Toolkit for Primary Care: Capacity Assessment

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Toolkit for Primary Care:

Capacity Assessment

This educational resource kit has been prepared for the Ontario primary care sector (Family Health Teams and Community Health Centres) to use as a learning tool for understanding capacity and capacity assessments in older adults. It can be used as a self-directed learning package, as well as, a resource tool for the inter-professional primary care health team.
This toolkit includes information on capacity and capacity assessment, decision aids/tools that can be used during the process of assessing capacity, a knowledge test and case studies.

Learning Objectives

At the completion of this module, the learner will be able to:

1. Describe the meaning of capacity assessment and its key elements.
2. Understand approaches to capacity assessment and risk identification.
3. Apply knowledge of capacity assessment using case studies.

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Capacity Assessment

Introduction

Assessing a patient's decision-making capacity is part of every patient encounter. For the most part the process is spontaneous and straight forward. Through dialogue, the clinician is able to confirm that the patient understands their health situation and options for care.

In recent years, some important socio-demographic changes have made capacity assessment more prominent. Our population is aging and the prevalence of cognitive deficits, dementia and co-morbidities has increased. The cognitive and physical changes that are occurring in the aging population are linked with declines in every-day functioning that includes the loss of decision-making skills. As a result, there are times when there is a need to assess a patient's decision-making capacity more thoroughly.

Capacity: What Is It?

Capacity is defined as the ability to both *understand* information relevant to a decision and to *appreciate* the consequences of a decision.

(Etchells et al 1996, Gregory et al 2007, Ministry of the Attorney General 2005)

Understand: Ability to focus on factual understanding.
Ability to cognitively grasp and retain information.
Ability to process information regarding available options and risks.

Appreciate: Ability to reason and the ability to attach personal meaning to decisions.
Ability to realistically appraise potential outcomes and the ability to justify choices.

(Etchells et al 1996, Gregory et al 2007, Ministry of the Attorney General 2005)

Required Decision-Making Abilities for Capacity

There are four decision-making abilities that patients require to be able to demonstrate capacity (Ganzini et al 2005, Lai & Karlawish 2007, Moye et al 2004, Qualls & Smyer 2007). These abilities are :

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

The presence of each of these abilities needs to be determined. Clinical presentation may vary and each decision-making ability is assessed individually. Probing questions can be used to assist in this process.

1. Ability to understand relevant information

This is the ability to comprehend basic information about a problem, its potential solutions, and the risks and benefits associated with those solutions. Factors influencing this ability include the patient's level of education and intelligence and how the information is presented.

Probing questions that can be used to determine:

- What is your understanding of your condition?
- What options are available for your situation?
- What do you understand about the benefits of treatment?
- How will the treatment help you?
- What do you think would happen if you decide not to have treatment?

2. Ability to appreciate the situation and its consequences

This is the ability to recognize how a problem or solution pertains to one's own situation. Factors influencing this ability include the type of decision to be made and the complexity of the situation.

Probing questions that can be used to determine:

- What do you believe is wrong with your health now?
- Do you believe that it is possible that this treatment/diagnostic test could benefit you?
- Do you believe that it is possible that this treatment/diagnostic test could harm you?
- We have talked about other possible treatments for you. Can you tell me what they are?

- What do you believe would happen to you if you decided not to have this treatment/diagnostic test?

3. Ability to reason

This is the ability to consider potential solutions to problems by:
- describing how a solution would affect his or her everyday life.
- demonstrating how one solution is better in comparison to another.
- demonstrating logical thought processes in determining a choice.

Probing questions that can be used to determine:
- Tell me how you reached your decision to have (or not have) this treatment/diagnostic test?
- What things were important to you in making this decision?

4. Ability to communicate and express a choice

This is the ability to render a clear choice for the decision under consideration. This choice should be consistent with:
- Expressed beliefs and values.
- Previous decisions and actions.
- Cultural or religious beliefs.

This ability is often preserved despite impairments in the other decision-making abilities.

Probing questions that can be used to determine:
- You have been given a lot of information about your condition/situation. Have you decided what option is best for you?
- Have you made a decision about which treatment you want to proceed with?

A reference tool outlining these decision-making abilities and probing questions is included in this toolkit (Appendix A).

(Lai & Karlawish 2007, Ganzini et al 2005, Moye et al 2004,Moye & Marson 2007, Qualls & Smyer 2007, Tunzi 2001)

KEY ELEMENTS OF CAPACITY

A. PRESUMPTION OF CAPACITY

In our society, people are presumed capable to make choices for themselves, unless proven otherwise. The onus is on the clinician to prove incapacity.

(Etchells et al 1996, Ganzini et al 2003, Ganzini et al 2005, Ministry of the Attorney General 2005, Qualls & Smyer 2007)

Incapacity is often reversible. Illness can temporarily impair capacity and it can be regained upon recovery. If a person appears incapable, the clinician should determine whether reversible factors are present.

Medical conditions which could temporarily impact capacity include:

- Infection eg. pneumonia, UTI, influenza, herpes zoster
- Endocrine disorders eg. diabetes, hypothyroidism, hyperthyroidism
- Cardiovascular disease, hypertension
- COPD
- Obstructive sleep apnea
- Disturbances in fluid/electrolyte balance eg. renal disease, dehydration, malnutrition
- Chronic pain
- Adverse effects of medication
- Delirium
- Mental health issues eg. Depression, psychosis.

Assessments should be focused on enhancing independence and allowing people to make decisions where possible. Recent research has demonstrated that most individuals in the earliest stages of dementia would not be deemed incapable and should be encouraged to participate in decision-making. There is evidence that many patients with more moderate Alzheimer's Disease can continue to express a choice when presented with two relatively simple options.

Retrospective studies have revealed that families recognize signs of declining cognitive abilities approximately one year before seeking medical evaluation. Typically, help is sought when safety is a concern.

(Etchells et al 1996, Ganzini et al 2003, Ganzini et al 2005, Ministry of the Attorney General 2005, Qualls & Smyer 2007)

B. CAPACITY IS DOMAIN-SPECIFIC AND DECISION-SPECIFIC

The concept of global capacity, that is, people considered capable or incapable for all decisions, is no longer held. Within personal care decision-making, for example, there are six domains: health care, nutrition, clothing, shelter, hygiene and safety. It is currently recognized that people may have capacity in one domain but lack capacity in another. Each domain is tested separately.

As well, within each domain, there is a hierarchy of decisions that could be made from simple to complex. A person may be capable of making simple decisions but incapable of making complex decisions.

eg. May be able to making simple grocery purchases but unable to handle banking activities.

May be able to make decision regarding having the flu vaccine but unable to consent to surgery.

Capacity assessment focuses on the specific abilities that an individual needs to make a decision regarding a specific decision/situation.

i.e medical care decisions, managing money, personal care decisions, driving a car, moving to LTCH

The seriousness of a decision does not always correspond with the complexity of the decision.

Factors that influence the complexity of a decision include:

- Number of choices available.
- Number and variety of potential consequences to be considered for each option.
- Degree of uncertainty about the chance of encountering each outcome.

(Ganzini et al 2003, Ganzini et al 2005, Ministry of the Attorney General 2005, Tunzi 2001, Zayas et al 2005)

RELEVANCE

A declaration of incapacity removes a fundamental freedom and right to make choices for oneself. People should only be declared incapable when it has been firmly established that they lack the ability to make decisions or are at serious risk because of their incapacity. (Silberfeld & Fish 1994, Qualls & Smyer 2007)

POINTS TO REMEMBER

- Capacity is an essential component of valid consent.
- Capacity is NOT a test result or a diagnosis.
- Capacity deals with the process of decision-making and does not depend on the actual choice made.
- Capable people are able to make rational decisions, based on their values, goals, knowledge and understanding of the issues facing them – they have the ability to identify and accept risks.
- Capacity is not a single ability that people have or not have – we use different abilities to make different kinds of choices – capacity is task-specific.
- Assessing capacity requires a consideration of the whole person – it is not related to an illness, diagnosis or living situation. Eg. Living in a LTCH does not make an individual "globally incapable"
- Need to balance autonomy (self-determination) and beneficence (protection)

(Cooney et al 2004, Etchells et al 1996, Ganzini et al 2003, Moye & Marson 2007, Qualls & Smyer 2007)

The Four C's of CAPACITY

There are other ways to understand capacity. One of these is The Four C`s of Capacity:

Context	Does the person understand the situation they are facing?
Choices	Does the person understand the options?
Consequences	Does the person understand the possible ramifications of choosing various options?
Consistency	Do they fluctuate in their understanding of choices?

MEASURING CAPACITY

There is no single assessment tool for capacity. However, as a minimum, clinicians need a reliable and valid process as capacity is a multi-dimensional concept (Cooney et al 2004, Etchells et al 1996, Ganzini et al 2003, Gregory et al 2007). Generally speaking, capacity assessment builds on the principles and techniques of good geriatric assessment, in which the process is tailored to the educational, cultural, psychological, social and sensory characteristics of the person being assessed (Qualls & Smyer 2007).

Capacity assessment should only be performed if it serves the best interests of the person – the assessment should not be performed to serve the interests of others.

There is no evidence that scores from standard tests of cognitive ability are a reliable indicator of capacity, partly because they are language-based and influenced by education, culture & language. Most measures of cognitive status do not evaluate cognitive functions such as judgment and reasoning, which are relevant to capacity. These can be used as screening tools to help inform a clinical capacity assessment but should not be used in isolation. A comprehensive assessment of the patient should always be undertaken.

(Cooney et al 2004, Etchells et al 1996, Ganzini et al 2003, Gregory et al 2007)

Assessment may fail to find capacity because:

- It is not present
- Process used was inadequate
- Person applying the process failed to understand, appreciate or apply the process properly. (Ganzini et al 2003)

Decisional tools/aids can be helpful to guide the process and include:

- Aid to Capacity Evaluation (ACE)
- Capacity Assessment Tool (CAT)
- Assessment of Capacity for Everyday Decision-Making (ACED)
- MacArthur Competence Assessment Tool – Treatment (Mac-CAT-T).

These are included to increase your awareness of available resources and are not endorsed by the author of this toolkit.

Aid to Capacity Evaluation (ACE)	Semi-structured interview Addresses 6 facets of capacity for a medical decision: □ medical problem □ treatment □ alternatives to treatment □ option of refusing treatment □ ability to perceive consequences of accepting or refusing □ ability to make decision, not based on depression or delusions → copy of ACE and case study using ACE tool are included in this toolkit (Appendix B and Appendix C). → available: www.utoronto.ca/jcb/ ace (Etchells et al 1996)
Capacity Assessment Tool (CAT)	Structured interview The specific use of this tool is to assess capacity to choose between two options in an actual treatment situation. Evaluates capacity based on 6 abilities: □ communication □ understanding choices □ insight □ decision/choice process □ comprehension of risks and benefits □ judgment Carney, M.T., Neugroschl, J., Morrison, R.S., Marin, D., & Sui, A.L. (2001). The development and piloting of a capacity assessment tool. *Journal of Clinical Ethics,* 12(1), 17-23.
Assessment of Capacity for Everyday Decision-Making (ACED)	Semi-structured interview Assesses four decision-making abilities: □ understanding □ appreciation □ reasoning □ expressing a choice Useful for assessing capacity of older persons with very mild to moderate cognitive impairment to make decisions about how to manage their Instrumental Activities of Daily Living (IADL) disabilities. Lai, James M., Gill, Thomas M., Cooney, Leo M., Bradley, Elizabeth H., Hawkins, Keith A., & Karlawish, Jason H. (2008). Everyday Decision-Making Ability in Older Persons With Cognitivie Impairment. American Journal of Geriatric Psychiatry, 16(8), 693-696.
MacArthur Competence Assessment Tool – Treatment (Mac-CAT-T)	Semi-structured interview Assesses and rates patient's abilities related to four standards for competence to consent to treatment: □ understanding □ appreciation □ reasoning □ expressing a choice Grisso, T. & Applebaum, P.S. (1998). *Assessing Competence to Consent to Treatment.* New York: Oxford University Press

RISK VS. CAPACITY

Embedded in a capacity assessment is a risk assessment. "At risk" means there is a chance of suffering or injury. The issues that triggered the capacity assessment need to be addressed regardless of the assessment outcome. (Silberfeld & Fish, 1994)

The clinician needs to distinguish between tolerable risks and intolerable risks. Only intolerable risks require assessment of capacity. The best evidence of intolerable risk is indication that:

- the behaviour is new and unprecedented - not consistent with past behaviour.
- the behaviour is causing harm.
  e.g. in past, paid bills and managed banking, prided himself in financial self-sufficiency to now, withdrawing large amounts of cash, inappropriate spending.

An important factor in risk assessment is whether a person chooses to engage in risky behaviour, despite being aware of the potential consequences. Competent people do sometimes choose to live at risk. (Qualls & Smyer 2007, Silberfeld & Fish, 1994)

Identifying risk

As a clinician, you will have patients who are living at risk. Questions to consider in identifying risk include:

- Is there concrete evidence to suggest a person is at risk of harm to themselves or others?
- Is the risk actual (is the problem happening now?) or potential (could the problem happen in the future)?

Worksheets to assist with the identification of risks are included in this toolkit (Appendix D).

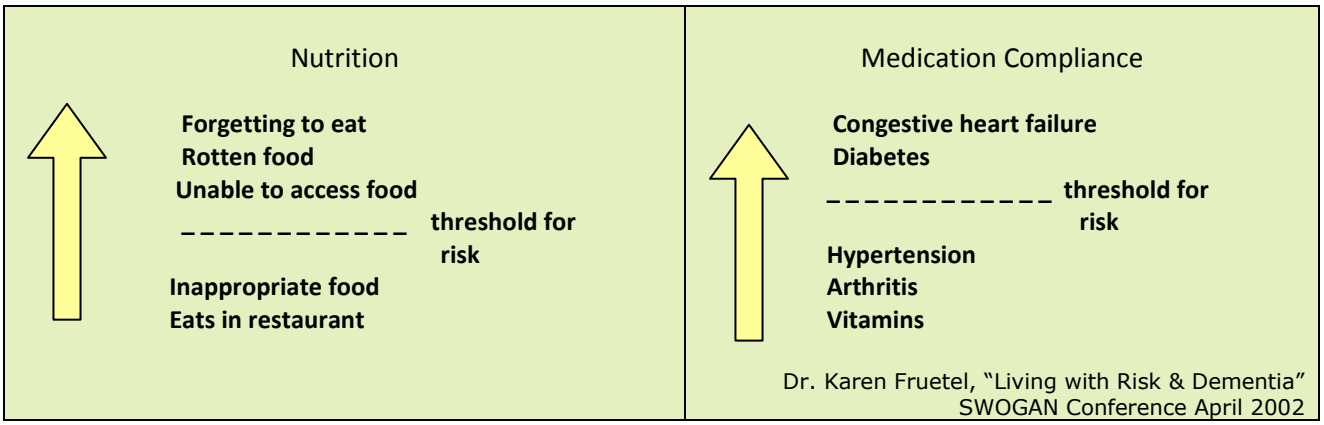
Assess the factors that may affect capacity and risk

There are a number of factors that can potentially affect capacity and risk. These factors need to be considered during the assessment and include:

- Supports (human & physical) that alleviate or contribute to the risk.
- Patient's ability and willingness to use these supports.
- Patient's values and beliefs.
- Patient's tolerance level for various risks.
- Caregiver's values and beliefs.
- Caregiver's tolerance level for various risks. (Silberfeld & Fish 1994)

Level of Risk

Geriatrician, Dr. Karen Fruetel has developed a model for considering levels of risk. In some situations, risk within a domain may be tolerable up to some point. However, beyond this identified level, the risk becomes intolerable.



Not following prescribed diet carries less risk than not eating.

Not taking OA meds will increase pain & decreases mobility but there is no imminent harm. Not taking anti-hypertensive increases risk of stroke. There is greater harm if diabetes meds are not taken.

Dr. Fruetel has developed a Patient Risk Assessment Framework. It can be used to guide the clinician through the process of identifying patient risks and is included in this toolkit (Appendix D)

Principles to Guide Patient Decisions

In situations where a patient is found to be incapable and decisions will be made on behalf of the patient, certain principles should be considered in rendering a decision. These principles include:

- Least restrictive environment.
- Balance autonomy and safety.
- Person-environment fit – optimal outcomes occur when a person's capabilities are optimally supported and challenged by the environment.

(Qualls & Smyer 2007)

LEGISLATION

In Ontario, there is legislation which impacts capacity assessment.

Health Care Consent Act (1996)

- Covers two areas of consent: Consent to treatment and Admission to LTC Home or Home for Aged

Consent to Treatment	Admission to LTC facility
The health practitioner proposing the treatment is responsible for getting the consent. A valid consent must be: ■ Informed – the patient must be given information needed to make a decision and have their questions answered. ■ Voluntary – not obtained through misrepresentation or fraud. ■ Obtained from a capable person – the patient must understand and must appreciate. ■ Documented. Consent may be : Implied vs. Explicit Verbal vs. Written	Same as for Consent to Treatment except capacity is defined as: ■ Be able to understand current challenges in living situation. ■ Be able to appreciate consequences of decisions about living situation.

- Identifies the appropriate Substitute Decision-Maker (SDM) for an incapable person
- SDMs should give/refuse consent based on:
    - Prior known wishes (written or verbal)
    - If no applicable wish is known or it is impossible to comply with the wish, the SDM shall give or refuse consent in the incapable person's best interests – considers person's values and beliefs, whether treatment will improve person's condition or well-being or prevent deterioration of condition, whether the expected benefits outweigh the risk of harm

Substitute Decisions Act (1992, amended 1996)

- Allows for a capable person to complete a Power of Attorney (POA) to grant another person or persons authority to make decisions on his or her behalf.
- Outlines how guardianship for property and/or personal care are created or appointed.
- Three types of POA:
    1. Power of Attorney for Personal Care – gives authority to make decisions about healthcare, nutrition, shelter, clothing, hygiene and safety.
    2. Continuing Power of Attorney for Property – gives authority to deal with property and money and remains valid if the person who signs it becomes incapable.
    4. General Power of Attorney for Property – valid only when the person who signs it is capable – not useful if planning for incapacity.

Mental Health Act

- Governs the fair and equal treatment of all persons who require mental health Services
- Requires the attending physician to assess capacity to manage property when a patients is admitted to a Schedule 1 Psychiatric Facility

(www.e-laws.gov.on.ca)

FORMAL CAPACITY ASSESSMENT

In certain circumstances, formal capacity assessments are required. These assessments are completed by assessors trained through the Ministry of the Attorney General. The most common reasons include:

- When there is no family and a guardian must be appointed.
- When there is conflict within a family.
- When some specific specific financial transaction must occur.

Additional Resources

1. **Educational slide deck on Capacity Assessment**
   - For Primary Care Inter-Professional Team
   - Contact Donna Scott, GIIC Resource Consultant
     Telephone : 519-685-4292 Ext. 42337
     Email : donna.scott@sjhc.london.on.ca

2. **Case Studies**
   Two case studies are provided in this toolkit and can be used to apply knowledge and understanding of capacity assessment (Appendix F).

3. **Knowledge Test - Test Your Understanding**
   – included in this toolkit (Appendix G)

4. **Tool on Capacity and Consent – Ontario Edition**
   Produced by the Advocacy Centre for the Elderly (website: www.advocacycentreelderly.org) and the National Initiative for the Care of the Elderly (website: www.nicenet.ca).

5. **Ministry of the Attorney General – The Capacity Assessment Office – Questions and Answers**
   Available:
   www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacityoffice.pdf

6. **A Practical Guide to Capacity and Consent Law of Ontario for Health Practitioners Working with People with Alzheimer Disease** - The Dementia Network of Ottawa
   Available : www.alzheimerott.org/graphics/center/consentlaw.pdf

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Appendix A: Determining Patient Decision-Making Abilities when Assessing Capacity

Ability	Probing Questions
Ability to understand relevant information This is the ability to comprehend basic information about a problem, its potential solutions, and the risks and benefits associated with those solutions. Factors influencing this ability include the patient's level of education and intelligence and how the information is presented.	• What is your understanding of your condition? • What options are available for your situation? • What do you understand about the benefits of treatment ? • How will the treatment help you? • What do you think would happen if you decide not to have treatment?
Ability to appreciate the situation and its consequences This is the ability to recognize how a problem or solution pertains to one's own situation. Factors influencing this ability include the type of decision to be made and the complexity of the situation.	• What do you believe is wrong with your health now? • Do you believe that it is possible that this treatment/diagnostic test could benefit you? • Do you believe that it is possible that this treatment/diagnostic test could harm you? • We have talked about other possible treatments for you. Can you tell me what they are? • What do you believe would happen to you if you decided not to have this treatment/diagnostic test?
Ability to reason This is the ability to consider potential solutions to problems by: ▪ describing how a solution would affect his or her everyday life. ▪ demonstrating how one solution is better in comparison to another. ▪ demonstrating logical thought processes in determining a choice.	• Tell me how you reached your decision to have (or not have) this treatment/diagnostic test? • What things were important to you in making this decision?
Ability to communicate and express a choice This is the ability to render a clear choice for the decision under consideration. This choice should be consistent with: expressed beliefs and values, previous decisions and actions and cultural or religious beliefs. This ability is often preserved despite impairments in the other decision-making abilities.	• You have been given a lot of information about your condition /situation. Have you decided which option is best for you? • Have you made a decision about which treatment you want to proceed with?

Appendix B: Aid to Capacity Evaluation (ACE)

Name of patient: _____ Date: _____

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a check mark.

1. Able to understand medical problem
(Sample questions: What problem are you having now? What problem is bothering you most? Why are you in the hospital? Do you have (name problem)?)
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

2. Able to understand proposed treatment
(Sample questions: What is the treatment for [your problem]? What else can we do to help you? Can you have [proposed treatment]?
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

3. Able to understand alternative to proposed treatment (if any)
(Sample questions: Are there any other [treatments]? What other options do you have? Can you have [alternative treatment]?
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**
- ▫ **None Disclosed**

4. Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment)
(Sample questions: Can you refuse [proposed treatment]? Can we stop [proposed treatment]?
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment
(Sample questions: What could happen to you if you have [proposed treatment]? Can [proposed treatment] cause problems/side effects? Can [proposed treatment] help you live longer?)
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

6. Able to appreciate reasonable foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment)
(Sample questions: What could happen to you if you don't have [proposed treatment]? Could you get sicker/die if you don't have [proposed treatment]? What could happen if you have [alternative treatment]? *(If alternatives are available)*
Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

(Note: for questions 7a and 7b, a "yes" answer means the person's decision is affected by depression or psychosis)

7a. The person's decision is affected by depression

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you feel that you're being punished? Do you think you're a bad person? Do you have any hope for the future? Do you deserve to be treated?)

Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

7b. The person's decision is affected by psychosis

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you think anyone is trying to hurt/harm you? Do you trust your doctor/nurse?)

Observations: _____

_____

- ▫ **Yes**
- ▫ **Unsure**
- ▫ **No**

Overall Impression

▫ **Definitely capable** ▫ **Probably capable** ▫ **Probably incapable** ▫ **Definitely incapable**

Comments:
(for example: need for psychiatric assessment, further disclosure and discussion with patient or consultation with family)

The initial ACE assessment is the first step in the capacity assessment process. If the ACE is definitely or probably incapable, considerable treatable or reversible causes of incapacity. Repeat the capacity assessment once these factors have been addressed. If the ACE result is probably incapable or probably capable, then take further steps to clarify the situation. For example, if you are unsure about the person's ability to understand the proposed treatment, then a further interview which specifically focuses on this area would be helpful. Similarly, consultation with family, cultural and religious figure and/or psychiatrist, may clarify some areas of uncertainty.
Never base a finding of incapacity solely on your interpretation of domain **7a** and **7b**. Even if you are sure that the decision is based on a delusion or depression, we suggest that you always get an independent assessment.

Time taken to administer ACE: _____ **minutes**

Date: _____

Assessor: _____

INSTRUCTIONS FOR SCORING

1. Domains **1-4** evaluate whether the person understands their current medical problem, the proposed treatment and other options (including withholding or withdrawing treatment). Domains 5-6 evaluate whether the person appreciates the consequences of their decision. *(See sample questions above.*
2. For domains **1-6**, if the person responds appropriately to open-ended questions, score YES. If they need repeated prompting by closed-ended questions, sore UNSURE. If they cannot respond appropriately despite repeated prompting, score NO.
3. For domain **7**, if the person appears depressed or psychotic, then decide if their decision is being affected by the depression or psychosis. For domain **7a**, if the person appears depressed, determine if the decision is affected by depression. Look for the cognitive signs of depression such as hopelessness, worthlessness, guilt, and punishment. *(See sample questions above.)* For domain **7b**, if the person may be psychotic, determine if the decision is affected by delusion/psychosis. *(See sample questions above.)*
4. Record observations which support your score in each domain, including exact responses of the patient.
5. Remember that people are presumed capable. Therefore, for your overall impression, if you are uncertain, then err on the side of calling a person capable.

Appendix C: Case Study Using Aid to Capacity Evaluation (ACE)

Case History:
Mr. C. is a 70 year old widower. His wife died two years ago and he has a daughter and three sons. His relationship with his children is marked by considerable conflict. He was recently hospitalized with gangrene in his right foot and lower leg. Problems with his foot began three years ago when he had an infection in a toe in his right foot which became gangrenous. It was then that he discovered that he was diabetic. The toe was amputated. Last year, he bruised his right leg while getting into a bus. The bruise developed into gangrene which resulted in an operation 6 months ago where a portion of his foot was amputated. At that time an arterial bypass was done to decrease the likelihood that gangrene would recur. He went from the hospital to a rehabilitation centre, where he remained for five months. It was found that he had gangrene in the remainder of the foot. He was started on intravenous antibiotics with no response. A below knee operation was then suggested to him. On the morning of the operation he withdrew his consent and went home to stay with his daughter for three days. He has now been brought back to hospital by his daughter. Mr. C. has been unhappy since the death of his wife. He does not wish to burden his children, and he does not believe the operation will cure him.

EXAMPLES OF SCORING

1. Able to Understand Medical Problem		
Sample Questions	**Sample Responses**	**Suggested Scoring**
What problem are you having right now?	*My foot hurts. I can't walk.*	YES
What problem are you having right now? Do you have a foot problem?	*I don't know.* *Yes, I can't walk.*	UNSURE
What is your most serious medical problem right now? Do you have a foot problem?	*I don't know.* *I don't know/no.*	NO
2. Able to Understand Proposed Treatment		
Sample Questions	**Sample Responses**	**Suggested Scoring**
What is the treatment for [your foot]?	*They will cut my leg off below-knee.*	YES
What is the treatment for [your foot]? Can you have an operation?	*I don't know. You tell me. Yes, they can cut off my leg.* [*Needs futher discussion to clarify that operation is below knee amputation, not entire leg.]	UNSURE

What is the treatment for [your foot]? Can you have an operation?	*I don't know.* *I don't know/no.*	NO
3. Able to Understand Alternatives to Proposed Treatment		
Sample Questions	**Sample Responses**	**Suggested Scoring**
Are there any other treatments?	*I was taking antibiotics.*	YES
Are there any other treatments? Can you take antibiotics?	*Nothing works.* *Yes.*	UNSURE
Are there any other treatments? Can you take antibiotics?	*I don't know.* *I don't know.*	NO
4. Able to Understand Option of Refusing Proposed Treatment (including withholding or withdrawing treatment)		
Sample Questions	**Sample Responses**	**Suggested Scoring**
What are your other options?	*You can't take off my leg unless I sign.*	YES
Can you refuse surgery?	*Yes.*	UNSURE
Can you refuse surgery?	*I don't know.*	NO
5. Able to Appreciate Reasonable Foreseeable Consequences of Accepting Proposed Treatment		
Sample Questions	**Sample Responses**	**Suggested Scoring**
What could happen if you have surgery?	*I could end up in a wheelchair.* [*Needs further discussion about rehabilitation/prosthesis / chance of recovering independence.]	YES
What could happen if you have surgery? Could surgery help you live longer?	*I don't know.* *Yes.*	UNSURE
Could surgery help you live longer?	*I don't know/no.*	NO
6. Able to Appreciate Reasonably Foreseeable Consequences of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment)		
Sample Questions	**Sample Responses**	**Suggested Scoring**

What could happen if you don't have surgery?	*I could die. I could have blood poisoning.*	YES
What could happen if you don't have surgery? Can you get sicker/die without the surgery?	*I don't know.* *Yes.* [*Try rediscussing consequences and repeat the questions. If no better answer, score unsure.]	UNSURE
What could happen if you don't have surgery? Can you get sicker/die without the surgery?	*I don't know/nothing.* *I don't know.* [*Try rediscussing consequences and repeat the questions. If no better answer, score no.]	NO
7a. The person's decision is affected by Depression		
Sample Questions	**Sample Responses**	**Suggested Scoring**
Why don't you want to have surgery?	*I'm a bad person. I've had a bad life. I deserve to die. I'm being punished. I'm not worth it.*	YES [definitely depressed]
Why don't you want to have surgery?	*Nothing seems to work. I have no hope. I'm very sad. I'm all alone. I've suffered too much.*	UNSURE [possibly depressed]
Why don't you want to have surgery?	*I've lived a full and complete life. I don't want to be in a wheelchair because I need to be independent.* [*Needs further discussion about rehabilitation/prosthesis / chance of recovering independence.]	NO [not depressed]
7b. The Person's Decision is Affected by Delusions/Psychosis		
Sample Questions	**Sample Responses**	**Suggested Scoring**
Why don't you want surgery?	*You are a vampire.*	YES [definitely delusional]
Why don't you want surgery?	*You're trying to kill me. You want me to be a cripple.*	UNSURE [possibly delusional]

Why don't you want surgery?	*I don't want to be in a wheelchair.* [*Needs further discussion about rehabilitation/prosthesis/chance of recovering independent mobility.]	NO [not delusional]

Why don't you want surgery?	*You are a vampire.*	YES [definitely delusional]
Why don't you want surgery?	*You're trying to kill me. You want me to be a cripple.*	UNSURE [possibly delusional]
Why don't you want surgery?	*I don't want to be in a wheelchair.* [*Needs further discussion about rehabilitation/prosthesis/chance of recovering independent mobility.]	NO [not delusional]

http://www.jointcentreforbioethics.ca/tools/documents/ace.pdf (Reprinted with permission)

Appendix D: Risk Assessment Framework (Page 1)

Patient Risk Assessment Framework

Patient Name: _____ Date: _____

Is there a disorder that might affect decision-making ability?	If no - STOP	Diagnosis: MMSE: /30 Other information:

What are the actual current risks?	List	Old or new? Imminent risk?	What have been the consequences?	What least restrictive means have been tried?

Are the risks intolerable? a) Risk has increased due to recent changes b) Person has suffered actual harm c) Person engaging in risky behaviour they would normally have avoided d) Exposes others to risk of harm	Explain:

Appendix D: Risk Assessment Framework (Page 2)

Whose interests are being served?	Patient's view:	Advanced directives / Power of Attorney	Caregivers / SDM
What intervention is recommended to deal with risk?			
Is formal capacity assessment required?	Type:	Expected results:	

Patient Care Resources and Duration/Nature of Contact
(family or other caregiver, formal caregiver – CCAC, physician, assessments – SGS)

1.

2.

3.

4.

5.

Developed by Dr. Karen Fruetel, Geriatrician, LHSC, London

Appendix E: Identifying Risks Worksheets

Capacity Assessment Worksheets : Identifying Risks

Key: **S** – satisfactory : fully independent or compensates for personal limitations (appreciates need and accepts assistance)
M – marginal: could be a problem depending on availability and acceptance of supports
U - unsatisfactory: no assistance available or refusing assistance, resulting in unmet need
N/A – skill is not required to manage personal care requirements

Personal Care

A. Nutrition	**Self report**	**Informant**	**Behavioural evidence**
Able to store, prepare food	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Able to arrange for purchase of food	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Able to eat unassisted	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Knowledge of special dietary needs	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Knows what to eat/has rudimentary knowledge of nutrition	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
B. Clothing	**Self report**	**Informant**	**Behavioural evidence**
Able to dress/undress	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Clothes are adequate for weather	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
C. Hygiene	**Self report**	**Informant**	**Behavioural evidence**
Able to wash/bathe	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Able to use bathroom	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Deals effectively with incontinence	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Keeps clothes clean	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Keeps living environment clean	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Personal grooming: teeth, hair, shaves	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
D. Safety	**Self report**	**Informant**	**Behavioural evidence**
Sufficient mobility to meet needs/ Circumstances	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Does not exhibit life-threatening behaviour (wandering, driving recklessly, provoking others, medication abuse)	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	

Able to recognize and avoid hazards (handles cigarettes carefully, remembers to turn off stove, manages meds)	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Able to handle emergencies (notification & evacuation, medical, fire, break-ins)	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Recognizes when others present a danger & takes precautions (careful when out alone at night, does not carry large sums)	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
E. Shelter	**Self report**	**Informant**	**Behavioural evidence**
Able to find shelter that meets minimum personal needs	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Type of shelter is appropriate to needs (manages steps, locks)	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Adequate temperature regulation maintained within shelter	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
F. Health Care	**Self report**	**Informant**	**Behavioural evidence**
Takes care of routine health problems	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Can follow medical regimen for essential or hazardous drugs	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Takes precautions against illness	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Recognizes and alerts others to serious health problems	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Knows primary medical diagnosis and need for treatment	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Can communicate symptoms of illness	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	

Adapted from : Ministry of the Attorney General, Capacity Assessment Office, Guidelines for Conducting Assessments of Capacity, May 2005
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Financial

A. Basic money management	Self report	Informant	Behavioural evidence
Maintain monthly rent/mortgage	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Handle small currency	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Handle large sums	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Safeguard valuables	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Make small purchases	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Pay bills, pay for services:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Manage income	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Issue cheques	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Budget weekly expenses	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Make donations / gifts	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Resist exploitation	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Knowledge of basic services	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
B. Complex Money Management	**Self report**	**Informant**	**Behavioural evidence**
Manage business	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Manage / advise investments	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Budget for major purchases	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Dispose of or acquire property	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Balance accounts	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Arrange for tax obligations	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Apply for pension benefits	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Knowledge of specialized services	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	
Other:	▫ S ▫ M ▫ U ▫ N/A	▫ S ▫ M ▫ U ▫ N/A	

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Appendix F: Case Studies

G2C Case Studies

Regional Geriatric Programs of Ontario
GIIC Initiative for FHTs and CHCs

think

Geriatrics
Interprofessional
Interorganizational
Collaborative Care

CAPACITY

Mrs. Clara Grey, aged 80, husband admitted to acute care 3 months ago and passed away 2 weeks later. Since her husband's death, she has been calling her daughter several times daily. Daughter is expressing concerns regarding her mother's ability to cope at home alone and frustration with the caregiver role.
Past History & Medications: Glaucoma—eye drops BID, Osteoporosis—Calcium and Vitamin D Note: did not tolerate Didrocal, Cataracts removed in summer 2005 and 2007, Dementia—Aricept 10 mg. o.d., Labs—normal 10 months ago. Note: Non-compliance with medication unless cued.
No physical complaints, independent ambulation, no witnessed falls, smoker—1 carton a week, long-standing limited appetite, with 20-25 lbs weight loss over past few years, suspect ETOH abuse, cognitive decline x 5 yrs—started on Aricept 2 yrs ago. Decreased short term memory, some disorientation to time (phoning at 1 am), decreased attention to personal care (not bathing, clothes soiled) . Dependent for IADL's—spouse had done shopping, meal prep, cueing for meds. Uses packaged foods, tea & toast—seldom uses microwave, does not cook. Still has valid driver's license. ? management of ADL's.
Retired secretary, son out of province, dtr. nearby but had not been involved in care due to "family conflict". Mood swings & stubbornness reported by dtr.
Dtr., who is a patient at your primary care centre, has brought Mrs. Grey in for assessment.

Collaborating for better patient outcomes . . .
- **Is the patient capable?**
- **What are the risks?**

Mrs. Grey demonstrates the complexities of care for older people who have chronic illnesses, frailty, and are living in the community. It is questionable if she was really managing with her husband's assistance. Now that this support is gone, her problems have become more apparent.

Assessment

Physical: has walker but does not use, unsteady gait noted, bruising on arms, legs, abrasion on side of face
Cognitive: socially appropriate to most questions. Showed anger when pressed for details, MMSE 21/30. Did not know medical history. Did not know 911.
Mood: decreased energy, sleeps through night, naps during day. Anger & frustration evident. Perceives daughter "trying to get me out of my house". Displayed humour appropriate to situation, able to verbalize husband died but showed little emotion.
Functional: Dishevelled, dirty clothes, scratching head frequently, smelled of cigarette smoke, alcohol, body odour. Clara reports bills are being paid but dtr. found final notices from hydro & gas companies. Dtr. now doing shopping & laundry weekly. Clara "only" drives to local store for milk, bread, cigarettes.
Environment:: Dtr. reports clutter throughout house, several days of unwashed dishes in sink, table & floors "sticky", cigarette burns on carpet & favourite chair. Scatter mats throughout home , observed lighting cigarette from electric stove burner.
Social: High school education, married 60 yrs., No POAs delegated. Minimizes alcohol use. Denies need for assistance stating "I don't need your help or anyone else's".

How and why ? Who and Where?

What are the issues/risks?
Are the risks actual or potential?
Are any of the risks tolerable?
Are there any risks that make capacity an issue?
How should the Primary Care IPC team approach this situation?
What is your role in a capacity assessment?
Who should be involved in her care? Why?
How will her choices and values be respected? Who will advocate?
How would you have a conversation with Clara and her daughter (what would you say)?
What parts of the conversation would you find difficult?
What are your recommendations?

Appendix G: Knowledge Test

Self-Directed Learning: Myths about Decision Making Capacity
Test Your Understanding

T F 1. Decision-making capacity and competency are different concepts.

T F 2. When a patient goes against medical advice, you can presume that they lack decision-making capacity.

T F 3. Decision-making capacity is an "all or nothing" phenomenon.

T F 4. Patients with some levels of cognitive impairment may still have decision-making capacity.

T F 5. Absence of decision-making capacity is a permanent condition.

T F 6. Decision-making capacity would not need to be assessed if the patient agrees with the proposed treatment.

T F 7. Decision-making capacity is impacted by the relevance and consistency of the information provided to the patient regarding their condition.

T F 8. Patients with certain psychiatric disorders lack decision-making capacity.

T F 9. A patient who is involuntarily committed may still be capable of making decisions regarding their care.

T F 10. Only mental health experts can assess decision-making capacity.

Recommended reading:

Ganzini, Linda, Volicer, Ladislav, Nelson, William A., Fox, Ellen, and Derse, Arthur R. (2005). Ten myths about decision-making capacity. Journal of the American Medical Directors Association, 6(3), S100-S104.