CASE FOUR

Ms. Grace Tester is a 63 year old woman with Down Syndrome who lives in a large institutional setting in Ohio. She has an intellectual disability, arthritis, and asthma. She has developed signs of dementia over the past half year. Her only living relative is an 80 year old sister who lives on the east coast and rarely sees her. Ms. Tester turned 18 while living in the institution and her parents never saw the need to pursue guardianship rights.

On a routine annual examination at the facility where she lives, the physician discovers a small lump in Ms. Tester’s left breast. She has a family history of breast cancer with both her mother and a sister dying of the disease. A mammogram confirms a characteristic mass indicative of cancer. The physician would like to have a needle biopsy, followed by surgery and further treatment if cancer is confirmed. He is not sure how to proceed since Ms. Tester does not have a guardian.

Before answering the questions that will be posed in this case, it may be helpful to learn more about the lives and health of people with Down Syndrome.

Two recent articles may be helpful:


Two books written by people with Down Syndrome provide personal insights:


Question 4.1

*Is it surprising that Ms. Tester does not have a guardian?*
**Answer 4.1 and Related Resources**

People with ID can be their own guardians and many are able to make their own decisions. Even if someone with ID needs help making decisions, if trusted family members, friends, and providers are there to assist it may not be necessary to take legal rights away from an individual through the guardianship process. Individuals under guardianship may lose many rights, including the right to vote, the right to marry, and the right to make decisions on where and how to live. In fact, guardianship should only be considered when all of the people in the individual’s life agree that the person with ID is incapable of making informed decisions with appropriate guidance and information. Health care powers of attorney or appointing a representative payee or designated representative can offer less restrictive methods to provide assistance in decision making. Some states have limited guardianship which allows for the retention of some rights.

We do not know Ms. Tester’s level of ability to make her own decisions. She may not have needed a guardian until recently, when she began to have dementia. It is not uncommon for someone who has lived in an institutional setting for many years to rely on the institution’s staff to assist and/or make decisions. However, in the absence of a formal appointment, the institution does not have the legal authority to make decisions for Ms. Tester.

Resources that can help people with ID, family and care providers to make decisions concerning guardianship include:

- The “Got Transition?” website: [http://www.gottransition.org/UploadedFiles/Files/FA_GTFinalCompToSend.pdf](http://www.gottransition.org/UploadedFiles/Files/FA_GTFinalCompToSend.pdf)

**Question 4.2**

**Can the physician obtain consent from Ms. Tester for the needle biopsy? For cancer treatment?**

**Answer 4.2 and Related Resources**

The American Medical Association’s Code of Ethics states that generally, any procedure where there is risk to the patient requires informed consent. The elements of informed consent include communicating with the patient about:

- The patient’s diagnosis, if known;
• The nature and purpose of a proposed treatment or procedure;
• The risks and benefits of a proposed treatment or procedure;
• Alternatives (regardless of their cost or the extent to which the treatment options are covered by health insurance);
• The risks and benefits of the alternative treatment or procedure; and
• The risks and benefits of not receiving or undergoing a treatment or procedure.
• An opportunity for the patient to ask questions/discuss options

Many individuals with ID have the ability to give informed consent and are competent to make their own medical decisions. In order to facilitate understanding, it may be necessary to use the simplest possible language in a form or a discussion with a patient with ID and a supported decision-making model may be warranted. For the physician to obtain informed consent from Ms. Tester she would need to be able to understand the risks and benefits of proposed treatments and alternatives and have the ability to make an informed decision based on that information.

Ms. Tester has been exhibiting signs of dementia and has some degree of intellectual disability. It would be important for the physician to assess Ms. Tester’s ability to understand her condition and the proposed treatment before determining whether she can give consent.

Additional Resources:

1) Stamford University School of Medicine Seminar in Psychiatry and Law. Session on Competency to Make Medical Decisions: [http://www.stanford.edu/group/psylawseminar/Competency.htm](http://www.stanford.edu/group/psylawseminar/Competency.htm)


**Question 4.3**

In the absence of a guardian, if Ms. Tester is unable to consent can she obtain medical treatment for her suspected cancer?

**Answer 4.3 and Related Resources**

Treatment may always be provided in an emergency even if the patient is not competent to make a decision. An emergency exists when care is required to alleviate severe pain or when a condition...
if not immediately treated is likely to result in serious disability or death. If a situation is not an emergency, consent must be obtained from the patient’s legal representative. If, as in this case, there is no legal representative, a court order may be appropriate to appoint a surrogate decision maker or guardian for the purposes of medical treatment.

Although a court order may be legally required, it is not uncommon for medical personnel in a situation like Ms. Tester’s to rely on close family members to make decisions for a patient who does not have the capacity to consent without requiring proof that the family has guardianship. In this case, Ms. Tester does not appear to have close family who know her wishes. Although, health care providers may rely on the institution’s staff to represent Ms. Tester’s wishes on minor medical matters if Ms. Tester is unable to express her wishes, for more serious matters – such as treatment for breast cancer - a better course of conduct would be to appoint a guardian, as the guardian would have a fiduciary duty to explore options and make a decision based on all the facts. If there is no one willing and able to serve as a guardian for Ms. Tester, every state has a public guardian or fiduciary which steps in to represent those individuals who do not have family members or friends who are able to act as guardian.

Case Continuation:

It is some months later and the worst has been confirmed: Ms. Tester’s cancer has turned out to be widespread and invasive and her treatment team believes that further treatment is not warranted.

Question 4.4

Is there any concern that Ms. Tester’s treatment team may be giving up too soon based on her disability and dementia?

Answer 4.4 and Related Resources

Historically, people with ID have often received care that is not comparable to that received by their peers without disabilities. Erroneous notions of health and quality of life with a disability have resulted in the failure of many health care providers to prescribe certain treatments or tests.

From the facts we have, it appears Ms. Tester’s physician was proactive in wanting her to have testing and treatment for the cancer. Her current treatment team may be acting as well based on the best current treatment recommendations. However, it would be appropriate if a guardian is appointed for Ms. Tester for that individual to obtain a second opinion or ask further questions of the treatment team as well as eliciting Ms. Testers’ preferences and wishes to determine the best course of action.

Question 4.5

Cases were created by the Association of University Centers on Disabilities (AUCD) and Westchester Institute for Human Development UCEDD; with input from the Nisonger Center UCEDD, Sonoran UCEDD, and other LEND and UCEDD Programs around the country; and with support from the HealthMeet Project of The Arc. Questions and comments about the cases are welcome: kedwards@wihd.org.
Are there particular considerations for end of life care for people with ID?

**Answer 4.5 and Related Resources**

Yes, there are particular considerations to take into account for end of life care for people with ID.

Awareness concerning end-of-life and palliative care issues has increased in recent years for the general public. People with intellectual disabilities have attained increased life expectancies; therefore, end-of-life care is now an emerging health care issue for them. People with ID, families, agencies, and healthcare providers have identified a need for information, training, and support. It is important that appropriate and accurate information be available to support sound decision-making.

Several comprehensive resources are now available:

- In 1998 a number of public and private organizations in New York joined together and developed a New York model of end-of-life care, and produced a handbook, supporting resource manual, and training seminar. This model was adapted for the “Last Passages” project, a Project of National Significance funded by the Administration on Developmental Disabilities and the Project on Death in America. “Last Passages: End of Life Care for Persons with Developmental Disabilities” is available at: [http://www.albany.edu/aging/lastpassages/lp-philosophy.htm](http://www.albany.edu/aging/lastpassages/lp-philosophy.htm)


- New York State has developed a “Legal Requirements Checklist for Individuals with Developmental Disabilities” ([http://www.compassionandsupport.org/index.php/for_professionals/molst/checklist_for_patients_with_developmental_disabilities](http://www.compassionandsupport.org/index.php/for_professionals/molst/checklist_for_patients_with_developmental_disabilities)), that is “required for [use with] individuals with developmental disabilities (DD) who lack the capacity to make their own health care decisions and do not have a health care proxy. Medical decisions which involve the withholding or withdrawing of life sustaining treatment (LST) for individuals with DD who lack capacity and do not have a health care proxy must comply with the process set forth in the Health Care Decisions Act for persons with MR (HCDA) [SCPA § 1750-b (4)]. Effective June 1, 2010, this includes the issuance of DNR orders.”

- The “End of Life/ Palliative Education Resource Center (EPCR)” of the Medical College of Wisconsin has created two “Fast Fact” Summaries concerning end of life issues of importance for PWID.
Two authors from the UCDEDD/LEND network have co-authored a book and articles concerning end of life issues for PWID:

Question 4.6

Are you surprised that a woman with Down Syndrome could live to be 63?

Answer 4.6 and Related Resources

People with Down Syndrome often have chronic health conditions. When these health challenges are managed well, people with Down Syndrome have increasing life expectancies. However, a recent study in the United Kingdom shows that suboptimal health care services for people with ID is a factor in their significantly reduced life expectancy compared with the general population [Heslop P, Blair P, Fleming P, Houghton M, Marriott A, & Russ L. (March 19, 2013). Confidential inquiry into the premature deaths of people with learning disabilities. Norah Fry Research Center, Bristol University, England. (http://www.bris.ac.uk/cipold/fullfinalreport.pdf]. Following established health care guidelines developed specifically for people with Down Syndrome helps to assure optimal health (http://www.ndss.org/Resources/Health-Care/Health-Care-Guidelines/). Additional information on this topic is found in: Virji-Babul N, Eichmann A, Kisly D, Down J, & Haslam RH. Use of health care guidelines in patients with Down Syndrome by family physicians across Canada. Paediatric Health Care. 2007;12(3): 179-83

Question 4.7

If Ms. Tester does have dementia, how might that affect her service needs?

Answer 4.7 and Related Resources

Dementia is now a recognized health risk in people with Down Syndrome and guidelines exist to assist caregivers. The Alzheimer’s Association provides this resource on Down Syndrome and Alzheimer’s Disease: http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp

The National Task Group (NTG) on Intellectual Disabilities and Dementia Practices provides many...
resources related to dementia in people with intellectual disabilities in general at [http://aadmd.org/NTG](http://aadmd.org/NTG). Several examples of resources available from this group include:

- 'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports (PDF)
- Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia (Booklet version) (PDF)
- NTG-Early Detection Screen for Dementia - English (PDF)
- The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities (PDF)

**Q 4.8**

If there was an opportunity to move Ms. Tester to a senior living facility with dementia expertise, what might be the pros and cons of such a move for Ms. Tester, especially after a lifetime in one “home” with familiar caregivers?

**Answer 4.8 and Related Resources**

A move at this point might be quite disorienting for Ms. Tester; every attempt should be made to assure that caregivers know her preferences on such a move.

The right of individuals with disabilities to live in their community was affirmed by the Supreme Court in the Olmstead decision in 1999. The Act laid down some general guidelines for ensuring how this option should be made available for everyone living in an institution. The guidelines developed by the National Task Group on Intellectual Disabilities and Dementia practices offer detailed strategies for how to structure community care and provide the appropriate supports.

One of the roles of an independent guardian would be to make sure that this option is fully considered both with professionals who know her well as well as by others who have expertise in helping people with intellectual disabilities move from institutional to community care.

[http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm](http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm)