Dementia and Capacity

NY Connects Fall 2016 Regional Trainings
Dementia and Capacity
Dementia

Dementia is a general term that describes a group of symptoms—such as loss of memory, judgment, language, complex motor skills, and other intellectual function—caused by the permanent damage or death of the brain's nerve cells, or neurons.
Difficult to diagnosis

- Medical diagnosis
- Rule out other causes
- Rule out nutritional problems
- Rule out depression
- Rule out toxicity
- Brain Scans (MRI, PET, CAT)
All confusion is not dementia!

• Cultural differences
• Hearing difficulties
• Poor vision
• English not first language
• Other?
Causes of Dementia

- Alzheimer’s Disease
- Lewy Body Dementia
- Vascular Disease
- Stroke
- Parkinson’s Disease
- Medications
- Brain injury
- Thyroid Function
- B12 deficiency
- Alcohol/ Substance abuse
Warning Signs of Dementia

- Memory loss
- Trouble planning or problem solving
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble with visual images/spatial relationships
- Problem with words or writing
- Losing or misplacing things
- Decreased or poor judgement
- Withdrawal from work or social activities
- Changes in mood or personality
Red Flags

• Repetitive
• Difficulty understanding/ following conversation
• General confusion
• Paranoia
• Impaired Logic
Questions

1. Does a person with Dementia have decisional capacity?
2. Are they able to give informed consent?
Capacity

“To have capacity a person must have the ability to understand information relative to a decision and to appreciate the consequences of a decision.”

(University of Toronto, 2008)
Presumption of Capacity

• People are presumed capable to make choices for themselves unless proven otherwise.

• Incapacity can be reversible. Illness can temporarily impair capacity and it can be regained upon recovery.
Capacity and Informed Consent

• Capacity is an essential component of Informed Consent.

• A caller **cannot give informed consent if they are not able to understand.**
Decision-making abilities

- Ability to understand relevant information
- Ability to appreciate the situation and its consequences
- Ability to reason
- Ability to communicate and express a choice
Capacity

• Capacity is NOT a test result or a diagnosis.
• Capacity is NOT a single ability that people have or have not
Points to Remember

• You are not able to make a determination of incapacity, capacity is presumed.
• Capacity is task specific.
• Don’t lead with consent! Have a conversation first to build trust.
• Schedule a home visit if you are in doubt.
Capacity is Decision Specific

• Concept of global capacity is no longer held to be true.
• It is currently recognized that people may have capacity in 1 area but not in another.
• A person may be capable of making simple decisions but incapable of making complex decisions.
Task Specific

• Capacity is not a single ability that people have or have not—we use different abilities to make different kinds of choices.

• Capacity deals with the process of decision-making and does not depend on the actual choice made.
Continuum

• Capacity to make decisions is on a continuum from simple to complex
What to do?

• To explain the consent process so that the caller understands.
• Offer to call back the next day.
• Ask if there is someone that helps them (to try and identify a caregiver) and get permission to speak with them.
• Schedule a home visit.
• Other ideas?
Communication Tips

- Be aware of your tone.
- Speak more slowly and use simple words and sentences.
- Allow more time for answers and repeat questions if necessary.
- Ask only one question at a time.
Important to remember

• Remember that the caller is a person first and someone with dementia second.
• Listen to their story and avoid interrupting.
• Do not dismiss a person’s worries-listen and show that you are there for them.
• A sense of humor may help if the moment feels right.
Sensitive Interviewing

• It may be difficult for a person to answer questions that draw on short-term memory.
• A person with dementia may often reply to a question with short concise answers rather than long comprehensive ones.
• Be prepared to move on to next question.
Things that help

• Interviewing a person with dementia requires patience.

• If you do not understand the answer you receive, repeat what you have understood for confirmation.
Identifying a family caregiver

• Do you have someone who helps you with (financial matters, getting around, making important decisions)?
• You mentioned you have a (son/daughter) does he/she live nearby?
• May I also contact him/her?
Whenever possible…

• Consent **must** be obtained from the individual with dementia.

• Schedule a home visit with a trusted family member or friend present for support.
Summary

- Decisional capacity is presumed.
- Watch for Red flags.
- Be patient and speak slowly.
- Listen and address their concerns.
- Show them you are there to help.
Questions

Oh what to do, what to dooo?
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