Patient and Family Advisor (PFA) Orientation Handbook

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About This Orientation Handbook

This orientation handbook will help prepare you for your role as an advisor. It is organized into the following sections:

- **Section 1.** Information to help you understand the responsibilities of and expectations for patient and family advisors (PFAs)
- **Section 2.** Tips for being an engaged patient and family advisor (PFA)
- **Section 3.** Information about how patient and family advisors help us improve hospital quality and safety
- **Section 4.** How things work at Tallahassee Memorial HealthCare (TMH)
- **Section 5.** Ways to learn more about health care quality, patient safety, and being a patient and family advisor (PFA)

This orientation handbook is intended to accompany other training you will receive from the hospital to help prepare you to be a PFA..

Section 1. Responsibilities and Expectations

As a patient and family advisor, your experiences are a powerful tool for inspiring change at our hospital. By sharing your perspectives and working with hospital staff and other patient and family advisors, you can make a real difference. The time and energy you invest help us make important changes and improve the care experience for other patients and families.

As an advisor, there are things that we will ask you to do. There also are things we will do to make sure we are doing our best to build a strong partnership with you.

We promise to:

- Provide you with the training you need to be an engaged advisor.
- Provide you with the resources and organizational support you need to do your job well.
- Identify a staff liaison who will help you prepare for meetings; provide you with information; and be available if you have comments, questions, or concerns about your role.
- Listen and respond to your ideas and suggestions.
- Keep you informed about how your feedback and ideas contribute to changes and improvements.
- Provide you with a light meal for your attendance at advisory meetings.

You promise to:

- Support and commit to the mission and vision of our hospital.
- Attend orientation and training.
- Prepare for meetings as needed by reviewing materials, reading a report, or completing a task before a meeting.
- Attend meetings as required. If for some reason, you cannot attend a meeting, please call your staff liaison. You can also ask if there is another way you can participate (for example, by phone).
- Actively participate in meetings by sharing your input and opinions.
- Maintain confidentiality. As a patient and family advisor, you may have access to health information about other patients that must remain private.

Key contacts for the patient and family advisor program

Patricia Kenney, Executive Director, Patient-Centered Care, coordinates all the activities of patient and family advisors. She will make sure you get the training you need and that you complete all the necessary requirements. Patricia also works with hospital staff to prepare them to work with patient and family advisors.

She is available to you by phone, email, or in person to answer any questions you have or to discuss your participation as an advisor. Her phone number is 850-431-5682 and her email is patricia.kenney@TMH.org.

Training and orientation

We are committed to making sure you have the training you need to feel confident in your role as a patient and family advisor. This manual is only one part of your training. There may be other parts of your training that may include hospital volunteer orientation, HIPAA training, and advisor orientation.

Other requirements

There may be other requirements for participation which will be discussed at the information session.

Time commitments

The amount of time you spend on advisor activities depends on your specific role. As a general rule, most PFAs spend a minimum of four (4) hours per month attending committee or council meetings.

- Meetings are usually held monthly (depending on the needs if the team).
- You may be asked to review materials to prepare for a meeting. We will make sure you have enough time to review them and will send them to you either by mail or by email, depending on your preference.

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Confidentiality agreements

As a patient and family advisor, you may have access to health information about other patients. It is important to know that a federal law called HIPAA (Health Insurance Portability and Accountability Act) protects how health information can be used and disclosed.

Health information cannot be shared outside the hospital or health care facility. It cannot be shared in any written, verbal, or email communications with friends, family, or anyone else unless specifically permitted.

The easiest way to remember what HIPAA means is the saying, "What you see or hear here must remain here." We will ask you to read and sign a confidentiality agreement to indicate your understanding of and cooperation with these requirements.

Feedback and review process

Your feedback helps us better understand how we can support you and your fellow advisors. The staff liaison will meet with you regularly to get your feedback on how things are going. These meetings are also a chance for you to let the staff liaison know how we can improve and expand our advisory activities. During these meetings, the staff liaison will also ask you about your goals and whether there are any areas in which you would like to strengthen or expand your skills.

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Section 2. Tips for Being an Engaged Advisor

This section contains tips from other patient and family advisors about how to be an engaged advisor. As you read, make note of things that you think might be challenging for you. Discuss these with your staff liaison and ask for more help if needed. Above all, have faith in your participation as an advisor and keep at it. Bring your sense of humor and expect the best from your experience.

Six tips for being an engaged advisor

Tip 1. Share your views

You have been asked to be an advisor because your ideas are valuable. You know what it is like to get care in our hospital. We want to hear your ideas about how we can improve the quality and safety of the care we provide and help make sure that other patients and families have a good experience.

- **Focus on problem solving.** It is important to build on positive experiences. For example, "*We found that things worked well for our family when…*" It also is helpful to share negative experiences. When you do, try to offer suggestions and possible solutions. Problemsolving is always appreciated.
- **Think carefully about the words you use.** If you want to tell a story that will bring up strong emotions, ask your staff liaison or another advisor to help you think about what you want to say and how you want to say it. Try to remember that anger usually does not produce good results.
- **Respect people's privacy.** Feel free to share your experiences and the experiences of patients and family members other than yourself. If you do share someone else's story, let people know that this experience did not happen to you and avoid using the person's name. When speaking about experiences in the hospital, try not to use the names of staff members.

Tip 2. Draw on your communication skills

As an advisor, you will work with many types of people from different backgrounds. You may work with health care providers, hospital staff, hospital leaders, and other patients and family members. Good communication skills will help you explain your ideas clearly and develop good working relationships.

- **Keep an open mind.** Be willing to see past your own views and experiences. You will be working with doctors, nurses, hospital staff, and other patient and family advisors who bring their own views. Different perspectives can lead to better conversations and outcomes.
- **Listen well.** When someone is speaking, it is natural to think about what you are going to say in response. However, it is important to give all of your attention to the person who is speaking and to hear them out before you respond.
- **Make sure you understand what other people are saying.** One way to make sure you understand someone's point is to say, "*What I hear you saying is…*" and then repeat what you heard them say. This gives people a chance to clarify their points if needed.
- **Be aware of how you are sharing time with others when you are speaking.** If needed, make adjustments to give others time to express their ideas.

Tip 3. Ask questions

When you or your family members were in the hospital, there may have been times when hospital staff used language that you did not understand. That can happen when you are working as an advisor, too. If it does, speak up and ask people to explain what they mean.

- **Ask clarifying questions.** For example, *"Let me make sure I understand correctly. I heard you say..."*
- **Ask for definitions of medical terms, abbreviations, or other terms.** For example, *"I'm not sure I know what CAHPS means. Would you please explain it to me?"* (See the Working With Advisors to Improve the Quality and Safety of Health Care section of this orientation manual for information about the CAHPS® Hospital Survey.)
- **Ask for more details.** For example, *"Can you walk me through this so I can picture it?"*

Tip 4. Be ready for disagreements

Disagreements are a natural part of working on a team. Expressing your views when they are different from the views of others can be challenging. However, your honest opinion can lead to greater understanding.

- **Describe your point of view in terms of your perception or opinion rather than as a fact or the truth for all patients and families.** For example: *"I see it differently," "I have a different priority,"* or *"That doesn't work so well for me."*
- **Ask for more background information when people say that a change is not possible.** For example: *"Help me understand why this change is not possible. What have you tried?"* Sometimes doctors, nurses, and other hospital staff are so used to the way things have always been done that it is hard for them to see other ways of doing things. Sometimes, there are things that really cannot be changed. In this case, you should ask about the reasons why.
- If you find yourself upset after a meeting, talk to your staff liaison at the hospital. Your staff liaison can make sure that your concerns are addressed and help you resolve them.

Tip 5. Ask for information to help you understand your commitments

When you agree to become an advisor, make sure you fully understand the commitment you are makin, and then keep that commitment.

- **Prepare for meetings.** If there are responsibilities that you are asked to fulfill between meetings, come to the meeting prepared to share information about your progress on these activities and projects. Be on time for meetings and stay until the end.
- **Keep the staff liaison informed about your schedule.** If you are not able to attend a meeting in person, ask if you can call in (through conference call or speaker phone) as an option. If you cannot participate in a meeting, notify your key contact or staff liaison. Ask if you can get an update before the next meeting. If you find that you are having difficulty balancing your personal and family life with advisory activities, talk to your staff liaison about whether you can cut back on some of your advisor duties or take a short-term break.

Tip 6. Ask for feedback

One of the best ways to develop your skills as an advisor is to ask for feedback. Talk to your staff liaison about your participation, including what is going well and what skills you would like to enhance. Getting feedback is especially important if you would like to expand your involvement and take on new roles and responsibilities.

- **Ask for feedback after you have completed a task.** If you are participating in a one-time discussion group or very short-term work group, ask your staff liaison if you can talk to him or her about your participation after you have completed the task.
- **Ask for regular feedback meetings with your staff liaison.** If you will be serving as an advisor for several months or more, ask your staff liaison to meet with you on a regular basis so that you can become aware of your strengths and areas for improvement.
- **Ask how you can learn more.** If there is a topic you would like to learn more about or some skill you would like to work on, ask your staff liaison for resources, individuals to meet with, or time to discuss it further.
- **Ask for support from other advisors when you need it** and always be ready to provide support to them.
- **Participate in the advisor review process.** The hospital's volunteer office will have your staff liaison complete an annual review with you to identify how to continue to best support you as an advisor and to help you improve your participation as an advisor.

Sharing your story

Sharing your story can help others understand your health care experiences and how these experiences have affected you and your family. It can also be a powerful way to show the need for specific changes and improvements at the hospital.

As an advisor, you may be asked to share your story with a variety of people. For example, you may be asked to share your story with hospital leaders to help them understand why it is important for our hospital to work with patient and family advisors. You may be asked to help educate doctors, nurses, and other hospital staff about why it is important to conduct bedside shift reports or involve patients and families in the discharge process. Or you may be asked to speak to a group of patients and family members about becoming advisors.

We will provide you with training and support for each of these opportunities. You should accept invitations to speak only if you are comfortable with the request.

Before you agree to share your story

Before you agree to share your story in a training, meeting, or presentation, get information about what is expected of you and what you can expect. Ask the following questions:

- When, where, and for how long do you want me to speak?
- What do you hope will happen as a result of me sharing my story?
- Who is the audience? How many people will be there?
- Who else will be speaking?
- Will I be answering audience questions?
- Will the session be audio or videotaped?
- Is there reimbursement for child-care or transportation?

Preparing to share your story

If you have decided to share your story, think about what you want to say and how you want to say it. Some people write down their main points to keep them focused. You can use the worksheet below called Sharing Your Story to help you organize your thoughts.

Before you speak in a meeting or to a group, it also helps to practice. Time yourself and see if you are staying within the requested time frame.

As you are preparing what you want to say, think about the following questions:

- Why was I asked to share my story?
- What are the key messages I want to share?
- What are the two or three specific points that I want to the audience to remember?
- What am I willing to share? What is too private to share?
- What examples can I give of when things went well?
- What examples can I give of things that could have gone better?
- What ideas do I have about how my experience could have been improved?

Also keep in mind the following tips:

- **Only share what you want to share.** If you still feel angry about a certain situation or event and do not think you can talk about it in a helpful manner, it may be best not to share that part. You can also talk about it with someone you trust. Ask for ideas about how to share that part of the story in a way in which people will listen.
- **Focus on experiences rather than individuals.** Try to avoid using the names of doctors, nurses, and other staff. If you talk about another facility where you have received care, please do not mention it by name.
- **Be prepared for emotional reactions.** Expect that some people who hear your story may be deeply moved. Also remember that you may feel emotional when you tell your story.
- **Remember that you are in control.** If people ask you questions and you do not know the answer, it is okay to say so. If you do not want to answer a question, it is okay to say that as well.

Sharing your story — A planning worksheet

Use this worksheet to help plan what you want to share about your hospital experience.

Key points about your hospital experiences

What went well during your hospital experience? What things did people say or do that were helpful?

What did not go well during your hospital experience? What things did people say or do that were not helpful?

What improvements would you suggest? What would you rather have happened?

Section 3. Working With Advisors to Improve the Quality and Safety of Health Care

At Tallahassee Memorial HealthCare (TMH), we want to make sure that everyone who comes into the hospital has the best experience possible. One of your jobs as a patient and family advisor is to give us feedback about your experiences and suggesting changes and improvements. This can help make care better for all patients.

How advisors help improve health care quality and safety

Improving health care quality and safety is a challenging task. Health care is a lot better when patients, families, doctors, nurses, and other hospital staff work together to ensure the quality and safety of the care we provide. Because health care quality and safety have a direct effect on patients and families, it is particularly important for patients and family members to participate in changes and improvements.

As an advisor, you will be asked to share your ideas about ways to improve the quality and safety of care that patients get in our hospital. This helps make sure the care and services we provide are based on "patient- and family-identified" needs rather than the assumptions of clinicians and hospital staff about what patients and families want.

Specific ways in which we may ask patient and family advisors to help include:

- **Participating in Focus groups as needed for hospital design and patient centered improvements** with hospital staff, architects, engineers and design team to help identify ways to have a better patient experience at TMH.
- **Participating in discussions about health care quality and safety** with doctors, nurses, hospital staff, and other patients and families, including helping to identify places where errors might occur
- **Sharing ideas** about how to make sure that patients and families have meaningful opportunities to participate in their care and decisions about their care
- **Revising or helping to create materials** for patients and families
- **Sharing your story** during training sessions for doctors, nurses, and other hospital staff

> *"Patient and family advisors have knowledge we don't have. It is so humbling to realize that patients and families know more about [the hospital] than you do."*
>
> *Pat Sodomka, Former Vice President for Patient and Family Centered Care, Georgia Health Sciences Health System (formerly MCGHealth), Augusta, GA*

Improving the care we provide

As an advisor, you may be able to think of times when you or your family member got good quality care in the hospital. You also may be able to think of times when you or your family member did not get good quality care.

We want to make sure that every patient who comes into the hospital gets good quality care. To us, this means that:

- **Patients get the right care for their condition.** Patients get the tests and treatments that are recommended for their condition.
- **Patients get care that is safe and free from medical errors.** The tests and treatments that

patients get do not cause them any harm. Health care providers follow appropriate safety precautions (for example, washing their hands and checking medications before giving them to patients).

- **There are no delays in care.** Patients get the care they need when they need it. They get the tests and treatments they need at the time when they will do the most good.
- **Patients are not treated differently based on their race, ethnicity, income, level of education, or social status.** Everyone is entitled to high-quality health care. This includes people of all cultures and backgrounds.
- **Patients get care that is patient- and family-centered**. This means that:(1)
    - Clinicians and hospital staff ask about and respect each patient's and family's values, preferences, goals, and cultural backgrounds
    - Clinicians and hospital staff communicate clearly and share complete, unbiased, and timely information with patients and families
    - Patients and families are encouraged to participate in their care and decisionmaking to the extent they choose
    - The patient's care represents a partnership between the patient, family, clinicians, and hospital staff

Above all, we want to make sure that patients and families have good experiences and feel supported while they are in the hospital. We welcome your thoughts and ideas about how to make sure this happens.

Identifying ways we can improve

In addition to asking patient and family advisors for feedback, there are other ways that we identify areas for improvement.

One way to identify areas for improvement is to look at **whether the right things happen as part of our patients' treatment.** For example, do patients get the medicines they need when they are supposed to? Do they get the correct tests and treatments? If not, why are these things not happening?

Another important way to identify areas for improvement is to **ask patients about their experiences**. For example, many hospitals ask patients to fill out surveys about their experiences in the hospital.

One survey that you may hear about as an advisor is called the HCAHPS® Hospital Survey (also called CAHPS). Most hospitals in the United States give this survey to patients. Results from the HCAHPS® Hospital Survey help us learn where we could be doing a better job.

The HCAHPS® Hospital Survey asks patients to answer questions on how well health care providers did at sharing information and listening. The survey also asks patients to rate how well their care was coordinated, how well their pain was managed, and whether they had the information they needed to take care of themselves after going home.

Section 4. How Things Work at Tallahassee Memorial HealthCare (TMH)

Tallahassee Memorial HealthCare

Early one morning on April 23, 1948, six people gathered in a small room *in a wooden barrack at Dale Mabry Field on the outskirts of Tallahassee. They were somewhat apprehensive as they took their seats, for the task at hand would be difficult but the decisions made would benefit the community for many years to come. They were creating Tallahassee Memorial Hospital (TMH).*

From the beginning, Tallahassee Memorial was created because of community need, and, over the years, it has grown and changed along with the community. Today, Tallahassee Memorial HealthCare is a private, not-for-profit community regional healthcare system serving 17 counties in North Florida and South Georgia. It includes a 772-bed acute care hospital and a variety of other services to meet the healthcare needs of the region it serves.

(TMH) is the leading healthcare system in the region *serving the surrounding 17 counties in North Florida and South Georgia.*

With 772 beds, 3,500 employees and over 500 medical staff members, Tallahassee Memorial HealthCare is the seventh largest hospital in the state of Florida. TMH is a private, not-for-profit healthcare system with ***a vision of leading the communities we serve to become the healthiest in the nation.***

Mark O'Bryant, President & CEO

Section 5. Ways to Learn More

The Web sites listed below have information about health care quality, patient safety, and being a patient and family advisor.

Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality (AHRQ) is a U.S. Government Agency that is part of the Department of Health and Human Services. AHRQ funds, conducts, and disseminates research to improve the quality, safety, efficiency, and effectiveness of health care. Its Web site has information to help patients, families, clinicians, leaders, and others make informed decisions about health care. Web site: http://www.ahrq.gov

Consumers Advancing Patient Safety

Consumers Advancing Patient Safety believes that consumers and health care providers should work together as partners to create health care systems that are safe, compassionate, and just. Its Web site has information and resources for patients and health care providers.

Web site: http://www.patientsafety.org/

Institute for Healthcare Improvement

The Institute for Healthcare Improvement is a nonprofit organization dedicated to improving health care. Its Web site has resources and improvement tools to promote health care quality and safety.

Web site: http://www.ihi.org/

Institute for Patient and Family-Centered Care

The Institute for Patient- and Family-Centered Care provides guidance, information, and resources related to multiple aspects of patient- and family-centered care, including how to involve patients and family advisors in the planning, delivery, and evaluation of care.

Web site: http://www.ipfcc.org

Josie King Foundation

The Josie King Foundation offers information and resources on patient safety, the prevention of medical errors, and how health care providers and consumers can work together.

Web site: http://www.josieking.org/

Medically Induced Trauma Support Services

Medically Induced Trauma Support Services is a nonprofit organization that creates awareness, promotes open and honest communication, and provides services to patients, families, and clinicians affected by medically induced trauma.

Web site: http://www.mitss.org/

Medline Plus

Medline Plus is the National Institutes of Health's Web site for patients and families. It has information about diseases, conditions, and wellness issues in plain language and includes a medical dictionary.

Web site: http://www.nlm.nih.gov/medlineplus

National Family Caregivers Association

The National Family Caregivers Association provides information and support for individuals who care for others who are aged, disabled, or chronically ill. Its Web site has tools and stories to educate and empower caregivers.

Web site: http://www.nfcacares.org/

National Patient Safety Foundation

The National Patient Safety Foundation is dedicated to improving the safety of patients through education and raising public awareness. Its Web site offers information on patient safety issues and has a variety of resource links.

Web site: http://www.npsf.org/

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Notes

Use the space below to make notes and write down any questions you have for your staff liaison.