CAPACITY AID FOR PRIMARY CARE

1. Capacity and Healthcare

1. a. WHY IS CAPACITY SUCH AN IMPORTANT TOPIC IN HEALTHCARE PRACTICE?

Consent and capacity are fundamental and inseparable issues in care provision and in the health practitioner's work. As health practitioners we are responsible for managing the care of our patients to ensure their health, well being and safety.

For the purpose of this guide, Patient means, a mentally incapable person or a person whose capacity to make decisions related to property or personal care is limited.

In order to do that:

- The health practitioner is responsible for determining his/her patient's ability to give informed consent for treatment and make health care decisions and thus to assess their capacity to make such decisions according to the practitioner's college regulations and guidelines for capacity and consent.

- If the patient is incapable the health practitioner is responsible for locating the highest hierarchy Substitute Decision Maker (as will be explained further in this document).

- The health practitioner is responsible for advising the patient or their family/substitute decision maker (if applicable) about the patient's abilities, limitations and the recommended care to ensure their safety and well being.

As a health practitioner you are not responsible for:

- Enforcing implementation of your recommendations for care on the patient.
  Many families look to the physician or the family health team to make sure the patient is following through with clinical recommendations at home. Even though the involvement and guidance of the practitioner is important in supporting the patient, family or substitute decision maker(SDM) in the management of the care, it is the responsibility of the patient (if capable) or family/SDM/Guardian trustee (if patient is incapable) to follow through with the recommendations. Health practitioners have the right to report family members/SDMs that are not performing in the best interest of the patient to the Guardian Office and Trustee (more details are specified in this document).

- A patient who is capable of making decisions but chooses not to accept your recommendations or to act on them.

1. b. WHY IS CAPACITY SOMETIMES A CHALLENGE FOR HEALTH PRACTITIONERS?

- ***Knowledge of the law*** - Much of the information is complex and may be confusing making it hard for health practitioners to understand. For example it may be difficult for a layperson to understand the various types of capacity and the Acts*.
- ***Confusion about roles and responsibilities***- It may be challenging for health practitioners at times, to determine when it is their responsibility to assess capacity and when a designated capacity assessor is required.
- ***Patient- clinician relationship*** - Determining someone as incapable can affect the patient-clinician relationship and create conflicts and therefore in many cases is an uncomfortable and burdening task for the clinician.
- ***Knowledge about resources*** - navigating the system for resources and services related to capacity can be complex and many practitioners find it hard and time consuming.
- ***Complex reality*** – in dementia care loss of insight and ability to make decisions present many challenges in the management and provision of care that go beyond the legal procedures of assessing capacity and locating/nominating an SDM. These include: resistance to care, dangerous behaviours including poor driving, non-compliance with medications or medical instructions, self neglect, etc. These often present the most difficult challenges in caring for patients with dementia and require multidisciplinary and multiple resources to create practical and meaningful solutions.
- ***Capacity is case specific*** – It is important to remember that even though a person may be incapable in one aspect of decision making they may still have capacity to make other decisions regarding their care and treatment. It therefore important to assess capacity to consent to/make health care decisions for each specific area or type of decision.
- ***Capacity vs***. ***Function –*** It is important to distinguish between the ability to make a decision and exercise good judgment vs. the ability to execute those decisions. For example: a patient may have the capacity to understand that they need to take medication, be aware of why it is important to their health and the consequences of not taking the medication according to prescription. Yet they still may be unable to follow through with their medication regimen due to memory problems. This is a case of dysfunction that requires instrumental assistance and not a case of capacity that requires substitute decision making.

In the following document we will attempt to provide practitioners with the necessary information tools and knowledge needed to manage dementia cases where incapacity to make a decision may play a role.

* The term “Acts” refers to the Healthcare and Consent Act and the Substitute Decision Act further defined in this document.

2. UNDERSTANDING THE LAW & HOW TO Determine WHO IS THE Substitute Decision Maker (SDM)?

2. a. WHAT IS CAPACITY?

In the Health Care Consent Act ("**HCCA**") Capacity and Capable both mean mentally capable.

2. b. WHAT ARE THE ACTs REGARDING DECISION MAKING?

CAPACITY MATTERS

Matters related to capacity are considered when a person's ability to make decisions related to such person's property and personal care arise:

Decisions Related to Property:

Section 6 of the Substitutes Decisions Act ("**SDA**") provides that "A person is incapable of managing property if the person is not able to understand information that is relevant to making a decision in the management of his or her property, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision."

Decisions related to Property may address, but are not limited to, investments, estates, expenses and benefits.

Decisions Related to Personal Care:

Section 45 of the SDA provides that "A person is incapable of personal care if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, nutrition, shelter, clothing, hygiene or safety, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision"

Decisions related to personal care may address, but are not limited to, healthcare, nutrition, clothing, hygiene, shelter, and safety. An individual whose capacity is under review may have capacity to make personal care decisions in some instances and lack the ability to make decisions in other instances.

1. PERSONAL CARE AND HEALTH CARE DECISION SUPPORT

Personal care matters are addressed in the HCCA and do not require a capacity assessment by a designated capacity assessor.

According to Section 4(1) of the HCCA, a Patient is deemed to have Capacity to make decisions when such "A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision."

The HCCA governs the activities of the health care professional who conducts capacity assessments. In most instances, if the assessing clinician deems a patient lacks the capacity to make decisions related to personal care, the assessor shall inform the patient that he or she is not capable of making decisions regarding treatment or personal care, and advise the patient that they will be turning to a substitute decision maker ("SDM"), according to the hierarchy set by the HCCA (see below).

Section 20(1) of the HCCA sets out a ranked list of people who may act as SDM. They are as follows:

1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment.
3. The incapable person's representative appointed by the Consent and Capacity board if the representative has authority to give or refuse consent to the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person

The requirements (the "Requirements"). which permit a person listed above to give or refuse consent is provided at sections 20(3)(4)(5) and (6), of the HCCA as follows;

1. A person described above may give or refuse consent only if no person described in an earlier paragraph,
    a) is capable with respect to the treatment;
    b) is at least 16 years old, unless he or she is the incapable person's parent;
    c) is not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf;
    d) is available; and
    e) is willing to assume the responsibility of giving or refusing consent

2. a person described in a paragraph above and who is present or has otherwise been contacted may give or refuse consent if he or she believes that no other person described in an earlier paragraph or the same paragraph exists, or that although such a person exists, the person is not a person described in paragraph 1, 2 or 3 and would not object to him or her making the decision.
3. If no person described above meets the Requirements, the public guardian and trustee shall make the decision to give or refuse consent.
4. If two or more persons who are described in the same paragraph above and who meet The Requirements disagree about whether to give or refuse consent, and if their claims rank ahead of all others, the public guardian and trustee shall make the decision in their stead.

In the event that no prospective SDM listed above is available, willing or capable of making a treatment decision on behalf of the Patient and the Patient is incapable of making decisions, the Office of Public Guardianship and Trustee ("**OPGT**") Treatment Decision Office may be contacted at, Phone number: 416-314-2788, for assistance.

The OPGT provides services that protect the rights and interests of mentally incapable adults and such services include, conducting investigations, managing finances, making decisions about personal care, appointing private guardians of property, arranging legal representation in capacity proceedings, making decisions about treatment and about admission to long-term care, reviewing accounts, and acting as litigation guardian or legal representative.

Some Patients (when still capable) may choose to prepare a power of attorney ("**POA**"), which appoints a SDM for personal care decisions. A Patient is not legally obligated to prepare a POA, however, a POA can be useful in the event that, (a) the person that the Patient prefers to make decisions on their behalf is ranked below a SDM that is listed at s.20(1) of the HCCA or is not listed in section 20(1) of the HCCA, or (b) more than one person exists within a group listed in section 20(1) of the HCCA and the Patient wishes to nominate a specific person within such group to rank the highest.

Long term care decision capacity

Decisions for long term care ("**LTC**") are governed by the HCCA. If a decision regarding a Patient's transfer to a long term care home needs to be made and the Patient is not capable of making such decision, the decision can be made by a person (SDM) who is appointed according to section 20(1) of the HCCA above.

Applications for LTC are processed by the Community Care Access Center ("**CCAC**"). In addition, the CCAC offers Patient capacity assessment services for LTC decisions. Alternate regulated health practitioners who treat Patients may also assess the Patient's capacity to make a decision for LTC decision.

In addition to assessing capacity to make a LTC decisions, the Patient needs to be evaluated for LTC eligibility. CCAC can assess LTC eligibility. For LTC refer to CCAC for patient's eligibility assessment and to process an application for LTC home placement.
CCAC can be contacted at, phone number: 416-506 9888 or at the primary care line at: 416-217-3935.

2. FINANCE AND PROPERTY DECISION MAKING SUPPORT

All capacity matters related to assessments for financial and property decisions are governed by the Substitute Decisions Act (SDA). In order to asses a patient's ability to make financial and property decisions a capacity assessment by a designated capacity assessor must occur (see more details below), except when an existing POA specifically appoints a person to conduct the assessment of the patient's capacity or when the POA is put in affect from the moment it is signed and the need for assessment is waived.

For more information, contact the Capacity Assessment Office for a list of designated capacity assessors in your area at, phone number 416-327-6766.

Once a capacity assessment has been completed and in cases where the patient is deemed by the assessor to be incapable, a statutory guardian can be appointed for the patient. A family member can apply through the Capacity and Consent Board (CCB) to become the patients' Guardian Trustee. If the family member's application is accepted, he or she may be supervised by the OPGT. (Government of Ontario (2000). A Guide To The Substitute Decision Act, P. 15)

A health practitioner may recommend a substitute decision maker, which it believes serves the best interests of the Patient, to the CCB, and they may notify the CCB that a prospective Guardian Trustee is not suitable for the role.

2.c. CAPACITY ASSESSMENT BY A DESIGNATED CAPACITY ASSESSOR

What is a Designated Capacity Assessor? A designated capacity assessor is a regulated health professional (doctor, nurse, occupational therapist, social worker, and psychologist) who have completed training and examinations with the Capacity Assessment Office and are designated by the Capacity Assessment Office under the SDA, to determine a Patient's capacity.

A list of Qualified Capacity Assessors can be found at the Capacity Assessment Office as stated above.

The average cost for a capacity assessment may range between $70-160/hour, and the cost depends on the nature and complexity of the person's condition, assessors experience in conducting assessment, the time required to complete the assessment and other expenses including travel.

Capacity assessors may assess the Patient's capacity to make financial management and property decisions. A Patient whose capacity is in question retains the right to refuse a capacity

assessment. Such Patient should be informed of his or her right to refuse assessment and the implications of the assessment. In the event that a Patient refuses a capacity assessment, in some cases "the court may order that a person's mental capacity be assessed if there are reasonable grounds to believe that the person is incapable of making decisions and needs a guardian. Under certain circumstances and conditions the court
may authorize the use of force to obtain the assessment." (Government of Ontario (2000). A Guide To The Substitute Decision Act, P. 15-17)

For more information and for a list of assessors in your area call the Capacity Assessment Office at phone number, 416-327-6766, or contact your Psychogeriatric Resource Consultant to discuss the case at, phone number. 416-586-4800 ext. 5251; e-mail. Prc-pc@mtsinai.on.ca.

3. WHEN SHOULD THE DISCUSSION OF CAPACITY BEGIN?

As previously mentioned, capacity and consent are daily components in our practice as health practitioners however we can also be proactive in discussing this issue with our patient to help them prepare for the future.

In the case of dementia, it is recommended to have a discussion with the patient and their family in the early stage of the disease when the patient can still be involved in decision making, and determine what they wish for the future in regards to personal and financial decisions. Discuss with your patient the advantages of creating an Advance Care Plan (ACP). You can also refer the patient and their family to the Alzheimer Society for consultation regarding the creation of an ACP and legal rights. **Alzheimer Society – T: 416-322 6560; F: 416-322 6566**

The patient and his/her family can also turn to a lawyer to set a Power of Attorney (POA) for financial and property decisions if they wish to.
OPGT office – information kit about POA and Living wills - T: 416-314-2800 (Option #2 on the menu)

Although an ACP is not a legal abiding document and may change over time according to the patients' wishes, this is a helpful tool for the family and substitute decision maker in guiding their decisions in times where the patient is incapable of making decisions on their own and expressing their wishes. Keep in mind that not all scenarios can be anticipated by the patient in advance and they might change their mind along the way. Therefore, the ACP is meant as a reference for the SDM to support decision making. It is not to be used as a legal document by healthcare professionals or others to counter the SDM decision.

4. WHAT TO DO WHEN THERE IS A CONCERN ABOUT CAPACITY?

If you are a concerned about your patients' capacity, first clarify:

- What is the concern about capacity?
- What are the decisions that need to be made?
- What are the consequences of the patient's incapacity?

4. a. RESOURCES AND PRACTICAL SOLUTIONS FOR MANAGING COMPLEX CASES

Many patients with dementia may develop behavioural and psychological symptoms that may result in: resistance to care, suspicion, non-compliance with treatment, physical and or verbal aggression, wandering, delusions, etc.

In order for any healthcare plan to work we should involve and engage the patient with dementia to the extent possible based on their cognitive ability and capacities.
. In more complex and challenging cases working in collaboration with a multidisciplinary team and community supports is key in managing care for individuals with dementia who are incapable of making competent decisions for themselves.

The next two sections will provide information regarding managing care and practical solutions you can offer your patient or their family in cases where patients may have poor insight into their condition and may not understand why they may need assistance or support.

4. b. TIPS FOR ENAGEGMENT OF PATIENTS WITH DEMENTIA IN CARE PLAN:

- Build the care plan to meet the patient's goals - relate the plan to what is important to them i.e. if staying in their home is important offer choices for home support to help them stay home safely, etc'. Ask the patient or if not possible ask their SDM what is important to them and what would they value most in their life to set priorities for intervention. For example some patients will value ability to function or comfort over prolonging life, etc'.
- Introduce assistance gradually from the least invasive support such as Meals on Wheels to more intensive supports such as Personal Support Worker (PSW). Introducing all the supports at once can at times overwhelm the patient and cause them to shut down.
- Have someone that the patient is most comfortable with facilitate introductions to new services.
- Be compassionate, reassuring and acknowledge fears and concerns.
- Refer the caregiver/family members to the CARERS program at Mount Sinai or Alzheimer Society of Toronto to receive additional support and skills to cope and communicate with the patient in need.
  CARERS program – T: 416-586-4800 ext. 5192; F: 416-586-3231
  Alzheimer Society – T: 416- 322-6560; F: 416-322-6566

4. C. Here are a few practical solutions and resources you can use/suggest for your patient:

In healthcare and personal care issues:

1. **Alternative Supports**: offered by family, friends or paid caregivers to assist with instrumental tasks in daily living, will often be welcomed by the vulnerable individual. Negotiate solutions that respect the person's capable wishes and enhance autonomy by providing assistance in key areas of need to reduce risk while maximizing independence.

2. **Community Resources**: Refer to community agencies that provide services such as: personal support workers, friendly visiting, home assistance, shopping assistance, nursing services. Social worker services, etc. These can be accessed via **Community Navigation and Access Program (CNAP) 1-877-540-6565** and the **Community Care Access Centre (CCAC) 416-506-9888**. Other support include of **Public Health Nurses 416-338-7600**; Psychogeriatric Outreach Teams or alternatively Specialized Geriatric Services, Social or cultural groups, etc.

Finance and property management support

1. **Family/friends supports**: Trusted friends and family members can assist the person instrumentally in performing tasks they might find challenging. This may include helping the person to arrange direct deposit and direct bill payments through the bank; Instrumental assistance with writing and depositing cheques;
2. **Professional Home support** - Personal Support Worker can assist with shopping, medications, food and other necessary home support, a nurse home visit to monitor health and medication intake. These services can be accessed through **Community Care Access Centre (CCAC) 416-506-9888** or the **Community Navigation and Access Program (CNAP) 1-877-540-6565**.
3. **Trustee** – A limited designation to manage a government pension benefit only such as CPP/OAS/GAINS for the purpose of bill payments and basic needs expenses such as food and medication.
   Here is what you need:

- Locate a trusted family member/friend that agrees to be trustee
- A regulated health practitioner (physician or other) will need to fill in an "*Incapability Certificate"* (see form attached).
- The person who is applying /agreeing to become the trustee will need to fill in an *"Agreement to administer benefits under the Old Age Security Act and/or the Canada Pension Plan by a Private Trustee"* form (see form attached).
- Put both forms together and submit to Service Canada (details in form)

4. **ODSP trustee** – there is an option to apply for trustee through the ODSP office as well if the patient is receiving ODSP funds. This will include similar stages as stated above only using ODSP forms and submitting to ODSP. Usually the patient has an ODSP agent that can assist in processing this application. If there is no available trustee, ODSP may be able to find trustees through community agencies or may arrange for direct payment of rent and utilities by ODSP.

5. **Power of Attorney (POA)**: If the person is willing to and capable of agreeing to a POA consider advising the Patient to retain a lawyer to prepare a POA. A lawyer may assess the Patient's ability to sign a POA. The Patient can also call the **OPGT** at - **Toll-free 1-800-518-7901** or **T: 416- 326-2220** to order a POA kit of information and forms.

4. d. OTHER SPECIFIC CASES:

- *The patient has a SDM but you suspect they are not performing their duty appropriately* –
    i. Contact the Guardianships investigation office **416-327-6348**. If a crime has been committed another option may be involving the Public Relations Officer at the local police department or involving the Advocacy Center for the Elderly (ACE) for cases of low income seniors at **416-598-2656**.
- *The patient refuses to be assessed and is at risk of self harm or self neglect or there are issues of fraud or financial abuse*
    i. Refer to Guardianships investigation office at **416-327-6348.**
- There is a dispute or disagreement between two Substitute Decision Makers.
    i. Suggest that they turn to the Capacity and Consent Board to settle their dispute or to assign one of them as the higher hierarchy SDM at **416-327-4142**
- *The patient needs an assessment and agrees to it but he or the person requesting the assessment on their behalf cannot pay for it due to having limited funds.*
    i. , turn to the Financial Assistance Program of the Capacity Assessment Office at: **416- 327 6766** (usually people on ODSP or CPP without other means are eligible). It is important to know that the person requesting the assessment whether a health practitioner or a relative will be requested to pay for the assessment themselves and will be refunded by the OPGT only once the patient is found incapable.

5. USEFUL LINKS

- Pocket Guide for Capacity Assessment – GiiC , RGP toolkit - http://giic.rgps.on.ca/files/5%20A%20Pocket%20Guide%20to%20Determining%20Decision%20Making%20Ability.pdf
- Aid to Capacity Evaluation – ACE - Aid to Capacity Evaluation – ACE - http://giic.rgps.on.ca/files/3%20An%20Aid%20To%20Capacity%20Evaluation.pdf
- Link to additional information on capacity, legal rights and HCCA and SDA –Advocacy Centre for the Elderly (ACE) – www.acelaw.ca
- Making Substitute Decisions for Health Care - http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/ISBN-0-7794-3016-6.pdf
- Link to guide for the Substitute Decision Act (SDA) - http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/pgtsda.pdf
- Power of Attorney and Living Will - http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf
- CLEO - for information about financial benefits and legal rights www.cleo.on.ca
- NICE – Tool on Capacity and Consent - http://www.nicenet.ca/files/Capacity.pdf

6. USEFUL CONTACTS:

NAME OF SERVICE	CONTACT INFO	PURPOSE OF SERVICE
The Office of Public Guardianship & Trustee	T: 1-800-366-0335 T:416-314-2800 http://www.attorneygeneral.jus.gov.on.ca	The OPGT's role is to serve people who are incapable of making their own decisions.
OPGT – Treatment Decisions Office	T:416-314-2788	The OPGT is obligated to make treatment decisions for patients that are incapable and there is no one who is available to do this for them on the HCCA hierarchy.
Capacity Assessment Office	T: 416-327-6766	To get contact information for designated capacity assessors in your area
Capacity Assessment Financial Assistance Program	T: 416-327-6766	For patients and/or people that request for capacity assessment and cannot afford to pay for it and there is no other relative that can pay for it. They may apply to this program to ask for funding.
Capacity and Consent Board (CCB)	416-327-4142 http://www.ccboard.on.ca	To nominate a guardian or SDM and /or to assist in settling disputes between SDMs, POAs, etc. If you feel a SDM or POA is not making decisions in the best interest of your patient or is not fit for this role you can report to the CCB.
Guardianship Investigation Office	T: 416-327-6348 or 1-800-366-0335 (through OPGT switch board)	The OPGT will conduct an investigation when it receives information that an individual that may be incapable and at risk of suffering serious financial or personal harm and no alternative solution is available or when SDM is suspected to put the patient in harm. Information can be shared with this office without patient's consent.
Power of Attorney and living will information	T:416-314-2800 (OPTION #2 ON THE MENUE)	To receive a power of attorney kit of information and forms. You can also find the kit on: www.attorneygeneral.jus.gov.on.ca
Advocacy Centre for the Elderly (ACE)	T: 416-598-2656 F: 416-598-7924	Legal advice and representation for low income seniors. http://www.acelaw.ca
Psychogeriatric Resource Consultant for Primary Care (PRC-PC)	T: 416-586-4800 EXT. 5251 F: 416-586-3231 prc-pc@mtsinai.on.ca	A resource dedicated to support primary care practitioners through information, resources and consultation in complex cases. Call your PRC-PC to discuss the case and identify possible solutions.

FORMS ATTACHED TO THIS KIT

1. Trustee application forms

DEMENTIA & CAPACITY IN A NUTSHELL