

GO TO THE HOSPITAL OR STAY HERE?

A Decision Guide for Patients
and Families





Did you know that almost half of transfers to the hospital may be avoidable?

This Guide will help you understand why these transfers are made and how you can be involved in the decision.

CHANGE IN CONDITION

The question of sending you to the hospital or keeping you here may come up if your condition changes. This change could be a fever, shortness of breath, pain, an injury from a fall, or other change in your condition. Your doctor, nurse or aide may have noticed this change or you may have reported it to them.

WHY THINK ABOUT THIS NOW?

This information is being provided to you so that you can make an informed decision if the question of going to the hospital arises.

It is difficult to weigh the pro's and con's of a transfer to the hospital when you become ill or to decide what treatment you prefer in the middle of a crisis.

IF IT IS NOT AN EMERGENCY

If this is not an emergency, the nurse will assess your condition

- Ask you what happened, how you feel, where it hurts
- Listen to your heart and lungs
- Take your temperature, blood pressure, oxygen level
- Test your blood and urine

You can ask the nurse for the results and if your doctor or family will be called. If you have concerns about being sent to the hospital, this is the time to express them.

IN AN EMERGENCY

In a life threatening situation, the staff may call 911 to send you to the emergency room right away. They will also call your doctor or other medical provider (such as nurse practitioner or physician assistant) and family.



*"I want to be involved 100%."
(Patient)*

*"We do our best to keep them here. We do tests first, the proper assessment, diagnostic tests, whatever we can do here before we would transfer to the hospital."
(Nurse)*



“It depends on what is going on, the severity of the illness. Give me a run down on what the hospital can do for me and what they can do for me here.”
(Patient)

“I don’t want to push the panic button and send her to a hospital if it can be kept under control here.” (Son)

REASONS TO PREFER BEING TREATED HERE

Many tests and treatments can be provided in the skilled facility or rehab center:

- Medications
- X-rays
- Blood tests
- Oxygen
- Wound care
- Checking on you and reporting to your doctor or other medical provider
- Comfort care (pain relief, fluids, bed rest)
- IV (intravenous) fluids in some facilities

You can ask your nurse, doctor or other medical provider what else can be done for you here.

REASONS TO PREFER BEING TREATED IN THE HOSPITAL

Hospitals can provide more complex tests and treatments including:

- Heart monitoring
- Body scans
- Intensive care
- Blood transfusion
- Surgery

THERE ARE ALSO RISKS TO GOING TO THE HOSPITAL

Being transported to the hospital can be stressful. You are likely to have to explain your concerns to new nurses and doctors. You also are at greater risk for skin breakdown, exposure to infection or falling in an unfamiliar place. You may feel more comfortable staying here and being cared for by staff who know you.



“They (resident and family) can only make an informed decision if they have all the information.”
(Doctor)

BEING INVOLVED IN THE DECISION

You have the right to know what is happening to you, how decisions about your care are being made and how you can be involved.

You may want to talk to the following people about your choices:

- Nurses
- Doctors and other medical providers
- Social workers
- Spiritual advisor
- Family members
- Close friends

These are very personal decisions. It’s up to you who you talk to and whose opinions you respect.

You can make your preferences known by:

- Talking with the people listed above
- Putting your wishes in writing and telling people where the documents can be found
- Completing advance directive documents including:
 - Power of attorney for healthcare
 - Health care proxy (naming someone to make health care decisions for you if you cannot)
 - Living will (specifies your preferences for end of life care)
 - Request for a DNR (do not resuscitate) or DNH (do not hospitalize) order
 - A Physician Orders for Life Sustaining Treatment or similar form

WHAT CAN WE DO TO HELP YOU WITH THIS PROCESS?

If you still have questions, please ask your nurse, social worker, doctor, nurse practitioner or physician assistant to talk with you. They may recommend others to talk with you as well.



SPECIAL INFORMATION FOR FAMILY MEMBERS OF RESIDENTS WHO HAVE DEMENTIA

“I usually ask her, what do you think? I explain and go over everything with her.” (Husband)

“Letting the family know, making sure they are aware of the tests being done, the results, definitely helps with the decisions. Her well-being is my primary concern.” (Sister)

1. Will my family member be sent to the hospital even if he/she has Alzheimer’s disease or dementia?

Your family member will be sent to the hospital if needed unless he or she is in the advanced stages of the disease, is in hospice or has advance directives specifying no hospital care.

2. Can my family member still participate in the discussion about transfer to the hospital?

That depends on how advanced the memory problem is and how sick your family member is at the time. Those who are in the early stages are capable of expressing their wishes. Those in advanced stages may not be.

3. Even if my family member cannot express his or her wishes, should we tell him or her what is happening?

Yes. Your family member has the right to know what is happening and may become anxious or frightened if moved to an unfamiliar place without explanation. Be sure to use simple, direct words (“you are sick”, “your doctor thinks you should go to the hospital”), a quiet voice and a calm manner when explaining the situation to your loved one.

4. How can I (as a family member) make sure that I will be fully involved in the decision making process?

You may need to complete some legal forms to do this. Ask your doctor or other medical provider or the social worker at the facility for more detailed information. It’s best to do this before a question about treatment or hospital transfer comes up.



FAQs (Frequently Asked Questions)

ABOUT TRANSFERS TO THE HOSPITAL

1. What is a “medical provider”?

Your medical provider may be a physician (MD), doctor of osteopathy (DO), nurse practitioner (NP) or physician assistant (PA).

2. Why would my doctor or other medical provider consider sending me to a hospital?

If you experience an injury or a serious change in condition, your medical provider may consider sending you to a hospital.

3. When would staying here be the best choice for me?

If we are able to provide the care you need, then staying here may be the best choice.

4. What kind of care can be provided here?

This varies from one facility to another but most are able to give you medications by mouth or injection, IV (intravenous) fluids except blood transfusions, order common lab tests and x-rays, and make periodic checks on your condition.

5. What other reasons would I have for preferring to be cared for here?

There are several reasons. The staff and routines are familiar to you. The staff already know you, your health history and your needs and there is less disruption to your routine if you stay here. The transfer itself may be tiring, even stressful for you. Complications may occur in the hospital.

6. When would going to a hospital be the best choice for me?

Hospitals have more equipment and staff than skilled facilities or rehab centers have. They can do more complex lab tests, x-rays and scans, monitor your condition more closely, give blood transfusions and do complex procedures such as surgery.

7. What other reasons would I have for preferring to be sent to a hospital?

If you have been here only a short time, you may not be very comfortable here yet. You may also have a preferred doctor or other medical provider who will see you in the hospital but not here.



FAQs (Frequently Asked Questions) *continued*

8. What is a hospitalist?

Hospitalists are doctors who have specialized in providing hospital care. In many hospitals, it will be a hospitalist that will oversee your care, not your primary care provider.

9. Who will make the final decision as to whether I should be sent to a hospital or stay here?

Your doctor, nurse practitioner, or physician assistant, in consultation with you, your family and your nurses, will make the final decision.

10. How much say do I have in making this decision?

That's up to you. People differ in terms of how much information they want and how much of a say they want to have in this decision. If for some reason you decide you want to be transferred or stay here against the advice of your medical provider and nurses, you may be asked to sign a form taking responsibility for your decision.

11. What happens if it's an emergency?

If 911 is called, you will receive on-the-spot treatment from the EMTs (ambulance crew) and then be sent to the nearest hospital.



FAQs (Frequently Asked Questions) *continued*

12. Can I request a certain hospital?

You may make this request but in an emergency, the EMTs will take you to the closest hospital if it can provide the care you need. If it is not an emergency and your preferred hospital is close by, they may be able to take you there.

13. Will my family know where I am? Will they know what is happening to me?

Sometimes during a 911 emergency, there isn't time to call family members until you are on your way to the hospital. You can ask that they be called as soon as possible. Both your provider and skilled facility or rehab center staff have a responsibility to keep them informed.

14. Will I be able to continue receiving physical and occupational therapy if I go to the hospital?

That depends on why you are going to the hospital and how sick you are. If therapy has to be discontinued, it will begin again when you are ready.

15. Will I return here after I am discharged from the hospital?

In most cases, you will return here but in some cases going to a rehabilitation hospital, a different skilled facility or even going home may be the better choice for you.

16. Will the facility hold my room for me while I'm in the hospital?

Most of the time, the facility will hold your room for several days. But these policies vary so you should ask someone at the facility what their policy is if this concerns you.

17. What happens to my personal effects if I am transferred to the hospital?

Your personal effects can be stored for you here.

18. Why are we talking about this now?

It is difficult to carefully consider options and your personal preferences in the midst of a crisis, such as being sick enough to be sent to the hospital. You may be upset, worried, or feeling too bad to talk about your preferences with your provider or your family.



FAQs (Frequently Asked Questions) continued

“It’s my lungs. There’s nothing they can do for me any more so I would rather stay here where they know me and I can be comfortable. It would be different if, when they were finished, they could say ‘you can get up out of that chair and go to the ball’. But that is not going to happen.”
(Patient)

19. Why is this decision so important?

There are several reasons why this decision is important. Sometimes patients or their family members become very anxious when the patient becomes ill and ask that the patient be sent to the hospital when treatment could be provided here. There are some risks and some discomfort associated with being sent to the hospital. The transfer itself, a new environment, new staff and new routines can be sources of discomfort. The risks include falls, skin breakdown (pressure sores) and more exposure to infection. Both the transfer and hospital care are very expensive. Some of these expenses may not be covered by your insurance. You may want to ask about this so that you can consider this information in making your decision.

COMFORT CARE, PALLIATIVE CARE, HOSPICE AND ADVANCE DIRECTIVES

1. What is the difference between hospice and palliative care?

The type of care provided is similar but hospice care is intended for those who are in the final months of their life (usually 6 months or less) while palliative care can continue for many months, even years. Hospice care focuses on pain control, symptom management, emotional and spiritual support.

2. What is “comfort care”?

Comfort care or palliative care focuses on easing pain and other symptoms such as nausea, fatigue, depression, constipation or diarrhea, or breathing problems that are the result of your illness or the treatment of your illness. Palliative care teams also help you cope with your illness, providing practical solutions, emotional and spiritual care.

3. What happens if I am getting hospice care when I go to the hospital?

If you go to the hospital, you may have to re-qualify for hospice after returning here. If there’s time, hospice should be called before you are transferred to the hospital.

4. What are advance directives? Should I have them?

Advance directives are documents that tell your family, medical provider, hospital, skilled facility or rehab center staff what kind of care you want to receive if you are unable to be involved in the decision because you are too ill. You can say you don’t want certain treatments such as CPR (resuscitation) if your heart stops or to be put on a breathing machine if you can’t breathe on your own. You can also state that you want all the treatment available if that’s your preference. You can designate someone (adult child, sibling, spouse) to make decisions for you if you cannot do it yourself.

5. If I have advance directives, will my wishes be honored?

To make sure that your wishes are honored, review them with the staff, your family and medical provider ahead of time. Be sure a copy is on your chart at the hospital and here. It’s a good idea to give copies of your advance directives to your family and medical care provider ahead of time.

6. Once I have expressed my wishes in advance directives, can I change my mind?

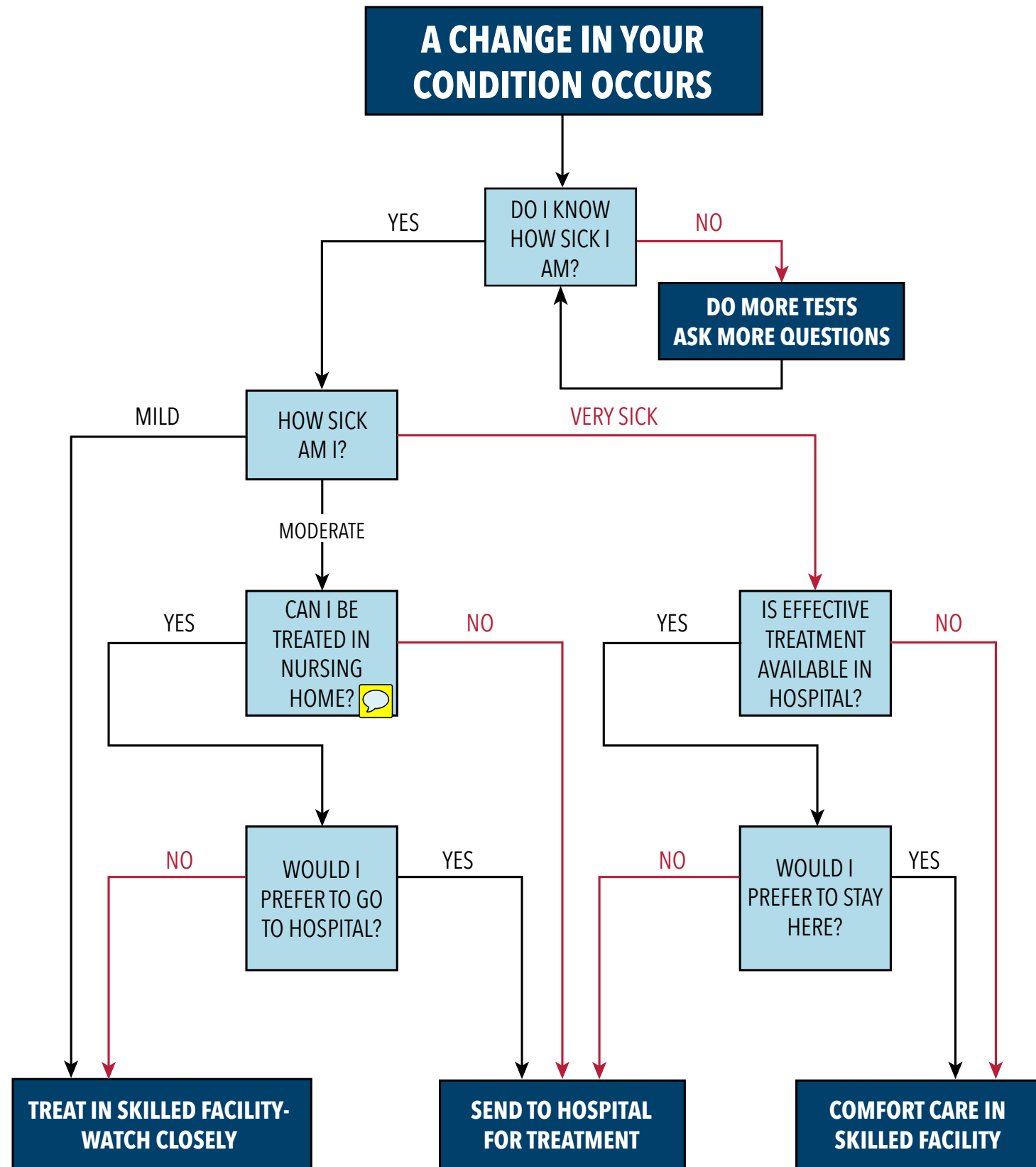
Yes, you can change your mind and your advance directives at any time.





Decision Tree

GO TO THE HOSPITAL OR STAY HERE?



What Patients Say About Going to the Hospital or Staying in the Skilled Facility When a Change in Condition Occurs



"I make my own decisions. I am capable at this point and don't need anybody else."

"I listen to the doctor, listen to the nurses and then I come to my own decision."

"My son and three daughters would help me make the decision. We would talk it over."

"I would leave it to the people who work here, my doctors and the nurses. They know more about it than I do. They just tell me if I have to go."

"I have had instances when I have stayed here and others when I needed to go to the hospital. I would rather stay here. I have been happy here and been treated very well."





What the Families Say about Going to the Hospital or Staying in the Skilled Facility When a Change in Condition Occurs

“This would be something we would discuss. If I thought she needed to go to the hospital, if she would get the best treatment there, I am more likely to recommend it to her.” (Daughter)

“No one wants to see a parent in the hospital – it really stresses me out but I realized she was in good hands. She was in intensive care but came out and is back to normal now.” (Son)

“I think families should know what is happening, that is very important. I want to be in the loop. The most important thing to me is the honesty of the staff, them being level with me about the problem. Then I could make the correct decision. He has to be comfortable with the decision.” (Wife)

“Lord knows, whatever they think they can cure, that would be alright.” (Husband)

“If it was cancer where there is no cure, then no question we would want hospice to come here. But if it was a serious infection I think he should go to the hospital to be treated.” (Wife)

“I want to be fully involved in the decision, want to know all the facts. Absolutely.” (Brother)

“My brother has power of attorney but we all make the decisions concerning him together.” (Daughter)

“I would want to know how serious it is and what outcome is expected.” (Lifelong friend who is health care surrogate)

“If it was just minor, then the nursing home can take care of it. Here they can do oral antibiotics, things like that. Depends on what it is.” (Stepdaughter)

“I would discuss it with my husband but I am more involved because I am here every day.” (Daughter-in-law)



What Care Providers Say About Going to the Hospital or Staying in the Skilled Facility When a Change in Condition Occurs



“We try treating the patient in the facility prior to transfer. We tell the patients, ‘we can take care of this here for now. But we have to watch it and if it’s not getting better, we will send you to the hospital’.” (Doctor)

“Most long term residents want to be involved in the decision because they prefer to be treated here. Rehab patients, too, if they are making good progress.” (Nurse)

“Most families want to have a voice. Patients, too, if they can.” (Doctor)

“Some families are very involved; others just leave it to the facility and the doctor but want to be kept informed.” (Nurse)

“The doctor is usually the gatekeeper.” (Administrator)

“Sometimes we say you need to go and they say no – that is their choice. They have a right to insist on what they feel is best after you have explained it to them, reassured them.” (Nurse)

“The benefit of them staying here is that they know the staff.” (Nurse)

“It’s about the resident. I prefer they be treated here if possible. We try to respect their preferences, get the doctors involved and the family as well.” (Administrator)

“They might be more comfortable here. But if we can’t manage the pain or if they need some diagnostic test or procedure we can’t do here, they truly need to go to the hospital.” (Social worker)

Funding for this Decision Guide was provided by
Patient-Centered Outcomes Research Institute (PCORI).

Grant #: PFA12001. 1P2PI000281-01.

Title: Involving Nursing Home Residents and Families in
Acute Care Transfer Decisions.

Ruth M. Tappen, EdD, RN, FAAN, *Principal Investigator*

