

SUPPLEMENTAL MATERIALS

1. Supplemental Methods

- *Modified* Aid to Capacity Evaluation for stroke. Pages: 1-4

2. Supplemental References

- *Original* Aid to Capacity Evaluation. Pages: 5-16
- Downloaded August 28, 2014 from <http://jointcentreforbioethics.ca/tools/documents/ace.pdf>

Modified Aid to Capacity Evaluation

1. Medical Condition:

Question	Response	Score
What medical Condition led to your admission to the hospital?	<ul style="list-style-type: none"> I had a stroke. I had a blood clot in the head. I'm weak/lost sensation/etc (stroke symptoms) on the right/left (body location) side of my body. 	Yes
What medical condition led to your admission to the hospital? What is/was your most serious medical problem during your hospital stay?	<ul style="list-style-type: none"> I don't know. I had a stroke. I had a blood clot in the head. I'm weak/lost sensation/etc (stroke symptoms) on the right/left (body location) side of my body. 	Unsure
What medical condition led to your admission to the hospital? Did you have a stroke? Why are/were you in the hospital?	<ul style="list-style-type: none"> I don't know. No / I don't know. 	No

STOP THE ASSESSMENT HERE [DEFINITELY INCAPABLE] IF THE PATIENT SCORES = NO

2. Proposed Treatment:

Say this: "For the next few questions, please answer using the scenario we are going to tell you. Here is the scenario...."

"Imagine you have suffered a second stroke that is disabling (you are paralyzed) and you are in the emergency room. The doctors offer you an optional new clotbuster medicine that gives you a good chance of being cured, but with a small risk of bleeding in the brain that could make you worse. If you don't want the clotbuster, you could receive standard treatment – aspirin, but your disability would probably stay the same. Of course, you have the right to refuse any treatment."

Question	Response	Score
What is the treatment that is offered?	<ul style="list-style-type: none"> Clotbuster for my stroke. 	Yes
What is the treatment that is offered?	<ul style="list-style-type: none"> I don't know. For my stroke. You tell me. 	Unsure
Can you have a new clotbuster medicine?	<ul style="list-style-type: none"> Yes. 	
What is the treatment that is offered?	<ul style="list-style-type: none"> I don't know. 	No
Can you have a new clotbuster medicine?	<ul style="list-style-type: none"> No / I don't know. 	

3. Alternatives

Question	Response	Score
Are there any other treatments? (From the scenario)	<ul style="list-style-type: none"> • Yes, aspirin/standard treatment/care. • I could have no treatment. 	Yes
Are there any other treatments? Can you take aspirin?	<ul style="list-style-type: none"> • I don't know. No. • Yes. 	Unsure
Are there any other treatments? Can you take aspirin?	<ul style="list-style-type: none"> • I don't know. • No / I don't know. 	No

4. Option of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):

Question	Response	Score
Who decides your treatment?	<ul style="list-style-type: none"> • I do. 	Yes
Who decides your treatment? Can you refuse the new clotbuster?	<ul style="list-style-type: none"> • I don't know. • Yes. 	Unsure
Who decides your treatment? Can you refuse the new clotbuster?	<ul style="list-style-type: none"> • I don't know. • No / I don't know. 	No

5. Consequences of Accepting Proposed Treatment:

Question	Response	Score
What could happen to you if you take the new clotbuster medicine?	<ul style="list-style-type: none"> • I could get better. • I could be cured. • I could bleed. • I could get worse. 	Yes
What could happen to you if you take the new clotbuster medicine? Could the clotbuster make you better? Could it also cause some bleeding?	<ul style="list-style-type: none"> • I don't know. • Yes. 	Unsure
What could happen to you if you take the new clotbuster medicine? Could the clotbuster make you better? Could it also cause some bleeding?	<ul style="list-style-type: none"> • I don't know. • No / I don't know. 	No

6. Consequences of Refusing Proposed Treatment:

Question	Response	Score
What could happen to you if you don't take the new clotbuster medicine?	<ul style="list-style-type: none"> • My stroke/symptoms/disability would stay the same. 	Yes
What could happen to you if you don't take the new clotbuster medicine? Would your stroke symptoms stay the same?	<ul style="list-style-type: none"> • I could take aspirin. I don't know. • Yes / Probably 	Unsure
What could happen to you if you don't take the new clotbuster medicine? Would your stroke symptoms stay the same?	<ul style="list-style-type: none"> • I don't know / Nothing. • I could get worse. <p>(*Try re-discussing consequences and repeat the question. If no better answer, score no.) For example: <i>"Remember, if you don't want the clotbuster medicine, you could take aspirin and your stroke symptoms would probably stay the same."</i></p>	No

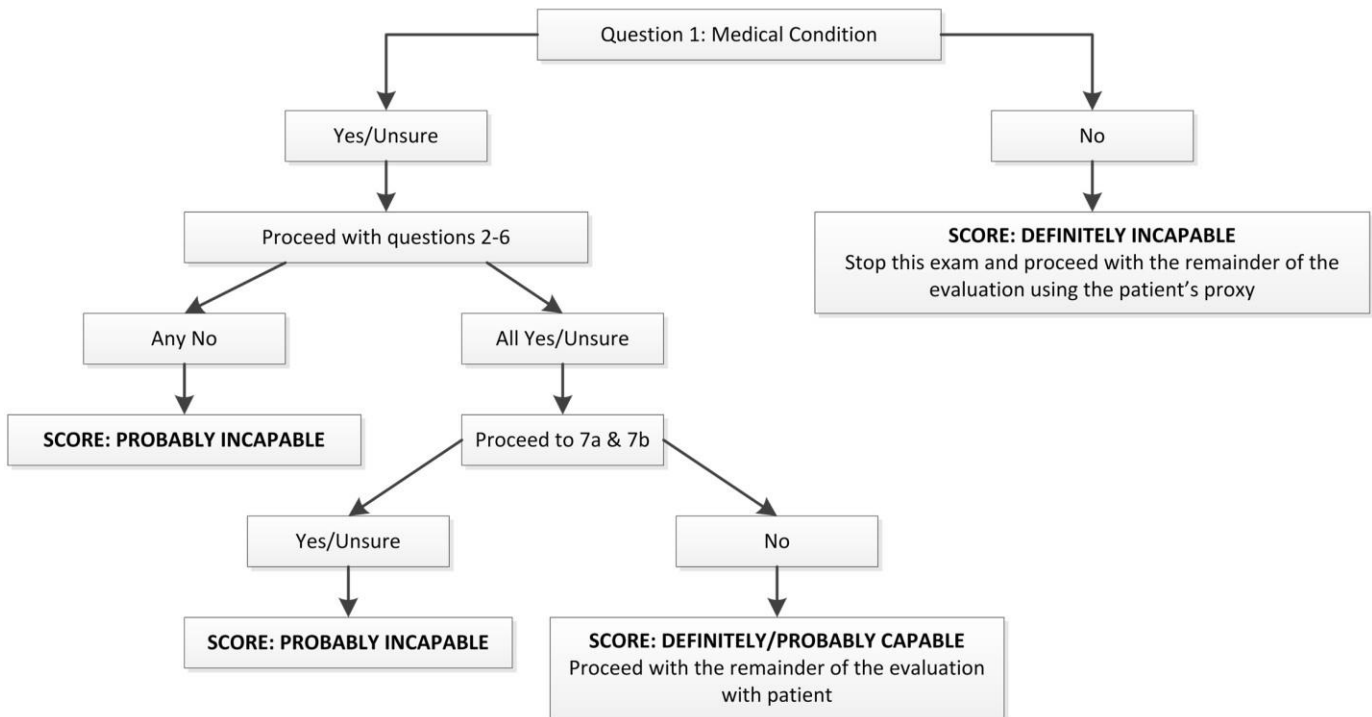
7a. The Person's Decision is affected by Depression:

Question	Response	Score
Why would you not want to have the new clotbuster medicine?	<ul style="list-style-type: none"> • 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 would you not want to have the new clotbuster medicine?	<ul style="list-style-type: none"> • 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 would you not want to have the new clotbuster medicine?	<ul style="list-style-type: none"> • I've lived a full and complete long life. • I don't want to have any bleeding in my brain. • I'm not sure it would work. <p>(*Needs further discussion of the good chance at a cure versus the small risk of brain bleeding).</p>	No – Not Depressed

7b. The Person's Decision is affected by Delusions / Psychosis:

Question	Response	Score
Do you think that the doctors offering the new clotbuster medicine are trying to hurt or harm you?	<ul style="list-style-type: none"> • Yes. • You are a vampire. (Or any other type of bizarre response) 	Yes – Definitely Delusional
Do you think that the doctors offering the new clotbuster medicine are trying to hurt or harm you?	<ul style="list-style-type: none"> • Yes. You are trying to kill me. You want me to bleed and die. 	Unsure – Possibly Delusional
Do you think that the doctors offering the new clotbuster medicine are trying to hurt or harm you?	<ul style="list-style-type: none"> • No. 	No – Not Delusional

Scoring:



- Definitely incapable
- Probably incapable
- Definitely capable
- Probably capable

Aid To Capacity Evaluation (ACE)

Capacity is the ability to understand information relevant to a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of a decision). The purpose of the Aid to Capacity Evaluation (ACE) is to help clinicians systematically evaluate capacity when a patient is facing a medical decision.

The developers of the ACE (i) assume no liability for any reliance by any person on the information contained herein; (ii) make no representations regarding the quality, accuracy or lawfulness related to the use of the ACE, and (iii) recommend that ACE users attend a standardized ACE training session.

The ACE was developed with the support of the physicians of Ontario through a grant from the Physicians' Services Incorporated Foundation.

The ACE may be copied by any person for non-commercial use. *If you have any questions regarding the ACE please contact:* Dr. E. Etchells
Sunnybrook & Women's College Health Sciences Centre
Sunnybrook Campus
Room C4-10, 2075 Bayview Avenue Toronto, Ontario,
M4N 3M5
Telephone: (416) 480-6100 x5996, Fax: (416) 480-5951
Email: edward.etchells@sw.ca

For an additional resource on capacity, please see Dr. Etchells' paper, "Bioethics for Clinicians: 3. Capacity" (*Canadian Medical Association Journal* 1996; 155: 657-61).

Aid To Capacity Evaluation (ACE) – Administration

INSTRUCTIONS FOR ADMINISTRATION

1. Capacity is the ability to understand information relevant to a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of a decision).*

*(This is the definition of capacity from 1996 legislation in Ontario, Canada. Although similar definitions exist across North America, we suggest that users check existing legislation, case law and professional policy statements in their own province or state).

2. The purpose of the ACE is to help clinicians systematically evaluate capacity when a patient is facing a medical decision.

3. Before assessing capacity, identify and address any barriers to communication (e.g. hearing impairment, visual impairment, language barrier, dysphasia, dysarthria). Other people may help a person communicate (e.g. by translating). These other people should not attempt to answer questions for the person being assessed.

4. While assessing capacity, the assessor must:

- Disclose information about the treatment, alternatives, the risks and side effects of treatment, and the consequences of not having treatment, that a reasonable person in the same circumstance would require in order to make a decision.
- Respond to any questions or requests for other information.

5. The process of disclosure may continue throughout the capacity of assessment. For example, if the person does not appreciate that they may be able to walk after a below the knee amputation, then re-disclose this information and reevaluate appreciation.

6. Use the patient's own words whenever possible (e.g. If the patient calls cancer a 'growth', then use the term 'growth' in your discussion).

7. Do not assess whether you agree or disagree with a person's decision. Assess the person's ability to understand and appreciate their decision.

ACE SAMPLE QUESTIONS

1. Medical Condition:

- What problems are you having right now?
- What problem is bothering you most?
- Why are you in the hospital?

- Do you have [name problem here]?
2. Proposed Treatment:
- What is the treatment for [your problem]?
 - What else can we do to help you?
 - Can you have [proposed treatment]?
3. Alternatives:
- Are there any other [treatments]?
 - What other options do you have?
 - Can you have [alternative treatment]?
4. Option of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):
- Can you refuse [proposed treatment]?
 - Can we stop [proposed treatment]?
5. Consequences of Accepting Proposed Treatment:
- What could happen to you if you have [proposed treatment]?
 - Can [proposed treatment] cause problems/side effects?
 - Can [proposed treatment] help you live longer?
6. Consequences of Refusing Proposed Treatment:
- 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*)
- 7a. The Person's Decision is Affected by Depression:
- 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?
- 7b. The Person's Decision is Affected by Psychosis:
- 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?

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, score 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.

Aid To Capacity Evaluation (ACE) - Training

ACE TRAINING SESSION

We have developed a one hour training session to demonstrate key concepts of capacity assessment for our undergraduates and postgraduates.

The session consists of:

- An introduction, including the ethical and legal importance
- A definition of capacity
- A case scenario
- Distribution of the ACE
- An interview with a standardized patient
- Scoring of the interview using the ACE
- Discussion emphasizing the key process issues in capacity assessment including: establishing effective communication, ensuring adequate disclosure, and probing the person's reasons for their decision.

ACE TRAINING CASE

Mr. C. can be portrayed by a standardized patient (or the instructor).

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.

Instructions:

Mr. C. will be interviewed by one of the members of your group. Use the ACE "Examples of Scoring" (see below) to help you assess Mr. C.'s capacity. Any additional information you need to fully assess Mr. C.'s capacity should be noted in the "Comments Section".

EXAMPLES OF SCORING

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

other treatments?		
Are there any other treatments? Can you take antibiotics?	<i>Nothing works.</i> <i>Yes.</i>	UNSURE
Are there any other treatments? Can you take antibiotics?	<i>I don't know.</i> <i>I don't know.</i>	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?	<i>You can't take off my leg unless I sign.</i>	YES
Can you refuse surgery?	<i>Yes.</i>	UNSURE
Can you refuse surgery?	<i>I don't know.</i>	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>I could end up in a wheelchair. [*Needs further discussion about rehabilitation/prosthesis/ chance of recovering independence.]</i>	YES
What could happen if you have surgery? Could surgery help you live longer?	<i>I don't know.</i> <i>Yes.</i>	UNSURE
Could surgery help you live longer?	<i>I don't know/no.</i>	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>I could die. I could have blood poisoning.</i>	YES
What could happen if you don't have surgery? Can you get sicker/die without the surgery?	<i>I don't know.</i> 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>I don't know/nothing.</i> <i>I don't know.</i> [*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>I'm a bad person. I've had a bad life. I deserve to die.</i> <i>I'm being punished. I'm not worth it.</i>	YES [definitely depressed]
Why don't you want to have surgery?	<i>Nothing seems to work. I have no hope.</i> <i>I'm very sad. I'm all alone.</i> <i>I've suffered too much.</i>	UNSURE [possibly depressed]
Why don't you want to have surgery?	<i>I've lived a full and complete life.</i> <i>I don't want to be in a wheelchair because I need to be independent.</i> [*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?	<i>You are a vampire.</i>	YES [definitely delusional]
Why don't you want surgery?	<i>You're trying to kill me.</i> <i>You want me to be a cripple.</i>	UNSURE [possibly delusional]
Why don't you want surgery?	<i>I don't want to be in a wheelchair.</i> [*Needs further discussion about rehabilitation/prosthesis/chance of recovering independent mobility.]	NO [not delusional]

Aid To Capacity Evaluation (ACE)-Form

Name of Patient: _____

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

2. Able to Understand Medical Problem:

YES UNSURE NO

Observations: _____

3. Able to Understand Proposed Treatment:

YES UNSURE NO

Observations: _____

4. Able to Understand Alternative to Proposed Treatment (if any):

YES UNSURE NO

Observations: _____

5. Able to Understand Option of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):

YES UNSURE NO

Observations: _____

6. Able to Appreciate Reasonably Foreseeable Consequences of Accepting Proposed Treatment:

YES UNSURE NO

Observations: _____

7. Able to Appreciate Reasonably Foreseeable Consequences of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):

YES UNSURE NO

Observations: _____

Note: for questions 7a/7b a "YES" answer means the person's decision is affected by depression of psychosis.

7a. The Person's Decision is Affected by Depression:

YES UNSURE NO

Observations: _____

7b. The Person's Decision is Affected by Delusion/Psychosis:

YES UNSURE NO

Observations: _____

Overall Impression:

Definitely Capable	<input type="checkbox"/>
Probably Capable	<input type="checkbox"/>
Probably Incapable	<input type="checkbox"/>
Definitely Incapable	<input type="checkbox"/>

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 (e.g. drug toxicity). 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: **Day:** _____ **Month:** _____ **Year:** _____ **Hour:** _____

Assessor: _____