Facilitating Advance Care Planning: An Interprofessional Educational Program

Curriculum Materials

Educating Future Physicians in Palliative and End-of-Life Care

Funding for the Educating Future Physicians in Palliative and End-of-Life Care and the Advance Care Planning project is provided by Health Canada

The views presented in this document are not endorsed by and do not necessarily reflect the views held by Health Canada
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Preface

As health care technologies improve and people with many complex diseases live longer, advance care planning is becoming increasingly important. There is considerable evidence that advance care planning is poorly done, often happening only at the very end of life when crises occur, when life-sustaining treatments have been instituted despite issues of poor prognosis, and when patients are not capable of making decisions about the care they want.

The Public Information and Advocacy Work Group of the Canadian Strategy on Palliative and End of Life Care recognized that health care professionals need better education in ACP. The Work Group’s concern led to the development of this interprofessional educational program for health care providers. The program is intended for use at all levels—undergraduate, postgraduate and continuing professional development.

With funding from Health Canada, Educating Future Physicians in Palliative and End of Life Care (EFPPEC) led the development of this program. EFPPEC created a Working Group, aided by a larger group of Editorial Advisors, to develop a learning module on ACP that is applicable across Canada to health care professionals across the range of disciplines.

The module has an accompanying Facilitator’s Guide, which describes a variety of teaching methods, contains cases to stimulate discussion, and guides teachers on how best to present the material. The preferred delivery method for this module is a small group teaching environment that allows for discussion. The module is available on-line, but the on-line version is not meant to replace face-to-face teaching.

This module builds on the excellent work that has already been done at the provincial/territorial level and in other jurisdictions. The Working Group included experts in advance care planning and in education for health care professionals. Rather than reinventing the wheel, this module used and adapted existing material as much as possible.
The main sources used for this module are as follows:

- Modules on End-of Life Decision-Making, Communication with Patients and Families, Culture, and Conflict Resolution, Ian Anderson Continuing Education Program in End-of-Life Care, A Joint Project of Continuing Education and the Joint Centre for Bioethics, University of Toronto and The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, University of Toronto, 2000.


- Education in Palliative and End of Life Care (EPEC) Project, Module 1: Advance Care Planning, Northwestern University, Chicago, 2003.

- Fraser Health Advance Care Planning website (www.fraserhealth.ca), Fraser Health Authority, British Columbia, 2007.

- A Summary of Canadian Legislation Concerning Advance Directives, The End of Life Project, Health Law Institute, Dalhousie University. (http://as01.ucis.dal.ca/dhli/cmp_advdirectives)


- Provincial and territorial government websites on advance care planning legislation across the country.
Working Group

Sue Grant  
Project Leader, Advance Care Planning  
End of Life Care, Fraser Health  
British Columbia

Jacinthe Guindon  
Acting Senior Policy Analyst  
Secretariat on Palliative and End-of-Life Care  
Health Canada

Cheryl Hamilton  
Freelance writer/editor

Louise Hanvey  
Project Manager  
Educating Future Physicians in Palliative and End-of-Life Care

Laura Hawryluck, MSc, MD, FRCPC  
Physician Leader, Ian Anderson Continuing Education Program  
Assistant Professor, Critical Care Medicine, University of Toronto  
Ontario

Jennifer Kavanagh  
Administrative Assistant  
Educating Future Physicians in Palliative and End-of-Life Care

Mary Lou Kelley, MSW, PhD  
Associate Professor, School of Social Work  
Director, Centre for Education and Research on Aging and Health  
Coordinator, Interdisciplinary Palliative Care Certificate, Lakehead University  
Ontario

S. Lawrence Librach, MD, CCFP, FCFP  
W. Gifford-Jones Professor, Pain Control and Palliative Care  
University of Toronto  
Director, Temmy Latner Centre for Palliative Care  
Mount Sinai Hospital  
Ontario

Gerard Yetman  
Senior Policy Analyst  
Secretariat on Palliative and End-of-Life Care  
Health Canada

This module was developed with significant review and editorial input from:  
Joan Rush, BComm, LLB, LLM  
Governance & Health Law Consultant  
Vancouver, British Columbia

The Working Group gratefully acknowledges her contribution.
Editorial Advisors

Janet Arnold, RSW
Education Specialist
Care at the End of Life Initiative, Calgary Health Region
Alberta

Dr. Doris Barwich, MD, CCFP
Medical Director, Hospice Palliative/End-of-Life Care Program
Fraser Health Authority, Surrey BC
Clinical Assistant Professor U of British Columbia Division of Palliative Care
Faculty of Medicine
Consultant, BC Cancer Agency
British Columbia

Esmeralda K. Bautista, BSC, LLB
Public Trustee for Nunavut

Lee Beliveau, RN CNephC
Renal Program
Fraser Health Authority
British Columbia

Kathy Bodell, RN, BSN, MSN, CHPCN(C)
Clinical Nurse Specialist - Hospice
Fraser Health, Surrey
British Columbia

Manuel Borod, MD
Clinical Director, Palliative Care
McGill University Health Center
Québec

Avis Boyar, MD, CCFP
Palliative Care Consultant
Calgary Health Region
EFPPEC Team Leader
University of Calgary
Alberta

Monica Elaine Campbell
Friends of Hospice Ottawa
Palliative Care Volunteer
Ontario

Lawrence Clein, MB, BS, FRCSC, ABHPM
Medical Director
Palliative Care Services
Pasqua Hospital, Regina
Saskatchewan

Jeanne Desveaux, BA Distinction (Cert. Gerontology) LLB (Health Law & Policy Specialization)
The Law Practice of Jeanne Desveaux Inc.
Canadian Bar Association – Elder Law Section (National Chair 2005-2007)

Deborah Docherty, MSW
Queen’s University
Ontario

Brenda Lee Doyle, MA
Provincial Director
Office of Public Guardian, Alberta
Masters in Clinical Psychology from Lakehead University
Ontario

Bert Enns, BZ, MTS
Project Manager, Care at the End of Life Initiative
Calgary Health Region
Alberta

Romayne Gallagher, MD, CCFP
Providence Health Care, Vancouver
British Columbia
Frank Wagner, MA, MHSc
Bioethicist, Toronto Central CCAC and
University of Toronto Joint Centre for
Bioethics
Asst. Professor, Dept. of Family and
Community Medicine, University of
Toronto
Ontario

Laura Watts, LLB
National Director
Canadian Centre for Elder Law Studies
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Educational Competencies in Advance Care Planning (ACP)

**Competency 1 – Define ACP and its importance.**

**Specific Objectives**
The learner will be able to:
1.1 Define advance care planning.
1.2 Discuss why it is important to have an advance care plan.
1.3 Discuss the common myths about ACP.
1.4 Discuss when it would be appropriate to begin having advance care planning discussions with patients and families.
1.5 Describe the process of ACP and who should be included in ACP discussions.
1.6 Identify pitfalls and limitations in advance care planning.
1.7 Discuss when health care providers, family, friends would apply someone’s advance care plan.
1.8 List the three elements of consent and discuss their importance clinically with respect to consent to treatments.
1.9 Discuss the laws related to advance care planning.
1.10 Discuss how to access specific information governing advance care planning, capacity and consent in their province and integrate it into the overall framework for ACP.

**Competency 2 – Initiate an ACP conversation with a patient and family and assist in the creation and/or documentation of an advance care plan.**

**Specific Objectives**
The learner will be able to:
2.1 Describe how to initiate an advance care planning conversation with a patient.
2.2 Discuss a person’s choice to advance plan or not plan, recognizing the most important element of ACP is the open, honest and informed discussions that occur between the person and his/her substitute decision-maker and family.
2.3 Identify how the personal and family values, life experiences, cultural background, experiences with dying and death, and feelings of the health care professionals, patients, family and friends all influence advance care planning conversations.
2.4 Focus on the person’s care wishes—longer term planning and end-of-life issues.
2.5 Promote the active participation of the person, family, significant others and substitute decision-maker in all aspects of advance care planning.
2.6 Assist patient in the documentation of an advance care plan with patient and family.
Competency 3 – Facilitate ongoing ACP conversations over the continuum of care.

Specific Objectives
The learner will be able to:
3.1 Discuss a process to review initial decisions and goals of care.
3.2 Describe how to give information in an unbiased manner on all options by providing links to resources and others persons to talk to.
3.3 Communicate decisions and changes to appropriate people.
3.4 Discuss why and how to involve other team members to help in decision-making and patient and family education and support.

Competency 4 – Identify potential conflicts in advance care planning and effectively manage conflicts.

Specific Objectives
The learner will be able to:
4.1 Know what to do if aware of wishes expressed by the person when capable but which the substitute decision-maker is not following.
4.2 Apply strategies for conflict resolution using patterns of conflict as a means of improving ability to assist individuals and their substitute decision-makers in good advance care planning.

Competency 5 – Serve as an ACP resource in an organization.

Specific Objectives
The learner will be able to:
5.1 Communicate with others to enhance personal, team, and an organization’s knowledge about ACP.
5.2 Help to identify strengths, limitations and gaps in the implementation of ACP.
5.3 Contribute to the development and improvement of the organization’s ACP policies and processes.
Chapter 1: Overview

Advance care planning or ACP is a process whereby a capable (mentally competent) adult engages in a plan for making personal health care decisions in the event that this person becomes incapable (legally incompetent to personally direct) his or her own health care.

Advance care planning describes what kind of care the person would want (or not want) if he or she were unable to make health care decisions. ACP is a process of exploring questions that often go unasked, such as: What gives life meaning? Are there circumstances (loss of physical functioning or loss of mental awareness, for example) in which the person would not want their life prolonged by certain treatments, but rather would want nature to be allowed to take its course and they be allowed to die?

You have an important role in ACP.

Before the prevalence of ventilators, feeding tubes and other life-sustaining interventions, there were few choices to make. Now, while people may have concerns about going through a prolonged and painful dying process and want to make their treatment choices known in advance to exert some control over what happens, few actually understand 21st century medical technologies.

Some people want to express wishes about where they die. But again, most people know very little about what care can and cannot be provided in different health care settings, and what the implications are of dying in a nursing home, a hospice, an acute care hospital bed or an Intensive Care Unit (ICU).

Health care providers can and should be a support and resource to people doing advance care planning. Health care providers should know how to assist an adult person who wants to complete an advance care plan.

Traditionally, advance care planning has not been an area of concentration in health care training. This education program has been developed to begin to fill that gap. It recognizes the important role of the health care provider as an ACP facilitator.

The role of facilitator can and should be played by people in a variety of health care professions, including physicians, nurses, social workers, spiritual counsellors, case managers and others. Ideally, the different members of a health care team, each with unique expertise and understanding, should be involved.
Facilitating advance care planning can and should happen in a variety of settings, such as hospitals, long-term care facilities, community clinics, physician’s offices, and residences.

Health care providers should encourage advance care planning not only by people who are facing a life-threatening condition or those who have a chronic disease, but also by people who are young and healthy. ACP conversations should be held, if at all possible, before a health care crisis occurs so that the person has time to consider his or her choices and talk with loved ones.

The tone of the conversation with people in different situations (for example, someone who is facing inoperable cancer or a lifetime with diabetes) will be different. But not the purpose—to help the person work through feelings and values so that if a time comes when the individual is incapacitated and is unable to make health care decisions, there will be a record of what that person wanted to happen.

To a considerable extent, this document focuses on the human side of advance care planning—the conversations that you, as a health care professional, will have with the person and his or her family, how to prepare, what to talk about and what to look out for. But there is also an ethical and legal side to advance care planning that you must understand.

**You have ethical and legal obligations.**

A number of Canadian professional bodies have expressed an ethical obligation on the part of their members to honour a person’s advance care choices wherever possible. They also refer to the obligation of the professional to know the legal requirements for decisions about care of an incapable (legally incompetent) person.

The Canadian Medical Association, the Canadian Healthcare Association, the Canadian Nurses Association, and the Catholic Healthcare Association of Canada advise their members that:

“…every effort must be made to ensure that health care decisions are consistent with [a patient’s] known preferences. These preferences may be found in an advance directive or may have been communicated orally. In jurisdictions where the issue of decision-making concerning care and medical treatment for incompetent persons is specifically addressed in law, the requirements of that legislation should be met.”

The Canadian Medical Association (CMA) in its Code of Ethics advises its members to:

1. Consider first the well-being of the patient.
2. Practise the profession of medicine in a manner that treats the patient with dignity and as a person worthy of respect.
3. Provide for appropriate care for your patient, even when cure is no longer possible, including physical comfort and spiritual and psychosocial support.

The CMA Code of Ethics also advises:

27. Ascertain wherever possible and recognize your patient’s wishes about the initiation, continuation or cessation of life-sustaining treatment.
28. Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.

The Code of Ethics for Registered Nurses (Canadian Nurses Association) states that:

10. Nurses must respect a person’s advance directives about present and future health care choices that have been given or written by a person prior to loss of decisional capacity.
11. When a person lacks decisional capacity, nurses must obtain consent for nursing care from a substitute decision-maker, subject to the laws in their jurisdiction.

Standard 7.0 in The Canadian Council on Health Services Accreditation for Hospice Palliative and End of Life Care states:

The team informs the client and family, verbally and in writing, of their right to establish advance directives and how to do so.

Canadian common law recognizes the right of capable adults to make oral or written advance directives that provide instructions about their health care choices during a time of future incapacity. Such directives may include the adult’s preferences regarding the type of treatment he or she wishes to accept or refuse under certain circumstances, and may appoint individuals to speak on the person’s behalf during a future period of incapacity.

Common law is judge-made or case law. Legislation or statute law may codify the common law or confirm that it is to be followed, add to the common law with details of specific requirements and rules, or diverge from the common law. Over the past 15 to 20 years, legislation has been enacted in almost all provinces and territories across Canada to codify the right of a capable adult to make arrangements about personal choices for future health care.

ACP laws across Canada are not harmonized, leading to different requirements under the various provincial/territorial statutes. In some jurisdictions, legislation enables a capable adult to appoint another person or persons to make decisions for him or her in the event of incapacity. For the purposes of this program, we call that other person a “substitute decision-maker”, but you may see other words used, like “proxy”, in the legislation of your province or territory.

Provinces and territories provide legal recognition for different forms of written advance directive. For example, Ontario has “powers of attorney for personal care”, Alberta has “personal directives” and Nova Scotia has “written authorizations”. Increasingly, for practical reasons, Canadians are putting what they want for future care in writing in formal signed documents. But advance care planning is not about a piece of paper although a written document is a helpful record of the person’s wishes. A person may indicate their wishes or preferences for future care in different ways. While still capable, the person may talk with loved ones and/or with health care providers about what they want. They may use alternative forms of communication such as a Bliss Board or an audiotape. Oral advance directives have legal force under the common law and medical ethics codes direct physicians to record and follow them as much as possible.
Most provincial/territorial laws make a distinction between capacity to make decisions about care and capacity to make decisions about financial affairs. We are focusing here on the capacity of the person needing care to decide about care and substitute decision-makers for care. You should be aware that a substitute decision-maker for financial affairs is not necessarily also empowered to make health care decisions.

We use the word “capable” and refer to “capacity”, although you will see “competent” and “competence” used. The meaning of the word “adult” (i.e., at what age is a person deemed an adult) when it comes to who can do advance care planning also varies among the various jurisdictions in Canada.

It is your responsibility to know what the law says in your province/territory.

*What form of advance directive is recognized?*

*Is there a definition of capacity or competence? What is it?*

*Does the law specify an age below which one cannot make an advance directive? What is it?*

*Does the law enable a person to appoint a substitute decision-maker?*

*Does it allow you, as a health care provider, to take instructions from an advance directive or must you speak with a substitute decision-maker before providing (or not providing) treatment?*

*If there is no substitute decision-maker appointed, to whom does the health care provider turn? Does the law specify a hierarchy of people who can make treatment decisions for an incapable person?*

This document cannot answer all these questions for each province and territory because of the variability in legislation and in interpretation of the law and because statutes are often amended (as this document was being prepared, a number of provinces/territories were reviewing their legislation).

Therefore, teachers/leaders of this small-group learning program will review the law in the relevant provinces and territories. Website references for all provinces and territories are provided in the References section of this document, along with other useful educational sources. If you have questions about the legislation in your jurisdiction, you should consult your legal advisors. In practice, you will have to keep yourself up to date on any legislative changes. You have ethical and legal obligations to do so.

This education program is designed to expand knowledge about advance care planning into all sectors of the health care community—to move ACP out of the shadows (where it is considered appropriate only for the elderly and the dying) and into routine health care practice.
It is important to be aware of concerns about the misuse or misunderstanding of advance directives. The following points reflect some of the issues that have been raised about ACP:

- No one should be pressured into doing advance care planning or signing an advance directive. It is the adult person’s right to refuse to do ACP. ACP cannot ethically or legally be made a pre-condition for admission to any facility or institution.

- Consent to treatment must be obtained from a capable adult. The fact that the person has an advance directive or has appointed a substitute decision-maker is NOT relevant as long as the person is capable of making his or her own decisions about care.

- If an individual becomes mentally incapable of making health care decisions and has left prior instructions or wishes about care in the event of incapacity, documented in an advance directive or in the medical record, those instructions or wishes may not provide consent to or refusal of treatment. Health care providers must be familiar with the legal requirements for obtaining consent to treatment of incapable persons.

There is discussion of capacity and consent in Chapter 2.

Let’s talk about it!

For many people, the most important thing to do in advance care planning will be to discuss deeply-held values and beliefs, including beliefs about life and death, with their loved ones and with their physician, nurse or other members of the health care team.

It is impossible to anticipate all potential events and possible treatments in one’s life. But someone who has gone through the ACP process should have a good idea of what life-sustaining interventions entail, what happens in an ICU, what CPR does and how well it works, and how all this health care information fits in the context of his or her beliefs, values, culture and experience.

Here is a brief rundown of what the process of facilitating advance care planning may involve. With support from health care providers, the person doing ACP may:

- consider what makes their life meaningful and under what circumstances the burdens of treatment would outweigh any benefits in terms of prolonging of life or quality of life that the treatment offers. This reflection helps identify the values and beliefs around end-of-life issues that are important.

- consider what options for care and treatment could be considered.

- learn about possible medical treatments for the very ill or injured and their implications through structured discussions with the care team and other resources (e.g., artificial ventilation, nutritional support, hydration and cardiopulmonary resuscitation or CPR).

- contemplate how treatment choices would reflect his or her values, culture, beliefs and goals and affect quality of life, given the person’s state of health, and decide when and
whether he or she would want future health care to focus on comfort care rather than life sustaining or prolonging measures.

- choose what care he or she would want, or would not want, in the event of incapacity under the circumstances contemplated above, so that the care the person receives honours their values, beliefs, wishes, culture and faith tradition.

- choose someone to act as a substitute decision-maker if the time comes when he or she cannot make their own medical decisions.

- document the advance care plan in some fashion. (This would have to be done following the requirements of the legislation of the province/territory in which the person lives.)

- discuss these choices and wishes with those closest to him or her and in particular with those who would be called upon to give or refuse consent to treatment and make health care decisions for the person in the event of incapacity. This discussion enables loved ones to know what the individual would want in a variety of situations.

The health care provider can help the person establish their treatment goals. The provider should also:

- document discussions about the person’s advance care plans in the medical record.

- implement a process for periodic review and updating of the advance care plan and treatment decisions, as necessary as the goals of care change.

People can do advance care planning for issues that are not directly related to health care. This kind of planning may be particularly important to someone in the early stages of Alzheimer Disease or related dementia. In such cases, the discussion about health care choices may be part of a broader discussion that includes, for example, living arrangements, spiritual care and social contact with family and friends.

**Why is doing an advance care plan worth the effort?**

There are major benefits from advance care planning for the person involved, their family and the health care team.

For the person, the process fosters personal resolution and should help to lessen anxiety about what lies ahead. The person can feel more confident that his or her wishes are known and will be followed if the person cannot make care decisions for themselves.

For the patient's loved ones, the benefit is knowing what choices the patient would likely have made when he or she was capable of making decisions about treatment. The substitute decision-maker will have the confidence that comes from having listened to what the person wanted to have happen. Having this knowledge can help avoid disputes among family members because the person’s voice has been heard. Finally, there are benefits for families after death. They can
look back with the knowledge that they were able to honour their family member's wishes, which provides a comfort for the families in the context of loss and grief.

For health care providers, integrating advance care planning into routine clinical encounters enables them to help patients, families and substitute decision-makers to prepare for the kinds of decisions they may face in future. In addition, members of the health care team will feel more comfortable providing care that they know is in accordance with the person's wishes. If everyone understands the person’s wishes, there should be less anguish associated with end-of-life decision-making, reducing the potential for conflict between the person’s loved ones and the health care team and between members of the health care team.

Advance care planning may be an important way of preventing problems in decision-making should a time occur when a person becomes incapable and may need to rely on others. An advance care plan can help to strengthen the relationship between health care providers and the people for whom they care.

**Pearls:**
- Make yourself familiar with the law in your province/territory. It will save time and help avoid mistakes in future.
- Enjoy this learning experience!

**Pitfalls:**
- Avoiding ACP conversations or thinking they are unimportant.

**What’s Next?**
The next chapter describes two issues that are related to ACP: capacity and consent.
Chapter 2: ACP and Capacity and Consent

The issue of capacity is crucial.

Mental capacity to make health care decisions is a central issue in advance care planning. Only a capable adult can make an advance directive, and the directive is only in effect if and when the person becomes incapable. Legally, adults are presumed capable unless proven otherwise.

There are definitions of “capacity” or “competence” in some provincial/territorial legislation, and you should be familiar with the law in your jurisdiction and with how to assess mental capacity in accordance with the legal definition.

The common law test for capacity centres on a person’s ability to understand the relevant information and appreciate the reasonably foreseeable consequences of a decision.

To understand: a person must be able to grasp and retain the information relevant to the decision at hand. If doubts about the person’s ability to understand arise, the following questions must be explored:

1. Has the person been given the relevant information in vocabulary appropriate to his or her ability to understand and in a language in which he or she is fluent?
2. Has the person been educated about the illness and the treatment alternatives and been given opportunities to ask any questions?
3. Does the person understand that there are choices, what each alternative involves and its risks, harms, benefits and potential benefits?
4. Can the person remember the information long enough to reach a decision?
5. Can the person remember the choices made previously and be consistent in decision-making over time? Note, however, that a person making a decision that the health care provider views as irrational does not mean the person is incapable. Equating irrationality and incapacity is a common error.

To appreciate: a person must be able to grasp how a given treatment will affect him or her personally. Some people describe appreciation as the person having an emotional understanding of the events and experiences for that person that will result from the decision.

The point is not whether a decision is reasonable or what the health care professional would have chosen, but whether the person had legal capacity as described above to make the decision.
If a person’s understanding or appreciation seems strange, health care providers may seek to delve deeper into them.

Respect for the intrinsic value and dignity of others means that incapable people must be protected. Declaring a person incapable places large restrictions on their autonomy and is therefore a very serious decision. If there is any doubt as to whether or not a person is mentally capable, there should be a capacity assessment.

Capacity is judged on a task or function specific basis; that is, is the person capable of doing or functioning in relation to making a decision about the particular task or function. Consequently, the nature and content of the task or function, the context and level of risk are all relevant in deciding on capacity. And this approach gives us three possible capacity assessment outcomes: full/complete capacity to consent; partial capacity (the person has capacity to consent to or refuse some things, but not others); or total incapacity. A person who occasionally forgets to turn the stove off may still be able to understand what it would mean to go on a breathing machine and be capable of indicating prior wishes and would therefore have full capacity to do ACP.

It is important to distinguish between capacity to consent to an advance care plan and capacity to consent to treatment. Capacity is needed in both instances.

**You must obtain consent to treatment from a capable adult.**

It is the responsibility of the health care provider to give the person “material information” to enable that person to make informed health care choices. The “material information” is all the information that would be material to a reasonable person in the same circumstances, as expanded by the person’s questions or what the health care provider knows the particular person would want to know.

The “material information” needed in order to make informed health care choices includes the risks, harms, benefits and potential benefits of the recommended treatment, of its reasonable alternatives, and of no treatment.

As explained above, to be capable of making a decision, the person must be able to understand and appreciate the “material information” and the outcome of accepting or refusing particular treatments. The capable person has, however, a right of waiver of information. The health care practitioner must offer the person the required information and be ready and willing to provide it, but if the capable person refuses it, their consent to or refusal of treatment is nonetheless legally valid.

Health care providers must obtain consent to treatment from a capable adult. The following are prerequisites or elements to a valid consent in Canadian law:

- it must be voluntary;
- the person must be mentally capable to provide the consent;
- it must be informed, in that the person must understand the nature and consequences of the treatment, including its harms, risks, benefits, and potential benefits, and those of any alternative treatments, including no treatment at all.
Some provinces/territories have consent to treatment legislation; in provinces/territories that do not have such legislation, these elements still apply through the common law. Some provincial health care consent legislation, and the common law where such legislation is absent, enables health care providers to treat incapable patients without consent in emergency situations, although this exception may be nullified if the patient has made an advance directive refusing treatment.

Some provincial legislation has declared an age at which competent minors may be allowed to give their own consent. Others do not have such legislation; in these provinces, under certain conditions, children may be capable of giving or refusing consent if they are mentally capable.

The three elements—competence, voluntariness and information—sufficient to meet legal requirements are also required from an ethical perspective, as well as some other elements that should be included. Both ethically and legally, a discussion regarding the goals of treatment should occur, and discussion of the nature, purpose, risks/benefits of proposed treatments and alternatives is required. The benefits and risks of no treatment should be covered as well. The health care provider should give reasons for recommending one treatment option over others. This is all part of the legal requirements for informed consent.

The bioethics literature identifies a mixture of five abilities and conditions to determine capacity to grant informed consent which closely track the legal requirements:

1. ability to understand information (the informed part) and communicate a decision;
2. ability to reason (to process information) and deliberate (assess risk/benefits of proposed treatments), alternatives and comprehend the consequences of accepting or refusing treatment;
3. ability to choose within a framework of personal goals, values and beliefs;
4. the choice is voluntary (no internal or external coercion),
5. capable of sustained co-operation (this last is controversial—not all bioethicists include this capacity).

It is an error to presume that if there is an advance directive that appoints a substitute decision-maker, you can obtain consent from the substitute instead of the capable person. It is also an error, if the person is capable, to use an advance directive as a form of consent. If the person is capable, he or she must give consent or refuse treatment. Prior wishes and substitute decision-makers only become relevant when the person is no longer capable.

**An advance directive may not constitute consent for an incapable person.**

Sometimes an advance directive is not specific enough in the situation in which it applies to function as a consent to or refusal of treatment.
A consent is a specific health care decision made after getting information on which to make an informed decision. However, advance care planning does not always result in a “decision” because it is not always possible to anticipate illness or injury. The person may not be able to get in advance all the information to make an informed decision about whether to consent to or refuse specific treatments contemplated for the future because the person has not yet experienced the illness or injury for which treatment is needed. In many instances, in advance care planning, the person is speculating, expressing “wishes” about his or her future care.

If the advance directive is not specific enough, and the person becomes incapable, the advance directive will provide direction, subject to interpretation, about what the person might have wanted, but it will not provide consent to treatment or refusal of consent. For that, the health care provider will have to follow the requirements of the law on obtaining consent for incapable persons.

Sometimes, an advance directive can provide specific guidance on a particular treatment. For example, a person who is on dialysis might specify in an advance directive that if they become incapable and their doctors believe there is no reasonable hope for recovery, then they no longer want to have dialysis.

Several provinces give the responsibility of giving or refusing consent to treatment for an incapable person to the person’s substitute decision-maker, who must make decisions that the substitute decision-maker believes the incapable person would likely have made if capable or must follow the person’s wishes as set out in an advance directive. In the above example, after discussion with the person’s physicians about the hope for recovery, the substitute decision-maker would have the legal right to give or withhold consent to dialysis to the physicians, but would have to follow the patient’s previously expressed wish to refuse consent to dialysis if the physicians believe there is no reasonable hope for recovery.

Other provinces provide for an advance directive that speaks directly to the health care provider about the person’s prior decisions about treatments that he or she would accept or refuse if incapable. Such directives may be used as consent to provide or withhold treatment. If provincial or territorial law enables people to make treatment “decisions” in advance, there would be a legal obligation on the health care provider’s part to ensure that the person had the specific information necessary to understand and appreciate the consequences of the decisions being expressed in the advance directive—the same information that a capable person would need for a valid consent. It is arguable whether or not the same requirement applies to just expressing “wishes” about care in advance.

**If capacity is in question, an assessment may be necessary.**

In situations where the health care provider who is offering treatment is not certain whether the adult person is capable, a second opinion may be sought from a colleague. That colleague does not have to be a psychiatrist. A psychiatrist should be consulted if you believe there are psychiatric issues involved.
There is no particular clinical test for determining whether a person is mentally capable of making a decision about a proposed treatment. The health care provider must use his or her own judgment, based on conversations with the person, to determine whether the person can understand and appreciate the treatment options and consequences.

None of the tests described in the medical literature (including the Mini-Mental Status Exam for cognitive impairment) measure mental capacity as defined in provincial/territorial legislation.

Capacity can change over time: delirium, drugs, fatigue, strong emotions (e.g. depression, shock, denial) and underlying illness may render a person incapable; however, the incapacity may only be temporary. Reversible causes must be ruled out, treated and capacity must be reassessed.

A person’s ability to give informed consent and make health care or other decisions may vary from month to month, day to day, or even from decision to decision. For this reason, the process of obtaining consent is ongoing, rather than a one-time event. Keep in mind also that different treatments may be offered and accepted or refused as health deteriorates or improves, and people can change their minds.

Remember that only a capable adult can do advance care planning for him or herself. And an advance directive will only come into effect if and when the person becomes incapable. The chapters that follow suggest potential scenarios in which health care providers run into disagreements over the capacity of a patient or the interpretation of an advance directive or prior wishes (perhaps the health care team feels the substitute decision-maker is not honouring the person’s wishes). These complications are not common, but they do occur. It is best to be prepared by understanding the ethical context and the legal framework for consent and for advance care planning.

Preventing and resolving conflict are discussed in Chapter 7.

Consent is not just a form or a formality.

Consent is not just a form or a formality—it is a process. A signed consent form is not a replacement for the process of obtaining consent. A signed form will not satisfy legal requirements if all the requirements for obtaining an informed consent were not fulfilled. A form may not satisfy the ethical obligations of the health care practitioner. Under the law, there is no one rule as to when a form is required. Treatment without a person’s basic consent is considered battery under common law, unless a justification is present. Failure to obtain informed consent—that is, inadequately informed consent—is negligence.

You may encounter different views of individual and family decision-making and the importance of individual autonomy. Many people want to make their own decisions about things that are important to their lives, like health care. However, some individuals and some cultures emphasize family or group decision-making over individual decision-making.

If you are discussing consent to treatment with a capable adult, and the person says he or she wants the family to decide, you can agree to include family members in the discussion, but you
should emphasize that the decision belongs to the person. The person may not want to hear about all the risks and benefits and alternatives, and family members may want to discuss them at length, but the consent must ultimately come from the capable person. As noted earlier, the consent is still valid even though the person has waived his or her right to information.

Be careful of circumstances where a capable person is difficult to communicate with and the family is not. If the person has a disability related to communication or the person speaks another language, there are steps you can take. For example, there may be a communication device or service that can be brought in, or you can ask for professional interpretation services. Or it may be that you have to take some extra time to talk more with this person and bridge the communication gap. You can’t just give up and talk to the family instead.

**Pearls:**
- Learn the law on capacity and consent.
- Identify resources on the law before an issue arises.

**Pitfalls:**
- Assuming the person is capable if he or she is passive.
- Assuming a person is incapable if he or she disagrees with you.
- Talking to a family member instead of the capable person.

**What’s Next?**

The next chapter describes how to initiate an ACP conversation.
Chapter 3: How to Initiate the Conversation

There are a number of things to think about and plan for when approaching a conversation about advance care planning. A key part of preparation is to explore your own feelings—as a human being, as well as a health care provider. What choices would you make? What do you fear the most?

The importance of self-knowledge in facilitating advance care planning for others is discussed in Chapter 6.

Your approach will be influenced by the person’s state of health.

A prevailing myth about advance care planning is that only people who are near the end of life—such as the elderly or people in palliative care—should engage in it. The fact is conversations about advance care planning are much better conducted before the end of life is near. It is best done when the individual has time and peace of mind to think about the goals of care and to talk openly about wishes and concerns with family or close friends and with health care providers who can provide information and support.

There is some advice below that applies whether you are talking to a healthy person or to someone with a life-threatening condition. There are also some points that are linked specifically to a person’s state of health.

Who should initiate/facilitate will depend on setting and circumstances.

One of the great benefits of health care teams is that there is different expertise and information around the table or at the bedside. Whoever is in the best position to encourage an advance care planning discussion is the team member who should initiate and facilitate the conversation. A physician may have the best information about treatment options, while a nurse may know the individual’s needs and preferences better than other members of the team. A social worker or spiritual care advisor may have the closest contact with the individual.

In different settings, the person who is best suited to the role may be different. In a long-term care facility, for example, it may be the nursing director or social worker/family relations manager who should take the lead. If the person is in hospital, staff should have access to a skilled facilitator for advance care planning.
Facilitating Advance Care Planning: An Interprofessional Educational Program
Curriculum Materials

Being prepared to facilitate advance care planning is very different from imposing an obligation to sign any kind of advance directive. The decision to engage in advance care planning belongs to the individual, not to the organization or facility.

**Remember that this is a personal choice.**
Facilities should never impose advance care planning decision-making on individuals as a condition of entry.

Someone who is coping with managing a serious health condition or who is entering a retirement home may be more open to having a conversation about advance care planning than a young, healthy person. However, just because someone has been diagnosed with a life-threatening disease or is elderly does not mean that they will necessarily want to do advance care planning. It is a personal choice that must be respected. And no one can do advance care planning for another person.

**Create an opening for discussion with a healthy person.**
To encourage a healthy person to think about ACP, you might start by saying:

"You are in excellent health and taking good care of yourself. Now is a good time to think about advance care planning. It is an important process that every one of us should do for ourselves and our loved ones. Are you familiar with advance care planning? Do you have an advance directive?"

If the person has an advance directive, the conversation can focus on what it says, when it was made (Does it need updating? Does it reflect current feelings and wishes?), whether it names a substitute decision-maker, and whether the person has discussed the contents with loved ones. A copy of the advance directive should be placed in the person’s medical record.

If the person is not familiar with advance care planning, you can make the case for doing ACP. For example, you might talk about how and why you did your own advance directive, if you are comfortable talking about your own life.

You might use an illustration from the news (for example, U.S. court cases where families have been divided over whether to withdraw breathing/feeding tubes from a person who has been unresponsive for years). You might use an illustration of an unexpected event happening to a healthy person.

"You never know what can happen in life. But what if an accident left you without the capacity to make your own health care decisions? What would you want to have happen? Who would you want to make decisions for you? Advance care planning deals with those kinds of questions."
Having take-home material available should help inform/educate the person, save the health care provider time, and encourage a conversation after the person has given ACP some serious thought.

“I have a brochure/video/DVD here that I hope you will read/watch and give some thought to. On your next visit, we can have a conversation about this, if you like. You may want to write down any questions you have and bring them with you. You can ask someone close to you to sit in. I would like to help you with this. But remember, if you really don’t want to talk about it, that’s okay too.”

You can check out the resource list at the back to see where you can find material that is designed specifically for the legal framework in your province.

**Consider the person’s emotional state.**

It is particularly important that people who have a serious or life-threatening illness discuss their wishes for care in advance. However, the meeting at which the person learns of the life-threatening illness (for example, a diagnosis of cancer) is often a bad time to introduce the subject. For one thing, the person will likely be shocked and emotionally upset. Usually, neither the person nor the family members who are with them will be able to digest further information. They will need time to absorb the news. They may want to hear what they have been told about the illness again later. Studies have shown that people retain, at best, half the medical information given to them. Bad news further decreases their ability to process information.

Unless urgent decisions are required, the discussion of advance care planning should be scheduled for another time.

**Create an opening for discussion with someone who has a serious or life-threatening illness.**

At the appropriate time, you might introduce the subject by saying:

“I want you to understand that our first priority is to make sure you get the very best care we can provide. Every person is unique, so it’s not possible to predict when your condition may change because of the illness you have. But it is important to talk about what might happen in the future and to know how you feel about it.

“Our team would like to talk to you, and to your family or a close friend if you want to have them with you, about planning for your future care. Are you familiar with advance care planning? Do you have an advance directive?”

If, as noted in the scenario involving a healthy person, the person has an advance directive, the conversation can focus on what it says, when it was made (Does it need updating based on the person’s current health status?), whether it names a substitute decision-maker, and whether the
person has discussed the contents with loved ones. A copy of the advance directive should be placed in the person’s medical record.

If the person has not done any advance care planning, use the opportunity to encourage engagement in the process. Again, having something to give the person and family members to read or watch would be helpful.

“Are you feeling up to having this conversation? If you are, I can set something up. You can choose who you want to be there. You can choose not to talk about this, but I urge you to try. We can describe some treatments that you might receive in an Intensive Care Unit, for example, that you may or may not want. Many people take comfort in having a greater sense of control over what may happen in the future. Family members often feel better when they know what their loved one wants.”

Create an appropriate environment.

Whatever the setting or circumstance, efforts should be made to have advance care planning conversations in an appropriate environment. Some basic things to think about:

▪ ensuring privacy and making people comfortable (e.g., adequate seating);
▪ setting aside adequate time for the discussion; and
▪ preventing interruptions.

In a primary care physician’s office, privacy should not be an issue, but allowing time for the discussion can be a challenge. In a hospital ward, finding private space may require some planning ahead. Preventing interruptions will be a challenge in most settings because of cell phones, beepers etc.

Arrange for appropriate support services/devices.

Appropriate supports may include professional interpretation services, which will have to be arranged ahead of time. Avoid using family members as interpreters, if at all possible. Their own views of the situation may colour their translation of the discussion. They may not understand medical terms and pass along inaccurate information to the person. Professional interpreters should have the necessary knowledge and objectivity.

Some people with disabilities are highly functioning cognitively, but cannot adequately communicate verbally. Do not assume that someone who has difficulty communicating does not understand or has nothing to say. Find out what supports they need to make communication possible. Appropriate supports may include interveners for the deaf-blind or computer devices that create speech, for example.

► Explore cultural considerations.

Find out if there are cultural considerations for which arrangements can be made. For example, people from some cultural backgrounds are reluctant to talk about their care or
share intimate details of their lives with professionals of the opposite sex. If possible, the role of facilitator should be assumed by someone with whom the person can communicate comfortably.

► **Ask the person whom he or she would like to include.**

Some people may prefer to meet one-on-one with a health care provider and no one else. Others may want to have one or more family members or perhaps a close friend with them. The person should be given the choice.

That also applies to inclusion of members of the health care team. Some people will be comfortable meeting with several people (e.g., nurse, social worker, spiritual care advisor and physician), while others will find being faced with a team of people overwhelming. You can advocate for having the whole team present for the discussion, but the decision should be up to the person who is doing the advance care planning.

► **Allow time for reflection.**

People need time to understand, reflect and discuss the elements of advance care planning. If the person is healthy and attending appointments with a doctor, nurse or social worker on a routine basis, the discussion could take place over several visits.

Even if the person is seriously ill or dying, you should try to give him or her some time to consider after you introduce the subject. If the person is in hospital, you could return later in the day to talk about it some more. Again, several conversations may be needed to help the person understand the implications of his or her choices.

► **Be prepared with information about the person and the prognosis/options.**

A conversation about advance care planning is very personal and can be difficult, depending on the circumstances. Having to flip through papers to remind yourself about the person’s condition during the meeting should be avoided. You should have a good grasp of the person’s state of health and the prognosis for the course of illness, if the person is ill. Before starting the conversation, confirm the medical facts and ensure that all the needed information is available. Plan what will be discussed and how you will open the conversation.
Pearls:
▪ Take the time to get ready, including arranging for necessary support services/devices.
▪ Help the person prepare for the conversation.
▪ Locate resource materials to give to people to help them think about ACP.
▪ Set aside time for the conversations and decision-making. Consider the person’s timing, not just yours.

Pitfalls:
▪ Not asking the person if he or she wants loved ones present for a discussion of advance care planning.
▪ Avoiding the conversation until the need for decisions is urgent.

What’s Next?
The next chapter is about having the conversation.
Chapter 4: Having the Conversation

At this point, you have done your preparation, scheduled the time and place to begin a conversation. You have given the person some initial information, some time to think, and a chance to involve family members or a close friend. Other health care team members may or may not be present, depending on the circumstances.

As in the previous chapter, the points below pertain to conversations with individuals in different states of health. Some points may be more relevant to conversations with a healthy person; some relate to someone who is very ill or dying; others could apply to any conversation with a patient (e.g., communicating clearly).

Don’t assume you understand. Ask.

Everyone is a unique individual who is influenced by experience, life circumstances, family, society, culture, and belief system. The choices that a person makes in advance care planning will be based not just on medical options, risks and benefits, but on personal values like what makes life worth living. While medical facts are taken into account, the ways in which they are interpreted and the importance placed on different risks and benefits are deeply personal.

It is important to go into a conversation about ACP without preconceived assumptions or predictions about what people will or should feel or believe. For instance, people with severe disabilities may have ideas about their quality of life and what they value that are very different from yours. People who come from a culture and background that is different from yours may have quite a different view of life and death.

Don’t assume that you understand how other people are feeling. Let them tell you.

You will have to listen carefully.

It is very important that you pay close attention to what the person is saying or trying to say. This may be the first time someone has explored their feelings about what is most important to them in life and how they feel about death and dying. Some people will have mixed feelings. Some may be unaware of feelings in this area.

You may want to take notes during these conversations. Explain the reason for that to the person. You are documenting the conversation so that the concerns raised or questions asked by the...
person are not forgotten, and so that follow-up conversations can build on some shared understandings.

The person or family member may want to take notes too. They may have brought their own questions in writing (as they were encouraged to do – see Chapter 3). Make sure those questions are dealt with as part of the ACP conversation.

**Exercise good communication skills.**

There are some basic rules for communication in health care situations. Being a good listener is one. Another is avoiding medical jargon. It gets in the way of understanding. There has been some interesting work done in oncology about how lay people may take the opposite meaning from some medical terms. One example is disease “progression” which can be misinterpreted as a good thing.

Euphemisms are another problem. Health care providers may feel they are showing sensitivity when what they may really be doing is confusing people. It is better to be clear and direct. Your role in advance care planning is to help people understand the implications of treatment choices they may make for the future. If they don’t really know what you mean, the ACP process won’t be very helpful.

Be aware that the person you are talking to may be too nervous or embarrassed or upset to tell you they have no idea what you are telling them. It is up to you to make sure you are communicating clearly.

Don’t talk too quickly. Pause often. The spaces between the questions below are for the person to answer. If you don’t really understand what they are trying to say, ask the question again another way. It is often useful to repeat back to someone what you heard them say. Ask them if you got it right or if you missed something important before moving on.

A useful technique to wrap up a conversation is to summarize. It provides an opening for the person to remember something else they meant to ask or to add to or revise your summary of the outcomes.

**If the person has a serious illness, start by finding out what they know about it and how they feel about it.**

For a person with a serious illness, one way to open an ACP conversation is to ask what the person knows about this illness and what he or she expects to happen.

A person may know a lot or very little about their own illness and its possible trajectory over time. Some patients are avid researchers and want to know everything that could happen and what the odds are of various outcomes; others may be much less interested, preferring to live day-to-day and face events when they happen.
How people feel about their illness is unique to the individual. If the person has a chronic condition that can be managed over many years, he or she may be optimistic or fatalistic or somewhere in between. If the prognosis for life is relatively short, the person may be angry, sad, overwhelmed or accepting.

You might start with these questions:

“Perhaps the best place to start this discussion is with how you are feeling right now.”

“What is the effect of this illness on your life?”

“What do you expect to happen down the road?”

Other questions that could be helpful include:

“What do you think has caused your problem/symptoms/illness?”

“How severe is the problem?”

“What kind of treatment do you believe is best?”

You have an opportunity to validate understanding, fill in gaps or correct misunderstandings about medical facts.

This conversation is not just about getting the medical facts clarified. It is about exploring how the person feels about the illness and what may happen in future, particularly when they may no longer be able to decide what kind of treatments they want or don’t want.

You can dig deeper by asking:

“What worries you most about your illness as time goes on?”

“Is there something you are especially afraid will happen?”

This may be the point where you can explain possible treatments that the person may need in the future and what these treatments entail (i.e., benefits, risks). The person may be worried about something that is very unlikely to happen (and you can provide reassurance). Or they may have honed in on something that leads to a conversation about life-sustaining therapies, e.g., “I am afraid of dying in hospital hooked up to a bunch of machines with my family pushed aside in some waiting room.”

What are the implications of that fear? You can talk about how some people prefer to go to a hospice for care at the end of life, while others use palliative home care services. Some hospitals also have palliative care units. Describe what services are available in these different settings.
You can explain that Intensive Care Units are most commonly the only places where feeding tubes and breathing machines are used. If the person has directed that they do not want to go to the ICU, or if they are in a long-term care facility and they don’t want to be taken to an emergency department, you can help the person clarify the implications.

“If that is how you feel, that is something you can put in an advance directive. But we should try to clarify under what circumstances you would not want to go to an ICU or emergency. We are hoping that you will be feeling quite well for some time. So what if you are hurt in a car accident tomorrow? Let’s work this through.”

See Chapter 5 for some suggestions for explaining life-sustaining therapies.

Explore values and beliefs about quality of life.

Exploring values and beliefs about quality of life and dying well is part of the ACP conversation regardless of the person’s health status. You might begin with:

“It’s one of the hardest and yet one of the most important questions we can ask ourselves. What makes life worth living? What matters most to you? What would have to happen for you not to want to go on living? Why?”

“Have you ever discussed this with your family? Do they understand how you feel?”

“If you weren’t able to make health care decisions for yourself at some point in your life, do you have someone you would trust to make them for you in a way that would reflect your values?”

Depending on the person’s response, you can dig deeper. Someone who is young and healthy may value physical and personal freedom above all. You can discuss how people’s views of what they can live with often change when they experience a limitation (e.g., using a wheelchair).

Someone may fear confusion and dependence; others may not worry about these things. People may fear pain, or breathlessness, or some medical treatments (e.g., needles). You can talk about what is and is not possible (e.g., has medical science eliminated pain? No, but there are new generations of drugs and new attitudes to pain control.)

Older people often worry about being “a burden” to family members. Having a family member present to discuss this concern may help.
If loved ones are not present, ask the person if he or she needs help talking to them about advance care planning.

Many people find it difficult to discuss ACP wishes and preferences with family members. In health care, the definition of family is broad, including those closest to the person in knowledge, care and affection. This may include his or her:

- biological family,
- family of acquisition (related by marriage/contract),
- family of choice and friends.

Ask the person if he or she would like any help in relation to having a conversation with loved ones. Again, the circumstances will vary. A healthy person may wonder about introducing this subject out of the blue. Having resource materials to give the person to take home may help. A person with a chronic illness may worry about sending the message that he or she is getting ready to die when that is not the case. You can offer to reassure the family that encouraging advance care planning is becoming part of routine health care. On the other hand, a person who is preparing to die may need moral support from you in helping loved ones to face that future.

You or other members of the health care team can offer to take part in a family meeting. If the family group wishes to meet alone, offer to be available to answer questions before or afterwards.

Is the person expecting disagreement or an emotional response from family? If so, discuss how the person might manage that response.

Some suggestions for mediating conflict are found in Chapter 7.

Be aware of the impact of culture and religion on ACP.

One of the most important pieces of advice in working cross-culturally is to be aware of how your own beliefs, values and culture affect your attitudes and behaviour.

The impact of self-awareness is discussed in Chapter 6.

Another important piece of advice is to get help if you do not feel professionally able to support the person who is engaged in ACP. Religious or cultural attunement may require the assistance of clergy or an elder, or someone with the same cultural background with whom the person can comfortably communicate. Understanding a religion or culture takes more than an open mind.

Some people believe that everything that happens to them is directed by a higher power. Some believe that advance care planning itself is negative because it focuses on future illness and death and because one cannot predict the future. Some believe negative thoughts create negative outcomes.
If the person seems uncomfortable with the ACP process, but hasn’t said why, you might try some questions to help promote better understanding:

“Do you believe that advance care planning is a good thing?”

“Do you think that there is a purpose to illness and suffering?”

“Do you believe that the timing and nature of death can be influenced?”

**Document decisions in the health record.**

All discussions around ACP should be documented in the health record. These may include, for example, decisions about goals of treatment (short-term and longer-term), treatment plans, questions or concerns raised by the person and perhaps the need for emotional psycho-social supports, and a schedule of future meetings. This information will enable the multidisciplinary team to provide the best quality of care. If the person has signed an advance directive, other members of the health care team should be advised so that everyone is in the loop.

**Revisit an individual’s choices over time.**

A health care provider may get to know a patient over a few days or over many years. If you are in regular contact with a person for many years—perhaps as a nurse or social worker in a long-term care facility or as a family physician—you should revisit the advance care planning discussion as the person’s condition or circumstances change. Advance care planning is a process, not a one-time event.

Be sure to tell the individual who is doing ACP that he or she can change their mind. The person can change his or her advance directive and appoint a different substitute decision-maker, for example, or change instructions about care.
Pearls:
- Take the time to ensure that you are communicating clearly. Pause often to assess the person’s understanding. Encourage the person to ask questions.
- Consider how personal values, beliefs, goals and culture influence decision-making.
- Build trust.
- Listen more than you talk.

Pitfalls:
- Making assumptions or generalizing based on culture, religion, age, gender, disability, etc.
- Talking to the family instead of the capable patient.

What’s Next?
The next chapter discusses explanations of life-sustaining therapy.
Chapter 5: Explaining Life-Sustaining Therapy

This chapter provides advice on how to explain life-sustaining therapy in ways that patients and families can understand.

A conversation about advance care planning often involves talking about what a person would want to happen should life-sustaining treatments be an option under certain circumstances (e.g., serious underlying illness or sudden acute condition). Typically, these conversations require that physicians or advance practice nurses be involved.

This conversation is not about recommending treatments or the withholding of treatments. It is about helping the person understand what is involved for the purpose of advance care planning. For some people, life is precious under any conditions and there is no way they would plan ahead to limit life-saving treatment. For others, there will be concerns about unduly prolonging their lives when death is imminent or when life as they value it will no longer be possible.

Health care providers, in facilitating ACP conversations, can help to correct misconceptions. With television full of hospital-based shows, many people have received a distorted view of the possible risks and benefits. On television, hearts are routinely restarted after cardiac arrest in people who are very ill and patients on the brink of death are restored quickly to robust health after administration of some miraculous cure.

If the person you are talking to is seriously ill or elderly, you may start by giving some reassurance that having an ACP conversation does not mean that the person is on the verge of needing emergency or intensive care:

“I am not suggesting we talk about life support because of your illness/condition. We have conversations like this with people who are perfectly healthy and quite young. This discussion is about helping us understand how you feel about life-sustaining treatments and helping you understand some things about what medicine can and can’t do.”

Find out what the person knows about life support.

“Life support” is a fairly well-known term, but most people do not know what it involves, nor do they know what going to an Intensive Care Unit (ICU) implies in terms of the severity of illness. The first thing to do is find out what the person knows. Rather than asking whether he or she would want to go on life support or would want “everything done”, you might start with:
“Can you tell me what you understand about life support? Have you had any experience with ICU? Lots of people only know ICU through what they see on television.”

Gauge the level of detail you provide by the person’s interest.

The level of detail the person wants to know will vary by individual and by state of health.

“When we talk about life support, we are talking about two broad categories of treatment: the ventilator or breathing machine and powerful drugs to support heart and blood pressure. The ICU is the place in a hospital where they use these machines and drugs to treat seriously ill people who could not survive without them. And sometimes these machines and drugs are not enough to keep people alive.

“Life support can prolong life and potentially restore people to the same quality of life as before. But life support is not a cure, so if there is an underlying illness, like cancer or heart disease, the person will still have that illness when they come out of the ICU. They may be weaker than they were before.”

If the person you are talking to is seriously ill, he or she may want to know more about what life support involves in order to decide if they wish to give any advance directions about being taken to an ICU. But a healthy person may want to learn more too. Take your cue from the person.

“The breathing machine works through a tube that is put down the patient’s throat into the windpipe. They give you something to make you drowsy when they do it. You can’t eat or talk with this tube in your throat. Another smaller tube is fed through your nose or mouth into your stomach for feeding. You may still be able to write or mouth words to communicate. Patients can be given painkillers like morphine and they are usually on sedatives. Many people are on the machine for a week or so until they can breathe on their own. But sometimes people have to stay on a ventilator because they can’t breathe without it.”

“The drugs that we are talking about are called inotropes or vasopressors, such as adrenaline. They are administered in an ICU and given through a special intravenous line. If you have a heart attack or a bad infection, and there is a big drop in blood pressure, these drugs can keep you alive. They support your blood pressure so that the brain and the rest of the body are supplied with oxygen until your own body can resume control. There is always a risk of bleeding and infection from intravenous procedures, but the staff in an ICU are experts in this kind of care.”
Bring in appropriate expert assistance if possible.

In some instances, the person may want to hear a level of detail about ICU that you do not feel comfortable with, given your own training and experience. If you have access to an intensive care physician or nurse, ask for help.

Someone who is having a difficult time emotionally may be helped by a therapist or spiritual advisor. You should be alert to the possibility that the person is making decisions about ACP because of depression (e.g., refusing any future life-sustaining treatments because it’s all pointless).

You should also make sure that the person you are talking with is not being coerced or manipulated into ACP decisions out of fear of being a burden (financial or otherwise) to loved ones.

The exploration of issues will be influenced by the person’s state of health, values and beliefs.

Talking with a healthy person, you might ask:

“Do you foresee any circumstances when you would not want to be kept alive with life support?

“We have all heard of cases where a person is kept alive for a long time with breathing and feeding tubes. The family does not want to let the person go. What would you want to happen in those circumstances?”

Some people may feel that life support under certain conditions is interfering with the natural course of dying, while others may feel the opposite—that not trying to save someone, regardless of the person’s quality of life, is to disregard the sanctity of life.

Exploring common fears is one way to find out how people feel about life support. Many people fear being alone or in pain or distress more than death.

An important issue is where a dying person should be cared for in his or her remaining life. There are limitations on the care that can be provided in different settings—nursing home, hospice, home care, hospital. If the person says “I want to die at home with my family”, he or she should understand that not every type of medical procedure or support is possible at home (e.g., the care patients receive in an ICU). The person should also be told that family can be present in any setting, including hospitals.

Having knowledge of, or information about, what resources are available, both institution-based and community-based, to help the dying is of enormous benefit for an ACP conversation, e.g., brochures, websites. If need for palliative care is imminent, start working with the person and the family as soon as possible to put the resources in place to meet their needs and preferences.
This is where teamwork across institutional and community networks is crucial. Fulfilling a person’s desire to die at home may take some time and creative planning. The medical team may need to train family members to administer drugs, for example.

**Time-limited trials are an option to be explored.**

Someone who is doing ACP may want to know if life support is an all-or-nothing scenario. Remember, this person is planning for their own treatment in the event they cannot decide for themselves at the time of a health crisis. You can reassure them that life-sustaining treatments can be tried for a limited time and withdrawn if the agreed upon treatment goals are not met, the anticipated benefits do not materialize, or if the burdens are greater than the benefits.

The advantage of time-limited trials is that they may allow a person to achieve a specific goal (e.g., live until the first grandchild is born or until the family has time to gather at the bedside) or allow the family to feel that they have tried “everything” even in the face of slim odds. The disadvantage is that it may be harder emotionally to stop life-sustaining treatments than to start them. While, ethically and legally, withholding and withdrawing treatments are considered equivalent, in practice they may feel very different. At the time life support is being withdrawn, death is expected and usually imminent.

A decision to withhold or withdraw certain therapies can occur at any time at the person’s request, with changes in their goals and priorities, with deterioration in their health due to either progression of an underlying illness or to unexpected acute illnesses, or when the health care setting changes from hospital to home, nursing home or hospice.

**Try to discourage some misconceptions about dying.**

One of the common criticisms of advance directives is that they are too vague to be much use to family and substitute decisions-makers when the time comes when the person can’t make health care decisions for themselves. That is why having a discussion of the person’s values and beliefs is so important; it provides a personal context for decisions.

Another way to make advance care planning more useful is for people to become more informed about death and dying. The ACP conversation is one way to help people understand some things about dying.

For example, people need to know that the timing of death is not within the power of health care providers to control. Wherever the dying person is, every effort will be made to keep the person as comfortable as possible for as along as it takes for death to occur. Some people go into hospital palliative care units with an expectation of imminent death, which does not occur for days or weeks. For some families, this will be a terrible experience; for others, holding a “vigil” in these circumstances will be appreciated as an opportunity to be with a loved one a little longer.

A more specific example of a common misconception involves nutritional support and hydration for a dying person who can no longer (or who refuses to) eat or drink. Families are generally horrified at the thought that their loved one would “starve to death”. If people understand that
decreased appetite and dehydration is a normal part of dying, it could help families cope. The dying person will not feel the thirst and hunger that would be expected from not eating or drinking. The emphasis should be on the dying person’s comfort.

Some people believe that to withhold or withdraw artificial hydration or nutritional support is euthanasia or assisted suicide. They are entitled to their beliefs which should be respected as far as possible. Sometimes, in such cases, conflict results when health care professionals believe that continuing artificial hydration or nutritional support is clearly unreasonable. These cases are rare in Canada but, when they occur, resort to a court may be necessary to resolve them, and determine the ethically and legally required course of action.

The alternative and more common view, however, is that artificial nutrition and hydration are medical treatments just like any other and carry burdens just like any other and consequently are subject to the same ethical and legal rules about withdrawing them as other treatments. Withholding and withdrawing such interventions is not done to hasten death, but is done in the realization that the burdens (e.g., insertion of tubes and needles, patient’s pain level) may outweigh the benefits.

**Provide a realistic picture of Cardio-Pulmonary Resuscitation (CPR)**

A discussion of CPR in the event of cardiac or respiratory arrest can be helpful as part of an ACP conversation. This should be a separate discussion from life support because CPR does not require ICU care. As with life support, many people have misconceptions about what is involved in CPR and its likelihood of success.

“What about CPR? Do you know what it is? Have you had any CPR training? Do you know how it’s done in hospital and by paramedics and other emergency personnel?”

Sometimes, health care providers perpetuate the misconception that CPR is easy and usually simple and successful. It is not the role of the health care provider to discourage use of CPR, but it is important to be realistic about the severity of the illness that can lead to a cardiac arrest, and what is involved in resuscitation, e.g., risks of neurological damage, multi-organ damage, the need for life support afterwards. CPR may worsen the patient’s overall health. The underlying state of health of the person affects the chances of CPR being successful.

“If your heart was to stop, you would die. A medical team or emergency paramedic team would use electric shocks to restart your heart. Even with CPR, unfortunately, the blood flow to your body is not as good as if your heart was still beating. The longer it takes to restart your heart, the more damage will occur. The sicker you are before, the less likely they are to be able to restart your heart at all.
“The biggest thing to worry about is damage to your brain. If your heart cannot be restarted quickly, brain damage will occur. This brain damage can be mild, yet it is often significant and can range from loss of memory to being permanently unconscious and chronically dependent on others to help with day-to-day activities.

“Within minutes of starting CPR, to increase chances of success, a tube would be put through your mouth into your windpipe to breathe for you since you would not be breathing. This is not an easy procedure and sometimes it is not successful. If your heart starts beating again, you will need to be on life support afterwards. How long you would be on life support is not clear.”

The age and health status of a person will make a big difference in how successful CPR will be.

For your own information, the Canadian Medical Association, Canadian Healthcare Association, Canadian Nurses Association, and Catholic Healthcare Association of Canada, in cooperation with the Canadian Bar Association, developed a Joint Statement on Resuscitative Interventions last updated in 1995. It distinguishes four general categories of CPR as a treatment option:

- people who are likely to benefit,
- people for whom benefit is uncertain,
- people for whom benefit is unlikely,
- people who will almost certainly not benefit—the person will either not recover due to underlying illness or will never be able to experience any benefit.

For the person doing ACP, you may refer to these statistics:

“The success statistics for CPR on people who are very sick are not good. Only one to four percent of patients with chronic illnesses survive CPR to leave the hospital.

“Many of the people who do survive the resuscitation do not leave hospital and may have brain damage.”

Here is another area where having resource materials to give people to digest would be useful.

You can help patients and families make choices that do not increase the likelihood of harm and that make “medical” sense: e.g., it does not make sense to undergo CPR without intubation, since poor oxygenation will decrease the chances of a successful resuscitation and increase chances of neurological injury. However, wanting intubation without CPR does make sense in the context of a respiratory arrest.
Instructions about CPR are just that, no more and no less.

CPR orders have a very narrow scope which states that in the event of a cardiopulmonary arrest, do not resuscitate (DNR). By themselves, these orders say nothing about admission to ICU and life support.

Unfortunately, health care providers often translate DNR to mean the person wants limited treatment for their underlying illness and any complications from that illness or for any unforeseen acute illness. Such assumptions may not accurately reflect the person’s wishes, expectations or values. Before assuming other treatments will not be undertaken, discussions must occur with the individual.

If the person you are talking to is living in his or her own home and does not want CPR to be performed, you should encourage discussion with the spouse or other relatives living in the same home or professional caregivers in the home, that the person has explicitly rejected CPR. If there is a do-not-resuscitate order signed by a physician or nurse, it should be readily accessible.

In some institutions, if no order has been signed, the default is to perform CPR. Most health care providers would try to resuscitate if the person had not specifically rejected CPR.

In hospital, there may be a tendency to think that a patient with a DNR order has given up and so should the medical team. That is an incorrect and inappropriate assumption. It does not mean that the patient has given up hope of quality of life or even, depending on the situation, of cure. It may simply mean the person recognizes the severity of illness and the gravity of the situation in which CPR would be needed and understands chances of successful resuscitation are uncertain or low and does not wish to undergo CPR.
Pearls:
- Discussions about CPR should be separated from discussions about ICU.
- Life-sustaining therapies can be withheld and, if initiated, can be withdrawn with consent.
- DNR does not mean “no care”.

Pitfalls:
- Assuming people understand what you are telling them about treatments like life support. Instead, ask them what they know and what they would like to know.

What’s Next?
The next chapter explores the importance of self-awareness among health care providers to the process of ACP facilitation with others.
Chapter 6: Advance Care Planning and the Values and Experiences of Health Care Providers

How often do health care providers take time to reflect on personal feelings? How often do health care providers think about the impact they have on others? How much attention is paid to considering the effects of personal values and past experiences on conversations with patients?

Not nearly enough. The issue of self-awareness and self-care is not generally popular in health care. It makes some professionals uncomfortable. But times are changing. There is growing recognition of the impact of the health care provider’s feelings, values and experiences on how he or she handles situations and people. There is also growing recognition of the toll that working in health care takes on its practitioners.

Engage in the advance care planning process yourself.

ACP can be a difficult topic to discuss. You are asking a person to think about circumstances when he or she will not be capable of making health care decisions. Maybe they will be in a terrible accident. Perhaps they are facing the prospect of death a few months or a year from now from a relentless disease. You are asking them to talk to loved ones about feelings about quality vs. quantity of life. Whether death is imminent or seems remote for this person, these are difficult things to discuss.

How do you feel about ACP? Have you lost loved ones under difficult circumstances? What choices would you make? If you have not done your own advance care planning, you will be less able to help someone else. If you have been through the process yourself, you will understand better what it feels like to broach the subject with family members, for example. Some people may be confused or upset by the conversation, while others may welcome the chance to talk about matters of life and death.

There is also a credibility issue. After you have given a preamble about how important it is to do advance care planning, what if the person asks: “Have you done this yourself?”

The best safeguard for maintaining the integrity of advance care planning for others is a clear understanding of your own personal position regarding the various issues related to ACP.
If you have not already done so, you should ask yourself:

\textit{What choices would I make for myself? }

\textit{What are my greatest fears? }

\textit{What is most important to me in planning for future care? }

\textit{When I am nearing death, what do I wish or not wish for? }

\section*{Consider how your experiences and values affect you as an ACP facilitator.}

Self-awareness is something you have to work to achieve. Like ACP, it is not a one-time event. It is a process. A measure of self-understanding requires thinking about where you come from (family, religion, culture) and the experiences of life that have shaped who you are.

This is not self-indulgence. Health care providers who are in touch with their own feelings and who are aware of how their own experiences and values influence their views of ACP will ultimately be more effective in helping patients and families.

Some questions to promote self-awareness include:

\textit{How did I learn from my family about relationships? How does that affect how I deal with family members of patients?}

\textit{How does my cultural background influence my values? How does that affect how I approach people from other cultural backgrounds?}

\textit{What do I think are appropriate gender roles? How do I communicate with males and females differently?}

\textit{How do I handle criticism or anger? In my caring role, how do I deal with people who are being “difficult”?}

\textit{When I think about death and dying, what words/images come to mind?}

You should be able to show empathy, while still being professional. You should be able to provide support to people struggling to make difficult decisions about ACP, without imposing your own views or values.

However, if you ever find that your own views and values are so at odds with what the person wants, to the point where you cannot do a good job of facilitating ACP, you may be better to refer the individual to another health care provider. Being aware of your own biases is important; you are not required to give up or contradict your values.
Use debriefing to explore feelings, promote team learning and provide mutual support.

If you are a member of a multi-disciplinary team, you should be in a position to debrief with trusted colleagues. If possible, ask an unbiased facilitator to help with the discussion. If you are working mostly on your own, organize a peer group to get and receive support and constructive feedback or look for a seminar or workshop that meets your needs.

Some questions you might ask:

- What are we doing that is working well and what isn’t?
- How do we know?
- What can we do to improve this experience for people doing ACP?
- How can we support each other?

Perhaps you have had a negative experience when trying to help someone through the process (e.g., a seriously ill person or a family member got angry and walked out of the meeting). What happened? Ask yourself:

- How did I react—defensive, upset? Why did I react the way I did?
- How could I have handled that situation differently?
- How did that encounter influence the next ACP conversation?

If you aren’t facilitating ACP, do you know why not?

Ask yourself:

- Am I avoiding these conversations? Why?
- What can I do to become comfortable with advance care planning issues?

Here are some common reasons why providers may resist facilitating ACP conversations.

- I don’t have time for these conversations.
- I will destroy the hope of this individual by mentioning it.
- I will make the person feel we are giving up on him or her.
If health care providers believe that these conversations are an important part of good health care, the time will be found. Other concerns should dissipate with experience. Studies show that patients feel more empowered and more hopeful when they are able to engage in advance care planning. If health care providers introduce the subject in a non-threatening way, if they tell and show the person that the team is not giving up on their care, the individual should feel more supported, not less.

**Acknowledge self-care as a core competency.**

There are many stressors in health care. Building strategies to ensure that you are not overwhelmed by stress should be given the attention it deserves.

Health care providers are trained to look for suffering in the people they treat in the physical, psychological, social and spiritual domains. Look for manifestations of stress in those domains in yourself. Ask colleagues what they can see that you can’t.

ACP conversations can be difficult and draining. Experiencing the grief of others can take an emotional toll. Consider it a professional competency to develop coping strategies that work for you. Ask yourself:

- *What positive support mechanisms work best for me? Am I using them?*

- *Are there opportunities in my organization/community (e.g. team social events, stress workshops) that I usually avoid? Why?*

- *How do I manage to learn from a difficult experience, like a conflict with a patient’s family, without taking it home with me?*

- *How can I avoid blowing off steam in ways that threaten my long-term health?*

- *How do I re-energize myself?*
Pearls:
- Reflect on your experience of planning in advance for your own health care.
- Reflect on your experience of facilitating advance care planning.
- Debrief.

Pitfalls:
- Imposing your belief system or personal experiences on others.

What’s Next?
The next chapter discusses conflict and ACP.
Chapter 7: Conflict: Prevention and Management

This chapter has suggestions for reducing the likelihood of disputes, preventing escalation of disagreements, and promoting resolution of conflicts.

Although conflict in advance care planning is rare, it is not surprising that it sometimes occurs, considering how much is at stake.

Conflict may arise in different situations and involve different parties. Perhaps a capable person and his or her family disagree about engaging in advance care planning. Or a capable person has a preference for future care that his or her substitute decision-maker does not feel able to honour. Perhaps a capable person or the family wants something that the health care team does not think is appropriate care, or members of the health care team disagree over interpretation of an incapable person’s wishes.

It is not possible to avoid all conflict. Recognizing that is important. Where possible, however, health care providers should try to reduce the likelihood of disputes, prevent the escalation of disagreements in the early stages, and promote the resolution of conflicts.

Some of this advice applies to any interaction with people in a health care setting. Others are specific to disputes involving a capable person, or involving family or other substitute decision-makers when a person is incapable.

Avoid miscommunication and adversarial approaches.

The source of many disagreements between health care providers and patients/families is miscommunication in the form of inconsistent information or poorly delivered information.

To provide consistency of information from health care teams in a hospital or long-term care setting requires that mechanisms (debriefs at shift changes, note-taking, team meetings) be in place to ensure that all members of the team are informed.

Chapter 4 reviewed some tips on good communication.

Good communication includes listening carefully, speaking clearly in plain language free of medical jargon and euphemisms, and pausing often to clarify what you have heard and to find out what the person has understood.
Think about how you come across.

Do I seem empathetic or impersonal?

Am I at the same level as the people I am talking to or do I tend to stand while they are seated (or lying down)?

Am I usually rushed or distracted or am I invested in this conversation and the time it will take?

Do I really listen when people talk about their lives and emotions (rather than their illness and treatment)?

Make an effort to understand where other people are coming from. What is another day at work for you may well be a life-altering moment for this person and family. If advance care planning is being done by a person facing a life-threatening disease, you can expect that both the individual and his or her loved ones will be under a lot of emotional stress.

Consider the example of a person whose health status is deteriorating quickly and who is weighing health care options as part of advance care planning. You have explained the reasons why you would not expect certain treatments to be successful. If the person seems to be resisting what you are saying, it may be that he or she does not understand. Getting impatient or pushing your opinion more aggressively may turn confusion into anger. Perhaps more time is needed to digest the information.

Ask yourself:

Have I given the information that the person needs to understand the risks/benefits of future care?

If not, it is appropriate to try again. But there is a danger in assuming that someone does not accept the advice you are giving just because he or she does not have all the facts. If you are not sure, consider the “reasonable person” standard of disclosure.

Have I given the information that a reasonable person would need to understand these risks/benefits?

Identify the basis for the disagreement.

If the answer to the question above (the reasonable person standard) is yes, the answer is not to badger the person with yet another round of the same set of facts. You need to identify the basis of the disagreement.
It may be that for spiritual, cultural or other reasons, this person does not agree with the view of the health care team. A capable adult has the right to plan in advance for a future incapability and to give instructions about treatment. The health care provider should explain options, but is not the decision-maker.

You also need to make sure you understand where the disagreement is coming from. Sometimes, you may come away from a family meeting not really having heard the views of the capable person. Or the person may be sending mixed messages. Step back and ask yourself:

*Am I listening more to the family or to other professionals than to the capable person?*

*Do I actually understand how this person feels and why?*

*Am I feeling a certain way because the request for care is being presented in a certain way?*

*What supports can we muster to resolve this?*

**Ask for assistance/support before conflict escalates.**

Bring in supports where appropriate. A social worker, bioethicist or religious or spiritual leader may help resolve a misunderstanding.

If a disagreement seems to be heating up, find out if your organization has a mediation service available to help resolve conflicts. A mediator is a knowledgeable and neutral third party who can help to bring the parties to some resolution.

Mediation involves some techniques that you can use when you are concerned that relations with a patient or family or within a health care team are breaking down. For example, a mediator will set ground rules for meeting (e.g., one party speaks at a time, no intimidation allowed). If you are “hosting” a family or team meeting, you can do the same.

Mediators attempt to get to the core of the argument, which is often different from what people are saying to or shouting at each other.

*What is really being said (that is not necessarily being spoken)?*

*What is at stake (e.g. quality care or team effectiveness)?*

*Why are these people upset or angry? What is the larger picture? What might people be reacting to?*

*Is this a clash of expectations/cultures/beliefs? If so, what are they?*

*Is there a common interest or goal?*
Consider what effect you are having on a dispute and its effect on you.

Recognize when you are in the midst of a conflict—whether it is with a patient, their family or your colleague—that your emotions and past experiences may be standing in the way of understanding and resolution of the dispute.

As discussed in Chapter 6, being aware of one's own cultural and other biases is critical.

You might ask yourself:

- How do I feel about this situation? Why?
- Is it making me angry? Am I being defensive or confrontational?
- Do I understand what the real issue is? Am I concerned about the issue or something else, such as how I have been treated?
- Am I being influenced by fear of legal liability or professional investigation?
- Do I understand the other side of this dispute?
- Am I listening to the person/family/colleague or am I reacting to what others have said about them?
- Can I help resolve this or can someone else help resolve this?

What if you cannot meet the person’s request?

If you have difficulty accepting the views being expressed by this person, you should refer the person to a second medical opinion or, if you are part of an interprofessional team, you may call in other members to carry the discussion forward.

Although a person has the right to give instructions, he or she does not have the right to insist on health care that is not medically indicated. For example, a patient cannot force a surgeon to try and remove a tumour if the surgeon feels that the surgery is impossible or futile. Such a patient may request a second opinion and that request must be honoured if time and resources permit.

Be aware of family dynamics at times of stress. Avoid labelling.

Even the most amiable family relationships can dissolve under the strain of a situation that disrupts the family system. Avoid labelling families who are having a hard time dealing with ACP issues as “dysfunctional” or “hysterical”.
There can be disputes among family members about what a loved one has requested, for example, if the person has specified some particular end-of-life care (e.g., I want to die at home—Which family members will be there to look after the person? Who will learn how to give injections? Does everyone understand what kind of care will not be given—ventilation, intubation, etc.?).

Avoid taking sides and try to mediate family disputes by concentrating on the patient’s needs, not past or current family dysfunction. Be careful that you get a balanced view of the family history and the various perspectives. Listening to only one family member may give you a distorted view of the family dynamic.

Sometimes families turn their anger about a loved one’s illness on health care providers. They may try to interfere with delivery of medical care, make excessive demands on staff time, and see everything as a crisis.

Sometimes when someone is dying, family members refuse to acknowledge it. They may pretend their loved one is getting better or demand procedures to “cure” the person. They may avoid the person. Family members may argue among themselves at the bedside or pass on inaccurate information to other family members. These reactions can make good end-of-life care difficult for everyone.

The health care team’s challenge is to understand these behaviours as much as possible and help the family in their coping and adaptation where possible. Different members of an interprofessional team will bring different expertise to this challenge. Health care providers are presumed to have the greater responsibility to adapt to the family than the family to the health care team.

Mediation requires unbiased facilitation. The team must assess its own strengths and limitations in trying to help resolve family conflict. If the situation is beyond your ability to manage, seek help from a skilled mediator.

**Sometimes families want to speak for a capable person.**

One problem to look out for is a family who tries to answer for a person who is capable of answering for him or herself.

Sometimes for cultural or other reasons, families may try to stand between the medical team and a capable person. The family may ask the person not be told about a diagnosis with a poor prognosis and not be consulted on options for care as the disease progresses, for example.

A person is not required to do advance care planning, but is entitled to be told about his or her medical condition. Most people want to be told the truth about their condition. It is not acceptable to talk to family members instead of the capable person. Tell the family that you must talk directly to the person, and that you will ask if the person wants to know about his or her state of health.
The family can ask to be present for this conversation, but who attends is up to the individual. If there is a problem with communication because of language or some other reason, make arrangements to solve it (e.g., you may need to have a professional interpreter present for the conversation or a communication device for a person who has difficulty speaking or hearing).

Be clear that while you cannot agree with the family’s position—that you are ethically obligated to speak to the person—you respect their feelings and understand that their motive is to protect their loved one. It may help to tell the family that you and they share the same goal—to provide the best care possible for this person.

Similarly, if the family objects to wishes that the person makes as part of his or her advance care planning, your professional obligation is to respect the wishes of the individual.

**What can happen when a person is incapable.**

If consent to treatment is needed when the person is mentally incapable, you will have to identify a substitute decision-maker unless the law in your province or territory allows health care providers to take instructions from a person’s advance directive as consent.

You will need to establish:

- *Who is the legal substitute decision-maker?*

- *Did the person name a substitute decision-maker in an advance directive?*

- *If not, who is the person who is legally empowered to make decisions?*

You will have to check the law in your province or territory. Some jurisdictions provide a hierarchy of persons who can act as substitute decision-makers if the person has not named a person or persons in an advance directive. The hierarchy means that certain people have decision-making authority before others (e.g., an adult child of the incapable person may come before a sibling). It is important that you know what the law in your province/territory says so that you are not taking direction from the wrong person.

Usually, there will not be conflict. There will be a family member or other substitute decision-maker who is empowered to make treatment decisions for the incapable person, and who will be grateful to meet with health care providers who are caring and willing to take the time to talk over the best care options.

You will need to consider:

- *If the person has expressed wishes, what is the best way to honour those wishes?*

- *If those wishes cannot be determined, what is in the best interests of the person, taking into account the factors required by applicable legislation?*
If more than one person has been named to share decision-making (e.g., both of the person’s children), there is no reason to anticipate that they will not agree on treatment decisions.

However, it is possible to run into complications. There may be disputes among family members/substitute decisions-makers over how best to follow the person’s wishes, for example. Often, wishes in advance directives are expressed in vague or general terms, leaving them open to interpretation. Or the incapable person may not have expressed prior wishes.

In either case, try to focus everyone on the person’s values and what would be the best way of respecting those values. Encourage an open discussion that brings out the different views in a non-confrontational way. Keep in mind that this is about exploring what was important in the person’s life. Seek to understand the reasons and emotions behind the arguments.

Perhaps you helped the person develop his or her advance care plan or talked with the person about end-of-life care shortly before he or she became incapable. You may be able to shed some light on the person’s intentions.

Explain to the substitute decision-makers that they are obligated to make treatment decisions in accordance with the wishes expressed by the person. If there are no known wishes that apply to a particular decision that has to be made, then the substitute decision-maker is required to make decisions that are in the “best interests” of the incapable person.

Always consider bringing in support from other members of the health care team or from mediation services in your organization, if available, or from community agencies (e.g., family counsellors, religious leaders), as needed.

It is in the best interests of the person to achieve resolution of conflict as early as possible.

**If all else fails, there are legal remedies.**

Some conflicts may have to be pursued in a more formal way.

If there is a dispute that cannot be resolved among substitute decision-makers who are on the same level in the hierarchy of substitute decision-makers (an example might be children of the person) or who are mandated in a directive to make shared decisions, you may have to go through legal channels to get a decision.

If you believe that a substitute decision-maker is not following the incapable person’s wishes, you may have to go through legal channels to ensure those wishes are respected.

If you question whether the substitute decision-maker is mentally capable, you may have to go through legal channels for a ruling on capacity.
There may also be situations where there is doubt about the incapacity of the person whose care is at issue. If you believe the person is capable and the substitute decision-maker does not, the substitute decision-maker may resort to legal action. Likewise, a person who is deemed “incapable” by a medical practitioner has a right to legally challenge this finding of incapacity.

There is a legal presumption that all adults are capable so the burden of proof of incapacity is on the person alleging incapacity.

Some provinces/territories have a designated legal authority (e.g., it may be called a tribunal or consent and capacity board) that can hold hearings to deal with a range of matters, including conflicts/issues related to consent to treatment, capacity, and advance care planning. If there is no designated legal authority, the matter may have to be taken to a court for a decision.

**Acknowledge the stress.**

Recognize that conflict is stressful and draining. Having to deal with angry people is not easy. Trying to resolve disputes in an emotionally-charged atmosphere, even if you are the mediator for a dispute among others, requires your own emotional investment.

**Revisit Chapter 6.** Review what it says about debriefing, asking colleagues to tell you if they see that the stress is getting to you, blowing off steam etc.

**Pearls:**

- Consistent communication from the team will often avoid conflict.
- You need to develop trusting relationships and see the world as it occurs for the patient and family.
- Have a clear conversation about the decision-making process to avoid conflict or perception of unfairness.
- Make sure everyone knows and agrees with the goals of care. If everyone knows the destination and is on the same page, then the importance of who “drives the bus” is reduced.
- Drop the desire to win.
- Have ready access to conflict resolution such as mediation.
- Learn from situations of conflict—debrief.
- Understand the legal process and remedies available if all else fails.
Pitfalls:
- Allowing anger/personal experiences/biases to interfere with conflict resolution.
- Failing to ask for support when it is needed.
- Taking direction from the wrong substitute decision-maker for an incapable person.
- Not knowing the law on advance directives and substitute decision-making in your province/territory.
- Giving up too easily on dispute resolution (legal avenues are a last resort).

What’s Next?
The next chapter focuses on building organizational capacity in advance care planning.
Chapter 8: Building Organizational Capacity for ACP

Health care organizations and institutions should have a commitment to advance care planning as part of quality care strategies and effective resource management. This chapter focuses on building organizational capacity for ACP through policy and staff development.

Health care institutions like hospitals and long-term care facilities should have specific policies to ensure that:

- advance care plans by patients or residents are respected,
- all patients or residents are asked about advance care planning,
- if an individual wants to do advance care planning, he or she receives encouragement and assistance,
- no one is pressured or required to have an advance directive as a condition of admission,
- a copy of a person’s written advance directive is put in the medical record and is easily accessible,
- oral wishes and preferences are also documented in the medical record and are easily accessible,
- staff are informed of organizational policies on advance care planning, and
- staff are appropriately trained, including provision of specific information on the legal framework in their province or territory.

Health care accreditation standards require implementation of effective advance care planning tools for patients. As the Canadian population ages, the importance of advance care planning will become more apparent.

Advance care planning is still not part of everyday practice, but it is becoming more prevalent. There are examples of this trend. “Respecting Choices”, a program developed in the United States, focuses on systemic change in training, practices and policies to ensure that advance care planning and end-of-life decision-making become part of the expected care provided throughout a health care organization or a community. Program Director Bud Hammes explains: “The goals of advance care planning can only be achieved by changing institutional and professional routines.” Similar programs are being developed in some regions in Canada.
Advance care planning needs champions.

Whatever your role—if you are a hospital administrator or operator of a long-term care facility, if you are involved in staff development or in organizational governance (e.g., board committees), if you are a physician, nurse, social worker or spiritual advisor—you can raise the issue of ACP and organizational readiness/capacity in your organization.

Does your organization have a policy on advance care planning?

If not, why not?

If so, is the policy adequate (e.g., is it restricted to DNR orders only)?

What staff training is being done, if any?

How can ACP policies/training be introduced and resourced (i.e., what is the process, where are the resources, where does the buck stop)?

You may have considerable personal experience with ACP. At the very least, having read this educational module, you have some knowledge and interest in the subject. Can you play the role of champion in your organization?

Organizational capacity-building for ACP must be multi-faceted.

Organizational capacity-building for ACP will require:

- the commitment of people in positions of authority (e.g., CEOs, Administrators, Ethics Committees, Boards) who must provide leadership and demonstrate their support for ACP,

- identification of leaders and champions throughout the organization, particularly among front-line health care providers,

- a policy development process that builds consensus,

- resources to provide educational opportunities and tools for staff,

- removal of barriers to learning (e.g., time allotted for training, internal marketing of ACP programs and policies),

- inclusion of ACP in the orientation of all new employees,

- creation of incentives through clear performance expectations and performance review,
- recognition of outstanding contributions to development of ACP in the organization,
- integration and codifying of new learning and experience into practice,
- ongoing feedback and review of practices in order to seek ways to improve quality and performance.

**Staff development is key.**

An ACP policy without education of staff will have little impact. An organization that promotes a culture of learning will benefit enormously from the experiences of those who learn about ACP and pass their learning on to others.

If ACP is not well supported in your organization, how might you get people interested? You might bring in speakers from outside the organization to make presentations or organize an interprofessional workshop. If a small group of interested people take an educational program, they may be able to train others.

Looking at your own organization, you will need to consider:

*What are the resources available to support ACP education?*

*What is standing in the way of ACP implementation? How can these barriers be removed?*

*Who will be accountable for what?*

*How best can we disseminate learning throughout the organization?*

*What will sustain the impact of this learning? Who will be involved in “coaching” participants after the training is over?*

*How can the application of new knowledge and skills be maximized? How can we continue to improve?*

*How will we know the investment has been worthwhile? What will improved performance look like? Who can help define success (i.e., ACP participants, residents/clients)?*
Policy development is essential too.

The success of organizational policy development requires a partnership of all health care professions, the administration and, if possible, community or patient/resident representatives. Effective policies should:

- not stress forms, but identify a patient and family-centred approach to advance care planning, excellent communication and methods for documenting wishes and preferences,

- provide information on different cultures that may assist professionals to understand how a family of a particular culture may make decisions,

- provide educational materials and resources, translated as appropriate, for persons engaged in ACP and their families,

- incorporate a process of review of advance care planning for individuals that is not based solely on a time interval, but based on assessing changing needs,

- develop process supports for ACP, including effective mediation services for resolving conflicts,

- include broad dissemination strategies so that all staff and as many patients/residents as possible are aware of the organization’s ACP policies.

Sometimes, current policies may be in conflict with good advance care planning, especially DNR policies and “levels of intervention” protocols. Policies that require an immediate decision on DNR or “treatment levels” as the patient enters an institution should not be part of an admission process. However, questions along the lines of: Have you done advance care planning? Do you have an advance directive? should be asked. There should be resource materials available for the person and family members, and the issue should be revisited as appropriate.

Responsibility for advance care planning in an organization should not rest entirely within an ethics committee or management committee. Committed front-line opinion leaders need to be involved as role models, mentors and educators.
**Pearls:**
- Involve front-line staff in ACP policy development.
- Get support of senior administration and clinical leaders.
- Ensure the facility’s ACP policies comply with provincial law.
- Recognize ACP is a process, not a form.

**Pitfalls:**
- Defining advance care planning as DNR only.
- Failure to orient new staff.
- Focusing ACP education too narrowly (only some parts of the organization or only some professions).
Chapter 9: Educational Resources

Resources for the Professional

A Summary of Canadian Legislation Concerning Advance Directives, The End of Life Project, Health Law Institute, Dalhousie University (http://as01.ucis.dal.ca/dhli/cmp_advdirectives)


Advance Directives: A guide for patient discussions. Christine L Maxfield; Joanne M Pohl; Kathleen Colling Nurse Practitioner; May 2003; 28, 5; Research Library pg. 38.

Calgary Health Region, Care at the end of Life Initiative for Health Care Professionals. (http://www.calgaryhealthregion.ca/carenlife/forhealthcareprofessionals.htm)

Canadian Medical Association, Code of Ethics. (http://www.cma.ca/index.cfm/ci_id/2419/la_id/1.htm)

Canadian Medical Association, Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care. (http://www.cma.ca/index.cfm/ci_id/3217/la_id/1.htm)

Canadian Medical Association, Principles for Medical Care of Older Persons. (http://www.cma.ca/index.cfm/ci_id/3205/la_id/1.htm)


Communication Issues and Advance Care Planning. Crystal Dea Moore; *Seminars in Oncology Nursing*; Vol 21, No 1 (February), 2005: pp 11-19  
(http://linkinghub.elsevier.com/retrieve/pii/S0749208104001287)


Crane, Monica K, et al. *Respecting End-of-Life Treatment Preferences.*  

Education in Palliative and End of Life Care (EPEC) Project, Module 1: Advance Care Planning, Northwestern University, Chicago, 2003. (http://www.epec.net/EPEC/webpages/index.cfm)

Fraser Health Advance Care Planning website (www.fraserhealth.ca), Fraser Health Authority, British Columbia, 2007.

Gundersen Lutheran, *Respecting Choices, Advance Care Planning Program Quality Improvement Toolkit:*  


Learning Essential Approaches to Palliative and End of Life Care Facilitators Kit, The Pallium Project (www.pallium.ca)


Modules on End-of Life Decision-Making, Communication with Patients and Families, Culture, and Conflict Resolution, Ian Anderson Continuing Education Program in End-of-Life Care, A Joint Project of Continuing Education and the Joint Centre for Bioethics, University of Toronto and The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, University of Toronto, 2000.


**Resources for the Patient and Family**

Advocacy Centre for the Elderly. www.advocacycentreelderly.org

Calgary Health Region, Care at the End of Life Initiative for the Public. (http://www.calgaryhealthregion.ca/carenlife/forthepublichomepage.htm)


Planning in Advance for Your Future Healthcare Choices – Fraser Health Authority: http://www.fraserhealth.ca/NR/rdonlyres/edjz6ofy7xy5nfos5wkzeu5thu6pj4a5hyst7i4zv6mto2uugzzfwhoyj22ohjevy2ysugh2hkgjij FraserHealthACPebook1.pdf


University of Toronto Joint Centre for BioEthics, Online Living Will: http://www.utoronto.ca/jcb/outreach/living_wills.htm

**Helpful Websites**

Calgary Health Region: www.calgaryhealthregion.ca

Canadian Association for Pastoral Practice and Education: http://www.cappe.org/

Canadian Association of Social Workers: http://www.casw-acts.ca/

Canadian Association of the Deaf: http://www.cad.ca/en/

Canadian Council on Health Services Accreditation: http://www.chla-absc.ca/task/cchsa.html

Canadian Hard of Hearing Association: http://www.chha.ca/chha/
FacilitatingAdvanceCarePlanning:AnInterprofessionalEducationalProgram
CurriculumMaterials

CanadianHomeCareAssociation: http://www.cdnhomecare.ca/index.php
CanadianHospicePalliativeCareAssociation: www.hospicepalliativecare.ca
CanadianMedicalAssociation: http://www.cma.ca
CanadianNursesAssociation: http://www.cna-nurses.ca/cna/
CatholicHealthAssociationofCanada: http://www.chac.ca/index.php
CollegeofNursesofOntario: http://www.cno.org/
FraserHealthAuthority www.fraserhealth.ca
GundersenLutheran – Respecting Choices: http://www.gundluth.org/eolprograms
HealthLawInstitute -TheEndofLifeProject: http://as01.ucis.dal.ca/dhli/cmp_advdirectives
TheCanadianBarAssociation: http://www.cba.org/CBA/Home.asp
TheIanAndersonProgram www.cme.utoronto.ca/endoflife/
ThePalliumProject www.pallium.ca
TheRoyalCollegeofPhysiciansandSurgeonsofCanada: https://www.medical.org/u/index_e.php?pass=spk

**Provincial and TerritorialGovernmentwebsites**

**BritishColumbia:** http://www.gov.bc.ca/bvprd/bc/home.do
- LegislativeAssemblyofBritishColumbia: http://www.leg.bc.ca/legislation/index.htm
- BritishColumbiaMinistryofHealthPoliciesandLegislation:
http://www.health.gov.bc.ca/navigation/policies.html

- Health Care (Consent) and Care Facility (Admission) Act, R.S.C. 1996, c. 181:
  http://www qp.gov.bc.ca/statreg/stat/H/96181_01.htm
- Health Care Consent Regulation, B.C. Reg. 20/00:
- Representation Agreement Act, R.S.B.C. 1996, c. 405:
  http://www.qp.gov.bc.ca/statreg/stat/R/96405_01.htm
- Representation Agreement Regulation, B.C. Reg. 199/01:

Alberta: http://www.gov.ab.ca/home/index.cfm

- Alberta Health and Wellness:
  http://www.health.gov.ab.ca/about/Minister_legislation.html
- Personal Directives Act, R.S.A. 2000, c. P-6:
  http://www.qp.gov.ab.ca/documents/acts/P06.cfm

Saskatchewan: http://www.gov.sk.ca/

- Government of Saskatchewan, Publications Centre Legislation:
  http://www.publications.gov.sk.ca/legislation.cfm
- The Health Care Directives and Substitute Health Care Decision Makers Act,
- The Health Care Directives and Substitute Health Care Decision Makers Regulations,
  Sask. Reg. 01/98:

Manitoba: http://www.gov.mb.ca/

- Manitoba Ministry of Healthy Living:
  http://www.gov.mb.ca/health/legislation/statutes.html
- Health Care Directives Act, C.C.S.M. 1992, c. H27:
  http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php

Ontario: http://www.gov.on.ca/

http://www.search.e-laws.gov.on.ca/en/isysquery/9e439d7f-607b-4c2d-a556-70c08e60bbac/7/frame/?search=browseStatutes&context=


- Ministère de la Santé et des Services sociaux:
- Civil Code of Quebec, S.Q. 1991, c. 64 (art. 11-25, Integrity of the Person – Care; art. 153, Capacity; art. 256-297, Protective Supervision of Persons of Full Age; art. 2130-2185, Mandate [i.e., power of attorney]:
- Revised Statutes and Regulations: http://www2.publicationsduquebec.gouv.qc.ca/home.php

New Brunswick: http://www.gnb.ca/
- Legislature Assembly of New Brunswick: http://www.gnb.ca/legis/index-e.asp

Prince Edward Island: http://www.gov.pe.ca/
- Legislative Assembly of PEI: http://www.assembly.pe.ca/index.php3
- Consent to Treatment and Health Care Directives Act, S.P.E.I. 1996, c. 10:
Nova Scotia: http://www.gov.ns.ca/
- Medical Consent Act, R.S.N.S. 1989, c. 279:
  http://www.gov.ns.ca/legislature/legc/statutes/medcons.htm

Newfoundland and Labrador: http://www.gov.nl.ca/
- Newfoundland and Labrador Department of Health and Community Services:
- House of Assembly Newfoundland and Labrador: http://www.assembly.nl.ca/default.htm
- Advanced Health Care Directives Act:
  http://www.assembly.nl.ca/legislation/sr/statutes/a04-1.htm

Yukon: http://www.gov.yk.ca/
- Care Consent Act, S.Y. 2003, c. 21, Sched.B:
  http://www.hss.gov.yk.ca/programs/decision_making/care_consent_act/

Northwest Territories: http://www.gov.nt.ca/
- Northwest Territories Health and Social Services:
  http://www.hlthss.gov.nt.ca/content/Legislation/default.asp
- Personal Directives Act, S.N.W.T. 2005, c. 16:
  http://www.canlii.org/nt/laws/sta/2005c.16/20060515/whole.html

Nunavut: http://www.gov.nu.ca/
- Nunavut Legislative Assembly:
- Consolidation of Public Health Act, R.S.N.W.T. 1988, c. P-12:
- Consolidation of Health Care Regulations, R-050-97:
- Consolidation of Mental Health Act R.S.N.W.T. 1988, c. M-10:
- Consolidation of Mental Health Regulations R-018-92: