The Who, What, When and How of ADVANCED CARE PLANNING

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SOUTHERN NETWORK OF SPECIALIZED CARE

Learning Objectives

- Who needs to initiate the planning?
- Who needs to be involved?
- What is "Advanced Care Planning"?
- What legislation is relevant?
- When do we need an advanced care plan?
- Why do we need to do this?
- Where can we access information on what is involved?

Who?

- The National Advanced Care Planning Task Group advises that all Canadian adults should have an advanced care plan.

www.advancecareplanning.ca

- "Advanced Care Planning can often make a positive difference to the outcome of difficult life transitions and crises, and for end of life care"

(Primary care of adults with developmental disabilities, Canadian Consensus Guidelines)

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

What is an Advanced Care Plan?

- Discussions
- Identification of a Substitute Decision Maker
- Sharing of information with those who need it to provide care to you, those who care about you and need to make sometimes difficult decisions on your behalf
- Documentation of your plan

When should a plan be made?

- Now
- For some individuals SDM's have been identified when they were children, however the SDM and the advanced care plan may not have been established with involvement of the individual as an adult
- Revisit the plan at least annually and at any time health crisis presents

How to establish a plan

- Start by discussing what an individual deems important, ensure information is presented in a manner that is meaningful and understandable to the person
- Involve the persons family, friends, health care provider
- In some cases a lawyer or legal representative

Legislation and Acts

- Health Care Consent Act
- Substitute Decisions Act
- Mental Health Act

- A substitute decision maker is required when an individual is not mentally capable of making decisions related to the following four areas.

- Legislation defines four areas of decision making:
  - Personal Care (Substitute Decision's Act)
  - Health Care (Health Care Consent Act)
  - Mental Health Care (Mental Health Act)
  - Property (Substitute Decisions Act)

- It is important to involve the individual with a developmental disability to the extent that they are able to understand the information presented and be able to appreciate the consequence of their decision
- Substitute Decision Makers can be court appointed, or can be identified as defined within the hierarchy of the Health Care Consent Act if there is not a SDM appointed by the person in need of medical treatment.

- The Health Care Consent Act hierarchy of people who are identified:
- **20.** (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:
- 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 Board under section 33, 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. 1996, c. 2, Sched. A, s. 20 (1).
- (Health Care Consent Act)

- A health care provider is not and cannot be a SDM
- A paid care provider is not and cannot be a SDM
- The most important thing to recognize in the determination of SDM is the identification of someone who is able to make decisions for the individual who has the persons best interest at heart and a willingness to carry out those duties.
- The individual must be part of the discussion when appropriate.

- An advanced care plan does not automatically mean there is a "Do Not Resuscitate" in place.
- The advanced care plans should be discussed with the individual, substitute decision maker and care providers and recorded. It should be reviewed each time there is a health crisis or a minimum annually with the primary care physician. (Canadian Consensus Guidelines for adults with developmental disabilities)

- Health Care Consent Act, Substitute Decisions Act and Mental Health Act are all in place to ensure the person is involved in their own decision making to the extent that they have capacity to understand the treatment and appreciate the consequence of their decisions.

- People may be capable of making some decisions but not others
- It is important to ensure that information is delivered in a context that the person can understand and that the decisions they are capable of making or contributing to are honored

- The Health Care Consent Act ensures that informed consent is obtained prior to the initiation of treatment. The determination of capacity is a critical component of this act.
- Multi-disciplinary teams of regulated health professionals may require multiple consents
- This does not reflect a lack of communication, rather compliance with the Health care Consent Act

- "Having an advanced care plan in place can make a positive difference to the outcome of a difficult life transition and crisis, and for end-of-life care." (Primary Care Guidelines of people with developmental disabilities)
- It is important to remember that as SDM's age themselves, it may be necessary to identify someone who will assume the responsibility should the SDM not be able to fulfill the responsibility. The individual should participate in this decision as possible.

- Interdisciplinary care teams are necessary in the provision of care for individuals with complex needs.
- Primary Care Physicians, nurses, medical specialists, mental health professionals, behavioural specialists, allied health professionals and care providers

- The identification of a coordinator is a key component of delivering an effective plan.
- Frequently this role is assumed by the primary care physician however it may be an alternate as many individuals do not have a primary care physician.
- Acquiring a primary care physician is important for individuals with a Dual Diagnosis given the complexity of their care due to the need for interdisciplinary care

Multiple professionals, multiple care sites, staff turnover, changes in SDM's, and multiple sectors of care all contribute to complexity and a break in continuity to the care of an individual with a Dual Diagnosis.

- The "Guidelines for the Primary Care of adults with developmental disabilities" outline the additional care areas that need consideration within the evaluation and ongoing management of health.
- The accompanying tools can work well to provide a common method of communication and provide continuity of health information across all sectors.

- Each sector of professionals have a defined area of service and care, navigating the "systems" can be confusing, and a great source of frustration and create gaps in care.

- Regional service coordination agencies and specialized interdisciplinary teams can help.
- Community Care Access Centers, Community Networks of Specialized Care, Developmental Services Ontario

- Understanding and being able to navigate though the defined roles of each sector of care is just the beginning
- Direct care of individuals during a health crisis continues to require cross sectoral involvement, especially for those individuals who cannot or choose not to communicate in a traditional manner

- Given the volume of information required to be proficient in any defined care role it is not surprising that professionals do not have a extensive knowledge of all sectors
- Advanced care planning that is inclusive of representation from each sector is optimal

- The Regulated Health Professions Act defines each disciplines scope in relation to regulated acts however there are also the Health Care Consent Act, Substitutes Decisions Act and Mental Health Act that identify responsibilities of regulated professionals in regard to evaluating capacity for decision making.
- This is not an assessment of capacity but is an evaluation of capacity at the point of treatment

- If a health practitioner finds that a person is not capable of making a decision about treatment and there is not an identified SDM, typically a family member will be approached to consent to treatment. If the person requiring treatment does not agree with the finding they may be entitled to apply to the Consent and Capacity Board to request a hearing to review the finding.

www.ccboard.on.ca

- Providing care at each stage of life transitioning, in a familiar environment by familiar care providers enhance the outcome for the individual with a Dual Diagnosis
- Levels of care needed at times can require a change in the environment to ensure care can be delivered

- This should not be seen as a failure but as meeting a need
- Choosing the environment for care delivery must be based on the ability to provide safe and effective care
- This may vary from sector to sector, agency to agency, and family home to family home

- Advanced care plans can ensure the person is in the **right environment** to receive the **right level of care** by the **right professional** skilled to provide that care as their wishes have been expressed.

What is a treatment plan?

- "plan of treatment" means a plan that,
- (a) is developed by one or more health practitioners,
- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and

- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition;
- Health Care Consent Act definition

Resources

- Ontario Partnership on Aging and Developmental Disabilities
  www.opadd.on.ca
- E-Laws Ontario
  www.search.e-laws.gov.on.ca/en/search/
- Ministry of The Attorney General
  www.attorneygeneral.jus.gov.on.ca

- Consent and Capacity Board
  www.ccboard.on.ca
- Developmental Disabilities Primary Care Initiative/Surrey Place Centre
  www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

- The National Advanced Care Planning Task Group
  www.advancecareplanning.ca