

DOROTHY'S STORY

This video is based on a story that one of Vancouver Coastal Health's community advisors shared during a 2008 forum on improving senior care.

After hearing the experience of Louise Donald and her mother Dorothy, participants decided this powerful lesson needed to be widely shared: when seniors get sick, it is critical that they, their families and health professionals all work together to improve their chances for recovery.

This is what happened to Louise's mother, Dorothy, an active, vibrant senior.

Dorothy had a fall and was taken to the emergency department of a local hospital to assess whether or not she had broken a bone. Once in hospital, Dorothy was treated with expert, focused care by compassionate staff.

But older patients are more complex due to the normal changes of aging, especially when they have a chronic illness like congestive heart failure, diabetes or high blood pressure. A small change in blood chemistry or fluid intake can have a big impact on the health of an older adult. Treatments that are effective on younger people may be less predictable on older patients.

After a number of days, Dorothy's health deteriorated. She did not react well to some of the treatments she received and she became delirious.

Despite the best efforts of her health care team and the loving support of her family, Dorothy passed away.

Although it is not possible to know if Dorothy's death could have been prevented, Louise and many at VCH who have heard the story believe that a more open, collaborative partnership with health care providers would have improved the process Dorothy and her loved ones went through, if not the outcome.

Health care professionals are experts in providing treatment, but patients and their family members are experts on the person receiving care and the possible impacts of treatment on that person. Professionals can benefit from such information and insights.

By watching this video and discussing it with people in your community, we hope you will be better equipped to deal with episodes of acute illness and hospitalization – yours or that of a loved one.

WORKING TOGETHER

During a hospital stay approximately 33% of people aged 70 or older experience a decline in everyday function, such as eating, dressing, bathing or walking. Seniors have a risk of further decline in some or all of these activities once they go back home. In many cases, this decline is preventable.

Seniors and their loved ones can work together with health care professionals to prevent unnecessary loss of function. The goal and focus of health care professionals is to treat the episode of illness and return seniors to their homes and communities as soon as possible so they can regain their independence and lead full lives.

In order to achieve this goal, it is important for patients to be proactive and participate in their own care.



Louise Donald - Dorothy's daughter

WHAT SENIORS AND THEIR FAMILIES CAN DO

Dr. Janet McElhaney, Head of Providence Health Care Division of Geriatric Medicine, offers the following advice for seniors and their families:



❖ **Ask Questions** – Don't be afraid to ask questions about your treatment or have someone you trust ask for you. ***Know and understand why you are receiving treatments, as well as any restrictions on your food, fluid or activity.***

If there are important considerations that are unique to your situation, be assertive and make sure that health professionals know about them. Don't assume that because you have told one health care professional, all the others are aware of your unique situation. You may have to repeat your story, questions and concerns.

Consider having a family member whom you trust to represent and support you when discussing your care with a professional.

❖ **Express yourself** – Be honest with caregivers and your family about how you feel and what your fears and wishes are. You may have to repeat your wishes several times as staff change throughout the day or week. If you have written wishes (for example: advanced health plan or “living will”) make sure that all the health professionals that you deal with are aware of this document. ***Don’t assume that discussions you had with your family doctor or other health professionals have been relayed to health care providers in other settings such as the emergency department or the hospital.*** Inform your health care team of any present or past issues that may affect your current condition.

❖ **Be vocal about changes** – If someone close to you notices a change in your condition, especially a sudden change to your thinking and memory, let your doctor or nurse know. They should ask why the change has occurred and how they can help. Remember, those close to you know your health better than anyone else.

An older person or anyone who has an acute illness is more susceptible to delirium. ***Delirium is a health emergency. It is a temporary, reversible change in consciousness, attention, thinking and memory. It can go unrecognized and be confused with dementia in older adults.***

It is very important for staff to know the difference between dementia and delirium and to identify delirium quickly so treatment can begin. However, in emergency departments and hospitals, health care professionals do not know the usual personality, alertness level and functional capabilities of the patients they are treating.

They may not recognize early changes as rapidly as family members can.

❖ **Stay active** – Older adults can lose up to 5% of their muscle strength for each day they are confined to bed. Add some action to your day. This can be walking down the hallway, alone or with assistance, or doing bed exercises such as sitting up from a lying position, bending your knees and ankles or moving your feet. Getting up to use the toilet is another way to stay active and maintain regular function.

In hospitals, where health care professionals are very busy, family members can be very helpful in assisting you to stay active while remaining safe. For example, if the staff recommends bed exercises, family members can remind you, coach you or do the activities with you. Or if you are able to be up walking, family members can walk with you to the lounge, to the hospital cafeteria or even down the hallway for a brief stroll.

❖ **Get enough to eat and drink** – Not getting enough to eat or drink can cause an older person to become dehydrated and could result in delirium. ***If you are in the emergency department and awaiting tests or treatment, let staff know you need to eat and drink to stay as healthy as possible.***

Let a family member or staff person know if you need assistance reaching the meal tray, opening packages or cutting food. If you are having trouble eating hospital food, check with your nurse if it is possible for a friend or family member to bring you food from home. Family members can be helpful in reminding you to drink lots of fluids and they can let staff members know if you can't

eat some of the foods on your tray.

❖ **Be aware of your medications** – Keep a list of your medications including dosages and schedules. Alert your caregiver to issues such as scheduling errors, missing medications, duplications, conflicting information or incorrect labels.

If you have allergies or intolerance to some medications, it is important to provide complete and accurate information about this to staff members. It is very important to share with your health care providers all the medications or supplements you are taking. If you are not sure about the medications provided by staff (or what they are for) make sure you ask before you take them. You will not be allowed to take your own medications while in hospital. The hospital will ensure you receive the same or similar medications while you are in care.

❖ **Hand washing** – Frequent use of cleaning foam or washing with soap and water is important for patients, family members and visitors. Make sure you wash your hands frequently, especially after using the bathroom, coughing, sneezing or blowing your nose. It is important to ask family members who are visiting you to do the same. Before a health care professional provides you with direct touch care, ask them politely if they have washed their hands.

COMMUNICATING WITH HEALTH PROFESSIONALS

It can be intimidating to talk to busy care providers. You may deal with many different people as the shifts change and have to start all over again with each new care team. It can be hard to distinguish among doctors, nurses, care aides, therapists and support staff who come to the bedside.

Sometimes care providers may seem abrupt – they must provide care to many patients.

Respect, patience, kindness and persistence can go a long way. Here are some suggestions to improve communication with health care providers:

- Find out who your primary physician and nurse are. Get to know them and be sure that they know you. Each patient has a Most Responsible Physician (MRP) who is responsible for decisions on treatment and medications. It is important to know who this physician is.
- Ask your care team how they want to be informed about your care wishes and needs.
- Ask questions about the care you are receiving. How you ask questions is important; if health care professionals perceive that you respect them and genuinely want to be involved with them in your care, they are more likely to provide the level of detail you require to be included in decisions about your care. (For example, “The pill that you are giving me is a different shape and color than any of the ones I take at home. Could you please tell me what it is and what it is for?”)

- Bring a note book and pen to the hospital. Make a list of the questions you want to discuss with the health care professional in advance of your appointment. Writing the questions down will help you remember what is important and make good use of your time with your doctor or nurse. You may also want to write their answers down to help you remember the discussion afterwards.
- If time is not provided to speak with your doctor or care provider, then make an appointment to discuss details of your illness. It is important to remember that health care professionals have a case load with many patients, all asking many questions.
- Expect that you will have to repeat information to different members of the health care team throughout your stay in hospital and provide the information when asked. However it is good to ask health providers why they need this information.

POSSIBLE DISCUSSION TOPIC

After viewing the video, you may want to discuss the following issues with your group:

- What is your experience with an older loved one in hospital?
- If you have developed a good partnership with health care professionals, how did you do it?
- What ways have you developed to communicate effectively with health care professionals (your family doctor and others)?

POSSIBLE GROUP ROLE-PLAY

1. You are visiting a loved one in hospital, and you notice her sentences sometimes don't make sense. She seems groggy and unfocused compared to her usual self.
 - What might you say to your loved one's health care providers that would help them provide appropriate care?
2. You are with a loved one in the emergency department. They have been there for more than 4 hours and have not had anything to eat or drink.
 - What might you say to your loved one's health care providers that would help them get what they need?

GLOSSARY

Delirium - delirium is a temporary, reversible change in consciousness, attention, thinking and memory. It is a medical emergency. Delirium has an unpredictable course and subtle symptoms may be unrecognized or confused with dementia in older adults.

Case Load - the number of patients cared for by an individual health care provider.

Most Responsible Physician (MRP) - the physician who has final responsibility and is accountable for the medical care of a patient.

Functionality - the ability to perform an activity.

FURTHER READING

The Essential Hospital Handbook - How to be an Effective Partner in a Loved One's Care by Patrick Conlon (Yale University Press, New Haven, 2009)

You can find it in book stores or order online at <http://yalepress.yale.edu/home.asp>

Who was Dorothy Margaret Donald? A Daughter's Tribute

Dorothy was born in Burnaby, BC on June 23rd, 1918. She lived most of her life in Vancouver with her husband Lew. Their early married life was a challenge with the Great Depression of the 30s ending and WW 2 looming on the horizon. But Dorothy and Lew were young and hopeful, and within 5 short years of marriage, their family grew to include four children with a fifth arriving after the War.

Life was busy and happy, guided by Mom's nurturing hand. Her strength and determination were evident even when times were tough. Mom was a very creative thinker and homemaker, a sensible business person - the glue that held our family together.



Always adventurous, in her 40s she took up driving, swimming, golfing and lawn bowling. By the time she was in her 50s she was volunteering at the Vancouver Art Gallery and teaching crafts to patients at VGH. In her early 60s she started painting, experimenting with water colours, oils, pencil sketching and palette work. Mom was also a skilled knitter and quilter and treasured the friendships she made over the years while pursuing her love of creating with her hands.

When Dad retired, he and Mom loved to just get in the car and drive around Vancouver, watch the sunsets over the

water and spot for eagles. They explored almost every corner of BC and traveled extensively. Mom treasured the special friends she had at the Arbutus, Shaughnessy and Kerrisdale Seniors Group and with the Native Daughters of BC. She enjoyed sharing her many skills, her special hugs and great sense of humour.

Mom also treasured her 6 grandsons and, in later years her great-grandchildren. She always looked forward to hearing from, or about, them and proudly shared all of their accomplishments with her friends.

The last 10 years were a struggle with the loss of two sons and her husband but Mom handled these losses with grace. When she moved to an assisted living residence in Vancouver, she adjusted well and quickly made many new friends. She joined various groups and was planning on taking up painting and piano playing once again.

Mom was such a special lady. I will always admire her creative and forward-thinking talents, the quiet words and gentle smiles she had for so many – these memories and so many more will keep her close until we meet again.



Special thanks to Louise Donald for sharing the story of her mother, Dorothy

The tips in the video and this brochure are meant to support patients and their families to work together with health care professionals in order to improve their chances for recovery while in hospital.

Your support is appreciated in sharing this information with others. If you know of a group that would be interested in viewing the video, please contact:

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Dorothy's Story
Seniors, Families and Professionals
Partners in Care

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