex Chronic Conditions and/or Cognitive Impairment

- **Family Caregiver Involvement:** Essential for effective shared decision-making.
- **Patient Participation:** Include individuals with chronic or cognitive conditions whenever possible.
- **Relational Care:** Caregivers and providers collaborate to align care with patient priorities.
- **Caregiver Outcomes:** Consider the impact of decision-making on caregivers' well-being.



# Difficult decisions: Patients & their Caregivers



**Treatment Options:** Choosing between aggressive treatments, palliative care, or no intervention.

**Risk vs. Benefit:** Evaluating potential benefits of treatments against possible risks and complications.

**Symptom Management:** Balancing quality of life vs. treatment side effects.

**Living Arrangements:** Transitioning to assisted living, long-term care, or home-based care.

**Transportation & Driving:** Deciding when to stop driving and arranging alternative transportation.

**Financial Impact:** Managing costs of treatments, medications, out-of-pocket costs (transportation, parking)

**Caregiver Role:** Balancing caregiving responsibilities with personal and professional life.

**Legal Planning:** Addressing legal issues, such as power of attorney and healthcare proxies.

**End-of-Life Care:** Determining preferences for hospice care, advance directives, or Do-Not-Resuscitate (DNR) orders.



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# Steps in the Relationship-Centered Decision-Making Process

## 1. Engagement:

- Involve all relevant parties in discussions

## 2. Empathetic Listening:

- Validate and consider care partners' insights on patient needs

## 3. Shared Understanding:

- Create a common agreement on treatment options and goals

## 4. Flexibility:

- Adapt decisions based on changing circumstances and preferences



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Think, Pair, Share

How do you prefer to include caregivers in shared decision-making?



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# Common Elements Across Triadic Decision-Making Frameworks

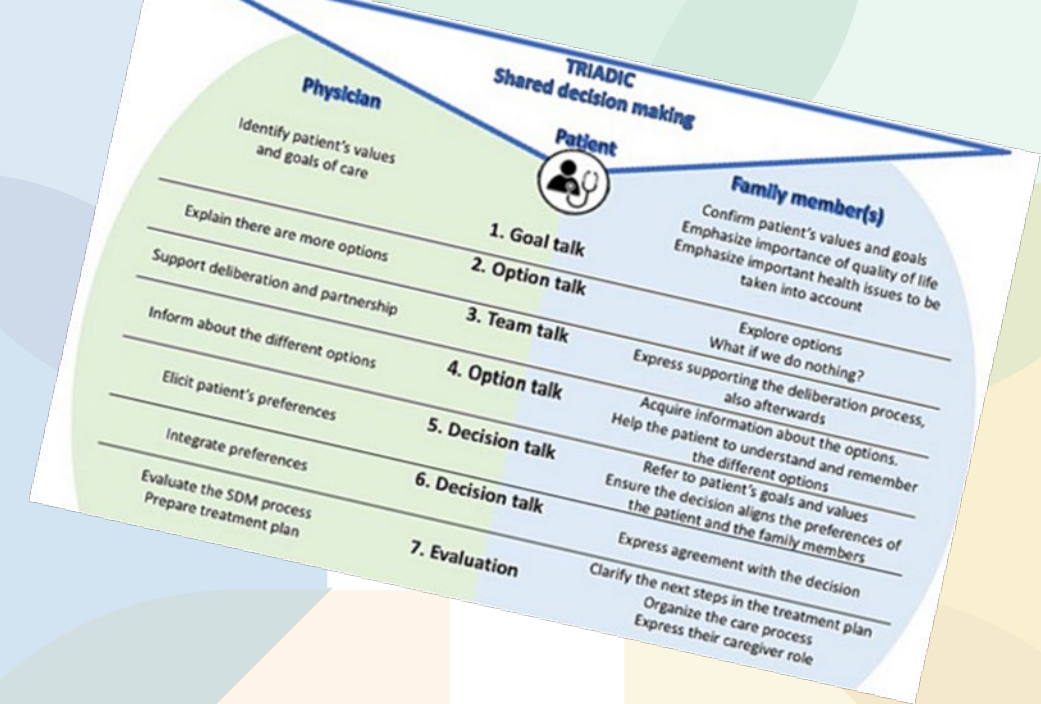
- **Respect for Each Role:** Acknowledging the lived experience of the older adult, the hands-on insights of the caregiver, and the professional's expertise.
- **Shared Goals:** Establishing mutual goals (e.g., quality of life, safety, autonomy) before deciding on interventions.
- **Open Communication:** Creating an environment where concerns, questions, and knowledge can be freely exchanged among all three parties.
- **Flexibility:** Allowing for evolving levels of input and decision-making capacity as health conditions or circumstances change.



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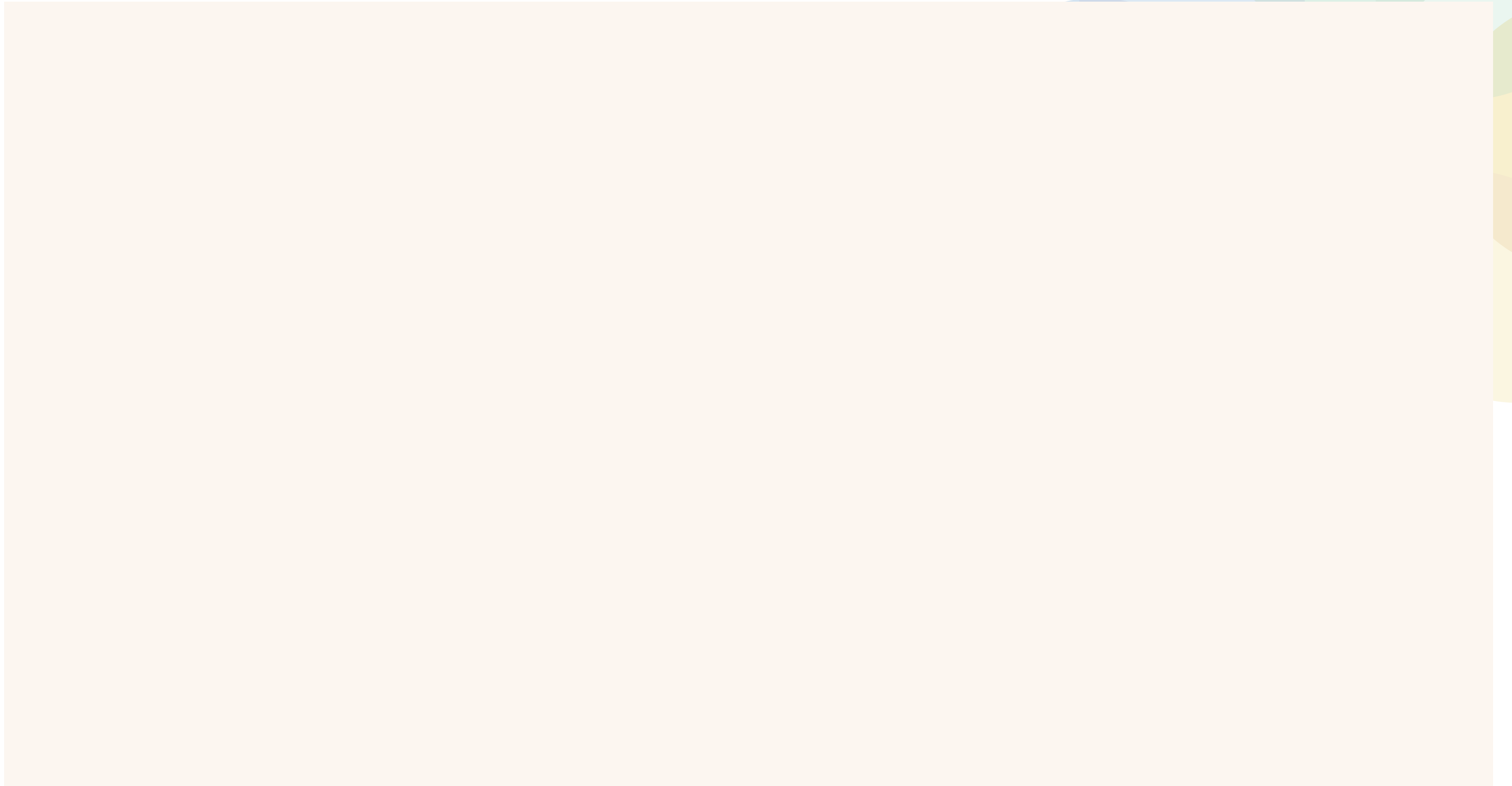
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# Triadic Shared Decision-Making Model



1. **Goal Talk:** Identify the Patient's values and goals of care. Family Caregiver confirms Patient's values and goals?
2. **Option Talk 1:** Explain the different treatment options and offer choices.
3. **Team Talk:** Support deliberation and partnership
4. **Option Talk 2:** Provide detailed information about options and verify understanding.
5. **Decision Talk 1:** Elicit the Patient's preferences. Determine if the decision aligns with the Patient's and Family Caregiver's preferences.
6. **Decision Talk 2:** Integrate preferences into decision-making.
7. **Evaluation:** Review the decision process and prepare a treatment plan.

# Organizing your practice to include caregivers – Joyce Lee



# Billing Codes to Facilitate Time Availability

- You can search for codes using “family” on the fee navigator:



- While our definition of family caregiver is broad, please note, per Governing Rules 1.7.1, “family” is defined as the following:

A patient's "family" means children, siblings, parents, legal guardian/agent (agent as defined in the Personal Directives Act (RSA 2007c37s3)), spouse or adult interdependent partner.

- Inviting family caregivers into your patient appointments does not require an additional code

# Resources

*“If we ask family caregivers what they need, then we will need to know what is available.”*

*Bernice Sewell, Social Worker, SAGE Seniors*



Medically At-Risk Driver Centre

# Physicians Education

<https://www.caregivercare.ca/physicians/physicians-education>

**Caregiver-Centered Care**  
Supporting Family Caregivers in Healthcare

EDUCATION ▾ STRATEGY ABOUT COMPETENCY FRAMEWORK RESOURCES ▾

PHYSICIANS DEVELOPMENT

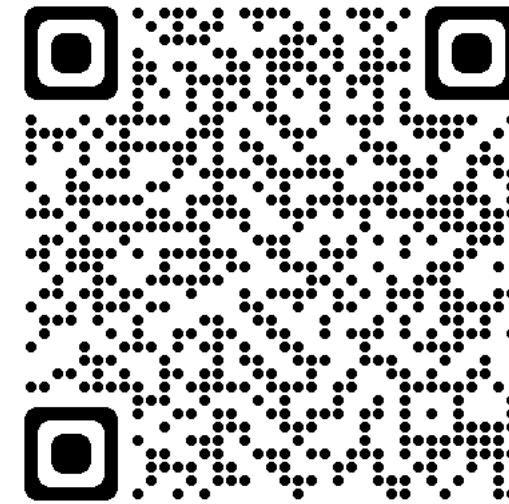
## Module 1: Recognizing the Role of the Family Caregiver



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# Thank you!

 [www.caregivercare.ca](http://www.caregivercare.ca)



 Contact information

 Dr. Jasneet Parmar (Lead) [Jasneet.Parmar@albertahealthservices.ca](mailto:Jasneet.Parmar@albertahealthservices.ca)

 Dr. Sheny Khera [skhera@ualberta.ca](mailto:skhera@ualberta.ca)

 Charlotte Douglas [charlotted@saspcn.com](mailto:charlotted@saspcn.com)