# SPECIAL INFORMATION FOR FAMILY MEMBERS OF RESIDENTS WHO HAVE DEMENTIA

## 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 hospice or has advance directives specifying no hospital care.

## 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 probably capable of expressing their wishes. Those in advanced stages may not be.

#### 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. Use simple, direct words ("you are sick", "your doctor thinks you should go to the hospital"), a quiet voice and a calm manner.

#### 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 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.



# FLORIDA ATLANTIC UNIVERSITY

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# 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.

#### **GO TO THE HOSPITAL OR STAY HERE?**

#### **CHANGE IN CONDITION**

The question of sending you to the hospital may come up if your health changes. Your doctor, nurse or aide may have noticed this change or you may have reported it to them.

#### WHY THINK ABOUT THIS NOW?

It is difficult to decide what treatment you prefer in the middle of a crisis.

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

#### IF IT IS NOT AN EMERGENCY

If this is not an emergency, the nurse will examine you and your doctor or family may 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. They will also call your medical provider (doctor, nurse practitioner, or physician assistant) and family.

#### **REASONS TO PREFER BEING TREATED HERE**

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

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

You can ask your nurse or 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 and 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 at greater risk for skin breakdown, exposure to infection or falling in an unfamiliar place. You are likely to have to explain your concerns to new nurses and doctors.

You may feel more comfortable staying here and being cared for by staff who know you.

#### You can make your preferences known by:

- Talking with your nurses, medical providers, social workers, spiritual advisor, family members or close friends.
- Putting your wishes in writing and telling people where the documents are kept.
- Completing advance directives which are documents that describe what kind of care you want to receive if you are unable to be involved in the decision 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 (POLST) or similar form

You can say you don't want certain treatments or that you want all the treatment available if that's your preference.

#### 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.



## COMFORT CARE, PALLIATIVE CARE, HOSPICE AND ADVANCE DIRECTIVES

1. 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. Emotional and spiritual support are also provided.

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

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.

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. 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 from time to time.

5. 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 either orally or in writing.