Alzheimer's Disease After the Diagnosis: Helping the Patient and Family Cope

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Educational Objectives
By the end of this activity, the participant should be better able to:
1. Help patients and families cope with a diagnosis of Alzheimer’s Disease.
2. Discuss safety issues with the patient and family.
3. Discuss how to keep the dementia patient in a safe, supportive family environment and when to consider long-term care.
4. Manage common memory and behavioral issues in the dementia patient.

Speaker Disclosure
Dr. Moquist has disclosed that he has no actual or potential conflict of interest in relation to this topic.
HELPING THE PATIENT AND FAMILY COPE
Dale C. Moquist, MD

Alzheimer’s Disease: After the Diagnosis

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4. Manage common memory and behavioral issues in the dementia patient.

DSM-IV Criteria
- Cognitive deficits include impaired memory and one of the following:
  - Aphasia—Language
  - Apraxia—Motor
  - Agnosia—Failure to Recognize Objects
  - Disturbance in Executive Functioning
- Impaired social and occupational functioning
- Gradual decline
- Not caused by another CNS or systemic or substance-induced condition
- Not due to another Axis I disorder

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Agenda
- Diagnosis
- The Caretaker
- Legal Issues
- Principles of Treatment
- Behavior Problems
- Pharmacologic Treatment
- Feeding Tube
- Hospice
Professional Obligation
- Do not abandon – call when you need Hospice
- You have two patients with the caretaker
- Provide a Patient-Centered Medical Home
- The big question is How?

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ARS Question
How many hours per year does a caretaker spend in direct care?
1. 353 Hours
2. 522 Hours
3. 856 Hours
4. 1152 Hours

ARS Question
What % of Alzheimer’s patients are taken care of at home?
1. 20%
2. 50%
3. 70%
4. 90%
The Other Patient: The Caretaker
- Alzheimer’s affects many people
- Alzheimer’s is a family disease
- 70% of patients cared for at home
- Caregivers spend an average of 863 hours per year in direct care
- Make sure caretaker has a FP
  - Angry
  - Captive
  - Fatigue
  - Stress-Related Illnesses

Message to Caretaker
- Understand their difficult job
- Alzheimer’s affects the entire family
- Best treated as a partnership with the patient, caretaker, and family physician
- We are here to educate, support, and treat the patient and caretaker

Difficult Transitions
- Making the Diagnosis
  - Brain failure
  - Change in future plans
  - Personality and behavior changes
- Disease Progression
  - Long-Lasting Disease: Years not months
  - 3 Stages
  - Never in control
- Transition to 24-hour Care
  - Many are reluctant to accept outside care
  - Increased caretaker stress

Caretaker Counseling
- Very important to prognosis: Stay healthy
- Get help from a social worker or Alz.org
- Attend a support group
- Respite care
- Seeking 24-hour care is not selfish but in best interest of patient
- No absolute right or wrong
- Plan ahead because 24-hour care comes at time of crisis
- Does not mean they will not be involved
- How to fill the void after patient’s death?

Factors for Nursing Home Placement
- Incontinence – both urinary and fecal
- Wandering during night
- Falls
- Behavior issues
- Safety
- Caregiver stress
- Resources

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Legal Documents
- Guardianship: Court appointed to make decisions regarding assets or healthcare when
- Living Will: Document for legally incompetent
- Living Will: Document for catastrophic event
- Power of Attorney: Names an individual to make legal and financial issues when unable
- Medical Power of Attorney: Name an individual to make medical decisions
  - Physicians
  - Types of RX
  - Long-term care facilities

Legal Capacity
- Can patient sign a legal document?
- Earlier the better
- With MCI or early Alzheimer’s (MMSE>17) most patients have capacity
- Important Questions:
  - What type of deliberation needs to be undertaken?
  - How impaired is the patient?
  - Is everyone on the same page?
- Legal papers in Harris County requires MMSE
- Alzheimer’s Association: www.alz.org

Evaluating Mental Capacity
- Four situations should alert physicians
  - Abrupt change in mental status
  - Patients refuse recommended RX
  - Hastily consent to risky or invasive RX
  - Have a known risk factor for impaired capacity
- Directed clinical interview
  - Understand RX
  - How information applies to them
  - Ability to reason with information with facts
  - Ability to express a clear choice

Aid to Capacity Evaluation (ACE)
- Short, clinically oriented tool administered and scored in 5-10 minutes
- Addresses 6 facets
  - Medical Problem
  - Proposed Treatment
  - Alternatives to Treatment
  - Option of Refusing Treatment
  - Appreciate Foreseeable Consequences
  - Ability to Make Decision
- Available at: www.utoronto.ca/jcb/_ace

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Basic Principles of RX
- Keep safe and happy is job #1
- Supportive therapy
- Exercise
- Regular appointments
- Environmental modification
- Attention to safety
- Sun downing
Supportive Therapy
- Emotion-oriented psychotherapy
- Pleasant events
- Reminiscence therapy
- Art
- Dance
- Well-controlled trials have not demonstrated efficacy

Exercise
- Take a walk in the morning
- Positive effects on:
  - Functional performance
  - Cognitive function
  - Behavioral symptoms – especially in the morning

Regular Appointments
- Schedule regular patient surveillance and health maintenance visits every 3–6 months
- Treat comorbid conditions
- Evaluate medications
- Ask about memory, mood, and function
- Consider medication free periods
- Sleep disturbance
- Behavioral disturbances

Environmental Modification
- Moderate level of stimulation is best
- Familiar surroundings
- Predictable daily routines
- Display of clocks and calendars
- Newspapers, TV, and radio
- Visual clues
- Consistent safe environment

Attention to Safety
- Early on safety concerns are minimal
- Supervision increases as disease progresses
- Balance between independence and ensuring safety
- Door locks or electronic guards
- Safe Return through Alzheimer’s association
- Driving safety

Reduce Sundowning
- Provide orientation clues
- Give adequate daytime stimulation
- Evaluate for delirium
- Maintain adequate levels of light
- Establish bedtime routine
- Consistent caregivers
- Discourage drinking stimulants or smoking
More on Sundowning
- Give diuretics & laxatives early in day
- Provide personal care at same time
- Glasses and hearing aid are Working
- Familiar objects at bedside
- Monitor amount of sensory stimulation
- Establish regular dose of drugs
- Avoid Prn hypnotics
- Assist caregiver in respite care

Remember the Three R’s
- Reassure
  - Let them know they will be cared for
  - Wishes respected
- Reconsider
  - Consider their point of view
- Redirect
  - Do NOT confront
  - Distract them by moving to different activity

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ARS Question
What is the most common behavioral problem?
1. Hallucinations
2. Delusions
3. Agitation
4. Apathy
5. Depression

Behavioral Problems
- 80–90% patients develop at least one psychotic or behavioral problem
- May precipitate admission to nursing home
- Potentially can be treated
- Psychiatric symptoms resemble discrete mental disorders such as depression/mania
- Apathy, poor self-care, or paranoia may be initial indication of dementia

Agitation
- Reflects loss of ability to modulate behavior in a socially acceptable way
- Behavior may involve
  - Resistance to bathing
  - Restless motor activity
  - Verbal outbursts/physical aggression
- Often occurs with Psychotic Symptoms:
  - Paranoia
  - Delusions
  - Hallucinations
Caregivers may use the word agitation to describe a variety of behaviors and psychologic.

The FP must consider agitation to be a nonspecific symptom and pursue more history.

Overt resistance to care is most often seen in later stages of dementia.

May be first sign of cognitive decline.

New, acute in onset or evolving rapidly may be due to a medical condition or medication toxicity.

Isolated behavior can be sole presenting symptoms of pneumonia, UTI, arthritis, pain, angina, constipation, or uncontrolled diabetes.

Medication toxicity can present as behavioral symptoms alone.

Life Stressor: Death of spouse/family member

Change to Daylight Savings

New routine, new caregivers, or new roommate

Overstimulation: Noise, crowded, too many people

Under stimulation: Absence of people, much time alone, TV is companion

Disruptive behavior of other patients.

May exacerbate or cause behavior disturbance.

Potential Relationships:

- Inexperienced caregivers
- Domineering caregivers
- Caregivers who are impaired by medical or psychiatric illness.

Persistent disturbances with insidious onset.

These behaviors fall into four groups:

- Mood symptoms
- Psychosis
- Specific behaviors

If disturbance is polysymptomatic, treat the prevailing feature:

- Psychosis - Delusions or hallucinations
- Mood - Dysphoria, sadness, irritability, lability
- Aggression
- Apathy

Manage pain, dehydration, hunger, and thirst.

Consider positional discomforts or nausea from meds.

Modify environment to improve orientation.

Good lighting.

One-to-one attention.

Attention to personal needs and wants.
Apathy
- Most common behavior symptom
- Not depression
- Get involved in activities they once enjoyed
- Simplify and organize what you ask the patient to do
- Don’t trade apathy for agitation
- Methylphenidate
- Modafinil

Depression
- Relationship with Alzheimer’s
  - History of depression earlier in life
  - Symptoms of depression in years preceding diagnosis
  - Common Early in Course of Alzheimer’s
- Questions to Ask:
  - If depression resolved, would the memory problems resolve?
  - Depression accounts for current level of deficits

Depression Treatment
- Avoid saying “Snap out of it”
- Encourage social interaction: Small groups
- Seek counseling for patients with mild disease
- Consider Meds:
  - Depression causes significant distress
  - No improvement after behavioral intervention
  - Avoid tricyclics

SSRIs

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage, mg</th>
<th>Precautions</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citalopram</td>
<td>Initial: 10 qam Final: 20-40</td>
<td>Nausea, tremor, reduce dosage in RI, serotonin syndrome</td>
<td>Fewer drug interactions, oral solution available</td>
</tr>
<tr>
<td>Escitalopram</td>
<td>Initial: 10 qam Final: 10-20</td>
<td>As above</td>
<td>FDA-approved for generalized anxiety disorder, oral solution available</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>Initial: 10 qam or 90 once/week Final: 20-40</td>
<td>Prolonged half-life, nausea, tremor, insomnia, drug interactions, serotonin syndrome</td>
<td>Liquid preparation available, Tend to Avoid</td>
</tr>
</tbody>
</table>

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<tbody>
<tr>
<td>Paroxetine</td>
<td>Initial: 10 qhs Final: 20-40</td>
<td>Nausea, tremor, drug interactions, reduce dosage in RI, serotonin syndrome</td>
<td>Mild sedative effect, Anticholinergic SSRI</td>
</tr>
<tr>
<td>Sertraline</td>
<td>Initial: 25 qam Final: 100-200</td>
<td>Nausea, tremor, insomnia, serotonin syndrome</td>
<td>Fewer drug interactions</td>
</tr>
<tr>
<td>Venlafaxine (SSRI + SNRI)</td>
<td>Initial: 25 qam Final: 50-200</td>
<td>Nausea, headache, serotonin syndrome, drug interactions</td>
<td>Fewer drug interactions</td>
</tr>
<tr>
<td>Desvenlafaxine</td>
<td>Initial: 25-50</td>
<td>Headache, nausea, hypertension, dizziness, reduce dosage in RI</td>
<td>Active metabolite of venlafaxine</td>
</tr>
<tr>
<td>Duloxetine (equally SSRI + SNRI)</td>
<td>Initial: 20 Final: 30-60</td>
<td>Drug interactions, hepatotoxicity, reduce dosage in RI or choose other agent, rare cases of liver toxicity</td>
<td>FDA-approved for neuropathic pain, generalized anxiety disorder, maintenance for MDD</td>
</tr>
<tr>
<td>Venlafaxine (SNRI)</td>
<td>Initial: 75-300</td>
<td>Mild hypertensive, headache, nausea, do not stop abruptly, reduce dosage in RI</td>
<td>Fewer drug interactions</td>
</tr>
</tbody>
</table>
Other Drug to Treat Depressive Features

<table>
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<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Bupropion</td>
<td>Initial: 75 q12h or 150 qam Final: 150-300 or 300 extended release qam</td>
<td>Dopaminergic, noradrenergic, agitation, insomnia, seizures</td>
<td>For apathetic depression resistant to TCA/SSRI; no anxiolytic properties; IR, SR, ER tablets</td>
</tr>
<tr>
<td>Mirtazapine</td>
<td>Initial: 7.5 Final: 15-45</td>
<td>Prolonged half-life, dry mouth, weight gain, reduce dosage in RI, potential for neutropenia</td>
<td>For depression resistant to TCA/SSRI; sedative, useful for insomnia</td>
</tr>
<tr>
<td>Trazodone</td>
<td>Initial: 25-50 Final: 100-400</td>
<td>Very sedating, rare cases of priapism with high dosages</td>
<td>Potentially useful for sleep disturbance Low Anticholinergic</td>
</tr>
</tbody>
</table>

Mood Stabilizers for Manic–Like Behavior

<table>
<thead>
<tr>
<th>Drug</th>
<th>Geriatric Dosage</th>
<th>Adverse Effects</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lamotrigine</td>
<td>25-200 mg/day</td>
<td>Sedation, skin Rash, Neutropenia, Anemia, Rare Stevens-Johnson Syndrome</td>
<td>Slow Dopamine Titration Required, Increased Adverse Effects &amp; Interactions When Used with Divalproex</td>
</tr>
<tr>
<td>Divalproex Sodium</td>
<td>250-2000 mg/day (therapeutic level 40-100 mcg/mL)</td>
<td>Nausea, GI upset, Ataxia, sedation, Hyponatremia</td>
<td>Requires monitoring of CBC, platelets, LFTs at baseline and q 6 months; better tolerated than other mood stabilizers in older patients</td>
</tr>
</tbody>
</table>

Manic–Like Behavior

- Symptoms resemble Bipolar Disorder
- Pressured speech
- Disinhibition
- Elevated mood
- Hyperactivity
- Intrusiveness
- Reduced sleep
- Frequent occurrence with confusional states

Treat Delusions & Hallucinations

- They require pharmacologic RX
- Disturbed by these experiences
- Symptoms lead to disruptions in patient’s environment that cannot be controlled
- Present for one month
- Intermittent
- Distress the patient

Atypical Psychotics

- Used for delusions and hallucinations
- Not for wandering and confusion
- Higher potency: Haloperidol
  - Extrapyramidal symptoms
  - Tardive Dyskinesia
- Atypical psychotics are preferred
- Off-label use for psychosis in dementia
- Warnings about hyperglycemia, CVAs, and increased all cause mortality

ARS Question

Above what daily dose of Risperidone do EPS appear?

1. 0.5 mgm
2. 1.0 mgm
3. 2.0 mgm
4. 5.0 mgm
### More on Antipsychotics
- Demonstrated efficacy
- Relatively modest overall positive effects
- Black-box Warning: Increased mortality
  - JAMA, October 19, 2005;294:1934-1943
- Risk of death with conventional antipsychotics is comparable and possibly greater than with atypicals
  - CMAJ, February 27, 2007;176:627-632

### Antipsychotic Agents

<table>
<thead>
<tr>
<th>Drug</th>
<th>Daily Dose</th>
<th>Adverse Effects</th>
<th>Comments</th>
<th>Forms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olanzapine</td>
<td>2.5–10 mg</td>
<td>Sedation, falls, gait disturbance</td>
<td>Weight gain</td>
<td>Tablet, RDT, IM injection</td>
</tr>
<tr>
<td>Risperidone</td>
<td>0.5 -2 mg</td>
<td>Sedation, Hypotension, EPS If Dose &gt; 1 mg/day</td>
<td>---</td>
<td>Tablet, RDT, Depot IM, Liquid Concentrate</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>25–200 mg</td>
<td>Sedation, hypotension</td>
<td>Ophthalmologic exam recommended every 6 months</td>
<td>Tablet, sustained-release tablet</td>
</tr>
</tbody>
</table>

### Common Delusions
- Relative or neighbor stealing possessions
- Delusion of infidelity
- Their house is not their home
- Their spouse is not their spouse

### Sleep Changes in Dementia
- More sleep disruption and arousals
- Lower sleep efficiency
- Circadian rhythm sleep disorders
- Excessive daytime sleeping and nighttime wakefulness
- Sedative hypnotics not adequately studied

### Manage Sleep Disturbances
- Treat associated depression and delusions
- Use Bright-Light Therapy
- Avoid Antihistamines: Acetaminophen with Diphenhydramine
- Improve Sleep Hygiene
- May Consider:
  - Trazodone 25–150 mgm HS
  - Mirtazapine 7.5–15 mgm HS
  - Melatonin
  - Zolpidem 5 mgm
  - Zaleplon 5 mgm

### Improving Sleep Hygiene
- Stable routine for going to bed and awakening
- Pay attention to noise, light, and temperature
- Increase daytime activity
- Reduce/Eliminate caffeine, nicotine, and alcohol
- Reduce evening fluid consumption
- Give activating meds early in the day
- Limit daytime napping to 20–30 minutes
- Do NOT use bed for reading or watching TV
**Agenda**
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**Pharmacologic RX of Dementia**
- Antidepressants
- Dietary Supplements
- Cholinesterase Inhibitors
- NMDA Receptors

**General Concerns**
- Older people vary in their response
- Decreased renal and hepatic clearance
- Take several meds: Interactions and ADEs
- Anticholinergic meds are problematic
- Watch for CNS sedation
- Start low and go slow

**Dietary Supplements**
- Vitamin E: Only 1 positive study and newer studies show CV side effects
- B Complex Vitamins: Large 18 month study showed no effect
- Gingko Biloba: Many studies show no benefit
- NSAIDS: No benefit
- Fish Oil: Most studies no benefit
- Curcumin – Found in Turmeric: Phase II Trial
- Vitamin D: Associated with cognitive deficiency

**Medical Foods**
- Regulated by USDA
- Decrease utilization of glucose in Dementia
- Hypometabolism makes Dementia worse
- Caprylic Triglyceride
- Ketone bodies as alternative energy source
- Axona 40 grams once daily
  - Diarrhea, Flatulence, and Dyspepsia
- Souvenaid

**More on Medical Foods**
- Memory and cognition improved in small study
- Funded by company
- Mild to moderate Alzheimer’s
- May need to titrate because of GI
- Mayo Clinic: More studies for effectiveness
- Alzheimer’s Org does NOT recommend use of medical foods until more is known
**ARS Question**
Which of the meds is superior in treating Alzheimer's Disease?
1. Rivastigmine
2. Donepezil
3. Galantamine
4. Memantine
5. None of the above

**Principles of Treatment**
- No med reverses pathologic process
- Stabilize Function: ADLs
- Minimize behavioral disturbances
- Preserve caregivers quality of life
- Studies show modest delay
- May delay placement in nursing home
- No evidence to suggest one med is superior
- Consider stopping when patient no longer enjoying life

**Medications for Dementia**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dosing</th>
<th>Interval</th>
<th>Titration</th>
<th>Labs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donepezil</td>
<td>5–10 mgm</td>
<td>QD</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>23 mgm</td>
<td>QD</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Galantamine</td>
<td>8–24 mgm</td>
<td>QD</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Rivastigmine</td>
<td>1.5–6.0 mgm</td>
<td>BID</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Memantine</td>
<td>5–10 mgm</td>
<td>BID</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Rivastigmine Patch</td>
<td>4.6–9.5 mgm</td>
<td>QD</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

**Side Effects**
- Cholinergic side effects
  - Nausea
  - Anorexia
  - Vomiting
  - Diarrhea
- Headache or vivid dreams
- Bradycardia and syncope
- Seizures: Lowers threshold
- Needs to be titrated
- Expense

**Contraindications**
- Uncontrolled asthma
- Angle–closure glaucoma
- Sick sinus syndrome
- Left bundle branch block

**My Recommendations**
- No Cure
- Cannot predict who will be helped
- Suggest a trial of medication
- Suggest 3–4 month trial
- No superior medication
- Start low and titrate
- Evaluate mood, memory, or function
- If no improvement then stop
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Feeding Tubes
- Most with advanced Dementia develop feeding problem: 86%
- Decisions are emotionally and ethically difficult
- Studies suggest expectations exceed outcomes
- Controlled observational studies:
  - Tube feeding does not prolong life
  - Does not promote wound healing

Results
- Few patients had sentinel events
- Dyspnea, pain, and agitation occurred in 50%
- Patients with fever, pneumonia, and aspiration have 50% chance of dying within 6 months
- Meaning:
  - Survival uncomfortable after fever, pneumonia, and aspiration
  - Alzheimer’s is a terminal illness requiring palliative care
  - Physician counseling is deficient

Advanced Dementia
- 323 nursing home patients with advanced dementia
- Followed for 18 months
- Age > 60 and MMSE 5
- Mean survival of 478 days
- 55% died over 18 months
- Distressing symptoms:
  - Dyspnea 46%
  - Pain 40%
  - Agitation 30%

Functional Assessment Staging
1. No difficulty
2. Subjective work difficulties
3. Decreased job functioning to coworkers
4. Decreased ability to perform complex tasks
5. Requires assistance in selecting clothing

NEJM 2009; 361: 1529-38

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NEJM 2009; 361: 1529-38
FAST Continued
6a. Difficulty getting dressed properly
6b. Unable to bathe properly
6c. Inability to handle mechanics of toileting
6d. Urinary incontinence
7a. Ability to speak limited (1–5 words)
7b. All intelligible vocabulary lost
7c. Nonambulatory
7d. Unable to smile
7e. Unable to hold head up

When to Refer to Hospice?
- FAST 7a likely to live less than 6 months
  - Speech limited to 1 or 2 words
  - Ambulatory ability is lost
- One study: Mean survival time 4.1 mo
- Use of antibiotics: No increase in survival
- Use of Foley Catheters shorten survival

iGeriatrics
- New app from the AGS
- Beers Criteria
- Geriatrics cultural navigator
- GeriPsych consult
- Guide to common immunizations
- Management of Atrial Fibrillation
- Prevention of falls

Summary
- In 2012, Alzheimer’s is a terminal disease
- Family Physicians can provide a PCMH
- Do not forget your second patient: The Caretaker
- Safety and happiness are job #1
- Try behavioral interventions first
- Pharmacologic treatment can be an aid
- Be comfortable in discussing end-of-life decisions

Resources
  - Chapter 32 Dementia
  - Chapter 33 Behavioral Problems in Dementia
  - Chapter 35 Sleep Problems
- Hanson L. Oral Feeding Options for People with Dementia. *JAGS*. March 2011;59:463–472
Questions

1. What is the most common behavioral?
2. How many hours does a caretaker spend per year?
3. Above what daily dose of risperidone, the EPS side effects increase?
4. There is no superior drug for treating Alzheimer’s. T or F
5. What % of patients are cared for at home?
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:

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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

<table>
<thead>
<tr>
<th>1. Able to Understand Medical Problem</th>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What problem are you having right now?</td>
<td>My foot hurts. I can't walk.</td>
<td></td>
<td>YES</td>
</tr>
<tr>
<td>What problem are you having right now?</td>
<td>I don't know.</td>
<td></td>
<td>UNSURE</td>
</tr>
<tr>
<td>Do you have a foot problem?</td>
<td>Yes, I can't walk.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is your most serious medical problem right now?</td>
<td>I don't know.</td>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Do you have a foot problem?</td>
<td>I don't know/no.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Able to Understand Proposed Treatment</th>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the treatment for [your foot]?</td>
<td>They will cut my leg off below-knee.</td>
<td></td>
<td>YES</td>
</tr>
<tr>
<td>What is the treatment for [your foot]?</td>
<td>I don't know. You tell me.</td>
<td></td>
<td>UNSURE</td>
</tr>
<tr>
<td>Can you have an operation?</td>
<td>Yes, they can cut off my leg. [<em>Needs further discussion to clarify that operation is below knee amputation, not entire leg.</em>]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is the treatment for [your foot]?</td>
<td>I don't know.</td>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Can you have an operation?</td>
<td>I don't know/no.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Able to Understand Alternatives to Proposed Treatment</th>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there any</td>
<td>I was taking antibiotics.</td>
<td></td>
<td>YES</td>
</tr>
<tr>
<td>Question</td>
<td>Sample Response</td>
<td>Suggested Scoring</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>Are there any other treatments?</td>
<td>Nothing works.</td>
<td>UNSURE</td>
<td></td>
</tr>
<tr>
<td>Can you take antibiotics?</td>
<td>Yes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are there any other treatments?</td>
<td>I don't know.</td>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Can you take antibiotics?</td>
<td>I don't know.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**4. Able to Understand Option of Refusing Proposed Treatment**

(including withholding or withdrawing treatment)

<table>
<thead>
<tr>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are your other options?</td>
<td>You can't take off my leg unless I sign.</td>
<td>YES</td>
</tr>
<tr>
<td>Can you refuse surgery?</td>
<td>Yes.</td>
<td>UNSURE</td>
</tr>
<tr>
<td>Can you refuse surgery?</td>
<td>I don't know.</td>
<td>NO</td>
</tr>
</tbody>
</table>

**5. Able to Appreciate Reasonable Foreseeable Consequences of Accepting Proposed Treatment**

<table>
<thead>
<tr>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What could happen if you have surgery?</td>
<td>I could end up in a wheelchair. [<em>Needs further discussion about rehabilitation/prosthesis/chance of recovering independence.</em>]</td>
<td>YES</td>
</tr>
<tr>
<td>What could happen if you have surgery? Could surgery help you live longer?</td>
<td>I don't know.</td>
<td>UNSURE</td>
</tr>
<tr>
<td>Could surgery help you live longer?</td>
<td>Yes.</td>
<td></td>
</tr>
<tr>
<td>Could surgery help you live longer?</td>
<td>I don't know/no.</td>
<td>NO</td>
</tr>
</tbody>
</table>

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

Joint Centre for Bioethics – Aid To Capacity Evaluation (ACE)
http://www.utoronto.ca/jcb/disclaimers/ace.htm
<table>
<thead>
<tr>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>What could happen if you don't have surgery?</td>
<td>I could die. I could have blood poisoning.</td>
<td>YES</td>
</tr>
<tr>
<td>What could happen if you don't have surgery?</td>
<td>I don't know.</td>
<td>UNSURE</td>
</tr>
<tr>
<td>Can you get sicker/die without the surgery?</td>
<td>Yes. [*Try rediscussing consequences and repeat the questions. If no better answer, score unsure.]</td>
<td></td>
</tr>
<tr>
<td>What could happen if you don't have surgery?</td>
<td>I don't know/nothing.</td>
<td>NO</td>
</tr>
<tr>
<td>Can you get sicker/die without the surgery?</td>
<td>I don't know. [*Try rediscussing consequences and repeat the questions. If no better answer, score no.]</td>
<td></td>
</tr>
</tbody>
</table>

### 7a. The person's decision is affected by Depression

<table>
<thead>
<tr>
<th>Sample Questions</th>
<th>Sample Responses</th>
<th>Suggested Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why don't you want to have surgery?</td>
<td>I'm a bad person. I've had a bad life. I deserve to die. I'm being punished. I'm not worth it.</td>
<td>YES [definitely depressed]</td>
</tr>
<tr>
<td>Why don't you want to have surgery?</td>
<td>Nothing seems to work. I have no hope. I'm very sad. I'm all alone. I've suffered too much.</td>
<td>UNSURE [possibly depressed]</td>
</tr>
<tr>
<td>Why don't you want to have surgery?</td>
<td>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.]</td>
<td>NO [not depressed]</td>
</tr>
</tbody>
</table>

### 7b. The Person's Decision is Affected by Delusions/Psychosis
<table>
<thead>
<tr>
<th>Why don't you want surgery?</th>
<th>You are a vampire.</th>
<th>YES [definitely delusional]</th>
</tr>
</thead>
</table>
| 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] |
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.

1. Able to Understand Medical Problem:

YES [ ] UNSURE [ ] NO [ ]

Observations: __________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

2. Able to Understand Proposed Treatment:

YES [ ] UNSURE [ ] NO [ ]

Observations: __________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

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

YES [ ] UNSURE [ ] NO [ ]

Observations: __________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

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

YES [ ] UNSURE [ ] NO [ ]

Observations: __________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

Joint Centre for Bioethics – Aid To Capacity Evaluation (ACE)
http://www.utoronto.ca/jcb/disclaimers/ace.htm
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.

1. Able to Understand Medical Problem:

YES [ ] UNSURE [ ] NO [ ]

Observations: ________________________________________

________________________________________________________________________

2. Able to Understand Proposed Treatment:

YES [ ] UNSURE [ ] NO [ ]

Observations: ________________________________________

________________________________________________________________________

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

YES [ ] UNSURE [ ] NO [ ]

Observations: ________________________________________

________________________________________________________________________

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

YES [ ] UNSURE [ ] NO [ ]

Observations: ________________________________________

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

YES [ ] UNSURE [ ] NO [ ]

Observations: ____________________________________________


6. 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 or 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:

<table>
<thead>
<tr>
<th>Definitely Capable</th>
<th>[]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probably Capable</td>
<td>[]</td>
</tr>
<tr>
<td>Probably Incapable</td>
<td>[]</td>
</tr>
<tr>
<td>Definitely Incapable</td>
<td>[]</td>
</tr>
</tbody>
</table>

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: ____________________________
Medication Index
Alzheimer's Disease After the Diagnosis: Helping the Patient and Family Cope

The following medications were discussed in this presentation. The table below lists the generic and trade name(s) of these medications.

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Trade Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bupropion</td>
<td>Aplenzin, Forfivo XL, Wellbutrin, Zyban</td>
</tr>
<tr>
<td>Citalopram</td>
<td>Celexa</td>
</tr>
<tr>
<td>Desvenlafaxine</td>
<td>Pristiq</td>
</tr>
<tr>
<td>Divalproex Sodium</td>
<td>Depakote</td>
</tr>
<tr>
<td>Donepezil</td>
<td>Aricept</td>
</tr>
<tr>
<td>Duloxetine</td>
<td>Cymbalta</td>
</tr>
<tr>
<td>Escitalopram</td>
<td>Lexapro</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>Prozac, Sarafem, Selfemra, Symbyax</td>
</tr>
<tr>
<td>Galantamine</td>
<td>Razadyne</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>Haldol</td>
</tr>
<tr>
<td>Lamotrigene</td>
<td>Lamictal</td>
</tr>
<tr>
<td>Memantine</td>
<td>Namenda</td>
</tr>
<tr>
<td>Memantine/Donepezil</td>
<td>Namzaric</td>
</tr>
<tr>
<td>Methylphenidate</td>
<td>Aptensio XR, Concerta, Daytrana, Focalin, Metadate, Metylin, Quillichew ER, Quillivant XR, Ritalin</td>
</tr>
<tr>
<td>Mirtazapine</td>
<td>Remeron</td>
</tr>
<tr>
<td>Modafinil</td>
<td>Nuvigil, Provigil</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>Zyprexa</td>
</tr>
<tr>
<td>Paroxetine</td>
<td>Brisdelle, Paxil, Pexeva</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>Seroquel</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Risperdal</td>
</tr>
<tr>
<td>Rivastigmine</td>
<td>Exelon</td>
</tr>
<tr>
<td>Sertraline</td>
<td>Zoloft</td>
</tr>
<tr>
<td>Trazodone</td>
<td>None</td>
</tr>
<tr>
<td>Venlafaxine</td>
<td>Effexor, Khedezla</td>
</tr>
<tr>
<td>Zaleplon</td>
<td>Sonata</td>
</tr>
<tr>
<td>Zolpidem</td>
<td>Ambien, Edluar, Intermezzo, Zolpimist</td>
</tr>
</tbody>
</table>