# CO-IMPACT Toolkit

Caring Others Increasing Patient EngageMent in Patient Aligned Care Teams

Resources for Building Patient-Care Partner-Healthcare Provider Partnerships in Diabetes Care The CO-IMPACT toolkit is based upon work supported by the Veterans Health Administration research study: VA Health Services Research and Development Grant IIR 14-074.

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# Introduction

Most adults with chronic health conditions like diabetes have family members or friends who are regularly involved in their medical and self-care. These 'family supporters' are an important resource who can help people with diabetes increase their confidence, their ability to manage diabetes day-to-day, and their active involvement in their healthcare. Many studies have shown that adults with active family supporters have better diabetes outcomes. However, healthcare teams lack structured and realistic approaches to work with family supporters of their patients.

The goal of the CO-IMPACT Program is to provide healthcare professionals with evidence-based, structured approaches to <u>working with patients' supporters</u> that improve patient engagement in care and health outcomes. This toolkit contains materials from the CO-IMPACT Program in a format that is flexible for use in various settings.

**Who Can Use These Tools?** The CO-IMPACT Program was designed to be used by healthcare professionals, adults with diabetes, or family supporters (called 'Care Partners' in this program). These materials were originally developed and tested for <u>adults with type 2 diabetes</u>, but they can be helpful for <u>adults with other types of diabetes or other chronic health conditions</u>.

# Definitions

Adult/Person with Diabetes	The person with diabetes whose care is being supported. The CO-IMPACT Program puts the person with diabetes in charge – they direct how Care Partners and healthcare professionals can best support them.
Care Partner	Unpaid adult family or friend supporter who volunteers to learn about helping the person with diabetes.
Healthcare Professional(s)	Any healthcare professional who helps care for adults with diabetes. This can include physicians, nurses, dietitians, educators, and community health workers.
Health Coach	A healthcare professional who is trained to coach patients in setting and working towards health behavior goals. In the study of the CO-IMPACT Program, a health coach delivered some of the tools.



# Why Involve a Care Partner in Diabetes Management?

Adults who have a Care Partner involved in their healthcare are better able to stick to their daily health regimen, communicate more effectively with healthcare professionals, and have better health (with fewer complications) in the long run. Importantly, most adults with chronic health conditions *want* their healthcare professionals to involve their family and friend supporters in their care.

Our research with adults with diabetes - who do <u>not</u> have significant physical or cognitive impairments - showed that Care Partners are actively involved in health tasks for the majority of these patients. Care Partners often help with these tasks:



Managing and using medications



Checking blood sugars or blood pressure at home



Making day-to-day decisions about self-care or illness



Tracking clinician recommendations & sharing information with other healthcare professionals



Navigating the health system

### In a study of Veterans with high-risk diabetes, we found:

- Over half had a Care Partner who regularly helped them prepare for medical visits.
- Almost three-quarters regularly discussed the medical visit with a Care Partner afterwards. However, nearly 80% were not confident they remembered the content of the visit correctly.

### In surveys and interviews of Care Partners of adults with diabetes, many reported feeling limited by:

- Not knowing what questions to ask the patient on a day-to-day basis about their diabetes.
- Lack of confidence in helping with more technical tasks like injecting insulin and using home glucometers.
- Lack of information about:
  - the patients's health status (e.g., blood test results)
  - what healthcare professionals are recommending to the patient (e.g. changes in medication regimen, recommended tests)

Read more about this topic in our paper: <u>Rosland et al, Diabetic</u> <u>Medicine, 2016</u>

Read more about this topic in our papers:

Rosland et al, Families, Systems& Health, 2012

Lee et al, Diabetes Care, 2018



# **Care Partners as Supporters**

The CO-IMPACT Program intentionally uses the term 'Care Partner' rather than 'caregiver' to refer to the supporters of people with diabetes. Although similarities exist, Care Partners differ from caregivers in that they may not be directly or physically *taking care of* the patient. Instead, their role is to *support* the patient in diabetes management while respecting the autonomy of the patient.

### The person with diabetes is in charge of his or her health and should be in the lead.

For patients capable of making their own health decisions, Care Partners play an important role in helping the patient—but without taking over. A critical component of the CO-IMPACT Program is training Care Partners how to be positive, and communicate in ways that support patient ownership of their health and healthcare.

### Who makes a good Care Partner:

In our work we've found that Care Partners come in many forms. Here are some tips for helping patients select a Care Partner:

- The ideal Care Partner is someone who talks with the patient regularly, and with whom the patient already feels comfortable sharing health information.
- A Care Partner can be any adult family member of friend the patient chooses. They do not need to be a 'blood relative'.
- Care Partners can live with the patient, or close by, but they can also live at a distance. Care Partners can participate remotely through phones, tablets, and computers.
- Choose adults as Care Partners, not children or teens.
- Care Partners do not need to have medical training or experience, as long as they are willing to learn more about the patient's health needs.

### The CO-IMPACT Program tools give Care Partners:

- Skills to promote and support patient-centered ("autonomy supportive") care and patient engagement in care.
- Guides for structuring pre, post, and between-visit discussions with patients.
- Information on how to handle diabetes 'medical' issues at home.
- Orientation to 'who's who' on the patient's healthcare team and best way to reach them.
- Clear methods for relaying patient information and Care Partner questions to and from the patient's healthcare team.





# Fundamentals of Patient – Care Partner – Healthcare Provider Teamwork

The following files contain educational materials that can be used as handouts for healthcare professionals, patients, or Care Partners. We recommend that they be used in conjunction with diabetes self-management education and support (DSME/S). Documents for this section are provided in the appendix.

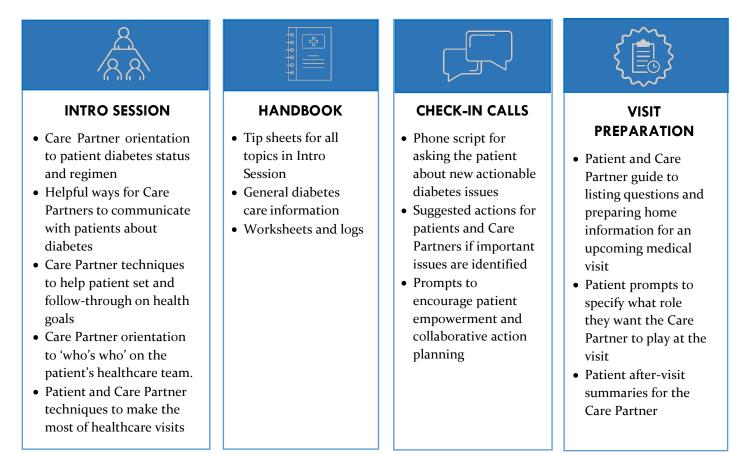
DOCUMENT	CONTENT	
Information and Tips for Healthcare Professionals Working with Care Partners	Potential benefits to healthcare professionals when involving Care Partners in patient care Tips on interacting with Care Partners during appointments and phone calls	
Guidelines for Weekly Patient-Care Partner Talks about Diabetes	<u>Recommendations for the patient and Care Partner's weekly talks</u> <u>about diabetes</u>	
Teamwork Tips for • Patients	How to talk with Care Partners about health	
Teamwork Tips for • Care Partners	What is a Care Partner and when to contact the patient's healthcare team	
•	Getting the conversation about diabetes flowing	
•	Tips for positive and helpful conversation	
•	Dos and Don'ts for supporting the patient's autonomy	
•	Examples of supportive Care Partner comments	
•	Additional ways to help with diabetes care	
Interacting with •	Patient role as an engaged member of the healthcare team	
Healthcare Professionals	Getting the most out of appointments for <u>Patients</u> & <u>Care Partners</u>	
•	Tips on how to follow-up on plans made during appointments, and when to call providers between appointments for <u>Patients</u> & <u>Care</u> <u>Partners</u>	





# Program Tools

The CO-IMPACT Program included these four main tools:



How Do I Use These Tools? Each tool in this toolkit can be used in part or in whole, on its own or in combination with other tools. Each tool can be used during in-person or virtual care.

In the CO-IMPACT Program, adults with diabetes and their Care Partner received each tool in sequence over one year. However, selected tools or parts of tools can be used during a single patient care or education session.

Later in this toolkit, we describe the content of each tool in detail, how healthcare professionals might use these tools, and how the tool was used in the original CO-IMPACT Program with recommendations from the original CO-IMPACT Health Coaches.



# **Intro Session**

**Description:** The Intro Session addresses these goals with the Patient – Care Partner pair:

- Care Partner orientation to patient diabetes status and regimen
- Helpful ways for Care Partners to communicate with patients about diabetes
- Care Partner techniques to help patient set and follow-through on health goals
- Care Partner orientation to 'who's who' on the patient's healthcare team.
- Patient and Care Partner techniques to make the most of healthcare visits.

### How healthcare professionals can use this tool:

Healthcare professionals could complete the full session with the pair, or they could use selected visuals or materials they believe would be most beneficial to the person with diabetes or their Care Partner. The material can be shared via printout, screen display, or electronic document.

DOCUMENT	CONTENT and USES	
Slide Deck and Healthcare Professional Script	<ul> <li>These layperson-friendly visuals introduce the pair to the idea of Patient-Care Partner partnership, then cover every topic in the Intro Session.</li> <li>The accompanying script suggests phrasing for healthcare professionals to use to describe each visual or topic.</li> <li>The slides and script indicate helpful points to use the other Intro Session Materials.</li> <li>The <u>Participant Handbook</u> also contains similar visuals. Participants can follow along in their handbook during the session if they cannot see the slides, or if they want to take notes.</li> </ul>	
Diabetes Health Profile	• The profile discusses items that impact the patient's diabetes complication risk status: most recent HbAic, blood pressure, lipid levels, and smoking status. It also summarizes the latest diabetes plan based on medical record notes and prescriptions. It is designed to bring the Care Partner up to speed on the patient's situation, and to help the pair identify areas to work on for their first goal.	
'Best Phrase' Activity Cards	• This game helps participants learn and reinforce the 'dos and donts' for communicating with each other about diabetes.	
Action Planning Worksheet	• This worksheet guides participants through the steps for setting a diabetes goal and SMART action plan, with a role for their Care Partner.	

### Intro Session Materials\*

\*Full Intro Session materials can be downloaded at: <u>https://www.complexcaring.pitt.edu/intro-session</u>





### How the Intro Session was used in the original CO-IMPACT Program:

To kick off the Program, the CO-IMPACT health coach met with the pair for a 60-minute session. If the Care Partner was unable to attend in person, they participated via speakerphone or video call.

### **Recommendations from the original CO-IMPACT Health Coaches:**

- Provide the patient with a clear picture of what they and their Care Partner can do to lower their risk of diabetes complications.
- Chat with the pair to assess the patient and Care Partner's existing knowledge of diabetes self-management, and current Care Partner roles. Take the opportunity to note items that resonate with the pair and use these as examples to guide their first Action Plan.
- Ask open-ended questions and use reflection (repeat and rephrase what the patient and Care Partner say) to ensure clarity and promote integration of ideas. Provide positive affirmations for any level of interest and engagement with the material and process.
- Focus on the pair's strengths. Point out what they are already doing well; then talk about build on those strengths to work together even more effectively.
- Keep the sessions as interactive as possible. Consider splitting the content into multiple sessions to allow time for more interacting, discussing experiences, and reflecting on the material.
- Model positive communication techniques. Praise instances when one person in the pair demonstrates positive communication during the session.

I was able to sit there and I was finally included. I didn't know somethings so I learned a lot and I was able to ask questions.

--Care Partner on CO-IMPACT Intro Session

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# Handbook

### **Description**:

The patient-Care Partner handbook contains useful information on diabetes care support that was generated by our research, and serves as a reliable reference for patients and Care Partners.

### How healthcare professionals can use this tool:

Healthcare professionals can give patients and Care Partners the entire handbook, or just selected sections that the provider feels would be most helpful to the pair. Handbook sections are in portable document file (pdf) format and can be printed or sent as electronic attachments. The material will be available in a patient-friendly website format in late 2021.

### Handbook Content\*:

SECTION	CONTENT	
Diabetes Health Information with Care Partner Roles	Sick days Sugar levels Blood pressure Medications	Smoking Foot care Helpful internet links
Action Planning with Care Partner Support	Planning to make healthy changes Make a SMART plan Examples of SMART plans Action planning worksheet	
Patient-Care Partner Teamwork	Tips for Patients: Talking with Care Partners about health Tips for Care Partners: Getting the conversation flowing, positive and helpful conversations	
Partnering with Healthcare Professionals	Getting the most out of appointments for patients and Care Partners Visit planning worksheet Patient event worksheet Between appointments for patients and Care Partners	
Logs and Charts	Blood sugar and blood pressure log Medication chart	

\*Handbook content can be downloaded at: <u>https://www.complexcaring.pitt.edu/handbook</u>





### Handbook

### How the Handbook was used in the original CO-IMPACT Program:

Patients and Care Partners were given the handbook at the Intro Session, then they were referred to it throughout the 12-month Program. For example, our automated check-in calls referred patients to specific handbook sections for information on issues identified during the call. Care Partner messages also referred to handbook pages to help address specific diabetes issues. The final pages of the handbook contain worksheets and logs that patients and Care Partners were encouraged to use throughout the Program.

### **Recommendations from original CO-IMPACT Health Coaches:**

- Instruct the patient and Care Partner team to store the handbook in a handy location for ongoing reference. This is especially helpful if the patient will be engaged in an ongoing program such as weekly talks with their Care Partner, visit preparation calls, or check-in calls.
- Give a separate handbook to the patient and Care Partner if they do not live together.
- Offer patients and Care Partners multiple copies of the logs to take home.

It gave us some of the tools to start looking at it from a different perspective and made us put it more to the forefront and gave us some tools at least thinking in the right direction.

-- Care Partner on CO-IMPACT handbook

"



# Check-In Calls

### **Description:**

This tool consists of scripts that can be used for regular telephone check-ins with patients. The scripts use customized, branching logic designed to:

- Monitor how well the patient is managing their diabetes and identify actionable diabetes issues.
- Ask questions about recent blood sugar and blood pressure readings, symptoms of high or low • sugars, problems with taking or filling medications, sick days, and new foot problems.
- Offer suggestions to the patient and Care Partner about how they can address any issues • identified during the call.
- Provide customized feedback to empower the patient and encourage collaborative action • planning with their Care Partner.

### How healthcare professionals can use this tool:

- This script was originally programmed to be delivered via automated phone calls. It could also be adapted to other automated systems using SMS (texting) or smart phone apps.
- Professionals could read the script out loud when calling patients to check-in with them . between medical visits or diabetes education sessions.
- Providers could also incorporate the tips from the Care Partner messagages during in-person healthcare appointments or phone calls that include the Care Partner.

CONTENT	EXAMPLES
Graphical Flow of Automated Calls	<ul> <li>Flowchart of all topics addressed during automated calls</li> <li>Detailed flowchart of one example topic (e.g., high sugar levels)</li> </ul>
Example from Automated Call Script	• Sample automated call script for one topic (e.g., high sugar levels)
Example Summary Email for Care Partners	• Sample of summary sent (via mail or email) to Care Partner after a completed call

### Check-In Call Content\*:

\*Check-in call content can be downloaded at: <u>https://www.complexcaring.pitt.edu/check-calls</u>



### How Check-In Calls were used in the original CO-IMPACT Program:

Patients received an automated call lasting 10-15 minutes every other week. During the call, the patient was prompted to report their diabetes self-management activities and data such as recent blood sugar and blood pressure readings, their current supply of prescribed medications, and any foot problems.

Responses were automatically tailored to provide positive feedback or identify potential issues and provide issue-specific recommendations. When an issue was identified, the patient was asked if they wished to work on addressing the issue over the following two weeks, and if so, they were encouraged at the end of the call to make an action plan with their Care Partner.

Following the call, the system generated a summary of data reported by the patient, issues identified, issues the patient wished to work on, and advice on how the Care Partner could help the patient with the issue. These tips were drawn from information also included in the CO-IMPACT handbook. This summary was automatically e-mailed to the Care Partner.

### **Recommendations from original CO-IMPACT Health Coaches:**

- Identify what modes of communication (mail, email, text, recorded phone message) the Care Partner prefers. Some Care Partners in our program used email but many did not.
- Allow patients to put calls on hold for a few weeks, or until patients returned to actively working on their diabetes regimen. Some patients grew bored with the automated phone calls as the script did not change over several months. Consider adapting the script to change content or frequency of calls in response to the pattern of patients' responses.
- Proactively follow-up with the patient if they miss three consecutive calls. They may have a new phone number, a new schedule, or they may have accidentally blocked the system.

Being in the study made us both a lot more aware about diabetes in general and different treatment options available...now she's more involved and she knows my medications and what they're for. -- Patient on how they work differently with the Care Partner after CO-IMPACT

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### **Description:**

Visit Preparation calls encourage patients and Care Partners to identify questions and concerns that they would like to discuss with the patient's healthcare professional in advance of the patient's next appointment or educational session. During the calls professionals:

- Guide patients and Care Partners in listing questions and preparing home information for an upcoming medical visit
- Prompt patients to specify what role they want the Care Partner to play at the visit
- Explain that they will send the patient's after-visit summary to the Care Partner

### How healthcare professionals can use this tool:

- Introduce the concept of Visit Preparation to the patient and Care Partner. Provide the "Getting The Most Out Of Appointments" hand-outs and the Visit Planning Worksheet.
- Send patients and Care Partners messages to prompt them to use the worksheet on their own before upcoming visits. Alternatively, have a team member call the patient (and Care Partner if possible) to guide them through preparing for the visit.
- If staffing is limited, prioritize patients who might particularly benefit from Visit Planning calls. Those with recent health events such as hospitalizations, changes in their medical regimens, or those doing active home monitoring may particularly benefit.

DOCUMENT	CONTENT and USES
Visit Preparation Calls Script	<ul> <li>The script is used when healthcare professionals call the patient about an upcoming appointment.</li> <li>Teach the patient how to identify, prioritize, and write down, their main questions to discuss with their provider.</li> <li>Coach the patient on how to best bring up their main questions or concerns during the appointment</li> <li>Optional sections including role playing and discussion of the Care Partners role at the upcoming appointment (if they are attending).</li> </ul>
Visit Planning Worksheet	• Patients are encouraged to complete the worksheet at home and take it with them before their upcoming appointment
Getting the Most Out of Appointments	<ul> <li>Tips for Patients and Care Partners to think about before the appointment</li> <li>Tips for Patients and Care Partners to follow up on after the appointment and what to before the next appointment</li> </ul>

### Visit Preparation Call Content\*:

\* Visit Preparation Call materials can be downloaded at: <u>https://www.complexcaring.pitt.edu/visit-preparation</u>





# > Visit Preparation

### How Visit Preparation was used in the original CO-IMPACT Program:

Health coaches used the Visit Preparation Script during call completed about a week before each primary care appointment. Patients and Care Partners were asked to have their visit preparation worksheet available during the call. If the Care Partner was available and the patient agreed, they would join the call by speakerphone, another phone on the same line, or 3-way call.

### **Recommendations from original CO-IMPACT Health Coaches:**

- Encourage patients to get the most out of these calls by suggesting they write down their 'agenda' for their medical visit during the call. Pause to allow them to get writing materials, and encourage them to complete the visit preparation in a place where they can write comfortably.
- Ask open-ended rather than yes/no questions. For example, patients would be more engaged if the health coach asked, What would you like to discuss at your visit? rather than Do you have any concerns for the doctor?
- Encourage the patient to ask their Care Partner to join the call when possible. If not possible, at the end of the call encourage the patient to go over the worksheet with their Care Partner and ask if they have anything to add.
- Ask for patient permission to send a copy of any 'after-visit summaries' to the Care Partner.
   Send a summary separately to the Care Partner, even if they live with the patient.

Before...if [the patient] had a question I wouldn't know what to do. I didn't know what to look for. The program taught me so much to watch for and prepared me to help answer his questions.

-- Care Partner on how they work differently with the patient after CO-IMPACT



### **CO-IMPACT STUDY PROTOCOL**

Rosland AM, Piette JD, Trivedi R, et al. Engaging Family Supporters of Adult Patients with Diabetes to Improve Clinical and Patient-Centered Outcomes: Study Protocol for a Randomized Controlled Trial (Trials, 2018). pubmed.ncbi.nlm.nih.gov/30041685

### **VA CAREGIVER SUPPORT PROGRAM**

The VA Caregiver Support Program provides support and online resources for those who care for Veterans. www.caregiver.va.gov

### **CO-IMPACT PROGRAM CONTACT INFORMATION**

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# Appendix

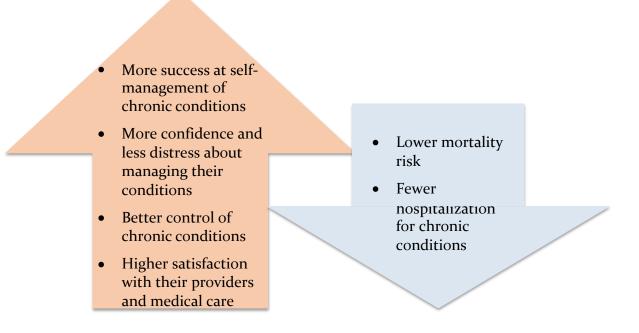
# INFORMATION AND TIPS FOR HEALTHCARE PROFESSIONALS WORKING WITH CARE PARTNERS

#### POTENTIAL BENEFITS WHEN INVOLVING CARE PARTNERS IN PATIENT CARE

For patients with chronic conditions (such as diabetes, heart failure) who do not have severe cognitive or physical limitations:

- 50-75% have regular family involvement in key self-management activities
- 50% regularly bring family members into the exam room

In general, patients with family involvement in health care have:



Chronically ill patients involve family members more often when the family member is familiar with doctors and nurses, and when the patient has:

- Low health literacy
- Depressive symptoms
- Multiple chronic illnesses

### INFORMATION AND TIPS FOR HEALTHCARE PROFESSIONALS WORKING WITH CARE PARTNERS - INTERACTING WITH CARE PARTNERS DURING VISITS OR PHONE CALLS

Adapt for patient needs, patient-family member dynamics, and the clinical issues addressed

#### BASIC

- Directly welcome family member at the beginning of the visit
  - o Invite family members in the waiting room into the exam room
- Encourage patients to bring involved family members to all visits
  - o Encourages family member familiarity with care team
  - o Family members often prioritize visits differently than providers would
- Patient as primary communicator when possible
  - o Patient describes concerns, symptoms, or thoughts about decisions first
  - o Offer papers, handouts to patient first
  - Patient hears new information first
- After talking to patient, specifically address the family member
  - "Do you have anything you'd like to add to that?"
  - "Are there any other concerns you'd like us to discuss today?"
  - o Quickly check with patient after family member describes a concern
  - When responding to family member concerns, try to maintain a 3-way conversation (you patient family member)
- Use same communication skills with family members that we use with patients
  - Establish rapport
  - Open ended questions at first
  - Empathy
  - o Point out discrepancies / disagreements in a neutral way

#### ADVANCED

- Encourage family members to use "autonomy supportive" techniques at home
  - Empathy, choices, problem solving, gentle reminders of rationale, praise small successes
  - o Reduce controlling, criticizing, guilt provoking language
- Family members can set SMART goals for how they will support patient

#### BARRIERS

- Privacy
  - In Person Ask patient for verbal permission and document in progress note (no specific format) the first time
    - Repeat for phone, letters, secure messages if needed
  - Let patient take the lead on discussing potentially sensitive issues
    - Urology, women's health, mental health
  - Can ask family member to step out for sensitive topics or exam

# **Patient - Care Partner Teamwork**

## **Guidelines for weekly talks**

It is helpful if the two of you talk regularly about the patient's diabetes care, either on the phone or in person. We recommend that you talk once a week so that you can go over the report from the patient's most recent CO-IMPACT automated call and any action plans the patient tried in the last week. Below are some guidelines for your weekly talks.

- 1. Try talking about diabetes care on the same day of the week and at the same time of day. This will help you both establish a routine.
- 2. Try to focus on the patient's health care for at least 10 minutes.
- 3. Over the course of a week, although you may talk about other family matters, what's in the news, or other interests you share, be sure to reserve a regular time to review the recent diabetes call summary or visit summary.
- 4.. Make sure that you don't feel rushed. Try to focus your full attention on the conversation without being distracted by other things such as children, work, or television. Some people find that making a written list of things you want to cover before the conversation can be helpful.



A. Piacquadio (photographer). Joyful adult daughter. [Digital image]. Retrieved from //www.pexels.com/photo/joyful-adult-daughter-greeting-happy-surprised-senior-mother-in-garden-3768131/

# **Tips for Patient Partners: Talking** with Care Partners About Health

• These conversations are meant to focus on how YOU are doing with your diabetes self-care.

Even if it feels a little uncomfortable at first, it is important to focus on your own health rather than other things that you both might like to discuss. After you've reviewed your health assessments and talked about your diabetes self-care, you can move on to other topics. Remember, your Care Partner has agreed that this is important.

### • Remember that your Care Partner is trying to help.

Even if you don't always agree with advice your Care Partner gives, try to listen carefully and be respectful.

#### • No one can manage their diabetes perfectly.

Everyone misses medications or eats things they probably shouldn't from time to time. It is very important to be as honest as possible with your Care Partner about how you are doing. Even if you are a little embarrassed or worried that they'll be disappointed, try letting your Care Partner know about the things that might not be going so well. Your Care Partner is there to help!



RODNAE Productions (photographer). Women drinking coffee. [Digital image]. Retrieved from //www.pexels.com/photo/man-people-woman-coffee-8124245/

• Do your best to come up with ideas and solutions to problems on your own, and then discuss them with your Care Partner.

YOU are the best person to know what will and what won't work, but sometimes it can be helpful to talk through the options with someone. If you don't know what to do, don't worry. You and your Care Partner can work on it together.



Light bulb [Digital image]. Retrieved from //creazilla.com/nodes/33377-light-bulb-clipart

• Agree on action plans with your Care Partner and try them out.

Try to be honest if you have doubts about your ability to follow-through on ways to meet your goals and come to an agreement with your Care Partner about what might be best to try. If things don't work out, you can discuss why it didn't work the next time that you talk and make a change of plans.

### What is a Care Partner?

Many people with diabetes have someone in their lives who helps them, or who would be willing to help them, manage their health conditions. These Care Partners are often family members or friends. A Care Partner might help their Patient Partner manage their health conditions by helping the Patient Partner:

- monitor how they are doing
- maintain healthy routines
- solve problems they may be facing
- communicate with their health care team

Care Partners do not 'take over' the patient's self-care. But they can support the patient in ways that the patient thinks will be helpful.



A Care Partner is <u>not</u> expected to counsel their Patient Partner about issues that they should discuss with their doctor or nurse. But Care Partners can play a vital role to help their *Patient Partner* choose a plan with their *health care team*, and follow that plan.

RODNAE Productions (photographer). Happy elderly couple. [Digital image]. Retrieved from //www.pexels.com/photo/portrait-of-a-happy-elderly-couple-5637731/

# Tips for Care Partners: When to contact the Patient's medical team

As a Care Partner, you can play a key role in helping your partner to remember upcoming medical appointments, knowing when to contact their healthcare team, and finding programs or resources that might help them tomanage their health.

We suggest that you support your Patient Partner in contacting their doctor or nurse themselves, whenever possible. Remember, your partner is in charge of their diabetes care, and their health care team can be much more helpful if they can ask the patient directly about any symptoms or other problems they are experiencing.

Being a Care Partner does not mean that you should give advice to your partner about changing or stopping medications. If you and your Patient Partner are wondering if medications should be changed, discuss this with the patient's doctor or nurse.



ffgimages (photographer). Elderly Hands Clasped Together [Digital image]. Retrieved from //www.canva.com/media/MAEaGcdHuAo

# Tips for Care Partners: Getting the Conversation Flowing

**Open-ended questions** will give you much more information than yes/no questions. Try asking questions like:

- "What's going on with your diabetes care now?"
- "What are you most concerned about this week?

**Reflective comments** help someone know that you are really trying to understand what they're saying and encourage them to tell you more. You are really focusing on them and trying to put yourself in 'their shoes'. Reflecting your partner's statements doesn't mean you agree, but it gives you both a chance to make sure you are under-standing what the patient is trying to tell you. You might try using phrases like:

- "It sounds to melike you're feeling...."
- "Let me know if I've got this right, you tried to...."
- "It seems like you thought that it was really difficult to..."



Marcus Aurelius (photographer). Lovely couple smiling. [Digital image]. Retrieved from //www.pexels.com/photo/lovely-couple-smiling-while-looking-at-each-other-6787758/

# **Tips for Care Partners: For a Positive and Helpful Conversation**

One of the best things you can do to help is to LISTEN. It may not seem like much, but listening to your partner can often help them to be clear about what they are feeling. Sometimes just being able to talk with another person (like you) can help a person with diabetes think through what they need to do.

Listening to your partner can help them see what steps they can take to improve their health, and it can help you realize how you might help them.

It's sometimes easy to be critical if your partner doesn't follow through with their plan, or doesn't change in ways that would help them manage their diabetes better. However, if you criticize, judge, or ridicule someone with a chronic illness, that can make them feel discouraged. Having diabetes can be frustrating, so it's important that you do your best to encourage your partner whenever you can.



Try to accept that your partner is the one responsible for their diabetes care choices and actions. People tend to be more successful at living healthier when they feel that their motivation comes from within themselves, and they are free to choose what they feel are the best ways to stay healthy.

Kampus Production (photographer). Bench Man. [Digital image]. Retrieved from //www.pexels.com/photo/bench-man-couple-love-6838536/

### DO:

- Ask for your partner's ideas for ways to solve problems before offering your own.
- Offer your ideas as choices, instead of telling your partner what to do.
- Congratulate your partner for trying to change, even if they are not successful.
- Congratulate them for the changes they do make, no matter how small.
- Acknowledge that managing diabetes can be frustrating when they are having difficulties.



High five. [Digital image]. Retrieved from //creazilla.com/nodes/858949-high-five-clipart

• Try to really understand what they are feeling and going through before offeringany suggestions of things they might do.

### DON'T:

- Don't criticize or be judgmental your role is to listen, to encourage, to be available, to help remember, to troubleshoot, to be regular and consistent, and simply to be involved!
- Don't "take over." Sometimes you may feel that it would be easier if you did things yourself, rather than allowing your partner to take action. But this won't help your patient-partner in the long run. The best strategy is to be a helper, not the boss.
- Don't tell your partner what to do make suggestions, but ultimately it's their decision.

# Examples of Supportive Care Partner Comments

### DO express empathy and concern

• "I appreciate how hard it is for you to think about walking again today."

### DO offer choices

- "Would you like me to help plan the menu for this week?"
- "What are some ways that you think might help you remember to take that evening dose of medicine?

### DO acknowledge accomplishments, even small ones

• "It's great that you tried. Remember, even small steps can get you where you need to be over time."

### DO help with problem solving

• "This is the second time that you have run out of that diabetes medication. What ideas do you have about how to keep that from happening again?"

### When you suggest changes, explain why

• "Remember, the doctor explained that sugars going up over a short time means that you may be getting sick. When your sugars are that high we need to call the doctor's office to let them know. They may tell you to take extra insulin or check your sugars more often until they are back to normal."

### AVOID language that is controlling, criticizing, or guilt provoking :

Say: "Your doctor said that checking your sugar every day is an important way to keep track of your health. How are you feeling about that?"
(NOT: "You know the doctor told you to check your sugar every day! I don't know why you won't do what he says!")

# More ways to help your Patient Partner with diabetes care:

- Attend diabetes self-management education classes with your partner.
- Learn how to read nutrition labels and share what you learned.
- Know the signs and symptoms of high and low blood sugars and what to do about each.
- Help develop a system for taking medicines or doing blood sugar checks regularly.



Magda Ehlers (photographer). Assorted vegetables. [Digital image]. Retrieved from //www.pexels.com/photo/assorted-vegetable-lot-1300972/

- Help with foot checks if your partner has trouble.
- Consider using website information sources that end with .edu, .gov, or .org.
- Ask your partner if there are specific tasks they need help with.



- Avoid being the "diabetes police" this can cause hard feelings.
- Buy and make healthy foods; pack healthy foods for on -the-go eating.
- Offer to go with your partner to doctor visits to be an extra "ear."
- Offer to do physical activities with them that they enjoy.
- Share how their diabetes affectsyou. Clear the air but don't nag.

SHVETS production (photographer). Holding Hands. [Digital image]. Retrieved from //www.pexels.com/photo/happy-elderly-couple-holdinghands-while-crossing-on-the-pedestrian-lane-8972263/

# **Partnering with Healthcare Providers**

### Your healthcare team includes you!

**Being an active member of your health care team** is one way you can make sure you get good quality health care. Patients who talk with or call their primary care team when they have questions tend to be happier with their care and have better medical results.

Your team wants you to contact them when you have a problem or a question. Your questions help your health care team learn more about you. Your doctor's or nurse's answers to your questions can help you make better decisions, avoid medical harm, and get better health care results.



RODNAE Productions (photographer). People in Scrubs [Digital image]. Retrieved from //www.canva.com/media/MAEPviiyUdQ

# Getting the Most Out of Appointments: For Patients

How often do you leave a medical visit feeling satisfied that your healthcare providers heard your concerns and responded to them? Successful communication with your health care team requires effort from the patient and the doctor or nurse.

# Here are a few tips to consider:

- Make a list of questions or concerns you would like to discuss at your appointment. Mark the ones that are most important to address. Put your list in a place where it will be easy to remember to bring it with you..
- Ask your questions *at the beginning* of your visit. Start by asking the ones that are most important to you.
- If you do not have a chance to ask your questions at the beginning of your visit, tell your doctor you have a list of questions and ask when is a good time to share it.
- Consider giving the doctor a copy of your list so he or she can follow along.



National Cancer Institute (photographer). Discussion. [Digital image]. Retrieved from //unsplash.com/photos/dC\_KGjeCld8

### When you ask your questions:

**Don't downplay the symptoms or situation.** Remarks like "it's just a little cough" or "my pain really isn't a problem" might lead your doctor to the same conclusion. If your real fear is that your sister's lung cancer started with a similar cough, let the doctor know. If your pain is preventing you from getting any sleep, say so. Being up front with your doctor helps them understand your problem.

**Listen.** Take some deep breaths and focus on what the doctor is saying. Consider bringing a tape recorder or taking notes on paper. If someone else is with you at the appointment, ask them to take notes for you.

Ask for explanations. Don't hesitate to ask when words the doctor is using are unfamiliar or his or her instructions are not clear to you. Make sure you hear—and understand—the answers you get. Consider bringing someone to your appointment to help you understand and remember what you heard. If you don't understand or are confused, ask your doctor to explain the answer again.



Pixabay (photographer). Question Mark. [Digital image]. Retrieved from //www.pexels.com/photo/question-markon-chalk-board-356079/

Make sure you understand the next steps. It is very important to understand the plan that your doctor recommends. Ask questions!

# Getting the Most Out of Appointments: For Care Partners

Not all Care Partners accompany their Patient Partners to their medical appointments. If your Patient Partner wants you to attend, and it fits into your schedule, consider going to at least one of their VA primary care appointments.

Patients who are accompanied to medical visits by a trusted supporter often communicate better with their doctors and nurses. They are able to get more of their questions answered and remember more of the information they hear.

Also, when you attend your partner's appointment, you can get to know your partner's doctors and nurses. That might make it easier if you need to contact them in between your Patient Partner's appointments.

# Some tips for Care Partners attending medical appointments:

- Educate yourself about your loved one's condition. Use the Internet as a tool, but try to stick with reliable sources. You can ask doctors or nurses which websites they respect.
- Write it down. Have everything that's on your mind written down before you talk with the doctor. The more organized you are, the more help you can get. You can discuss with your Patient Partner what you both think should be on the visit planning worksheet you can find in the back of this handbook.



Ylanite Koppens (photographer). Silver Pen. [Digital image]. Retrieved from //www.pexels.com/photo/personholding-silver-retractable-pen-in-white-ruled-book-796603/

- Let your Patient Partner take the lead when possible. You can prompt your Patient Partner to use the question list that the two of you prepared before your appointment.
- It is best to ask questions at the beginning of the appointment. Talk about the most important concerns first. Be brief and stick to the point.
- After your Patient Partner is finished describing a problem or concern, you can fill in extra details.
- After your Patient Partner has finished asking their questions, you can add any of your own.
- If you disagree with your Patient Partner, try to point it out in a neutral and specific way. For example, "Hmmm. He used to check his sugar three times per day but when I look at his sugar log I only see numbers written down once per day." Don't overgeneralize or make accusations. (*NOT* "He is so lazy. He never tries to take care of his health.") Staying positive is helpful to everyone.
- If the doctor or nurse gives recommendations, make sure you and your Patient Partner understand. Don't hesitate to ask when the instructions are not clear. Make sure you understand what the next steps are.



studioroman (photographer). Senior Couple Talking to Doctor Online. [Digital image]. Retrieved from //www.canva.com/media/MAEMkrC1kJo

- Help the doctors and nurses understand your role. If there are certain parts of health care you help with, or certain health information you keep track of, tell the doctors and nurses. Make sure the doctor tells you all the information related to what you do. Ask them to keep you informed even when you can't come to the patient's medical visits.
- Appoint one family member as the main family contact with healthcare professionals when possible. This will avoid confusion and save time for everyone.
- Ask about other resources. The primary care staff can often point you to health programs or resources that might help your Patient Partner.



National Cancer Institue(photographer). Doctor and Patient. [Digital image]. Retrieved from //unsplash.com/photos/RrG1XKyOBIY

# **Between Appointments: For Patients**

## After your appointment

- Make plans to follow your doctor's or nurse's recommendations. Discuss your plans with your Care Partner.
- Make appointments to have tests done or see a specialist if you need to.
- Review your (or your Care Partner's) notes from the appointment, or the printed visit summary you receive, to make sure you haven't forgotten any key things you discussed at your appointment.

## Call your primary care team at any time:

- If you do not understand, or have trouble following, the doctor's or nurse's instructions after you get home.
- To find out test results if you haven't received them within a week of the test date. Do not assume that no news is good news. Ask what you should do about the results.
- To ask about test results you do not understand.
- If you experience any side effects or problems with your medicines.



Tima Miroshnicheko (photographer). Man on Phone. [Digital image]. Retrieved from //www.pexels.com/photo/man-inbrown-sweater-and-jeans-talking-on-the-phone-5708710/

- If your symptoms get worse (or do not get better).
- If you receive any new prescriptions from another doctor or start taking any over-the-counter medicines.
- If you have any questions about your self-care regimen.

# Between Appointments: For Care Partners

# After an appointment

- Help and encourage your Patient Partner to make plans for how to follow their doctor's or nurse's recommendations.
- Discuss the Visit Summary that you and your partner receive.
- Talk to your Patient Partner about making appointments to have tests done or to see specialists if your partner needs to.

# You and your partner should plan to contact your partner's primary care team if your partner:

- Has problems following, or does not understand the doctor or nurse's instructions.
- Does not receive test results within a week of the test date. Do not assume that nonews is good news.
- Does not understand test results.
- Experiences any side effects or other problems with their medicines.
- Has symptoms that get worse (or do not get better).
- Receives any new prescriptions from another doctor or starts taking any overthe-counter medicines.
- has any questions about their self-care regimen.

Patients who talk with or call their primary care team tend to be happier with their care and have better medical results. You should encourage your Patient Partner to contact their primary care team themselves whenever possible. However, if your Patient Partner feels that you are the best person to call, that is OK too. If you call, be sure to write down what the doctor or nurse says, and share it with your Patient Partner as soon as possible.