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**Dementia Journal**  
**March 2015**

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## Let's Make Hospital Stays Safer for People Living with Dementia

People living with dementia (PLWD) visit hospitals more frequently than their non-cognitively impaired peers. Surprisingly, however, the vast majority of hospital staff are not educated about the unique needs of PLWD.

Common symptoms often go unrecognized. Systems are not yet in place to effectively cope with the challenging situations that accompany the diagnoses. The *Wristband Project*, highlighted in this journal, is one innovative way people are working to solve this problem.

Let's say your mother or father, spouse or sibling has mild dementia. They have pneumonia or a bladder infection. Maybe they've become dehydrated or they've fallen and broken a bone. These conditions are the top reasons people with dementia end up in the hospital. But instead of getting better there, a majority of PLWD lose ground, develop new problems, and require more help or new care settings before they are discharged.

Such was the situation with Mary\*, who wrote to me last month:

*"My 90 year old mother who has Alzheimer's has just moved into a nursing home following a fall four months ago. She is now a wheelchair user and lost a significant amount of weight while in hospital (10kg). While we anticipated the worse, Mum seemed to pick up. She was eating red grapes and this seemed to satisfy her thirst. Combined with Maltesers, Mum got her appetite back, began eating again, and feeding herself using a fork or spoon!*

*"After five days of being at the nursing home (Mum showing an improvement cognitively), we were told that Risperidone had been prescribed to relieve the hallucinations and modify her behavior as she lashed out during intimate care routines. Since then, we have noticed a great change in our mum. She appears to be distant, cannot hold a fork or spoon, and today she struggled to drink. The nursing staff report that she is sleeping during the night and is more compliant during care however I am concerned for my mum's well-being. Can you offer any advice or reassurance in this matter please?"*

Mary's story is all too common.

In one study, PLWD who were in the hospital for a hip fracture repair, were given only a quarter of the pain medication given to their counterparts without a dementia diagnosis, but three times the antipsychotic medication.

The problem? Most hospital staff don't know how to accurately identify and manage the pain behaviors of PLWD, so they conclude that patients are delirious or psychotic and try to manage those symptoms.

Here's an excerpt of my reply to Mary:

*"I am so sorry to hear about the negative changes with your mom after the bright and positive change that followed the hospitalization.*

*The culprit is very likely the Risperidone. It is not recommended for elders with dementia because of the very side effect you are noticing.*

*It has extrapyramidal toxicity for many people. It can actually cause somnolence, inability to move, problems with swallowing, and even responding to any stimuli, if it gets bad enough. It is one of the atypical anti-psychotics.*

*It is not a good idea to use it to control her distress behaviors during care, unless all other means of interacting, helping and offering other support are tried first and documented.*

*You can ask to have the medication decreased or stopped. There has been great effort at the federal and national level to help reduce the overmedication of PLWD but it is still a big problem. Hospital staff need more education and support to know how to help without the use of medications!"*

### **What can you do if you find yourself in a similar situation to Mary's?**

- Plan for the future now.
  - Gather information early. I recommend this article: [Hospitalization Happens -- A Guide to Hospital Visits for Individuals with Memory Loss.](#)
  - Have frank discussions while the dementia is still mild. Talk about advance care directives and desires. What treatment options does

the person want to consider? For example, when should curative medical treatment be replaced by palliative care?

- o Decide in advance what to bring to the hospital.

[Download and review this important resource document from Teepa.](#)

- Upon arrival at the hospital, provide information to the emergency department and admitting staff on the history and current status of the patient. An assessment to determine their background and their current abilities is critical. Hospital staff should seek information from multiple sources about any recent changes in abilities and circumstances. Use this information to implement a plan for the hospital stay, and include discharge options that provide support and care.
- In the hospital, see that special accommodations are made. For example, patients will need support, based on their abilities, with personal care and meals. Due to limits in communication and comprehension ability they may need help with call systems or with filling their free time. Surprises should be minimized and comfort measures tailored to the individual. People living with later stages of dementia often engage in repetitive activities such as clapping, calling out, getting up and down to both express pain or distress and to calm themselves. Each person should have a plan of care developed to address these issues.

Mary remains involved in her mother's care. She sent this follow up:

*"We (my sister and I) met with the senior nurse who tried to reassure us that the drug was having a positive effect with regards to sleep at night. We were told the swallowing concern was ultimately going to happen so there was no way of preventing that in the long term. We insisted with a review and, today I met with a doctor who listened to my concerns. She has agreed to stop the Risperidone and to try a sleeping tablet to help with sleep."*

As I told Mary, it is hard standing up to authority figures who maintain, "This is for the best." I'm so proud she and her sister stuck to their point. They caught this quickly, pushed for change, and found a doctor willing to listen and respond.

By preparing in advance and remaining involved, family members can improve hospital care for PLWD.

Additional Resources:

- From *Alzheimer's Society - The Journal of Quality Research in Dementia* Issue 8: [The Care of People With Dementia in General Hospital](#)
- From *Alzforum: Networking for a Cure - Dementia Patients Hospitalized Twice As Often as Healthy Peers*
- From *MedPage Today - Dementia Patients More Likely to Be Hospitalized*
- From *National Center for Biotechnology Information - Association of Incident Dementia with Hospitalizations*

*\*Positive Approach has permission to use this correspondence. "Mary" is a pseudonym.*



## TODAY'S VOICE FOR DEMENTIA

Teepa is an advocate for those living with dementia and has made it her personal mission to help families and professionals better understand how it feels to be living with dementia related challenges and change. Her company, Positive Approach, LLC was founded in 2005 and offers education to family and professional care partners all over the world. Her goal? Making a difference...one mind at a time.

## Introducing a New Video from the Dementia Care Academy of the Pines Education Institute



**"Dementia Patients in the Hospital: Offering Help  
with Eating" with Teepa Snow**

Dementia is rarely the primary diagnosis in a hospital, but offers special challenges that can significantly affect a patient's stay and treatment outcome. Learn from Teepa why being prepared is key to advocating for your loved one when he or she no longer can. This 2 hour video guides care partners in:

- How to positively impact the outcome of a loved one's stay
- Which possible problems may arise, and how to overcome them
- How to ask the right questions and make the best choices when communicating with medical staff
- Which drugs are commonly prescribed in hospitals that can have severe side effects for the person living with dementia
- How to detect pain and offer comforting solutions
- How to work as a team with all involved in the journey

To learn more or order your copy of this DVD, please visit the Pines Education Institute's [Dementia Care Academy](#).

## ALZHEIMER'S/DEMENTIA WRISTBAND PROJECT

Having recognized the need firsthand, advocate and writer Gary LeBlanc, has founded the [Alzheimer's/Dementia Wristband Project](#). The pilot program is now underway at Brooksville Regional Hospital in Hernando County, Florida.

**Some initiatives of the wristband project:**

- Upon admission, patients with a prior diagnosis have a Purple Angel affixed to their standard issue hospital wristband for identification purposes.
- A Purple Angel is placed on their door so that anyone entering knows they should approach with the patient's special needs in mind.
- Hospital staff, volunteers, and first responders receive training developed by LeBlanc in partnership with the [Alzheimer's Association-Florida Gulf Coast Chapter](#).

Education is key. LeBlanc stresses that knowledge, understanding, and compassion will lead to improved care. Visit [Teepa's Website](#) to learn more.

*"It is our sincere hope that adoption will be swift so one day soon every hospital staff member across the U.S. (and beyond) will recognize the Purple Angel and its significance - leading to world-class dementia care!"*

- From the [Alzheimer's/Dementia Wristband Project](#).



The [Purple Angel](#) logo, originally developed and inspired by Norman McNamara, is quickly becoming an internationally accepted symbol for Dementia Awareness for all dementia related diseases.

## CONGRATULATIONS to the first PAC Approved Consultants



**We extend a warm welcome to the new  
PAC Approved Consultants  
who completed their certification training with Teepa  
on January 30th in Burbank, California at  
[Leeza's Care Connection](#).**

**Special thanks to Leeza Gibbons and her team for hosting  
the full day of PAC training, and her hard work and  
efforts in raising dementia awareness on  
[Celebrity Apprentice](#). Congratulations on the [win!](#)**

The Consultants completed a program designed for professionals who counsel and advise families working through dementia related challenges.

In addition to dementia related awareness and knowledge, they learned effective communication techniques, strategies to connect with clients in a meaningful way, and methods of providing the right resources at the right time.

If you're interested in becoming a Certified Consultant, more information is available on our [website](#) .

## If your organization would like to host a 2017 PAC Training Certification, please [connect](#) with us.



**Teepa with Consultant Trainees at Leeza's Care Connection**

Leeza's Care Connection, located in Burbank, CA, is expanding and looking for energetic and innovative volunteers or professionals who have expertise in: Grief Counseling, Art Therapy, Laughter Yoga, Reiki, Sound Therapy or Tonal Healing, Wellness Prevention Programs. They are also in need of a bi-lingual licensed counselor for their Spanish monthly support group. Please [connect](#) for more info.

## MEDITATION: Breathe for stress relief and more

Pittsburgh musician, [Jim Donovan](#) is using his talent to help people ease stress, boost energy and energize the brain. "Sound empowerment is the idea that people can use sound as a way to better personal wellness," Donovan says. "You can utilize the power of rhythm and sound to relieve stress, get better sleep, etc. It is one of the most natural human tools," he says.

As a retired music teacher, Annette Bernazzoli, 60, began studying under Donovan four years ago to help with complications she experienced from multiple sclerosis. "Whenever I get tired or achy, it relieves all that stress and makes me feel calmer," she says. "It helps me deal with everyday life and relationships in different ways." Bernazzoli also applies the training to drum circles she leads in her community, at nursing homes and with cerebral palsy patients at hospitals.

Jim Donovan's Stopwatch Tap Technique can help reduce stress in two minutes. He recommends you read all five steps first, and then give it a try.

- Close your eyes and imagine the sound of a stopwatch, like the one at the beginning of the show "60 Minutes."
- Place your hands on the top of your thighs or on your chest.
- Begin to alternate your hands back and forth (right, left, right, left) mimicking the speed and sound of a ticking stopwatch. This tapping need

not be loud, nor do you need to use much energy. In fact, the less physical effort you put into the tapping, the better.

- Try to keep the tapping going for at least 60 seconds or for as long as it feels good to do so.
- Breathe very slowly for the duration of the exercise.
- If at any time you feel uncomfortable, open your eyes, take a few deep breaths and stop the technique.



**Rhythmic Stress Relief: Stopwatch Tap Technique with Jim Donovan**

## Living Well...Dementia World News

**GEMS™** Dementia Aware  
Dementia Knowledgeable  
Dementia Skilled  
Dementia Competent

### **Aware:**

#### ***Where Did You Go? Film Campaign Update***

Thank you to everyone who gave support and pledged to fund the making of *Where Did You Go?* the dramatic short film and accompanying documentary to be produced in the UK this August.

While [Shared Syndicate](#) did not receive enough pledges to enable funding through Kickstarter, and pledges were not collected, everyone on the production team is motivated more than ever to make this project a success.



Positive Approach continues to support the fundraising drive to produce this film and raise awareness. We are currently collecting pledges made to the campaign and invite you to be a part of this exciting endeavor.

Donate

### Knowledgeable:

### Caregiver Relief Shares About a New Antibiotic Resistant Bacteria Superbug

For the past hundred years, we have relied on antibiotics to help us overcome the harmful bacteria that makes us sick. Unfortunately, many bacteria have evolved into "superbugs" resistant to present day antibiotics. These bacteria survive and continue to multiply, causing more harm.

What can we do to protect ourselves from antibiotic-resistant superbugs?

Caregiver Relief offers suggestions [here](#).

More tips from the [Centers for Disease Control and Prevention](#).

### Skilled:

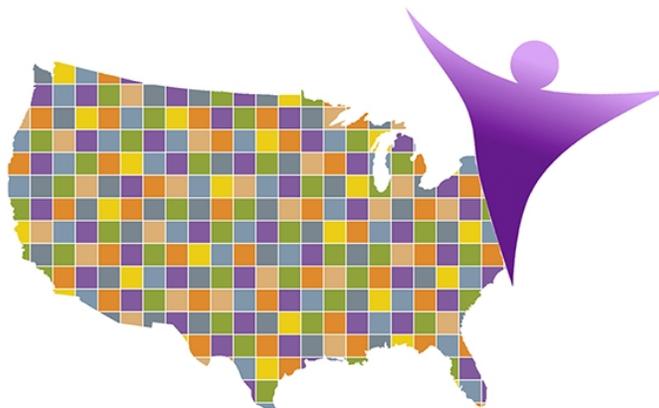
### Documentary from Norman McNamara, the Inspiration Behind the Purple Angel



## Living Well with Dementia - Documentary

### Competent: News from the Dementia Action Alliance

#### [A Nation Joined Together Will Make a Difference](#)



### Dementia Action Alliance

[Learn More](#)

About the US Dementia Action Alliance and how you can get involved!



### DEMENTIA ALLIANCE INTERNATIONAL

February 9-10, 2015

#### Alzheimer's Disease Research Summit 2015: Path to Treatment and Prevention

The National Institutes of Health (NIH) has posted videos of the Summit.

[Video of Summit Day 1](#) includes plenary lectures on the socioeconomic burden of Alzheimer's in the U.S. and globally and what we now understand about the complexity of the disease. The day also covered sessions on the biology of Alzheimer's disease, updates on drug and therapy development, and new strategies for prevention.

[Video of Summit Day 2](#) explores innovations in disease monitoring, assessment, and care; engaging and empowering people in research, and enabling partnerships for collaboration.

Visit the [Summit website](#) to learn more about the diverse group of speakers and view the Summit agenda.

## HELP OTHERS LIVE WELL

If you know someone working or living with dementia who might benefit from the teachings of Teepa Snow, please forward this to them now.

**Be knowledgeable. Be prepared. Be positive.**

If this journal was helpful to you, we would appreciate your feedback. Please share your comments and further interest .

STAY CONNECTED



Visit our [website](#) for resources and program offerings!

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