



Following is the Better Together Expanded Guide for Families, set up to print in a booklet format. **This is a high resolution PDF file with crop marks, and is set up for a professional print or copy shop to produce.** To view this guide in a screen format, use the PDF file entitled: IPFCC_Better_Together_Expanded_Family_Screen.pdf

A professional print or copy shop can print the Better Together Expanded Guide for Families in a 5 1/2" x 8 1/2" booklet format by using the following pages. The next page of this PDF file shows the front cover, subsequent pages show the inside pages, and the last page shows the back cover.

You may choose to specify a heavier stock for the cover, and there is space on the top of the back cover to place your institution's logo if desired.

You may also order printed Better Together Expanded Guide for Families booklets from the Institute for Patient- and Family-Centered Care.





EXPANDED GUIDE FOR FAMILIES

As a *family member or friend* who has been identified by a patient as a care partner, you are an important member of the health care team, **TOGETHER** with doctors, nurses, and other staff and your loved one or friend, the patient. Participate in that role in ways that are comfortable to both you and the patient—whether you are simply present, or you are participating in care and helping to make decisions. The questions which follow highlight some issues which other family members and care partners have identified as important. Use them as a starting point as you work **TOGETHER** with health care staff. Jot down information as you think of it and share with staff.

Talk about your role with your loved one. Introduce yourself to staff and describe your relationship to the patient and how you'd like to participate in care.

Observe changes (physical, behavioral, emotional) in the patient and report them to health care providers. Ask staff what observations they would like you to routinely share.

Gather helpful information (current medications, medical history, other health care providers, and insurance) and bring it all to the hospital.

Ensure that you're present, if possible, at times when information will be shared and decisions need to be made. Keep your schedule for coming to the hospital manageable. Let staff members know how to reach you and be sure you know whom to contact for information when you're away from the bedside.

Tell staff if you have any concerns about the patient's condition or safety or if you are uncomfortable because "something just doesn't feel right."

Help with decision-making about care and treatment. Be a second set of eyes and ears for the patient. Ask questions and take notes. Encourage your loved one to participate in decision-making to the extent he or she chooses.

Enlist help from staff members with whom you are comfortable so that they can support you and your loved one as you participate in care and decision-making.

Ready yourself for the transition to home or community care. Before you leave the hospital, make sure your questions and those of the patient have been answered. Know what will be needed afterwards (medications, treatment, equipment, follow-up appointments) and what changes in the patient's condition should be reported to health care providers.

Talk about your role . . .

Hospitals like ours recognize that patients define “family” in various ways. Even if you are not biologically or legally related to the patient, he/she has identified you as having a special relationship as a care partner.

- What is your relationship to your loved one, the patient? How long have you known him/her?
- What authority do you have to make decisions for your loved one, if needed (i.e., health care agent or power of attorney)?
- What is your interaction with other family members? Will you be the patient’s main spokesperson and how will information be communicated to other family members?
- Before this hospitalization, what medical or health-related activities did you engage in with the patient? What kind of care did you provide?
- What care does your loved one want you to provide in the hospital?

- What care are you comfortable providing (getting beverages and/or food, assisting with getting to the bathroom or walking in the hall, helping with physical therapy, asking questions)?
- Do you know the names and roles of various staff members? Have you had an opportunity to talk to them about how you can work together?

Notes

Help with decision-making . . .

At different times during the hospital stay, decisions will need to be made about care and treatment. As members of the health care team, you and your loved one will be asked to participate in the decision-making, along with doctors, nurses, and other staff. Sometimes, staff may present information and options which are unfamiliar to you. Don't hesitate to ask questions, to take notes, and to say that you and your loved one need more time to consider.

- Have you and your loved one been asked about your preferences related to care—and has that information been included in the care plan?
 - How can you provide regular input as the care plan is revised?
 - After important diagnostic tests (lab work, CT scan), when will staff discuss the results with you and your loved one? What do the results suggest for care and treatment?
 - Have the risks, side effects, and benefits of different treatment options been clearly explained so that you and your loved one have the information you need to make decisions?
- How have you and your loved one made important decisions in the past, especially about health care? Who else have you involved in decision-making?
 - If you and your loved one are unsure about a proposed treatment plan, who else can give you additional medical advice—your primary care doctor, other specialists?
 - Does the hospital have a list of other patients who've had the same diagnosis or treatment and would be willing to talk to you?

Notes

Ready yourself for transitions . . .

Although everyone wants to leave the hospital, the prospect can be intimidating for your loved one and for you as a care partner. It's normal to have many questions at this time, and it's crucial that you get the answers you need, before leaving the hospital.

- Have there been any discussions about getting ready to go to another unit in the hospital or a different facility (physical rehabilitation center, or home or community care), even if this transition is far in the future?
- Have you and your loved one discussed preferences and concerns related to transitioning with the discharge planner, doctors, nurses, or other staff?
- Do you know what the patient will be able to do for him/herself at home or in community care? Are there restrictions on foods or types of activities?

- Is it clear what will be needed at home or in community care:
 - Medications or special nutrition?
 - Equipment (walker, chair for shower, oxygen)?
 - Professional services (nurse or nursing assistant, physical therapy, occupational therapy)?
 - Follow-up visits with the primary care doctor and/or specialists?
- Have you and your loved one been given a written summary of the discharge plan and reviewed it with a staff member? Have all of your questions about discharge instructions been answered?
- Based on your loved one's needs and your schedule and other responsibilities, what care can you reasonably provide at home? What other help might be needed and who can help you find it?
- Do you know what symptoms or signs to be watching for to determine whether you need to call the doctor?
- After you leave the hospital, if you have concerns or questions, do you and your loved one know whom to call?

BETTER TOGETHER

Notes



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