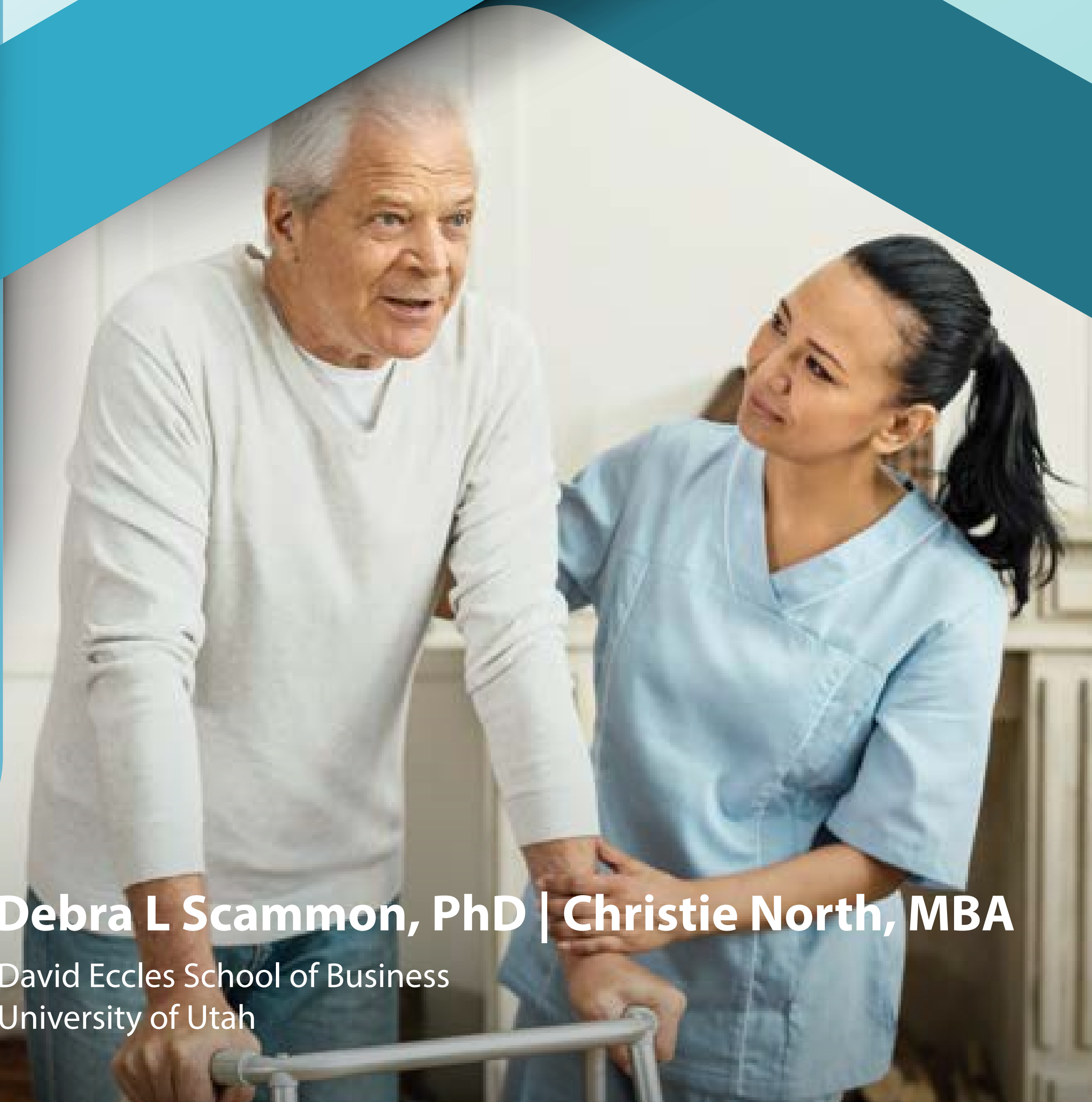
A GUIDE FOR PRIMARY CARE PROVIDERS

Creating Caregiver Provider Partnerships



Debra L Scammon, PhD | Christie North, MBA

David Eccles School of Business
University of Utah

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David Eccles School of Business
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Taking Care of Our Parents

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> “America’s caregivers deserve to be seen as valuable members of the health care team. They should be included in decision making, given opportunities to voice their concerns, and provided appropriate instruction. They should not be taken for granted—or worse, criticized for their perceived failures and inadequacies.”

Home Alone Revisited, AARP 2019

A GUIDE FOR PRIMARY CARE PROVIDERS

Creating Caregiver Provider Partnerships (CCPP)

Executive Summary

Intended Audience

This guide is addressed to primary care clinicians, especially physicians, nurse practitioners, and physician assistants, serving older adult patients (65+ years of age). We'd like to ask you:

> "Have you ever been asking a question of an older adult patient and felt you were not getting the whole story?"

You may have been frustrated thinking it was difficult to diagnose, and especially challenging to recommend treatment, without good information. There is a partner with answers, maybe in your waiting area or hopefully in the exam room with your patient. That family caregiver can help you paint a full picture and help you understand what may or may not be possible for the patient at home.

The Purpose of Our Guide

Although family caregivers are responsible for a major share of support and services for older adults, they are rarely included as full partners within the care teams of primary care or specialists. Adding one or more individuals into the patient/clinician dynamic can be challenging. However, the context and depth of knowledge a family caregiver can share are invaluable. Strategies are needed to improve communication with and care processes that systematically include the family caregiver.

Our Process

This Patient Centered Outcomes Research Institute (PCORI) funded work is the product of direct experience with family caregiving. We wanted to better understand the challenges of chronic disease and aging and spent more than five years getting to know family caregivers, the loved ones they care for, as well as the clinicians, and researchers interested in reducing the burden of family caregivers. These stakeholder insights inform this guide.

Integrating family caregivers into primary care practice is the focal point of this work. Literature supports our recommendation that the family caregiver/patient dyad should be included as a valued partner with your professional care team. Examine your clinic's workflow to find areas where one or more of the beneficial practices we identify can be adapted or adopted.

The Summary Table on the next page previews some of the lessons learned, highlights helpful practices and provides implementation tips. Further detail is available in the guide. References are included as is a page of resources for caregivers that you may want to give to your patients. We encourage you to share our companion Guide for Family Caregivers with your patients.

Summary of Lessons Learned

A number of the lessons we have learned are things that you can implement immediately and can be accomplished within 2 minutes during a new patient or follow-up visit. Others can become a roadmap for development of your practice culture to fully embrace family caregivers as partners with you in caring for your older adult patients. The benefits to you as the clinician will be a more complete understanding of the home environment and what your patients and their family caregivers can manage.

Promising Tactics for Implementation

IMMEDIATE ACTIONS	PROMISING TACTICS
Take two minutes out of every visit	• Encourage family caregiver participation; build opportunities for engagement • Suggest ways the family caregiver can participate in the visit ◦ Listen, ask questions, and take notes ◦ Encourage and support the patient ◦ Provide additional information • Take time to learn what matters most to your patient • Set up post-visit success ◦ Encourage patient and family caregiver to use the patient portal to communicate with the care team ◦ Share access to full progress notes through the patient portal

LONGER TERM PLANNING	PROMISING TACTICS
Valuing caregivers' contributions	• The clinician sets the tone; leadership comes from you • Recognize and acknowledge the family caregiver's critical and unique understanding • Articulate inclusion of family caregiver with patients and staff • Practice triadic communication skills: ask the patient if they want to include their family caregiver in discussions and ask the family caregiver to share observations about their loved one at home
Preparing for the visit	• Create a practice introduction primer • Involve all members of the care team in pre-visit planning and utilize EHR pre-planning tools • Use the patient portal to send questionnaires to patients and caregivers before each visit • Try the patient/caregiver agenda setting exercise to assess their shared and divergent priorities
Help caregiver learn medical and nursing tasks for care at home	• Provide instructions and demonstrate correct methods for performing medical/nursing tasks • Use teach-back method to be sure family caregiver understands and can perform task • Refer patient and family caregiver to relevant resources they need • Assign a member of your care team, the MA or social worker, to be the link to community resources

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A GUIDE FOR PRIMARY CARE PROVIDERS

Creating Caregiver Provider Partnerships (CCPP)

Introduction

By 2030 more than 72.7 million adults in the United States will be older than 65. 20% of people over 65, and more that 40% of those over age 85 need assistance with at least one activity of daily living (ADLs). The number of Americans who need help with ADLs and other activities like paying bills or taking medication is expected to rise from a current figure of 12 million to over 27 million in 2050. Their assistance is primarily provided by Family Caregivers.

According to a recent national study, "at least 17.7 million individuals in the United States are family caregivers of someone 65 and older" (Shultz and Eden 2016). They often know their loved one better than anyone else and have a wealth of information about their health and home environment. Nearly 4 in 10 older patients are accompanied to appointments by a family caregiver (Wolff and Roter 2011). Clinicians should be prepared to utilize this invaluable resource by including family caregivers in medical visits of older patients.

As the need for family caregivers is increasing, so too is an awareness that they will need both support and training. In 2019 Congress passed the RAISE Act establishing an advisory council charged with developing a strategy to support family caregivers. In 2016 Congress passed the CARE (Caregiver Advise, Record, and Empower) Act and since then more than 40 states have adopted a version of it. Several states have expanded coverage of the Family Medical Leave Act (FMLA) to explicitly cover leave for taking care of a family member, and many are making paid leave available for family caregiving.

State and federal laws, as well as business and HR practices, are beginning to recognize the crucial role of family caregivers. Similarly, health systems and clinicians have an opportunity to prioritize and include family caregivers' critical insights and skills.

Vision

Having family caregivers partner with the care team can increase the efficiency and effectiveness of care overall. Full partnership with the team will improve their understanding of the care plan, and they will be better prepared and more confident in their caregiving role. If you give a family caregiver two minutes during the visit, you will get much more than that in return in the form of better care, better health and quality of life for the patient, and greater satisfaction and joy in practice for you.

This Guide provides strategies and tactics to strengthen the partnership between clinicians, patients, and family caregivers. Particular emphasis is placed on improved communication techniques and workflow modifications that help clinicians and other care team members more effectively engage family caregivers.

Organization

Patient/clinician relationships strengthen over time. Continuity is critical in developing a successful plan of care, especially for older adults with multiple chronic conditions. Many of the recommendations in this guide can be helpful across the longitudinal stages in the care process, but some may be more useful at specific times.

We pay particular attention to ways you and your care team can help family caregivers prepare for caring at home. We suggest ways in which the team can help educate and train family caregivers. We include resources readily available on the Internet for your staff and a handout with caregiver resources you can give to patients and their family caregivers. We encourage you and your staff to become knowledgeable about the resources available in your local community and help connect your patients and their family caregivers to them.

We include descriptions of several promising practices that are being tried in various healthcare settings and suggest some future directions in which more can be done with inclusion of family caregivers in medical visits.

We have also written, a Guide for Family Caregivers, and encourage you to share it with your patients and their family members.

Value Family Caregiver Input

A 2010 Health Affairs article made the case for family caregivers' invaluable contribution, "In a fragmented system, family caregivers are often the only people who have experienced the entire trajectory of their family member's illness" (Levine, Halper, Peist and Gold 2010). Caregivers are with your patient day in and day out. Medical visits may be thorough, but a comprehensive understanding of a patient's condition requires details about their daily life that sometimes only family caregivers can provide.

Millions of Americans need help with activities of daily living-- dressing, bathing and getting around the house. Help at home often extends to help getting to and from medical appointments as well as participation in the medical appointment.

In geriatric practices, and in cases of dementia, the dyad of family caregiver and patient is the norm.

Patients and family caregivers expect to be treated with **respect**. They want clinicians to be **honest** and **transparent** in sharing information.

> When the patient-caregiver dyad is treated as the unit of care, important synergies are achieved that contribute to the well-being of patients and caregivers.
>
> Northouse, et al 2012
> J Clin Oncol

Family caregivers have unique insights about their loved one's health, and they expect to be included in decision-making and **trusted** for their valuable knowledge. Valuing the family caregiver's input and feedback strengthens the care team as a whole.

VALUES

RESPECT **HONESTY** **TRANSPARENCY** **TRUST**

A 2013 Journal of Family Medicine and Primary Care study asked when and why family members accompanied patients to visits. More than half the time, "effective communication" was the stated goal of those accompanying loved ones to medical appointments. Research shows that the presence of a family caregiver improves communication and understanding (Schilling et al, J of Family Practice, 2002).

Formal planning for increased engagement with family caregivers is needed. Building a partnership requires leadership from clinicians, and accountability from all members of the care team. It also requires respect for one another's contributions to patient care and commitment to the common goal of best possible care for the patient.

CLINICIAN LEADERSHIP

As leader of the team, your orientation toward family caregivers demonstrates the value of their participation. A positive example positions the patient/family caregiver dyad at the center of the visit. With this foundation, each care team member can participate in an environment of honesty and respect.

Family caregivers support the patient between office visits, when much of the required care is delivered. Changes in ability, adherence, or behavior are most likely to be recognized by the family caregiver. You can develop and strengthen your partnership with caregivers by valuing their input and respecting their insights about circumstances at home. Ask what patients and family can feasibly do. Productive partnerships will save time and help create a more efficient patient care process.

> Patients believed that examination room companions influenced 75% of medical encounters, mainly by improving communication between physician and patient. Physicians agreed that examination room companions favorably influenced physician and patient understanding (60% and 46% of encounters, respectively).
>
> Shilling et al 2002
> Journal of Family Practice

ESTABLISH EXPECTATIONS FOR INCLUSION OF FAMILY CAREGIVERS

The clinician team can create a culture of inclusiveness. A welcoming culture is everyone's responsibility. Each member of the care team should be sensitive to the presence of family caregivers and encourage their participation.

Acknowledge and welcome

Reception staff can greet the patient and family caregiver by name, welcome them to the clinic and introduce them to the medical assistant. As team members get to know family caregivers, let them know they are appreciated.

> **Reception Staff:** "Hello Mr and Mrs Smith. Its nice to see you."
>
> **Physician:** "Hello, John. I'm glad you have come in today to follow up on how you are doing with the new medication you started. It is good to see you again, Mrs. Smith, I'm sure you have insights to add about how John is doing with this new medication.
>
> Let's start by you telling me what you want to be sure to discuss today."

Ask, don't assume

Staff should ask whether patients have a family caregiver. Patients may have someone with them at appointments, but that companion is not necessarily a caregiver. The individual could be a driver, a translator, or a friend. It is important to ask who the companion is and not assume they are a caregiver. It is helpful to determine the relationship of the companion to the patient and note both their identity and their relationship in a specific and prominent place in the patient's record. It is helpful for the care team to know if a family caregiver will be present, and staff can ask whether a family caregiver will accompany the patient to future visits.

Look for opportunities to encourage family caregiver engagement

- Upon arrival the patient and family caregiver can be given an information sheet with suggestions for effective ways to engage in the visit
- When escorting the patient to the exam room, the medical assistant can encourage the family caregiver to ask questions and/or take notes
- When entering the exam room, the clinician can ask about the role of the family caregiver and suggest ways in which they could help and support the care team

"Hello John, we are glad that you have come in today.

I see you have brought someone with you today; would you please introduce me to your companion? And, what is your relationship to Ms Adams? Does she help you with tasks at home? Will she be accompanying you to the exam room?"

Using triadic communication

Family caregivers can help the care team create and maintain a realistic care plan that can be implemented at home.

A family caregiver changes the clinician/patient dynamic as a new 'communication triad' is formed. Triadic communication can be challenging. The challenges can be overcome by following these steps:

- Set clear expectations around family caregiver participation in the visit
- Define a few ground rules for communication among the triad
- Listen to the family caregiver demonstrating respect and appreciation of their unique insights

Finding ways to elicit and incorporate input from the family caregiver into the interaction that occurs during a medical visit can help build a strong partnership.

"… we hypothesize that over the next decade there will be many more encounters in which a third person is present, due to:

- rapid growth of the aging of the population
- greater recognition of medical errors (and the potential role that accompanying third parties may play in reducing errors)
- the increasing size of the immigrant population
- the consumerist approach to health care."

Green and Adelman 2013, Journal of Family Medicine and Primary Care

The ways the team communicates with one another and with the patient will determine how effective the care and treatment is, as well as how the team members feel about their work.

Health & Medicine, 2015

Preparing for the Visit

An efficient, effective visit requires preparation from the care team as well as from the patient and family caregiver. This chapter includes ideas about ways to prepare patients and family caregivers for the clinic visit. The right preparation will help both of you make the most of your time together.

The following areas are described:

1. A primer for new patients to help patients and family caregivers know what to expect
2. Pre-visit planning by the whole care team using available EHR tools
3. A patient and family caregiver questionnaire to increase engagement of family caregivers in the visit
4. Promising Practice: Patient/family caregiver agenda setting

Clinicians can help patients and family caregivers to prepare for upcoming visits. Pre-visit information exchange can help ensure priorities of both the patient/caregiver dyad and the clinical care team are met.

A PRIMER INTRODUCING THE PRACTICE

Clear expectations among and between the care team and the family caregiver/patient dyad can achieve improved work flow in the clinic and better patient care at home. Some advanced preparation can help make the visit less stressful and more productive.

Each appointment is an opportunity for mutual goal-setting and clarifying expectations.

PATIENTS AND CAREGIVERS EXPECT TO:

- See the clinician promptly
- Describe their current status and reason for the visit
- Understand the visit summary
- Understand next steps

CLINICIANS EXPECT TO:

- Track patient's preventive care
- Evaluate progress and changes in the patient's health
- Comply with state or federal care requirements

New patients and those with changing care needs can benefit from an introduction to a clinic, including its providers, staff, and services so that they know what to expect from a visit. A primer can include information about:

- Team structure, team member roles, and clinic process flow
- Different types of visits, such as a New Patient Visit or an Annual Wellness Visit
- The staff a patient might interact with, and the approximate time allocated for each type of visit

Hard copies could be mailed to patients, or electronic versions could be sent via the patient's portal.

It is a good idea to let the patient and caregiver know what paperwork and information the clinic needs from them and if they need to come in early to get that done.

PRE-VISIT PLANNING

Pre-visit planning is typically an internal activity engaged in by the clinic care team prior to an upcoming visit. Planning ahead is always a good idea and reduces the chance that something important will be overlooked during the visit. Clinicians' pre-visit planning increases visit efficiency and improves care quality. The team may:

- Review the patient's care plan together
- Have every member of the care team engage in pre-planning
- Use the pre-charting module in the EHR if available

In some EHR's, a staff member can add in requests for diagnostic tests that are due, and other items that may be required for a particular type of visit (such as an Annual Wellness Visit). The provider can review the suggestions and accept or not. The chart cannot be closed until those items are cleared by the clinician.

Team-based practices often tailor assignments to meet specific patient needs. Each team member can engage in pre-visit planning focused on their role. Multiple pre-visit planning templates increase the probability that all concerns will be seen and addressed.

A designated care team member (often a medical assistant) may compile the notes and present them to the team during a team huddle or review session.

FAMILY CAREGIVER/PATIENT QUESTIONNAIRE

It is especially important that the patient/family caregiver dyad be included in pre-visit planning to increase visit efficiency and improve care quality. If the care team organizes priorities for the visit without input from the patient and family caregiver, even the best laid plan may miss key details.

A brief questionnaire completed before the visit allows patients to communicate a few key priorities. Consistent use of tools like this can increase the patient's and caregiver's engagement in the visit.

Eliciting patient and family caregiver priorities in advance can help the clinician adjust the alloted time and sequence of topics to cover in the visit, and help the patient and family caregiver feel included. Questions can be as simple as, "what are your top three reasons for today's visit?" This is also an appropriate place to ask if a caregiver will accompany the patient to the visit.

Regardless the size or type of questionnaire, the clinic must have a protocol to incorporate the responses to the questionnaire into the visit.

PROMISING PRACTICE: PATIENT/FAMILY CAREGIVER AGENDA SETTING

An innovative strategy called agenda setting has recently been used successfully in several clinics (Wolff et al, 2016, 2018, 2019). It is intended to establish ground rules for relational exchanges and identify the priorities of the patient and their caregiver. It uses a structured process to establish shared expectations for the visit.

Using a two-step exercise, patients and family caregivers are encouraged to discuss in advance the preferred role for the family caregiver during the visit. Together, they decide what issues are most important to discuss. Here is an example of an agenda setting form:

> Creating opportunities for patients and family caregivers to discuss and decide together the roles that family caregivers will play in medical visits and the shared priorities for an upcoming visit are intended to improve visits for the benefit of all…patients, family caregivers, and providers. The concept is showing positive results.

Making the Most of Your Doctor Visit

This conversation guide is for patients who attend doctor visits with a family member or friend. Together, use this guide to prepare for today's visit.

STEP ONE: How can your family member or friend be most helpful today?

Together, decide what types of help you would like. Mark (✓) all that apply.

☐ Listen to what the doctor says and take notes
☐ Help you to understand what the doctor says or means
☐ Remind you to ask questions or tell the doctor concerns
☐ Ask questions or give the doctor information
☐ Allow you time alone with the doctor for some or all of the visit

STEP TWO: What do you want to discuss with your doctor today?

Together, decide which concerns are most important

	Mark (✓) if a concern to:	
Issues affecting the patient:	Patient	Family
Hearing or vision		
Fear of falls, dizziness, or balance		
Bladder or bowel problems		
Safety at home or when driving		
Difficulty bathing, dressing, or walking		
Financial matters that affect patient health		
Planning for serious illness or progression of current illness		
Changes in personality or behavior		
Stress, worry, or feeling sad or blue		
Trouble concentrating or making decisions		
Memory problems		
Managing or taking medications		
Other:		

WOLFF ET AL., J GEN INT MED, 2018

Clinics implementing this tool have seen several positive outcomes:

- Efficient use of limited visit time
- Shared priorities between clinician and patient/family caregiver
- Increased patient-centered communication
- Reduced tension/arguments between patient and family caregiver during the visit
- Increased family caregiver engagement in care planning

Implementation of agenda setting is not without its challenges. The following steps may help familiarize clinicians and patients with its intended benefits.

- Use the Primer to introduce the concept to new patients
    - Establish the expectation that the clinic feels this is important, not just an after-thought
    - Reinforce this expectation by including the agenda setting exercise at an initial office visit
- Include the agenda setting concept as part of pre-visit planning
    - Include questions in the patient questionnaire to probe the willingness of the patient for the family caregiver to participate in the visit. Ask about the level of inclusion that is comfortable for the patient and if they mind having the clinician direct questions to and discuss with the family caregiver
    - Send the full agenda setting questionnaire to patients through the patient portal prior to each visit
    - Establish the expectation that this information will be requested by the clinician introducing the exercise at one visit then including it in the patient questionnaire sent prior to subsequent visits.

During the Clinic Visit

This chapter introduces specific tactics to encourage family caregivers' visit participation in ways that are rewarding to them, helpful to the care team, and beneficial to your patients. It also suggests things you can do to support your patients and their family caregivers between visits.

THE CLINICIAN SETS THE TONE FOR THE VISIT

During the visit the clinician leads the discussion and can shape the family caregiver's role. Clinicians can include the family caregiver as a supplemental, not a substitute voice. Their perspective and priorities should not overshadow those of the patient.

WAYS THE CLINICIAN CAN ENCOURAGE FAMILY CAREGIVER PARTICIPATION IN THE VISIT

- **Ask** for detailed context
- **Clarify** patient input
- **Probe** for what's happened since the last visit including:
    - New/different reactions to medications
    - Observations about patient's health
    - Concerns patient shared with the family caregiver
- **Build** opportunities to communicate outside the exam room. The family caregiver may speak more freely away from the patient
- **Identify** communication preferences. Reliable communication between visits increases caregiver confidence
- **Discourage** unhelpful participation. If the family caregiver is too dominant or distracting during visits, the clinician can help the family caregiver see ways in which their participation could be more helpful

"Good morning, John. I see you have your wife with you again today, welcome Margaret."

"John, I noticed that you signed a release of information form, so does that mean you want your wife to participate in your visit? "

"Ok, then with your permission, I will ask her some questions and let her share in the dialogue. Is that ok with you?"

WAYS THE FAMILY CAREGIVER CAN PARTICIPATE IN THE VISIT

- **Listen** to the clinician's recommendations and patient's concerns
- **Take notes** about medication changes, specialist referrals, recommended tests or scans, and next steps. Caregiver notes can be a great resource for patients at home
- **Remember** details of the visit and the care plan
- **Encourage** the patient to be responsive and engaged
- **Ask** questions about anything that the patient or caregiver don't understand
- **Clarify** clinician instructions
- **Invite** the family caregiver to discuss:
  - Assessment of the patient's health status
  - Recommended care plan
  - Alternative treatments and likely outcomes of different options
- **Provide** additional patient information
  - Expand on patient history
  - Convey patient's questions or concerns
  - Context about patient's health or life goals

IDENTIFY PATIENTS WHO CAN BENEFIT FROM FAMILY CAREGIVER INCLUSION

Family caregivers often assist older adults in poor health who have transportation, mobility or memory challenges. Many other patients could also benefit from caregiver support. Patients may need help with shopping, meal preparation, medication management, and other regular tasks, but not know how to ask for it.

Suggest inviting a family caregiver to attend an upcoming visit. It might be helpful for them to hear directly from you. For example, if attention to your patient's diet is important, you could explain what foods should be avoided and the family caregiver could ask questions about how to prepare more healthy meals.

"Hello John, I'm glad that you have come in today so that we can talk about how you are doing with the dietary recommendations we discussed at your last visit.

You told me you were having trouble avoiding some of the foods that may increase your blood sugar."

"Who helps you at home shopping and preparing meals? Have you thought about bringing them with you to your medical visits?"

DEVELOP SCRIPTS FOR STAFF MEMBERS TO USE

Noting the name and contact details of the family caregiver in the EHR is one of the most important tasks for ensuring their inclusion and engagement.

Scripts can help staff become comfortable establishing a friendly rapport with patients and their caregivers, while at the same time obtaining and recording important information. They can also be used to encourage patients and family caregivers to take advantage of resources that the clinic uses to ensure quality patient care. Have your staff try some of these scripts with your patients.

> "Hi, I'm Tracey, Dr. Wright's medical assistant. I see you have come with Mr. Smith today, and you are? Are you related to Mr. Smith? Do you assist Mr. Smith with otherthings at home?"

> "Mr. Smith, would you like us to give (family caregiver) information about your visit today and other information about your health? (If yes), Then we will need you to sign a Release of Information form for our records."

> "Did you know that you can have access on-line to your medical record? Our office uses MyChart as a portal through which patients can see information that is included in their medical record. It's really easy for you to sign up to use MyChart. All you have to do is fill out this form and chose a User ID and Password. Then you can get access to your medical record from any computer.
>
> I'd be glad to show you how to access your medical information through MyChart."

PROMISING PRACTICE: UNDERSTANDING WHAT MATTERS MOST TO PATIENTS

An on-going exchange of information between clinicians, patients and family caregivers is essential for making good decisions about treatment and care. Patient choice is a key to an effective plan of care (Fulmer et al, J Am Geriatric Society, 2017).

Working to understand a patient's values, goals, and motivations is sometimes called a "What Matters Most" conversation. They help explore what is important to the patient in addition to their health (e.g., children, family, pets, hobbies). Questions should focus on how treatment could facilitate or impede the patient's ability to do the things they enjoy (e.g., walking, cooking) or attain certain life goals.

These conversations may be most appropriate when there is a new diagnosis, treatment decision, or change in health status. They may also be held in conjunction with an annual wellness check or another extended visit. A patient's goals for their health and thus for their care, are likely to change as their health status changes, so regular conversations about what matters most are helpful.

To prepare for the discussion, patients can clarify their values as well as their health goals and care preferences. The conversations are more fruitful when patients reflect on goals and priorities in advance of a visit.

Team insights about the patient's values, goals, and preferences should be coordinated and shared. Regardless of who conducts the conversations, there should be a clear process for documenting them and sharing this information.

Operationalizing a system to understand, record, and act on what matters to older adults may require organizational culture change as well as training. Every care team member needs to know where to record conversations, and where to find documentation of previous conversations in the electronic health record.

SETTING UP POST-VISIT SUCCESS

The care team has an important role of extending care beyond the clinic visit, into the patient's home. The care team helps support both the patient and the family caregiver in receiving and providing safe, appropriate treatment. There are several things you and your staff can do during a visit to help ensure effective communication with the patient and family caregiver after the visit.

Using the Patient Portal

The care team can educate patients and family caregivers about the role of the patient portal in facilitating better communication and more responsive care. A team member can show patients and family caregivers:

- How to register and gain access
- What information is available
- How to exchange messages with team members including questions and concerns
- How to review after-visit summaries
- How to check scheduled appointments

> "Mr. Smith, did you know that your family caregiver can also have access to your patient portal? Because the portal gives users access to your medical information you must grant your family member access by signing a form. Then your family member can have their own login credentials and can use your patient portal to review the clinician's notes about visits, the medications you are taking, and follow-up care your clinician recommends."

It is especially helpful for family caregivers to have proxy access to the patient portal (Wolff et al, Breast Cancer Research and Treatment, 2019). Patients and family caregivers should each have their own credentials for portal access.

Promising Practice: Sharing Access to Full Progress Notes

Access to progress notes gives patients and caregivers a convenient place to find changes in the patient's health status and care plan. Improving a family caregiver's access to provider communication and patient information is likely to increase their engagement and confidence. Improved caregiver engagement can help keep patients out of the ED and/or other care facilities (Heath, 2017). Research suggests that sharing notes results in stronger relationships and better engagement with patients and family caregivers (OpenNotes.org).

Access to progress notes has a variety of benefits for the family caregiver including:

- Details about diagnoses and care plans
- Upcoming appointments and treatments
- Medication reminders
- Chronic disease management

OpenNotes.org has developed educational materials for clinicians, patients, caregivers and researchers about the importance of transparency and trust when sharing progress notes. Resources are available at www.opennotes.org.

Preparing to Care at Home

Family caregivers are often expected to complete tasks that were previously done by a medical professional. Support and training from the care team can improve their skills and increase their confidence.

INSTRUCTION AND DEMONSTRATION

It is helpful to provide written explanations and live instructions for tasks caregivers are expected to perform, such as medication management, wound care and transfers. Demonstrations, in the home or clinic, can help them see what they understand and areas where they may need additional help.

ADDITIONAL RESOURCES

There are many online and community resources that can provide additional support to patients and family caregivers. State Aging Services and Area Agencies on Aging publish comprehensive directories. Some of the organizations will have printed materials patients can take home. Among the many good online resources, some of the most helpful are listed below.

Patient and Family Caregiver Training

AARP's Prepare to Care program can be downloaded from: https://www.aarp.org/caregiving/prepare-to-care-planning-guide/.

Websites curated by health care institutions, including the Mayo Clinic (https://www.mayoclinic.org/healthy-lifestyle/caregivers/basics/aging-parents/hlv-20049441) and Harvard Medical School (https://www.health.harvard.edu/staying-healthy/caregiver-nation-new-tools-to-manage-a-family-members-health-as-well-as-your-own), offer content devoted to caregiving tasks.

The Family Caregiver Alliance (https://www.caregiver.org) has a variety of webinars and videos under categories including Daily Care, Planning for Care and Self-Care. Topics range from dementia-proofing your home to caregiving through the holidays.

The National Association of Area Agencies on Aging (https://www.n4a.org/caregivers) website provides information for caregivers and links to local agencies for information and assistance.

The Home Alone Alliance has produced videos that can be found on AARP's website at Family Caregiving Video Series (www.aarp.org/nolongeralone). The videos are a joint project developed by the AARP Public Policy Institute and the Betty Irene Moore School of Nursing at UC, Davis. Currently videos are available in three categories: medication management, mobility, and wound care. Some of the most common issues about which video instruction is available include:

- Medication Management
    - Giving Insulin Injections
    - Organizing and Administering Pills

- Mobility
  - Preparing Your Home for Safe Mobility
  - What to Do When Someone Falls
  - Using a Walker or Cane and Navigating Stairs
  - Moving from a Walker to Shower or Bed
- Wound Care
  - Treatment of Skin Tears
  - Pressure Ulcers: Prevention and Skin Care

Additional videos are under development with two new series on managing incontinence and preparing special diets to be available soon.

Staff Training

There are resources designed to support your staff in educating patients and family caregivers. Written Resource Guides are available on the Home Alone Alliance website: www.aarp.org/nolongeralone. In addition, a series of articles was published in the American Journal of Nursing in 2018. The Supporting Family Caregivers: No Longer Home Alone series includes guides written to help nurses provide family caregivers with tools to manage their loved one's health care at home. Each article includes an informational tear sheet and links to educational videos for caregivers. Topics that are currently available can be found at https://journals.lww.com/ajnonline/pages/collectiondetails.aspx?TopicalCollectionId=38 and include:

- Teaching Wound Care to Family Caregivers
- Caring for Aging Skin
- Preventing Falls and Fall-Related Injuries at Home
- Teaching Family Caregivers to Assist Safely with Mobility

Future Developments

A number of practices discussed in this guide were particularly helpful to providers, patients and caregivers' who tried them. More study and wider adoption may yield positive results. There are also some areas that may prove fruitful for future attention.

- Family Caregiver Assessment
- CARE Act implementation
- Family Meetings
- Planning Ahead for Caregiving

FAMILY CAREGIVER ASSESSMENT

When the patient/family caregiver dyad is viewed as the "unit of care," both members of the dyad can be assessed and receive the appropriate care and support.

Caregiver assessment can involve a systematic process of gathering information to identify their skills, needs, and resources. Assessment can be performed by the provider or other team members. It can be informal or formal.

Informal Assessment

- Providers can help assess the family caregiver's burden. This can start with a simple conversation and may include suggesting a more formal assessment
- In addition to documenting a patient's family caregiver, some providers also identify the family caregiver's provider
- When all family members see the same provider, it may be easier for the provider to get a more complete understanding of the health of both members of the dyad and to share each other's health information with both members
- Shared medical appointments can be a place in which to bring patient and family caregiver together with the focus being on both members of the dyad. When the patient is getting one type of assessment (e.g, HbA1C), the family caregiver could be doing a caregiver burden assessment; completing a PHQ9 for example

> "*Identifying* those in need of support and then finding ways to help them *(family caregivers)* should be added to the list of the things that ***professional caregivers*** should do at every opportunity."
>
> *-Barry Jacobs CFHA blog 2019*

Formal Assessments

The experience of informal caregiving can be stressful and create psychological as well as physiological impacts to loved ones of chronically ill older adults. Caregiver burden may not be recognized by the caregiver and yet they need help in relieving the stress causing it.

A more systematic means for identifying family caregivers' burden may be warranted (Bevans and Sternbert, J Am Medical Association, 2012). Although assessment processes may seem cumbersome to use, there are several assessment tools available that can be adapted to most clinic practices.

Practice guidelines have been incorporated in the Guided Care model and promoted by numerous national organizations.

- Suggestions for practical questions to ask in the in-office setting are offered in the Tool Kit from the Family Caregiver Alliance that can be found at https://www.caregiver.org/caregivers-count-too-toolkit
- The Modified Caregiver Strain Index can be found at Onega LL (2018) https://consultgeri.org/tools/try-this-series
- The adapted Zarit Burden Interview is another validated tool that can be used to assess caregiver burden; see appendix (The Gerontologist, 41(5):652-657. https://bit.ly/2Hso3qt)

Comprehensive caregiver assessments should cover six domains:

- Context
- Caregiver's perceptions of care receiver's health
- Caregiver's values
- Caregiver's well-being
- Skills needed to provide care
- Potential resources

(https://www.caregiver.org/national-consensus-report-caregiver-assessment-volumes-1-2).

THE CARE ACT

The CARE Act is named for the essential activities recommended for all patients experiencing a hospitalization – Caregiver Advise, Record, and Enable. It has been adopted by 42 states and requires hospitals to:

- Identify the CAREGIVER, the unpaid informal family member or friend who helps the patient
- ADVISE individuals of their opportunity to identify a family caregiver
- RECORD the caregiver's name and contact information in the health record (with the patient's permission)
- ENABLE family caregivers by providing as much notice as possible about discharge timing, consulting with them about the discharge plan, discussing their role in carrying out that plan, and instructing them about the medical/nursing tasks they will handle at home

Since passage of the CARE Act, researchers have conducted site visits to study its implementation. Hospitals report that the process helped them recognize the benefits of standardizing, expanding, and formalizing their identification of and interactions with family caregivers. Hospital staff report that family caregivers were more engaged and confident when taking the patient home. They noted that when engagement of the family caregiver happened early, family caregivers were more likely to ask important questions (Reinhard et al, AARP, 2019). These same benefits could be realized if the essential elements of care planning were implemented in ambulatory care.

> Having willing family caregivers is just the first step toward enabling older adult patients to live in the community, outside of assisted care facilities. These family caregivers must be prepared and capable of performing these tasks required to keep their loved one safe and as healthy as possible.

BUILD IN OPPORTUNITIES FOR FAMILY MEETINGS

Patients may have more than one family caregiver. Communication between multiple, sometimes competing perspectives of family members can be a challenge for the care team. Family meetings either before or after medical appointments can help keep everyone on the same page.

- Include family caregivers in conjunction with an annual wellness visit or a new patient chronic care management visit
- Invite patient to bring multiple family caregivers to accompany them over the course of several appointments
- Suggest the frequency of family meetings that will facilitate two-way exchange of important information about the patient’s health status

PLANNING AHEAD FOR CAREGIVING

It can be helpful for patients to plan ahead for the assistance they may need with other aspects of their lives. As providers and care team members are talking with patients about advance care planning, they can broaden the discussion to include logistical tasks the patient may need to address if they are facing hospitalizations or required stays at skilled nursing facilities. It can help reduce stress for the family caregiver to know that arrangements have been made for mowing the lawn, shoveling the walks in winter, and feeding pets.

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Appendix I: Resources for Family Caregivers

Websites maintained by health care institutions offer content about caregiving tasks:

- Mayo Clinic (https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/Mayo Clinichlv-20049441)
- Harvard Medical School (www.health.harvard.edu/staying-healthy/attention-caregiversmaking-use-of-helpful-services),

The Family Caregiver Alliance (https://www.caregiver.org/resources-health-issue-or-condition) has a variety of webinars and videos under categories including Daily Care, Planning for Care, and Self-Care. Topics range from dementia-proofing your home to caregiving through the holidays.

The National Association of Area Agencies on Aging (https://www.n4a.org/caregivers) provides information for caregivers and links to local agencies for information and assistance.

AARP's Prepare to Care program is a valuable resource with helpful tips on how to have vital conversations with older family members, organize important documents, assess your loved one's needs and locate important resources. A guide to AARPs Prepare to Care can be downloaded from: https://www.aarp.org/caregiving/prepare-to-care-planning-guide/.

The Home Alone Alliance has produced videos that can be found on AARP's website at Family Caregiving Video Series (https://www.aarp.org/ppi/initiatives/home-alone-alliance/).

The videos currently available include Medication Management, Mobility, and Wound Care.

- Giving Insulin Injections
- What to Do When Someone Falls
- Treatment of Skin Tears
- Pressure Ulcers: Prevention and Skin Care
- Organizing and Administering Pills
- Using a Walker or Cane and Navigating Stairs
- Moving from a Walker to Shower or Bed

Alzheimer's Association General Caregiver's Landing Page https://alz.org/help-support/caregiving

- Stages and Behaviors
- Early-Stage Caregiving
- Middle-Stage Caregiving
- Late-Stage Caregiving
- Activities
- Daily Care Plan
- In-Home Care
- Planning for Care Costs
- Caregiver Health
- Care Training Resources
- Support Groups
- Communication and Alzheimer's
- Safety
- Planning Ahead for Legal Matters
- Residential Care

Utah Commission on Aging has resources for family caregivers ucoa.utah.edu

Appendix II: Background to the CCPP Project

The need to care for our aging population highlights the critical place family caregivers hold in our society. The importance of a sustainable cadre of family caregivers has been demonstrated through several recent studies.

Although family caregivers, patients and clinicians each have unique and different points of view, by better understanding one another's perspectives, they will come to recognize the challenges each face and to realize they ALL ultimately are striving for the same outcome – better care and higher quality of life for everyone: patients, caregivers and clinicians.

HISTORY OF CCPP

Our journey began as a result of our personal experiences with caring for our parents and loved ones through their struggles with chronic diseases and aging. We applied for and received awards from the Patient Centered Outcomes Research Institute (PCORI) to support two projects, Taking Care of Our Parents and Creating Caregiver Provider Partnerships, designed to understand the challenges faced by family caregivers and clinicians and explore solutions that might be helpful.

This Guide is a culmination of more than 5 years of getting to know individual family caregivers, the loved ones they care for, the clinicians who care for them as well as researchers and support service providers who are all interested in reducing the burden of family caregivers. We gathered information about what caregivers felt was missing in their interactions with clinicians and what would help them do the tasks of caregiving more effectively. We developed lists of areas that could be improved and from those lists we distilled down to the few areas we thought would have impact and be most meaningful to our stakeholders; not just patients and their caregivers, but also clinicians and their teams.

The focal point for this work to date is the integration of family caregivers into primary care practice. Thus, the process of Creating Caregiver Provider Partnerships has been to learn everything we could about the experiences of family caregivers and professional healthcare clinicians and the challenges and opportunities faced in trying to integrate family caregivers into primary care practice. Our aim has been to identify promising practices, specifically around communication and clinic work flow processes, that have the potential to contribute to the development of a true partnership between professional care teams and informal family care teams. Through these partnerships we envision that family caregivers will be better able to reap the rewards of caregiving while managing the stresses and burdens, and that members of the professional care team will experience increased joy in practice.

A number of practices have emerged that we believe can make a difference for clinicians, patients, and family caregivers. From our dialogues with patient/family caregivers and clinical practice teams we believe that these strategies are straight-forward to implement and will have beneficial outcomes for both family caregiver/patient dyads and professional care teams.

Appendix III: CCPP Advisory Board

RONNIE DANIEL - EXECUTIVE DIRECTOR
Alzheimer's Association Utah Chapter

JULIE DAY, MD - MEDICAL DIRECTOR
for Quality Improvement and Population
Health, Community Physician Group,
University of Utah Health

RACHEL DAY - FAMILY CAREGIVER
Technical Writer/Editor

ROB ENCE, MBA - EXECUTIVE DIRECTOR
Utah Commission on Aging
Bateman Horne Center

LEE ELLINGTON, PHD - PROFESSOR
Robert S. and Beth M. Carter Endowed Chair,
College of Nursing
University of Utah

TIMOTHY W. FARRELL, MD - AGSF
ASSOCIATE PROFESSOR OF MEDICINE
Adjunct Associate Professor of Family
Medicine
Director, Health Interprofessional
Education Program
University of Utah

LAURA HEALEY - FAMILY CAREGIVER

RACHEL HESS, MD, MS - CHIEF, DIVISION
OF HEALTH SYSTEM INNOVATION
AND RESEARCH
Associate Dean for Clinical and
Translational Science
University of Utah

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Salt Lake County Aging and Adult Services

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Association for Utah Community Health
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Comagine Health

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DEBRA SCAMMON, PHD, MS - EMMA
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David Eccles School of Business
Adjunct Professor, Family and Preventive
Medicine and Population Health Sciences,
School of Medicine
University of Utah

REBECCA UTZ, PHD -
ASSOCIATE PROFESSOR,
Dept of Sociology
Co-director, Consortium for Families
and Health
University of Utah

Comagine Health

David Eccles School of Business
THE UNIVERSITY OF UTAH

Taking Care of Our Parents