



Following is the **Better Together Expanded Guide for Families**. **This PDF file is set up for screen viewing.** The next page of this file shows the front cover, subsequent pages show the inside spreads, and the last page shows the back cover.

You may print this file, but the guide will not be in a booklet format. 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 PDF file entitled:

IPFCC_Better_Together_Expanded_Family_Print.pdf

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





Better Together

Partnering with Families

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

Observe changes in the patient . . .

As a family member or friend, you know your loved one outside of the hospital setting. You know what’s “normal” for him or her—physical appearance, level of activity, typical behavior, or emotions. Any noticeable changes could be important indicators of health status and would be helpful to share with staff. For example, does your loved one:

- Look different to you and how (paler, more flushed, out of breath, unsteady when walking)?
- Seem to be behaving differently (more/less talkative, more/less active, more withdrawn, anxious, agitated, or confused)?
- Seem uncomfortable or in pain? How can you tell?
- Show noticeable changes in appetite, toileting, or other daily activities?

Notes

Gather helpful information . . .

As much as possible, make sure you are aware of important information about your loved one and where certain documents are located in case they are needed.

- What significant medical conditions, treatments, and medications has the patient had before?
- Has the patient been hospitalized before? When, where, and why?
- Who are his/her doctors outside the hospital? What is their contact information?
- What insurance does your loved one have? If there is more than one insurance company, do you know which is primary and secondary?
- Who has financial/health care power of attorney?
- Does your loved one have a living will/advance directive?

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Ensure that you're present at important times ...

Together with your loved one, you will decide when it's best for you to be at the hospital. However, there will be times when you may want to be present because important information will be shared.

- Based on your own schedule (work, home responsibilities), when is the best time for you to be with your loved one on a regular basis?
- Does the patient want you to be there at particular times (mealtime, before bedtime, during tests or procedures)?
- Based on your schedule, when can you interact regularly with doctors and other staff about treatment and care?
- When will key doctors see the patient? What time are rounds (when doctors and other staff discuss the patient's progress and care plan, treatments, and tests)? How might you participate?
- What time are nursing change of shift reports (when a nurse shares information about a patient with the oncoming nurse and informs him/her about progress, changes in a patient's condition or care, and other important information)? How might you participate?

- In addition to the patient's chart, is there an appropriate place (white board in the room) where you can leave your contact information (cell number, work number) and your daily schedule for staff?
- When will important diagnostic tests (lab work, CT scan) be scheduled? When will staff discuss the results with you and your loved one?

Notes

Tell staff, if you have concerns ...

Because you are the care partner, don't hesitate to ask or comment if something happens that doesn't make sense or doesn't feel right to you or your loved one.

- Have you received information from staff members that seems different or contradictory?
- Has there been a sudden, unexplained change in medications, treatment, or therapy?
- Has the patient been told he/she will have a diagnostic test without being told why?
- Did a new staff member come to provide care and seem uncertain about the medical history and treatment?
- Was a staff member impatient or abrupt with you or your loved one when you asked for help or had a question?
- Is hand washing done consistently by everyone who comes into the room?

- Have medications and meals been delivered on time?
- Has your loved one received timely help for position changes (in bed, from chair to bed) and have call bells been answered in a timely way?

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

Enlist help from staff members . . .

As a care partner and member of the health care team, it's important that you feel comfortable in your role, as you and your loved one have defined it. Continue to clarify your role with staff. Feel free to participate as much or as little as you want on any given day. When participating in care, ask for advice if you need it.

- Do you feel comfortable asking questions and expressing concerns about the patient and his/her condition or treatment?
- Have you and staff members talked about how you can partner together in care?
- Together with staff members, have you identified new ways you might participate in care and what information might make you feel more confident and comfortable in your role as care partner?

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BETTER TOGETHER

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