A GUIDE FOR CAREGIVERS

A HEALTHY HOSPITAL PROGRAM FOR PERSONS WITH DEMENTIA

Hospitals are an important part of care for persons with dementia. Most hospitals provide excellent care and America has one of the finest healthcare systems in the world. Demented patients may require medical or surgical care during the course of their illness. High quality hospital care is essential to maintaining quality of life for patients. Studies show that more than 2 million Americans will develop complications that may be avoided by simple, low-tech interventions available through simple, cost-effective programs such as H.E.L.P. (HospitalElderLife@yale.edu). Recent studies show that 3% of hospital admissions result in some avoidable, adverse event.

Some hospitals struggle with care for persons with dementia. Physicians, nursing staff, dietary staff, and support personnel can misunderstand the special needs of an Alzheimer patient. This guide alerts families to common problems encountered during hospital stays referred to as the "seven deadly sins" of hospitalization. Family caregivers should be aware of these complications and discuss specific potential problems with nurses and physicians at the hospital. Hospital administrators and patient advocates should be sensitive to this issue. The seven deadly sins of hospital care include delirium, dehydration, demobilization, diminished nutrition, diagnostic confusion, drug reactions, and decubiti.

7 DEADLY SINS OF HOSPITAL CARE FOR PERSONS WITH DEMENTIA

1. **Delirium:** Delirium, an abrupt worsening of confusion, is a common avoidable problem that occurs during hospitalization. Many demented patients are admitted with delirium. Many individuals develop delirium from treatable causes like medication side effects, dehydration, sensory overload, etc. A specific handout is available to physicians, surgeons, anesthesiologists, recovery room staff, and families on ways to protect patients from delirium.

2. **Decubiti:** Decubiti are bed sores that are produced by the pressure of a human body on a bony point. Decubiti can begin in a period of hours if patients are not turned properly. All bed-bound, older patients need a skin protection plan during the hospital stay that includes skin care, skin inspection, and turning the patient on a regular basis. Each hospital has different plans for protecting the skin of patients; however, the families are encouraged to discuss skin care on admission. Some patients may be restrained to prevent problems with medical devices such as breathing tubes, chest tubes, etc. Hospitals should be attentive to the skin care needs of the immobile Alzheimer patient and make reasonable efforts to reduce the risks for skin breakdown. The development of a decubitus during a hospital stay does not necessarily indicate poor care if the hospital made reasonable efforts to protect the patient's skin based on national standards of care.

3. **Dehydration:** Dehydration is a common problem during hospitalization and patients often drink inadequate amounts of fluid to sustain adequate body-water content. Families should discuss appropriate hydration and determine whether the staff is monitoring the daily amounts of oral intake. The federal nursing home guidelines suggest that a 150-lb. person requires about 2,000cc or 2 quarts of water per day. Patients who develop dry mouth, dry eyes, dry skin, poor urinary output, and skin that is doughy rather than plump may be dehydrated. Patients can become dehydrated even when they receive fluid in IV solutions. Oral hydration is usually the preferred method to maintain body fluids.

4. **Diminished Nutrition:** Diminished nutrition is a major problem for frail, hospitalized older patients with dementia. Many self-sufficient patients are no longer able to manage in the hospital because of disorientation and confusion. The family caregiver and the nursing staff should discuss the need for assistance with feeding. Patients should not have dramatic weight loss during hospitalization.

   Each scale weighs a patient differently and patients may have significant weight gain or weight loss identified during the admission process. Patients should be weighed on the same scale, at the same time of day, with the same clothing to assure accurate estimates of weight. Starting with the baseline admission weight, the patient should not lose considerable amounts of weight. Abrupt loss of weight suggests either malnutrition or dehydration. Abrupt increases of weight suggests excessive fluid intake, e.g., excessive intravenous hydration.

5. **Demobilization**: Demobilization is a serious problem in frail elders. Demented patients are sometimes allowed to lie in bed for prolonged periods of time. Confusion associated with medical problems or disorientation from a hospital stay

may worsen the walking ability of a patient. Walking or ambulation has many benefits to the demented patient: 1) the movement of the leg diminishes the risk of blood clots, 2) constant practice of walking reduces the likelihood that the patient will forget how to walk during the course of the hospitalization, 3) walking may help to expand breathing airways and reduce the likelihood of lung infections, and 4) walking reduces pressure on skin and diminishes the risk for decubiti. Families should discuss with the hospital staff the plan to walk the patient based on the patient's ability. Moderate to severely demented patients who remain bed-bound for many days or weeks are less likely to resume ambulation after they return home or return to the nursing home. Walking is a "use it" or "lose it" skill in many demented patients. Although ambulation does carry the risk of falls with injury, confinement to bed also carries significant risks.

6. **Drug Reactions**: Demented patients are unable to ask questions and monitor medications administered to them. The family is entitled to ask about specific medications and the benefit provided to the patient through those medications. Pain pills, tranquilizers and other medications that alter brain function require careful review and consideration. Confusion about medications is possible when multiple physicians are caring for the patient.

7. **Diagnostic and Therapeutic Confusion**: Moderate or severely demented patients react differently to health problems than intellectually normal individuals. Patients are unable to explain pain or physical symptoms. Demented patients respond differently to infections than intellectually intact persons. Diseases such as coronary artery disease or heart failure have different manifestations in the older patient as compared to younger individuals. Persons with dementia respond differently to infections and demonstrate less elevation of temperature. Healthcare providers should be aware of clinical differences in care for persons with dementia as opposed to individuals with normal brains.

Physician guidance and information is available through the DETA Program

1-800-457-5679

CAREGIVER BILL OF RIGHTS

Family caregivers must speak for patients who lose the ability to comprehend healthcare issues. These family caregivers have certain rights including:

1. The right to receive complete, unbiased information about every procedure proposed for their patient.
2. A complete description of short-term and long-term complications for every intervention.
3. The right to seek a second opinion about diagnosis and treatment.
4. The right to insist that healthcare professionals obey the patients' written advanced directives.
5. The right to assume the role as the expert on the patient's unwritten wishes about end-of-life issues.
6. The right to respectfully disagree with the medical team.
7. The authority to have the wishes of the patient honored.

For more information or inquiries, call the Dementia Education & Training Program at

1-800-457-5679.

THE DETA HEALTHY HOSPITAL PROGRAM

The DETA Healthy Hospital Program is designed to forge a therapeutic alliance between the hospital that treats an older patient and the family caregiver who assists with their care after discharge from the facility. The program is designed to promote communication between the patient, the family caregiver, and the hospital treatment team, which is responsible for care. This program defines seven basic quality-of-care issues that are based on expected community standards of care for hospitalized elders.

1. Delirium

Delirium is temporary confusion produced by medical problems or confusing medications. Delirium is common in many hospitalized elders, especially those with dementia. Hospitals should take necessary steps to lower the risk of producing delirium in older patients. Excessive use of sedatives, tranquilizers, and pain pills are a very common cause of delirium.

Patients who become acutely confused during a hospitalization need a careful evaluation to understand the cause of the confusion. Confusion may represent brain failure like shortness of breath may represent heart failure. Like heart failure, brain failure needs an aggressive evaluation and treatment of every potential cause. The risk for nursing home placement rises dramatically in the confused patient in the hospital. The longer the patient remains confused, the more likely the patient will have a poor outcome. Hospital acquired delirium; i.e., confusion, is a hospital complication that should be addressed by the hospital staff prior to discharge.

Things To Do If The Patient Becomes Confused

1. Call the confusion to the staff's attention.
2. Ask about why the patient is confused.
3. Do not accept the assurance that all old people become confused.
4. Ask the physician to conduct a confusion assessment.
5. Ask for a neurology or a psychiatry consultation to examine the cause of confusion.

6. Ask the doctor to explain all the potential risk factors for confusion and how they are treating each risk factor.
7. Avoid restraints to "manage" confusion.
8. Use sitters to protect the patient who wanders or climbs out of bed.
9. Beware of dehydration or malnutrition in the confused patient.
10. Do not authorize the transfer of your patient to a nursing home unless the doctor can explain how it will help your patient's confusion.

2. Decubiti (Bed Sores)

Patients with dementia often become less mobile when they are sick and in the hospital. Skin problems can occur in as little as 12 hours with continuous pressure on a bony point. Frail, older people with poor nutrition are at greater risk for developing skin breakdown. Skin problems can lead to local or blood infections and other complications. Families should monitor the position of the patient in the hospital to determine whether these individuals are being moved to redistribute weight. Patients lying flat on their back need protection for certain body areas such as the heels of feet, elbows, buttocks, and between the shoulder blades.

Nurses should check the skin of your patient on a regular basis and the immobile patient should be turned on a regular basis. The nursing staff and the doctor should explain to the family how they will avoid skin breakdown in these individuals. Families should be allowed to see the schedule for turning the patient and signatures indicating that the patient has been turned. Special mattresses, heel protectors, and other devices can be used to reduce the risk of skin problems.

A skin problem does not necessarily mean that the patient is receiving poor care. If a patient develops a pressure sore in the hospital, it is the responsibility of the hospital to assess the problem and develop a plan to correct the ulcer. The wound specialist for the hospital should examine the patient and help the nursing staff to manage the problem. Skin problems cannot wait for the patient to be transferred to another facility such as a rehabilitation hospital or a nursing home. Hospitals have the responsibility to treat the skin problem and avoid complications such as infection.

Things To Do To Prevent Skin Problems

1. Watch your patient to see if staff is turning them or moving them in bed.
2. Ask the nurse about how the nursing staff will protect your patient's skin.
3. Ask to see areas such as the back of heal, hip bones, back, and shoulder blades.

4. Insist that the nursing staff inform you about any skin breakdown immediately.
5. Insist that the nursing staff explain the treatment strategy for any skin breakdown.
6. Ask for the hospital wound specialist to examine your patient.
7. Ask for a conference with the doctor and the hospital wound specialist to discuss any new pressure ulcers.
8. Insist that a plan be developed prior to discharge that deals with the skin problem.
9. Ask for a written plan to heal the skin sores.

3. Dehydration (Fluid Loss)

Many Alzheimer's patients are admitted to the hospital with dehydration. Studies show that up to one-third of persons admitted from nursing homes to the hospital are dehydrated. Dehydration is defined as a significant deficit of water in the body. Patients with dehydration have dry mouth, dry eyes, waxy skin, diminished urine production, and low blood pressure that cause dizziness on standing.

The doctor in the hospital should be aware of your patient's fluid status at all times. Too much fluid causes heart problems and too little fluid causes dehydration. An IV does not mean that the patient is receiving adequate fluid. The doctor must determine how much fluid the patient is missing and how much fluid the patient needs on a daily basis and add the two together to correct the fluid imbalance. Your doctor should be willing to discuss the fluid status of your patient.

Patients require at least six glasses of water per day to maintain adequate fluid balance. Patients who do not receive intravenous fluids must be drinking fluids throughout the hospital stay. If your patient is not taking fluids by mouth and does not have an IV, then you should discuss fluid problems with the doctor.

Patients who are discharged from the hospital with dehydration may be more difficult to manage and these patients may be more likely to develop worsening of dehydration in the nursing home or assisted living facility. Patients should not be discharged with untreated dehydration unless the hospital doctor explains how this problem will be corrected.

Things To Do If Your Patient Is Dehydrated

1. Ask the doctor about dehydration.
2. Ask the doctor to describe how he will fix the patient's dehydration.

3. Monitor the fluid intake of the patient.
4. Ask the nurse about I&O (intake and output) on a daily basis.
5. Ask the doctor if the patient's laboratory values suggest serious dehydration.
6. Do not allow the patient to be discharged without discussing the correction of continued dehydration.
7. Ask for a written plan to correct dehydration after discharge.

4. Malnutrition (Diminished Nutrition)

Many older people are malnourished upon entering the hospital. Sick older persons often stop eating or become so confused during the hospitalization that they forget how to feed themselves. Patients should eat at least 75% of their tray on a daily basis. Hospitals have dieticians who can alter a diet to enhance eating by the patient. Poor nutrition can slow recovery and reduce wound healing for the patient. If your patient is not eating in the hospital, you should discuss nutritional problems with the hospital doctor. Even a few days of poor nutrition creates problems for the patient. Patients who are not eating food are often not drinking water and these patients are at risk for dehydration. Hospital acquired malnutrition is a hospital-based complication that should be addressed prior to discharge. The staff should assess the nutritional problem prior to discharge and develop a plan to correct the malnutrition. Hospital patients should be weighed on admission and on a regular basis. Patients who are losing weight may need to be weighed on a daily basis.

Things To Do For Diminished Nutrition

1. Watch the hospital staff feed your patient to assure that the patient is eating.
2. Assist with feeding the patient yourself if allowed by hospital policy.
3. Ask to see the weight chart for the patient.
4. Ask the nurse about snacks or special supplements to increase caloric or protein intake.
5. Ask to speak with the hospital dietician about your patient's nutritional status.
6. Discuss nutritional problems with the doctor and nursing supervisor.
7. Ask for a written plan to correct weight loss after discharge from the hospital.

5. Demobilization

Many older patients with dementia remain in bed while they are hospitalized. Staff may use restraints or bed rails to prevent the patient from getting out of bed. All

hospitals are concerned about patient falls and some react to this risk by limiting patient activity.

Prolonged bed rest is bad for old people. Extended periods in bed increase the risk for blood clots, lung infections, skin breakdown, decreased appetite, and many other problems. Demented patients who walk into the hospital are expected to walk out of the hospital. Patients stop walking for many reasons including delirium and generalized weakness produced by medical problems.

Family and staff can walk patients with assistance. Physical therapy can visit the patient and assist with ambulation. Patients who walk into the hospital should not be discharged from the hospital until the doctors and nurses explain how the patient will begin to walk again. This ambulation plan should be communicated from the hospital to the rehab hospital or nursing home that is receiving the patient.

Some patients stop walking because of stroke, heart failure, broken bones, or other identifiable disease or condition. The doctor should be able to explain the specific reason why the patient has stopped walking and why they do not expect them to walk again. The hospital-acquired problem with ambulation is a hospital-based complication. Patients should not be discharged from the hospital until a plan is developed to assist the patient to regain their strength and ability to walk.

Things To Do About Demobilization

1. Discuss plans to continue walking with the doctor prior to surgery or on admission.
2. Discuss your willingness to accept the risk of falls from walking with assistance as opposed to lying in bed.
3. Determine that the patient will get up and walk after surgery as quickly as possible.
4. Avoid restraints to “protect” the patient.
5. Ask for a sitter to watch the patient.
6. Request a physical therapy consult to help with a walking plan.
7. Request an evaluation by a rehabilitation specialist to regain lost walking skills.
8. Ask that doctors limit the number of pain pills, tranquilizers, and sedatives given to the patient so your patient will be steadier.

6. Drug Reactions (Adverse Drug Reactions)

Patients receive many drugs while in the hospital. Frequently, a patient will have a primary doctor plus several consultants, and each doctor may order medications. In general, the prescription of two medications from the same family of drugs should raise concerns about communication among the doctors. Families should monitor the medications received by the patient and inquire about the reason for the prescription of each drug. Pain pills, tranquilizers, and sleeping pills can produce significant complications in the frail older person. Dosages of medications should be adjusted for the special needs of the older patient, especially those with kidney or heart problems. Tranquilizers should be prescribed for very specific reasons.

Patients can have reactions to drugs termed "adverse drug reactions". An adverse drug reaction does not suggest poor care or lack of attention by the doctor. Drugs can interact with other drugs to increase or decrease their concentration in the body. Many hospitals have consulting pharmacists who can advise doctors on specific dosing ranges for older patients and warn about potential drug-drug interaction.

Ways To Understand Medications

1. Ask what drugs the patient is receiving and how the medicine will help the patient.
2. Determine which doctor is ordering each particular drug.
3. Inquire if any of the drugs do the same thing.
4. Inquire why your patient is receiving two drugs that do the same thing.
5. Ask whether dosages have been adjusted for older patients.
6. Ask about any mind altering drug termed "psychotropic medications".
7. Inquire about why the patient is receiving psychotropic medication and what the expected side effects are.
8. If a patient appears to have adverse reactions to medications, ask for a consultation by the hospital Pharm-D to assess the drug program.

7. Diagnostic And Therapeutic Confusion

Persons with dementia respond differently to health problems than younger patients. Demented persons are less able to explain symptoms and follow directions during diagnostic procedures. Patients with dementia may have lower baseline temperatures that mask temperature elevation. The clinician should have familiarity with demented patients. Treatment complications should be measured

against possible benefit. Diagnostic examinations should be employed when results will be used to determine treatment that is appropriate for the patient's stage of dementia. Hospitals or geriatricians can be consulted for complicated cases. Some hospitals now hire hospitalists and medical doctors who specialize in hospital care.

1. Expect that all doctors will ask you about symptoms, problems, and medical history.
2. Ask the doctor about their experience in treating persons with dementia.
3. Ask how each test will help your patient.
4. Ask the doctor if an ordered diagnostic procedure has a treatable outcome if a problem is revealed.
5. If the doctor seems unsure about your patient's care, inquire about the availability of a hospitalist or geriatrician.
6. Go online to learn more about specific diseases and treatment.
7. Remember your caregiver's bill of rights.

The Dementia Education and Training Act (DETA)
1-800-457-5679

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