



Better Together

Partnering with Families

**Implementing a Family Presence Policy:
Educational Activities for
Frontline Staff and Clinicians**

June 2014

**Implementing a Family Presence Policy:
Educational Activities for Frontline Staff and Clinicians**

Table of Contents

Notes for Leaders/Facilitators	3
The Impetus for Change.....	5
Beginning the Change Process.....	7
Clarifying the Impact of a Welcoming Policy	10
Clarifying the Impact of a Welcoming Policy on Privacy.....	14
Benefits of Family Presence and Participation	18
Initiating Partnerships with Families and Other Care Partners	21

© 2014 Institute for Patient- and Family-Centered Care

All rights reserved. Intended for educational use only.

Notes for Leaders/Facilitators

Background

Changing policies and practices related to family presence and participation will have a significant, immediate, day-to-day impact on frontline staff and clinicians. It is not uncommon for some staff to welcome the changes and others to be reluctant. In most instances, effective communication and appropriate education and support can make the difference between successful implementation and continuing resistance to change. Hospitals that have successfully implemented new policies and practices have offered a variety of learning opportunities for staff and clinicians. (From Better Together Toolkit, [Strategies for Educating Staff](#))

Intended Audiences/Participants

These educational activities can be used for a variety of audiences, including:

- Members of the hospital's leadership team to help them articulate the need to change "visiting" policies and establish an effective change process as an organizational priority
- Managers, frontline staff, and clinicians to discuss the need for changing restrictive "visiting" policies and to support them in acquiring effective communication skills

Members of the task force or committee formed to provide leadership for the process of changing policies and practice (See [Strategies for Changing "Visiting" Policies](#) included in the Toolkit)

In addition to these educational activities, the **Better Together: Partnering with Families** campaign has developed a PowerPoint presentation that a Chief Nursing Officer or other senior executive can tailor and use in presenting "[A Call for Action](#)" to the Executive team and/or to the hospital's board of trustees.

Purpose

These activities are designed to help participants understand the need to change from restrictive policies to ones that recognize family members as active partners in care, according to patient preferences. The activities also provide a forum for staff and clinicians to openly discuss their concerns about the change and the impact on practice. Because the activities are discussion-based and rely on the organizational experience of the participants, facilitators do **not** need to be experts in research and practice related to family presence policies, but instead should be individuals who are committed to working **with** patients and families as well as being comfortable eliciting input from an interdisciplinary group – and guiding and summarizing discussions without judgment. The facilitator can plan to do each of these activities over a period of time to prepare for changes in policy or select specific activities that will be most helpful to clinicians and staff.

Structure and Time

Some of the educational activities are based on short video “triggers,” followed by questions to begin discussion among participants. Each activity can be done in about 20 minutes. If more time is available, several of the activities have short scenarios to extend and deepen the discussion.

Facilitator Guidance

Guidance is provided for facilitators of these educational activities. There is guidance for how to prepare for the session and how to facilitate discussion for each topic. Questions to facilitate discussion are provided and possible facilitator responses are also provided (in italics). These answers are not intended to be the only responses. They should not be read to the participants. They are included only to suggest possible ways for facilitators to guide the sessions and discussions and assist facilitators to gain confidence in delivering the content.

Co-Facilitators

Several of the educational activities suggest that staff from specific departments such as Security or Risk Management co-facilitate or be available to answer questions. The 12 hospitals that serve as exemplars for the Better Together campaign worked with patient and family advisors when planning and implementing changes to policy and practice. Patient and family advisors are individuals who have experienced care and are prepared and supported to partner with staff to improve care and services. If you have advisors at your hospital, they can also be asked to co-facilitate several of these activities. (If you want to know more about advisors, visit IPFCC website at www.ipfcc.org.)

Equipment/Supplies

Little is needed to conduct these educational activities. The facilitator must, of course, download the video “trigger” and have a way to show it to participants. It’s helpful to have copies of the suggested resources available. If possible, it’s recommended to have a flip chart and easel in the room so that participants’ discussion can be recorded. (The facilitator may want to identify a recorder beforehand.)

The Impetus for Change

Trigger: [Video clip](#), “*Visitor No More*,” Ellie Crawford, Jaspreet Benepal, and Anna Roth (20 sec.)

Facilitator Guidance:

Preparing prior to the session:

- Review the video clip as well as the questions outlined below.
- Review [Strategies for Changing “Visiting” Policies](#) as well as the [Facts and Figures](#) document in the Toolkit.
- If you have patients and families who serve as advisors at your hospital (e.g., as members of an advisory council or on a committee), consider asking one of them to present with you.

After viewing the video, ask participants the following questions:

- In this video clip, we hear from three different perspectives (family member, nurse leader, and hospital CEO) that families are **not** visitors. What does that mean to you? Possible responses might include:

Families can come at any time. They are able to remain at the bedside for rounds, nurse change of shift report, and procedures, all according to the patient’s preference. Staff and clinicians respect families as essential members of the care team, serving as allies for quality and safety. They recognize that families often have vital information about the patient and how they respond to illness and various medications and therapies.

- Anna Roth, CEO, says, “*We will welcome people 24 hours a day, seven days a week.*” What would it mean to really “**welcome**” families and other care partners in our hospital? Is that different than just instituting more “open visitation? How is it different? Possible responses might include:

Hospital signs welcome families and other care partners as important to the health and well-being of patients. Signage that uses words such as “no visitors,” “allowed,” “permitted,” are removed. Staff and clinicians welcome, encourage, and support the presence and participation of families and other care partners through the language they use, their attitudes, and their actions. Families and other care partners have meaningful roles in contributing to the comfort and well-being of their loved ones according to the patient’s preference.

Invite participants to share stories from their personal or professional lives that relate to family presence or family participation in decision-making and care that had a profound effect on them. The stories can be either:

- Positive, such as when a family member was welcomed, encouraged, and supported in being with a hospitalized patient **OR**
- Negative, such as when participation by family members was not welcomed and a patient or family “suffered” in some way

Facilitator Tips:

- If people don't share personal stories spontaneously, be prepared to share a short story of your own and then ask again if anyone has a story to share.

Beginning the Change Process

Trigger: [Video clip](#), “*The Process of Change*,” Anna Roth, CEO (3 min.)

Facilitator Guidance:

Preparing prior to the session:

- Review the video clip as well as the questions outlined below.
- Review [Strategies for Changing “Visiting” Policies](#) as well as the [Facts and Figures](#) document in the Toolkit
- Review the [Profiles](#) of exemplar hospitals in the Toolkit
- If you have patients and families who serve as advisors at your hospital (e.g., as members of an advisory council or on a committee), consider asking one of them to present with you.

After viewing the video, ask participants the following questions:

- In the beginning of the video, CEO Anna Roth shares the story of the young boy who could not be with his grandfather when he died. She then says, “*We decided, No more; we could do better.*” What is the impetus for changing the policy at our hospital?
- During the video, Anna Roth outlines a few key strategies used by their medical center as it began the process of changing the “visiting” policy. What are some of the strategies that Anna mentioned? (If participants need prompting, below are many of the ideas Anna Roth shared.)

Use stories of patients and families to illustrate the need for change.

Bring everyone together—all the key stakeholders (patients and families, clinical and support staff, security staff, members of the community).

Identify all the things (barriers, challenges) that are preventing our hospital from changing the policy and, then, problem-solve, one-by-one.

Acknowledge the real anxieties of staff and develop ways to overcome them.

Learn as you go; engage in continuous learning. Be willing to make changes in your plan.

Evaluate your progress, publish the results, and share with staff. Acknowledge your successes.

- What might be an important first step for *our* organization in beginning this process?

For some hospitals, a first step might be to review the current policy and then do a walk-about of the facility and evaluate how welcoming the hospital is. (Guidance for [“How to Conduct a “Walk-About” From the Patient and Family Perspective”](#) is available.) Other hospitals might find it helpful to begin with a process of learning about family presence and participation — appointing a group to review and discuss all the materials on the Better Together website.

- Among the key strategies, Anna Roth says that they initially “*identified all the things that are preventing us from doing this*” and then “*problem-solved, one-by-one.*” What are some of the most significant barriers and challenges we’ll face in our organization in beginning this process?

Some of the barriers mentioned might be that nurses believe this change in policy will interfere with their work, will take time to answer questions from families, will violate confidentiality, will interfere with patients’ rest, and will increase the noise on the unit. Less experienced nurses may be uncomfortable performing clinical tasks when families are present.

- Consider asking staff to identify some of the positives for implementing a welcoming family presence policy...what would delight them about the new policy. Some of their replies might be:

Getting out of the “visitor policing role.”

More positive, helpful relationships with families.

Having families as a “safety check” (e.g., alerting staff when they see a change in the patient that staff may not have observed).

Having families provide useful information about the patient.

Being able to share information in a timely manner so that families do not have to track them down during the day.

Being able to connect with families throughout a hospital stay to prepare them for the transition to home instead of “cramming” all the education into the last day.

Families helping comfort the patient and even providing some of the care.

There won’t be so many angry families to deal with...

Facilitator Tips:

- If it doesn't happen spontaneously, encourage participants to respectfully give different perspectives in the discussion – with examples from their own experience.
- If time permits, you may want to follow this discussion by highlighting some of the hospitals profiled in the Toolkit materials and their processes for change.
- You might also want to use the [*Facts and Figures*](#) document as a handout.

Clarifying the Impact of a Welcoming Policy

Trigger: [Video clip](#) of Sherry Perkins, COO/CNO (20 sec.)

(“There are no restrictions on family presence in our hospital . . . it’s wide open.”)

Facilitator Guidance:

Preparing prior to the session:

- Review the video clip as well as the statements outlined below.
- Review the [Facts and Figures](#) document in the Toolkit for evidence about impact of family presence on patient satisfaction, rate of infection, falls, etc.

Review your own organization’s existing guidelines about “challenging situations” and have a copy available at the educational session. Ask a member of the hospital’s Security Department to present with you. Share a copy of the document, [Implementing a Welcoming Family Presence Policy: The Role of Security](#) from the Toolkit.

After viewing the video clip, ask participants the following questions:

- What is your reaction to what Sherry Perkins says?
- What are your concerns about a new policy which doesn’t restrict family presence – and welcomes families as partners in care?

Participants’ responses may include some or all of the statements below . . . possible replies to participants’ responses are included in italics:

With the new policy, there are fewer “rules;” patients and families will think they can have or do whatever they want.

Families have the same goal as staff — the safest, highest quality patient care. With the new policy, frontline staff have more flexibility to partner respectfully with the patient and honor patient preferences for family presence and for their participation in care and decision-making. Nurses no longer have to be the “visitor police.”

Rude or disruptive behavior on the part of patients and families may be more common.

*Rude or disruptive behavior happened with the old policy. This behavior is not acceptable and should be dealt with in a professional manner. A welcoming family presence and participation policy does not mean there are **no boundaries** for families. With a welcoming policy, when families have the flexibility to be with their loved ones on their schedule, there is often less anger, confrontation, stress, and fewer challenging situations.*

Staff must relinquish decision-making and control to patients and families.

Too many health care policies and practices have taken decision-making responsibilities away from patients and families and have been disempowering to them. Better practice is to encourage and support patients and their families in actively engaging in health care planning and decision-making. This includes having patients decide who their care partners are and how they will be involved in care, care planning, and decision-making.

Having families present and participating in care can make staff jobs harder and more time-consuming.

Actually, once you determine patient preferences, for how they want their family members involved, families can make the jobs of frontline staff easier. Families can be helpful, especially if a little time is invested in getting to know them and finding out how they would like to be involved in care and decision-making.

Having family members present more often and participating in care may increase infection rates.

This is a misperception. Evidence does not support this statement even in intensive care settings.

It is difficult to maintain privacy and confidentiality when family members are at the bedside 24/7.

It is important to balance privacy and confidentiality with access to a family member or care partner. Patients and families report that they hear information about other patients throughout their stay and in areas other than the patient room like hallways, elevators, and cafeterias. If there are sensitive issues or patients have identified subjects that they want to remain private, these can be managed on an individual basis. (If privacy and confidentiality is an issue for staff, see the activity, “Clarifying the Impact of a Welcoming Policy on Privacy,” on pages, 14-16.)

Having a family member at the bedside 24/7 may be a burden to patients.

This is also a misperception. Evidence does not support this broad assumption. It is known that social isolation is a risk factor and the presence of a family member brings comfort to a patient and can lessen their stress and anxiety. It is helpful when families are given guidance for how to be supportive of the hospitalized patient. This information can be part of the admission process.

Staff time may be diverted in order to monitor children who come to the hospital.

Family policy guidance should include the expectations that an adult family member must take responsibility for a child; and children cannot be disruptive of other patient’s rest.

Facilitator Tips:

- If it doesn't happen spontaneously, encourage participants to respectfully give different perspectives during the discussion – with examples from their own experience.
- You may want to distribute copies of the pocket [Guide for Families, Guide for Staff, and the Expanded Guide for Families](#) for participants to review and discuss as part of this educational activity.
- Be prepared to deal with concerns about increased incidence of disruptive and/or uncomfortable behaviors (e.g., inebriated or visibly sick family members).
- You might want to share a quote from the President of the American Society of Healthcare Risk Management (ASHRM), “Families of patients are not **just visitors**, they are a vital part of the team caring for the patient. ASHRM believes that changing the concept of families as “visitors” to one of partnership is a proactive approach to risk management.”
- Point out that those “worst-case” scenarios happen under current policy and there are already procedures for managing them; those same procedures will continue to be used under the new policy. Sometimes it is helpful for frontline staff to reflect about having policies that are welcoming, positive, and proactively supportive of patients and families making decisions. This works usually at least 98% of the time. Then strategies can be developed to deal with the challenging situations that may occur 1-2% of the time.
- Let participants know that outcomes and incidents will be monitored and documented to measure changes associated with the new policy.
- Ask your co-presenter from Security to review existing guidelines for “challenging situations.”

Additional Activity:

If time permits, read one or both of the challenging situations below and ask participants to discuss the question that follows each one.

- A nurse enters a patient's room to handle his admission. She finds that his wife and their two grandchildren (ages 1-1/2 and 5) are already there. The wife explains that she cares for the children. When she received the call that her husband had collapsed at work and was taken to the hospital, she came immediately, bringing the children with her.

What should the nurse do?

Possible approaches might include: Asking if the wife could find a friend or family member who might be able to come to the hospital and care for her grandchildren on a short-term basis while she is with her husband. Does the hospital have or know of a short-term day care program? Perhaps social work or the volunteer office knows of options. If the hospital has a Child Life Department, perhaps a staff member could help.

- A nurse knocks on a patient’s door to administer her pre-op medication and to finish prepping her for surgery. As she enters the room, the nurse notices that the patient’s husband is unsteady as he begins to move around the bed and, when he speaks, his words are slurred. As the nurse steps closer to the patient, she can smell alcohol.

What should the nurse do?

Possible initial approaches might be to offer a chair, a glass of water or cup of coffee to the husband, and observe. Perhaps ask him if he is planning to stay or ask if there is anyone who could come to pick him up. Is there anyone that he would like the nurse to call. If this situation continues, it may be necessary to talk with the husband respectfully about behavioral expectations. This conversation can involve someone from a mental health team, security, chaplain, or others in the hospital.

Invite participants to tell their own stories of “challenging situations” – and to share the strategies they used.

Clarifying the Impact of a Welcoming Policy on Privacy

Facilitator Guidance:

Preparing prior to the session:

- Review your own organization's HIPAA Policy and any educational materials used for staff orientation and/or training.
- From the IPFCC website (www.ipfcc.org), download the article, [*HIPAA – Providing New Opportunities for Collaboration*](#) and the fact sheet created by the National Partnership for Women & Families, [*HIPAA Privacy and Security Rules*](#). Review them beforehand and have copies available at the educational session.
- For further information on HIPAA, check www.hhs.gov/ocr/hipaa and be prepared to tell participants what resources are available there (e.g., *A Patient's Guide to the HIPAA Privacy Rule: When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved in Your Care*). Encourage participants to visit the website themselves.
- Consider having someone from the hospital's Risk Management department be available to respond to questions.

Read the following statements to the group and ask whether they are true (possible replies to participants' responses are included in italics):

(Note: The resources listed above contain important clarification about HIPAA and these statements.)

- HIPAA limits family presence and participation.

There is no wording within the HIPAA privacy and security rules that prohibits health care providers from partnering with patients and designated family members or other care partners.

- HIPAA prohibits a patient from accessing his or her medical record.

HIPAA guarantees patients' access to medical records.

- Patients' personal health information cannot be discussed at the bedside in semi-private rooms.

With HIPAA, the importance of access to information must be balanced with the need for privacy. It is certainly better to discuss confidential matters in a patient room than in a hallway where many people can overhear the conversation. Some hospitals provide patients and families in semi-private or multi-bed rooms guidance about being respectful of the privacy of other patients. They can even be asked to sign a statement that they will join with staff in protecting the privacy and confidentiality of others and not repeat conversations overheard in the hospital. A tone of mutual respect can be set in the initial admitting process on a clinical unit.

- Family presence changes the information that can be written on white boards in patient rooms.

HIPAA allows for “normal hospital and physician operations.” Information boards, including in patient rooms, are often necessary for safe and effective care and can still be used.

- Change of shift bedside report and rounds can only be done in private rooms when family members are not present.

Quality of care is improved with both patient and family participation. The HIPAA Privacy Rule specifically refers to the role of family, friends, or others involved in the care of a patient.

- Only the designated Emergency Contact has access to information about a patient who is unconscious or incompetent.

According to HIPAA’s Patient Guide, health care providers “may share or discuss health information with family, friends, or others involved in care or payment for care,” if they believe it is in the best interest of the patient. HIPAA does not mean that professional judgment is suspended.

Additional Activity:

If time permits, read one or all of the three scenarios below and ask participants to discuss the question that follows each one.

- A new nurse joins the ICU staff and suggests that they should begin doing change of shift rounds at the bedside with family members present. The Nurse Manager and some staff are concerned about HIPAA implications since the unit does not have private rooms.

How can this be dealt with?

It is not a violation of HIPAA to share information at the bedside and involve the patient and their care partners in care planning and decision-making. The hospital should make clear in its standard operating procedures that patient and family access to information and participation in care planning and decision-making are essential aspects of the care model.

- A physician walks into a hospital room to go over a patient's test results with him. There are two younger people sitting on the bed next to the patient who appear to be his sons. One of the young men jumps up and says, "Do you have the test results?"

What should the physician do?

It is helpful to determine at admission the names of people with whom medical information can be shared, and this should be documented in the medical record. Assuming that the patient has the capacity to make his own health care decisions, he should be consulted about having others present when his results are discussed. This can be done in an affirming way. For example, the physician might say, "Who do I have the pleasure of meeting today?" as she/he notes the presence of the other individuals, and might follow that by expressing appreciation for the support they are providing for the patient. The physician can then indicate that they are going to discuss test results. If the patient affirms that he wants the others in the room with him, or doesn't overtly object to their presence, the physician can discuss the information with them.

If the patient doesn't have the capacity to make health care decisions, either as a long-term consequence of his medical condition or transiently due to the effects of medication or illness, the physician can exercise professional judgment regarding communication of medical information. It is optimal to know who has durable power of attorney (DPOA) for health care on behalf of the patient, particularly in situations like this, but the absence of clarity about the DPOA does not prevent communication based on professional judgment.

- A patient arrives in the ER. He is unconscious. The EMTs have gone through his personal items and have found his brother's name and where he works. The charge nurse declines to call him citing concerns about HIPAA.

What would you do?

It is not a HIPAA violation to call the brother. HIPAA does not mean that you suspend judgment. The brother may have useful information that could be helpful to the care of this patient.

Invite participants to tell their own stories related to privacy and confidentiality – and to share the strategies they used.

Benefits of Family Presence and Participation

Trigger: [Video clip](#) of Mary Chatman (20 sec.)

“If family members were at the bedside, the healing process would begin sooner. Those individuals know more about the patients than we can ever glean.”

Facilitator Guidance:

Preparing prior to the session:

- Review the video clip as well as the questions outlined below.
- Review [Understanding the Historical Context for Visiting Policies](#), and the [Facts and Figures](#) document in the Toolkit
- If you have patients and families who serve as advisors at your hospital (e.g., as members of an advisory council or on a committee), consider asking one of them to present with you.

After viewing the video clip, ask participants the following questions:

- What is your reaction to what Mary Chatman says? Responses might include:

Some staff may describe personal and professional experiences that relate to Mary Chatman’s points...some may show some skepticism. It is important to encourage the dialogue.

- What does she mean when she says, “If family members were at the bedside, the healing process would begin sooner.” Do you agree or disagree? Why?

Some staff may mention that they have had hospital experiences where they felt alone and vulnerable when they were separated from their loved one. Often having a loved one, someone who knows you well, can be comforting and reassuring, and the patient will then rest better and can devote his/her energy to healing and recovery.

- What do families and care partners “know about” patients that is important to care?

Often families or other care partners know a lot about the patient and how the patient responds to illness, specific medications, activity, and treatments. They also know how a patient typically functions and what kind of support and help they may have needed prior to the hospitalization. These care partners can be allies and partners with frontline staff in ensuring safety, quality, and continuity of care. They usually have knowledge about what is comforting and calming for the patient which can also aid in the care.

- How can you elicit that information from families and care partners?
(See Additional Activity below)

*At the time of admission or at the beginning of your first shift with the patient, you can introduce yourself to the family and discuss some of the following:
Tell me about your loved one...what is important to him/her for this hospital stay or at this time...what are your concerns about this hospitalization...How has he responded in the past (or in the last 24 hours)...What has been most comforting to him...How does your loved one want you to participate in care and decision-making? What are you comfortable doing?*

- Using examples from your own experience or from evidence, how would you describe the benefits of family presence and participation?

Families are holders of vital information. They can help you know the patient and the patient's priorities and preferences. They can help you learn how the patient responds to illness and treatments. Families can help in calming the patient and alert staff when the patient is in pain or when there is a safety risk. They can offer non-pharmacological pain relief measures. In many ways they are the continuity in transitions between units and departments and in transition to home and community care.

Facilitator Tips:

- If it doesn't happen spontaneously, encourage participants to respectfully give different perspectives during the discussion – with examples from their own experience.

Additional Activities:

1. If time permits, follow this discussion by introducing the pocket [Guide for Families](#), [Expanded Guide for Families](#), and the pocket [Guide for Staff](#) in the Toolkit, explaining that they provide a simple framework for eliciting important information from care partners. Have participants break into pairs and role-play introducing the *Guide* to a family member or other care partner.
2. Pass out copies of the case, “Melissa’s Story,” and ask participants to share their reactions. Possible probing questions might be:
 - How would you feel if this situation happened to you or your loved one?
 - How would you feel as the nurse?
 - Isn't there a better way to care for patients? What would that look like?

Follow-up note to Melissa's story to share with participants after the above discussion:

Melissa now serves as a patient advisor in a large health system and has spoken regionally and nationally about better ways to partner with patients and families. She partnered with staff to develop a communication board that would be easy for patients in the ICU to use when they could not communicate verbally.

Melissa's Story . . .

I woke up after my second surgery: I was still intubated and in Cardiac ICU. I was in horrible pain. I opened my eyes and began looking around the room for my family. No one was there. It didn't make any sense. They'd never left me alone, not for one minute, during my first recovery at another hospital. Every moment for those six weeks, they'd been by my side.

My nurse came in shortly and said, "Hi I'm . . . , and I'll be your nurse tonight. Your surgery went well. . . Your family has already seen you. Visiting hours start again at 7am." I'd just survived an enormous surgery. I was in pain, and I didn't want to be alone. I needed to hear my husband say, "You look good this time around. You *are* going to be okay." But I couldn't tell my nurse that. I couldn't tell her anything with the breathing tube down my throat.

The pain was horrible, and my nurse noticed. I heard her talking to someone outside my door. "She's on Dilaudid. . . Maybe they could add Fentanyl. . ." I immediately started shaking my head. I wanted to shout, "No, wait a second! Doctors put me on Dilaudid after my first surgery, and when they added a Fentanyl patch on top of it, it overdosed me! Nothing came out of my mouth but a whimper. I wanted to rip the breathing tube out. I was terrified. I made as much noise as I could, trying to get the nurse's attention. She came to my bedside, "Are you okay?" And I tried spelling out a warning with my hands. I used the sign language letters I'd learned as a child, "N-O. F-E-N-T. . ." And the nurse shook her head, agitated, "I don't know sign language." Then, she walked away.

She came back with letters handwritten on a sheet of paper. "Here," she said. "Drag your fingers to the letters." I knew I'd never be able to explain everything that she needed to know with these letters, so I dragged my fingers along the paper spelling the only answer I had for it all, "H-U-S-B-A. . ." The nurse asked me, "Husband? Are you saying husband?" I nodded. "I told you! It's not time for visiting hours," she said. He will be here in the morning!" And more tears ran down my face. "Fine," she said finally. "I will call him. He and your parents are at the hotel across the street. They left a number."

Within minutes my husband walked through my door. “What’s wrong? Are you okay?” I wanted to tell him everything all at once, “They say they’re going to give me Fentanyl, but I’m already on Dilaudid! But, of course, I couldn’t. So I signed those letters one more time and prayed that he would understand, “F-E-N-T-A-N-Y-L.” And my husband knew exactly what I was saying. He said to the nurse, “They put a Fentanyl patch on top of Dilaudid after her last surgery, and it almost killed her.” And the nurse looked back at my husband, shocked, as what I’d been trying to tell her all along registered on her face. I made it through that night, but I will never forget it. None of us will. My husband says he still remembers the fear in my eyes when he came through my door and the look on the nurse’s face once she realized what I’d been trying to say.

That night changed me. I am a fierce supporter of family presence now. Family presence is about me having someone by my side to speak for me when I can’t, to encourage me when the pain is horrible, to remind me what I am fighting for constantly. It is about recognizing the power my loved ones have to motivate me, to help me, to remind me, and to protect me.

Initiating Partnerships with Families and Other Care Partners

Trigger: [Video clip](#) of Ellie Crawford with Dr. Kuruvilla in ICU (1 min.)

“I’m not a visitor . . . Your part has been really important. You help him remember who he is outside these hospital walls . . . our family partners are just one of the most important things in caring for loved ones.”

Facilitator Guidance:

Preparing prior to the session:

- Review the video clip of Ellie and Dr. Kuruvilla as well as the questions outlined below.
- Print copies of the [Guide for Families](#) and the [Guide for Staff](#) from the Toolkit.
- If you have patients and families who serve as advisors at your hospital (e.g., as members of an advisory council or on a committee), consider asking one of them to present with you.

After viewing the video clip, ask participants the following questions:

- What is your reaction to the exchange between Ellie and Dr. Kuruvilla?

Staff may see the physician’s support and reinforcement of the family partnership role. They may say it is doesn’t happen in their hospital now. You might explore how that might change.

- What does Dr. Kuruvilla mean when she says, “You help him remember who he is outside of the hospital?” Why is that important?

Critical care can be very dehumanizing, frightening, and disorienting. ICU delirium is a serious risk factor. Families can help patients stay oriented in time and space. Families can inspire hope for recovery and reassure the patient. In end-of-life situations, they can assure the patient that family and/or her loved ones will be there.

- How do you think Dr. Kuruvilla could continue the conversation with Ellie about her role and participation in her brother’s care while he’s in the ICU?

Your observations of your brother are important to the ICU team. You know him best. Please share them with us. We will want to plan with you the transition to the medical unit and then the transition to home and community care.

- As a nurse, how could you have a conversation similar to the one Dr. Kuruvilla had with this family member?

The nurse can reinforce the importance of family at the time of admission, in bedside report, and in numerous informal conversations throughout the day or night. The nurse can provide guidance for the family about who can be most helpful to the patient and elicit ideas and suggestions from the family.

- What concerns you the most about interacting with families and care partners in your own practice?

Responses might include lack of confidence in communication skills, interference with tasks and workflow, lack of space, not having answers to questions, worries about HIPAA or liability. Each one of these may need individualized follow up and coaching to allay concerns and develop constructive strategies.

Facilitator Tips:

- If it doesn't happen spontaneously, encourage participants to respectfully give different perspectives during the discussion – with examples from their own experience.
- Be prepared to deal with concerns about family presence and participation in the ICU (increased rate of infection, disruption of staff). Point out that evidence does not support these concerns. (See the [Changing the Concept of Families as Visitors Bibliography](#) and the [Facts and Figures](#) document in the Toolkit).
- If time permits, you may want to follow this discussion by introducing the [Guide for Families](#) and the [Guide for Staff](#) in the Toolkit, explaining that they provide simple guidance for encouraging the participation of care partners.