

Acute Care and the Person With Dementia: Chaos or Calm?



Jane Marks, CDP

Certified Dementia Practitioner,
Trainer, Speaker

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Learning Objectives: At the conclusion of this workshop, participants will be able to:



- Discuss the challenges dementia poses for both the patient and the staff in the acute care setting.
- Explore and debate a newly proposed recommendation for the *acute care setting presented at the Alzheimer's Association International Conference on Alzheimer's Disease in Copenhagen Denmark*
- Summarize and discuss dementia responsive acute care programs in both the U.S. and Europe.

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Acute Care Setting:

A patient receives active care from health care professionals from a range of medical and surgical specialties. Acute care may require a stay in a hospital, emergency department, ambulatory surgical center, urgent care center or other short-term stay facility.



A pattern of health care in which a patient is treated for a brief but severe episode of illness, for the condition caused by an accident or other trauma, or during recovery from surgery. Acute care is usually given in a hospital by specialized personnel using complex and sophisticated technical equipment and materials, and it may involve intensive or emergency care. This pattern of care is often necessary for only a short time, unlike chronic care.



Hospital, urgent care, surgical center.

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Dr. William Osler — one of the founders of Johns Hopkins Hospital. "The father of modern medicine" - "physician heal thyself" believed student should learn by TALKING to patients and "invented" the first residency program.



*"It is important to know what disease the person has but **MORE important** to know what person has the disease."*

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The disease causes:



- Memory loss. "Where am I? Why am I here? How did I get here? Where is my husband/daughter/wife/son? Where am I?"
- Confusion to time and place. "Where am I? How did I get here? What time is it? I have to get to work/feed the kids, meet the school bus... Where am I???"
- Wandering – "Where did Mr. Smith go??? I thought he was going to smoke!"
- Sensitivity to and aversion to change. "This is not my room. Where am I? What are those noises? Who are you people? Why am I in this bed? are those people? Where is my cat? WHO ARE YOU?"
- Sensitivity to light and sounds. "Mrs. Smith I need to get some blood!"
- Increased likelihood of dehydration – "Drink? What drink? Where is my cup?"
- Increased chance of delirium – "These people are trying to kill me!"

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Then add ...

- Noise
- Lights
- Numerous people
- Busy
- Unfamiliar language and clothing
- And pain or discomfort from an acute issue.



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We could have...

Chaos



Anger



I'm out of here!!!

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Your first time caregiver arrives...

Trusting
Assumes you will fix the problem



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But then.....

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It's inconvenient and annoying...

84 year old female with Alzheimer's admitted to the hospital after a fall.

86 year old husband said " I told them she had Alzheimer's and that I would probably need to stay with her. They said they didn't have any private rooms and I couldn't stay in the room with another female patient.

At 2:30 in the morning the hospital called. They said they couldn't handle my wife, they had found a private room and they needed me to come and be with her."



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"Our mother, who is 78 and has Alzheimer's was in a car accident. She was in the hospital for six days. She did not have a bath, not even a sponge bath, for the first four days as the staff said she was too difficult to handle. My sister and I finally gave her a sponge bath on day 5. "



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87 year old female with Parkinson's and dementia in ER

Accompanied by caregiver daughter

Mom has been complaining of stomach pain, and fell at the assisted living.

Daughter reports Mom has UTI, always causes delirium - thus her wandering and the ensuing fall.

ER Dr. orders CT scan and other tests due to fall and stomach pain. Mom can't have food or drink pending test results. Can't have regular dose of meds as this ER policy is no regular meds until admitted and in room.

6 hours later after no food or drink, missed scheduled dose of Parkinson's medication Mom is raging, trying to get up off the table, screams when Doctor enters cubicle,

"Don't touch me!"

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ER Dr. informs daughter, CT scans are normal, Mom is full of poop and needs to have a good bowel movement, probably needs an enema. Daughter should understand this rage and behavior is probably her dementia worsening. He is discharging mom.

Daughter asks if they can give Mom an enema. Dr. says "We don't do that here."



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86 year old female with dementia, hospitalized for broken shoulder

Mom in hospital five days. Does not have capacity, POA is listed in chart.

One of two daughters with mom 24/7 (One of whom is designated POA)

Discussion on day three with PT on whether Mom's assisted living can provide adequate for up PT or whether skilled rehab facility would be better. PT says not sure, will investigate

Daughters notice gentleman with glasses, wearing a white coat at nurses desk frequently, in hallway, etc.

On day 4, daughter informed by nurse that Mom will be discharged that day. Daughter, shocked, inquires as to the "plan". Nurse says social worker has developed plan. Daughter asks to see social worker

Social worker arrives, an hour later. He is "the man with the glasses and white coat." Daughter asks why he has not discussed plan with daughters, he answers "Well, I read the notes in the chart."

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And then....



Angry daughter lectures social worker on working and communicating with FAMILY, one of whom had been present at all times during stay.

Dr. is called and says Mom won't be discharged until tomorrow and will be there soon to discuss plan with daughters.

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It's confusing.



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It impacts recovery.

78 year old man admitted to hospital with a broken hip. Staff reports he has not eaten for three days.

Daughter arrives from out of town. Assesses the situation and *reports* "Me Da has dementia and is not used to eatin' from under a mushroom."



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It's dangerous



"My Dad's 62. My brother and I took him to the ER last week and they admitted him with pneumonia. He has Early Onset Alzheimer's but sometimes he can fake it really well and sound like he is making sense.

First they wouldn't give him his Aricept because he said he didn't need it and they wouldn't believe us that he takes it. We finally got his family doctor to contact the hospital.

Yesterday morning they called to say he was being discharged. My brother couldn't go to get him and I had to leave work to go get him. I had an important meeting so I told the nurse I would be there by 3:00 in the afternoon.

When I arrived at the hospital, they said they had discharged my Dad and put him in a cab. Now we cannot find him. What should we do?"

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It's dangerous.

Dad had retained good verbal skills though his memory was gone. X-ray Tech asked "are you diabetic?" Dad answered "No", yet he had an insulin pump which can be damaged by x-rays. Daughter was present and intervened.

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Pennsylvania Patient Safety Authority analyzed data from January 2005 to December 2014 and found 3,710 "safety events" involving patients with dementia or unrecognized dementia. ^# were "near misses" but fell into other categories besides "safety".

Elderly patient reported before amputation surgery that he had no metal in his body. During surgery his surgeon found a metal rod that had to be cut. The surgery went fine.

Philly.com Health and Science, March 28, 2106.

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It's emotionally tough.

The worst part was how many times I had to say to hospital staff, right in front of my Dad, "He has Alzheimer's". It broke my heart. Couldn't they write it down????

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But now you have...



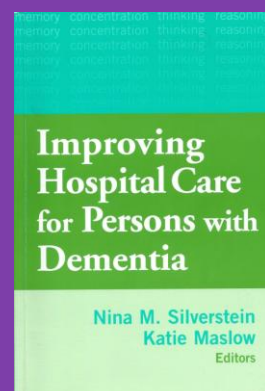
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"Dementia diagnoses frequently are not noted in hospital records and it is often not recognized or considered at admission, during a hospital stay or in the discharge planning process."

Silverstein and Maddox, *Improving Hospital Care for Persons with Dementia* 2006

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2006



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Katie Maslow, M.S.W.

is a Scholar-in-Residence at the Institute of Medicine (IOM), with a primary focus on care-related issues for older people with dementia, mental illness and co-existing medical conditions. Before joining the IOM in 2011, Ms. Maslow worked for 15 years for the Alzheimer's Association, where she directed practice, research and policy initiatives to improve the quality, coordination, and outcomes of health care and long-term services for people with Alzheimer's disease and other dementias and their family caregivers. *She directed the Association's initiatives on hospital care and managed care for people with Alzheimer's and other dementias and co-directed its multi-site demonstration project, Chronic Care Networks for Alzheimer's Disease.*

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A White Paper
September 2012

Alliance for Aging Research, Administration on Aging and Met Life Foundation.

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Nina M. Silverstein, PhD.
Professor of Gerontology at the University of Massachusetts, Boston, College of Public and Community Service.

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24 Contributors that include geriatric physicians, nurses, hospital administrators.

Compilation of what is known in the research literature and what has been experienced in practice in order to define the gaps that must be addressed as well as offer examples of best practice.

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"Hospital care of older adults with dementia has received surprisingly little attention among healthcare professionals. This text represents a new frontier in geriatric care".

Mathy Mezey, EdD, RN, FAAN
Director of the John A. Hartford Foundation
Institute for Geriatric Nursing at New York
University College of Nursing.

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It's a global problem.

Recent article in "The Conversation", a British publication: Why hospitals are dangerous for people with dementia – and why it's up to families to help



Professor June Andrews FRCN, author of "Dementia - the One-stop Guide" was Director of the Dementia Services Development Centre (DSDC) in the School of Applied Social Science at the University of Stirling.

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"An acute hospital is like a meat grinder for people with dementia – it chews them up and spits them out – so it is worth both avoiding admission in the first place, and learning how to support someone if admission is really necessary."

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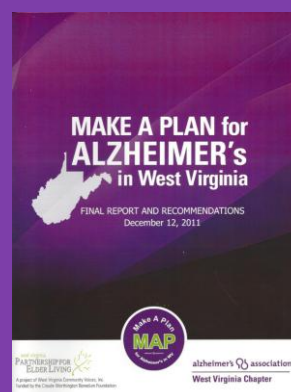
Some facts.

- At least 3.2 million hospital admissions of seniors involve a person with dementia.
- Up to 40% of elderly hospital patients have some form of cognitive impairment, including delirium.
- In fiscal year 2010, 17.6% of all Medicare hospital admissions were return hospitalizations, accounting for \$15 billion in costs.
- On average, 1/3 of all persons with dementia are admitted to a hospital at least one time in a one year period. There are currently more than 5 million people in the U.S. with *Alzheimer's*.
- Patients with dementia who are admitted to a hospital average an additional 1.5-2 admissions in that same year.

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- Less than 25% of delirium cases are diagnosed in hospitals.
- Studies show that experiencing delirium can increase the risk of dementia by eight fold.
- 10,000 Baby Boomers are turning 65 every day in the United States.
- 12.5% of people will have Alzheimer's past the age of 65.
- 50% of people will have Alzheimer's at age 85.
- 50-80% of cognitively impaired individuals have no formal diagnosis.
- 1 in 7 people with dementia live alone, making post acute care more difficult.
- Hospital costs are 79% higher for Medicare beneficiaries with *Alzheimer's disease or other dementias*.

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Cognitive Impairment Recognition in Acute Care

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 Mary Brown, PhD, OAMC Research Institute, Charleston, West Virginia, USA
 E. M. Nish, MD, FACP, Marshall University/John C. Stennis School of Medicine, Huntington, West Virginia, USA
 and the Acute Care Workgroup of West Virginia's Make a Plan for Alzheimer's (MAP) Program - Coordinated by Alzheimer's Association, West Virginia Chapter

The Problem:

Failure to recognize cognitive impairment (CI) in hospitalized patients leads to poor outcomes.

There is much literature about screening for and/or diagnosing CI. However, an error (the failure to recognize) is often made before the screening step is reached. Evidence of cognitive lapses must be seen and documented before screening/diagnosing would be considered, but in the current inpatient hospitalization climate, speedy diagnosis and treatment of the acute problem take precedence over comprehensiveness of care. Subtle signs of cognitive change may be missed or never recognized as problematic.

A Suggested Corrective Measure:

Universal Observation

Just as staff members know about and use Universal Precautions, we propose that ALL staff members also be taught, and be allowed to report on, a set of *Universal Observations*.

Staff should be educated on behaviors which may indicate CI, and must report the observation to a clinician who is directly responsible for the patient's care. The observer does not make a diagnosis; they must only report observations.

Suggested Citations:

• Melis, J. and Sadowsky, C. Practical Guidelines for the Recognition and Diagnosis of Dementia. *J Am Board of Fam Med* 2012;25: 387-392.
 • Lowe, P. A New Strategy for Patients with Dementia. *Emergency Nurse* 2012; 20: 4. Accessed 4/7/12.
 • Chivers, N. and Maslow, K. Improving Hospital Care for Persons with Dementia. Springer, NY 2005, p 211.
 • Statins, M. National Institutes in Hospital Care for Persons with Dementia. Poster presentation at AAC, Boston, MA, USA, July 2013.

Potential Adverse Outcomes of Failure to Recognize CI
 • Inappropriate treatment (of the primary condition and the CI)
 • Inappropriate testing; wrong diagnostic decisions
 • Increased patient agitation
 • Failure of patients to be adequately nourished and hydrated
 • Patient and family dissatisfaction
 • Poor discharge planning
 • Increased readmissions

Universal Observation Workflow:

Behavior/event observed

Recorded on patient log

Reviewed by charge nurse during shift

Reported to primary clinician for evaluation

Definition of CI in Acute Care
 As many as 45% of hospitalized elders may have cognitive impairment due to:
 • Delirium
 • Disease states including acute illness, surgery, sensory deficits, sleep deprivation, etc.
 • Medications
 • Delusions or dementia

Behavioral events to be recorded – "RED FLAGS"

"Patient is described as a 'poor historian'"

Is obviously confused, disoriented, or hallucinating

Is given food tray but does not attempt to eat or drink, or attempts to feed self but cannot

Pl. wanders or engages in other non-purposeful psychomotor activity (e.g., "poking at things")

Unexpectedly wets or soils bed or is persistently incontinent

Appears bewildered or fearful

Becomes extremely agitated over small incidents

Repeatedly fails to follow instructions

And – any other event which concerns the observer in regards to the patient's cognition

Next step: Research underway to determine optimal non-screening method to identify "at-risk" patients with CI

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There is much literature about screening for and/or diagnosing CI. However, an error (the failure to recognize) is often made before the screening step is reached. Evidence of cognitive lapses must be seen and documented before screening/diagnosing would be considered, but in the current inpatient hospitalization climate, speedy diagnosis and treatment of the acute problem take precedence over comprehensiveness of care. Subtle signs of cognitive change may be ignored or never recognized as problematic.

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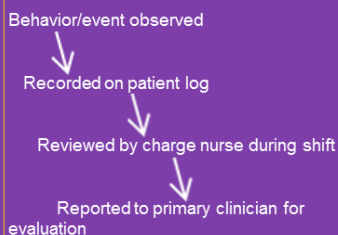
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If you see something, say something.



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Universal Observation Workflow:



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Dementia Friendly

A place where people with dementia can have hope, confidence and the knowledge they are valued.



There would be :

No stigma

Activities appropriate for the person with dementia

Acceptance

Services to meet needs.

Nancy Smith Hunnicutt RN
Mission Hospital, Asheville, NC

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What's going on around the world?



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Common Themes in Other Countries

- 1) Making hospital physical environments dementia capable;
- 2) Identifying specific staff within each hospital as a dementia leader;
- 3) Emphasizing assessment for dementia in the Emergency Department and at admission;
- 4) Utilizing mental health consultation teams based on the hospital for challenging cases;
- 5) Relying on partnerships with community-based organizations to improve discharge processes; and,
- 6) Training for all staff on dementia



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What's happening in other places?



Scotland National Dementia Strategy

"Committed to delivering world class dementia services in Scotland by...improving staff skills in all health settings

In general hospital settings by improving the overall response to dementia including alternatives to admission as well as better planning while in hospital. Being in the hospital can cause stress and anxiety for anyone. For the person with dementia, it is particularly difficult and can significantly impact their ability to function.

...Hospital staff need to know who has dementia or a cognitive impairment in order to provide the best care. We need to improve the assessment of people admitted to hospital who might have a dementia or cognitive impairment and we need to ensure that information about the person's cognitive impairment and needs is communicated to all staff."

Published by the Scottish Government, June 2010

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Two key areas for change outlined in the National Dementia Strategy are improving the support a person receives after diagnosis and improving hospital care.



Some of the key acute care challenges outlined in the report are:

- 1) Longer and more complicated hospital stays by people with dementia;
- 2) Lack of competency by hospital staff concerning the unique needs of people with dementia, especially Emergency Departments and General Ward Staff;
- 3) Inappropriate admission of people with dementia who live at home due to the lack of "step up" temporary intermediate care services and lack of high quality home care; and,
- 4) Poor discharge planning and lack of appropriate "step down" rehabilitation services.

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Solutions identified in the report include:

- 1) Transforming the physical environment of the hospital to be "dementia friendly;"
- 2) Reducing the number of times a person changes beds;
- 3) Training staff on the needs of people with dementia and providing them information about each person with dementia they treat including the person's likes, dislikes and routines to help staff "work with the person, not just the diagnosis;"
- 4) Assessment for cognitive impairment upon admission, especially in Emergency Departments;
- 5) Ensuring dementia diagnosis and related information is communicated to staff and included in the care planning process;
- 6) Multi-agency information sharing to ensure a smooth admission for someone with dementia, as well as utilizing these same partnerships to create a smooth discharge;
- 7) Resisting the urge to simply discharge to long-term care and instead utilize intermediate "step down" care to help improve the chances a person can return home; and,
- 8) As part of discharge planning, assess the needs of the caregiver.

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Australia

Dementia Care Clinical Nurse Consultant



This category of nurse is trained to provide information and support, conduct assessments, and act as an advocate for people with dementia and their care teams (informal and formal).

The Dementia Care Clinical Nurse Consultant typically works from a hospital setting. The New South Wales Department of Health lists the Dementia Care Clinical Nurse Consultant as a service available in the New South Wales area. Its scope of practice appears equivalent to a nurse practitioner in the United States.

More information:

http://www.ncahs.nsw.gov.au/services/results_detailed.php?serviceid=822

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Little Red Trolley

Very similar to the poster project.

Information is relayed through staff training as well as info posted on inside of staff bathroom stalls. "Dunny Dits"



Once a week, the Little Red Trolley goes from unit to unit, with pop quizzes on dementia and dementia friendly policies. "Have you noted a cognitive impairment today?"

Winners receive small prizes such as gift certificates to restaurants, etc.

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Sweden

Hospital in Kristianstad has a "brain protocol" when any confusion seems to be noted.

Actions to implement include:

Minimize noise from hallways, TV, radio, visitors

Make eye contact and introduce your self and explain in simple terms

Provide simple occupation such as folding socks.

Use clear light to avoid shadows and close all draperies or blinds at night.

Limit large groups of visitors. Two at a time only.

"Meeting needs with kind approach is most important."



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In Cincinnati, a project with The Christ Hospital, Trihealth Inc, and The Alzheimer's Association of Greater Cincinnati undertook a project to train staff on identifying dementia and delirium.

Saw a drastic decrease in falls, and in post training surveys, staff overwhelmingly reported more confidence in identifying and managing the patient with dementia.

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Brooksville Regional Hospital now called Bayfront Health in Brooksville. Florida – North of Tampa



Wrist Band Project



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Interview with Gary LeBlanc, founder of the project in PARADE Magazine in June.



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Outer Banks Hospital, a critical care hospital in Nags Head, NC OBH has been recognized as a Top 100 U.S. Community Hospital and named in the top 100 of the best Critical Access Hospitals in the nation.



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Photo

All About Me is about the person at the time the document is completed and will need to be updated as necessary.

All About Me should be completed by the person or persons who know the patient best and wherever possible with the person themselves.

Please refer to the back page for guidance notes to help you complete **All About Me**.



My name: full name and the name I prefer to be known by

I currently live

Caregiver – The person who knows me best

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My home and family, things that are important to me

My life so far

My hobbies and interests

Things which may worry or upset me

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My hearing and eyesight

My communication

My mobility

My sleep

I need assistance for

☐ Hygiene ☐ Eating / Drinking

☐ Toileting ☐ Dressing

My eating and drinking

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My medication(s) What works best?

☐ Crushed ☐ Whole ☐ Apple Sauce ☐ Pudding

Date Completed: _____ By whom: _____

Relationship to patient: _____ Phone: _____

In signing this document, I agree that the information in this document may be shared with health and care workers.

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Guidance notes to help you to complete **All About Me**

All About Me is intended to provide professionals with information about the person with dementia as an individual. This will enhance the care and support given while the person is in an unfamiliar environment. It is not a medical document.

All About Me is about the person at the time the document is completed and will need to be updated as necessary. This form can be completed by the person with dementia or their caregiver with help from the person with dementia where possible.

My Name: Full name and the name I prefer to be known by.

Where I Currently Live: The area (not the address) where I live. Include details about how long I have lived there, and where I lived before.

Caregiver – The Person Who Knows Me Best: It may be a spouse, relative, friend or caregiver.

I Would Like You To Know: Include anything I feel is important and will help staff to get to know and care for me, eg I have dementia, I have never been in hospital before, I prefer female caregivers, I don't like the dark, I am left handed, I am allergic to ... etc.

I Like To Relax By: Things which may help if I become unhappy or distressed. What usually reassures me, for example comforting words, music or TV? Do I like company and someone sitting and talking with me or prefer quiet time alone? Who could be contacted to help and if so when?

My Hearing And Eyesight: Can I hear well or do I need a hearing aid? How is it best to approach me? Is the use of touch appropriate? Do I need eye contact to establish communication? Do I wear glasses or need any other vision aids?

My Communication: How do I usually communicate? Verbally, using gestures, pointing or a mixture of both? Can I read and write and does writing things down help? How do I indicate pain, discomfort, thirst or hunger? Include anything that may help staff identify my needs.

My Mobility: Am I fully mobile or do I need help? Do I need a walking aid? Is my mobility affected by surfaces? Can I use stairs? Can I stand unaided from sitting position? Do I need handrails? Do I need a special chair or cushion, or do my feet need raising to make me comfortable?

My Sleep: How do I sleep? Do I need help to get to sleep? Do I need help to get up?

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The study revealed that:

- Caregivers were frustrated with the hospital experience.
- Caregivers were now expected to give more and more complicated care once a loved one was discharged from the hospital.
- Caregivers felt ill- prepared to provide such care.

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The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

CARE Act goes into effect:
 California, 1/1/14; Colorado, 8/8/15; New Jersey, 8/1/15; New Mexico, 6/8/15; New York, 6/1/15; Montana, 7/1/15; Virginia, 7/1/15; Arkansas, 1/2/16; Louisiana, 9/1/16; Nevada, 1/1/16; New York, 6/1/16; North Carolina, 1/1/16; North Dakota, 1/1/16; Oregon, 1/1/16; Rhode Island, 1/1/16; South Carolina, 1/1/16; South Dakota, 1/1/16; Tennessee, 1/1/16; Texas, 1/1/16; Utah, 1/1/16; Vermont, 1/1/16; Washington, 1/1/16; Wisconsin, 1/1/16; Wyoming, 1/1/16.

CARE Act Signed into Law
CARE Act Passed by Legislature
CARE Act Introduced in 2015

iHeartCaregivers
www.iheartcaregivers.org

www.sandwichcaring.com

19 states plus Puerto Rico have passed ...

The CARE Act features three important parts:

- The name of the family caregiver is recorded when a loved one is admitted into a hospital or rehabilitation facility.
- The family caregiver is notified if the loved one is to be discharged to another facility or back home.
- The hospital or rehabilitation facility must provide an explanation and live instruction of the medical tasks – such as medication management, injections, wound care and transfers – that the family caregiver will perform at home.

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So what if you...

- *Institute “Care Act” procedures even if you are not aware of Care Act.*
- Viewed caregivers as part of the team.
- *Treat “them” with respect.*
- TALK to them.
- *Consider them “the expert” on their loved one.*

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Simple things.



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Caregivers:

Go in prepared – *have all your "stuff" with you.*

Be willing to cooperate, but be willing to be an advocate for your person.

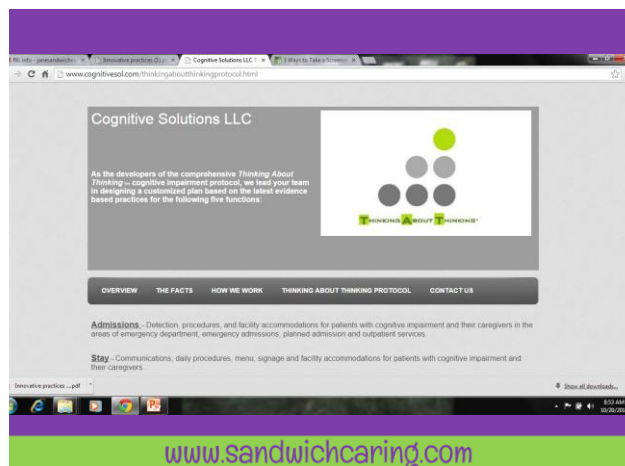
Find out who is in charge – discharge planner, social worker, Doc in charge.

Be prepared to stay.

Remind about the Care Act.

Find the place that "gets it".

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Mission Hospital – Asheville NC is a not-for-profit hospital that serves as the regional referral center for tertiary and quaternary care in western North Carolina and the surrounding region.

Mission Hospital houses the region's only dedicated Level II trauma center.

Mission Hospital is licensed for 795 beds

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Dementia Responsive Care

All private rooms and in new construction section rooms are larger and include equipment for family members to comfortably spend the night. Families encouraged to stay and trained sitters available.

History taken upon admission of any cognitive issues. Immediately flagged as a delirium risk. Screened for possible dementia but NO diagnosis while in hospital.

Personalized elder care form filled out by family.

Immediate geriatric med reconciliation and pain assessment.

Patient's favorite foods are noted upon admission and are served throughout stay and prepped based on family recommendation. (cut up, etc)

Meals are served to patient sitting in chair if at all possible.

Patient is walked with assistance as soon as possible.

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Hydration is pushed.

Foleys out as soon as possible.

Constipation prevention.

NO SLEEP MEDS if cognitive impairment suspected. Five minute back rub, warm milk, relaxation channel on TV.

Patient is ambulating with assistance as soon as possible.

Use their own shoes when walking

Eldercare activity kits with large print puzzles, Large print decks of cards, Beanie Babies, stuffed animals, purses and wallets, activity aprons.

No hospital blankets, but quilts, similar to what they might use at home.



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Dementia Response Specialist on staff.



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"People living with dementia rely on everyone in their surroundings to guarantee their personhood."

Nancy Smith Hunnicutt, RN
Dementia Response Specialist
Mission Hospital, Asheville NC

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