

# Using Case Study Betsy to Understand Down's Syndrome & Dementia Teaching Strategy

## Overview of Teaching Strategy

This case study is about an aging woman experiencing Down's Syndrome (DS) and dementia. People with Down's Syndrome are living longer than ever before. Since the 1980s their life expectancy has doubled and many now live into their 60s, most likely because of advances in medical treatment and improved living conditions.

Patients with DS and dementia typically experience several residential relocations during their lifetime and these may be traumatic events for these individuals. This study explores the complex needs of aging clients with intellectual disabilities. Target students for this teaching strategy have completed medical-surgical or geriatric nursing.

## Download All Files for This Teaching Strategy

- [Betsy's case study](#)

## Learning Objectives

Students will:

- Perform physical, functional, and social assessment on the older adult with Down's Syndrome and dementia and recognize pertinent assessment findings
- Use therapeutic communication to address the unique needs of the client with Down's Syndrome and dementia.
- Identify family needs and expectations related to disease progression and the support needed for caregivers now and in the future.
- Address issues of advanced directives and durable power of attorney with patient and family.

## Learner Prework

Ask the students to read and discuss Betsy's case study focusing on the following questions\*:

1. What are your concerns about this patient?
2. What is the cause of the concern?

3. What information do you need?
4. What are you going to do about it?
5. What is the patient experiencing?

\* from Benner, P., Sutphen, M., Leonard, V., Day, L., & Shulman, L. (2010). Paradigm case: Lisa Day, classroom and clinical instructor. In *Educating nurses: A call for radical transformation* (p. 133). San Francisco, CA: Jossey-Bass.

## Suggested Learning Activities

The activities are focused on student reflection on concerns about Betsy, what information they need, what Betsy is experiencing, and how they plan to care for Betsy. Consider these questions when initiating this reflection:

### Social/Family Issues

- What happens to elderly clients with DS? How do we help families?
- Parents die and aging siblings become responsible for care of their sibling with DS.
- Siblings may incur increased financial burden when caring for a sibling with DS, and these health care costs only increase as the sibling with DS ages.
- Who makes long-term health care decisions for clients with DS?
- Who is the most appropriate professional health care provider to assist with this decision?
- Should there be an interdisciplinary approach to assist the family with planning care for Betsy with DS and Alzheimer's disease?

### Long-term Care Issues

Students should discuss with faculty potential options (below) and the pros and cons of each:

1. Aging in place – supports people where they are, in their homes.
2. In place progression – developing a dementia specialty program that is provided in the residential facility.
3. Refer person to generic health-related facility for extended care.
  - What is the best living situation for Betsy? Betsy is no longer responsive to Alzheimer's medications because they have not slowed her cognitive decline. She has been living at the same residential placement for the past 20 years. She is no longer able to leave the facility (with ease). The unskilled workers at the residential facility may not be the most able health care providers for complex care required by Betsy. End-of-life care issues

may overwhelm the residential facility staff. Betsy's siblings and family are divided about moving her to another long-term care facility, nursing home, or into a hospice care center because she is used to her surroundings and caregivers. On the other hand, family is unsure of how aware is Betsy to her surroundings and her caregivers.

- Betsy's family remains supportive and three of Betsy's siblings visit on either a weekly or bi-weekly basis. The family is conflicted related to her placement and will need support in making this decision.
- Family conferences were held twice during the past year. Betsy met criteria for hospice and hospice providers came into the facility and set up program for her skin care and other hospice needs.
- The residential facility where Betsy lives is closing but the agency will continue to operate two cottages open for aging women with DS. Younger clients with DS will be moved to homes into the *Parish Community*. This new model allows eight DS clients to live in a residential home within the *Parish Community* with house parents. The house parents will speak for the needs of the DS clients to their *Parish Community*. The *Parish Community* will become responsible to meet the ongoing needs of the younger DS clients.

### **Priority Health Care and Nursing Care Issues**

What are Betsy's priority health care and nursing issues?

Physical priority concerns include aspiration pneumonia, nutritional issues, immobility and the potential for falls and fractures, immobility-related pain of undetermined origin, and ongoing management of seizures and high blood pressure.

Suggested questions to consider explore:

- Does the health care team need to differentiate between palliative and hospice care?
- How does Betsy's family feel about hospice or palliative care? Are there any religious or cultural factors influencing their decision making?
- What are the economic ramifications of this determination (palliative care vs. hospice) for the aging client with DS?
- Most care for clients with DS is paid for by state and federal funding. How will care be affected by new health care programs?
- What is the optimal standard of care provided to clients with DS and general public?
- Have there been standards of care established for the aging client with DS?
- Are there current recommendations for when Alzheimer's screening and disease management begin for a client with DS?
- Will early recognition of Alzheimer's symptoms and prompt treatment with medication provide a better quality of life, postponing negative progression of Alzheimer's disease? (UCLA, Kentucky and CN studies on DS website.)

## Legal-Ethical issues

Advanced directives are written instructions regarding what actions an individual wants if they are unable to make decisions for themselves. In the case study, Betsy's brother is identified as her medical and legal guardian. Ask the students to write their own advanced directives as an exercise to help raise their consciousness about quality-of-life issues and what measures they may want to sustain life in the face of illness or incapacity. This exercise can lead to a discussion of the legal and ethical decision making for Betsy.

## Suggested Reading

Blair, J. (2011). Care adjustments for people with learning disabilities in hospitals. *Nursing Management - UK*, 18(8), 21-24.

Hirst, S. (2013). Victoria has a developmental disability. *Journal Of Gerontological Nursing*, 39(3), 3-4. doi:10.3928/00989134-20130130-05

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