



IT'S TIME TO TALK:

Advance Care Planning
in British Columbia

A Policy Paper by BC's Doctors
March 2014

115 - 1665 West Broadway
Vancouver BC V6J 5A4
doctorsofbc.ca

doctors
of bc
Better. Together.

Doctors of BC's Council on Health Economics and Policy (CHEP) reviews and formulates policy through the use of project-oriented groups of practising physicians and professional staff.

Advance Care Planning Project Group

Dr David Attwell, Chair – General Practice, Victoria
Dr Clifford Chan-Yan – Nephrology, Vancouver
Dr Catherine Clelland – General Practice, Vancouver
Dr Valorie Cunningham – General Practice, Duncan
Dr Paul Sugar – General Practice, West Vancouver
Dr Joanne Young – General Practice, Vancouver

Doctors of BC Council on Health Economics and Policy (CHEP) Membership 2012–2013

Dr Alexander (Don) Milliken, Chair – Psychiatry, Victoria
Dr Andrew Attwell – Internal Medicine, Victoria
Dr David Attwell – General Practice, Victoria
Dr Brian Gregory – Dermatology, Vancouver
Dr Jeff Harries – General Practice, Penticton
Dr Lloyd Opper – General Practice, Vancouver
Dr Alan Ruddiman – General Practice, Oliver
Dr Kimberly Shaw – General Practice, Port Coquitlam
Dr David Smith – Pediatrics, Vancouver
Dr Trina Larsen Soles – General Practice, Golden
Dr Rardi Van Heest – General Surgery, New Westminster
Dr Charles Webb – General Practice, Vancouver
Dr Joanne Young – General Practice, Vancouver

Doctors of BC Staff Support

Mr Jim Aikman – Executive Director of Economics and Policy Analysis
Ms Deborah Viccars – Director of Policy
Ms Mary George – Policy Analyst
Ms Linda Grime – Executive Assistant

Contents of this publication may be reproduced in whole or in part, provided the intended use is for non-commercial purposes and full acknowledgment is given to Doctors of BC.

Table of Contents

Executive Summary	4
Doctors of BC Policy	5
Commitments.....	5
Recommendations.....	5
Susan’s Story	6
1. Introduction.....	8
2. What is Advance Care Planning?.....	8
3. Policy Problem and Opportunity.....	11
4. Advance Care Planning in BC and Canada.....	12
BC Demographics.....	12
Support for Health Care Providers.....	14
5. Challenges in Advance Care Planning.....	17
6. Benefits of Advance Care Planning.....	22
7. Conclusion	25
References.....	26
Appendix A: Alberta Health Services Goals of Care Designation Order.....	28
Appendix B: Fraser Health Medical Orders for Scope of Treatment.....	29
Appendix C: Fraser Health Advance Care Planning Record.....	30
Appendix D: Advance Care Planning Discussion Script.....	32

Executive Summary

People think about dying. Individuals think about it when they are diagnosed with a terminal illness. Families think about it when their loved one becomes seriously ill. Physicians think about it when their patient's health starts to deteriorate. Nobody, however, wants to talk about it.

People have many reasons to delay discussing the end of their own life or that of a loved one. Patients may want to keep a brave face and not want to give the impression they've given up hope for recovery. Family members may think it's inappropriate or depressing. Some physicians may hesitate because they fear upsetting their patient. Others may be reluctant to talk about death because their training, and the entire culture of health care, centres on the preservation of life.

Evidence shows, though, that introducing discussions about values, goals, and wishes for end of life is better for both patients and providers. These discussions are not easy, but normalizing them by introducing them early can have tremendous impact. The process of advance care planning improves the patient, family, and provider experience at the end of life in a number of ways, including:

- Decreasing the likelihood of overly aggressive treatment at the end of life.
- Increasing patient and family satisfaction with care received at the end of life.
- Easing the bereavement process for surviving loved ones.

Despite the availability of excellent resources aimed at assisting with advance care planning, few British Columbians have engaged in the process. There is an opportunity to increase awareness of, and engagement in, advance care planning. Further, potential exists to better integrate services so that when an individual creates a plan, providers and family members are aware and can better support the patient. Given the unique nature of the physician-patient relationship, physicians are best suited to initiate advance care planning and support the process over the long-term as their patients transition through various life stages.

In an effort to ensure the best possible care for patients and their families, this policy paper explores the benefits of advance care planning, its associated challenges and opportunities, and makes commitments and recommendations to support advance care planning in BC.

Doctors of BC Policy

Doctors of BC supports physician-initiated advance care planning as a standard of care for all patients regardless of age, life stage, or health status.

To support this policy, Doctors of BC has identified the following commitments and recommendations.

Commitments

Doctors of BC commits to the following:

- a. Supporting advance care planning discussions that reflect age, life stage, and health status as a standard of care for all patients. Doctors of BC supports identifying transition periods to prompt physicians to initiate or revisit advance care plans with patients.
- b. Supporting physicians and patients in their use of existing resources for advance care planning for all patients and families within the context of each patient's age, life stage, and/or health status.
- c. Collaborating with government to ensure all health care providers have access to appropriate patient information with respect to advance care planning.
- d. Continuing to support training on the subject of advance care planning and endeavouring to make these resources available to all physicians.

Recommendations

Doctors of BC recommends the following:

- a. Physicians in British Columbia include in consultation notes, when possible and appropriate, details about prognosis, including details about transitions in health status, as a standard of communication for all patients with chronic, complex, or life-limiting illnesses.
- b. The British Columbia Ministry of Health amend or expand upon existing advance care planning resources to increase their relevance for all British Columbians, regardless of age, life stage and/or health status.
- c. Integration of advance care plans with patient records to provide all health care providers with access to patient plans.
- d. Advance care planning form part of the required standard of care for patients with chronic or complex illness.

Susan's Story

Aged 55 and fit, Susan and her husband Mike were enjoying life. They had worked hard and planned carefully for their retirement.

They kicked off their early retirement with a European vacation, but several weeks into the trip, Susan began coughing constantly. At first they assumed it was from the big city smog, but Susan was feeling worse. Mike was cautious and cut the trip short.

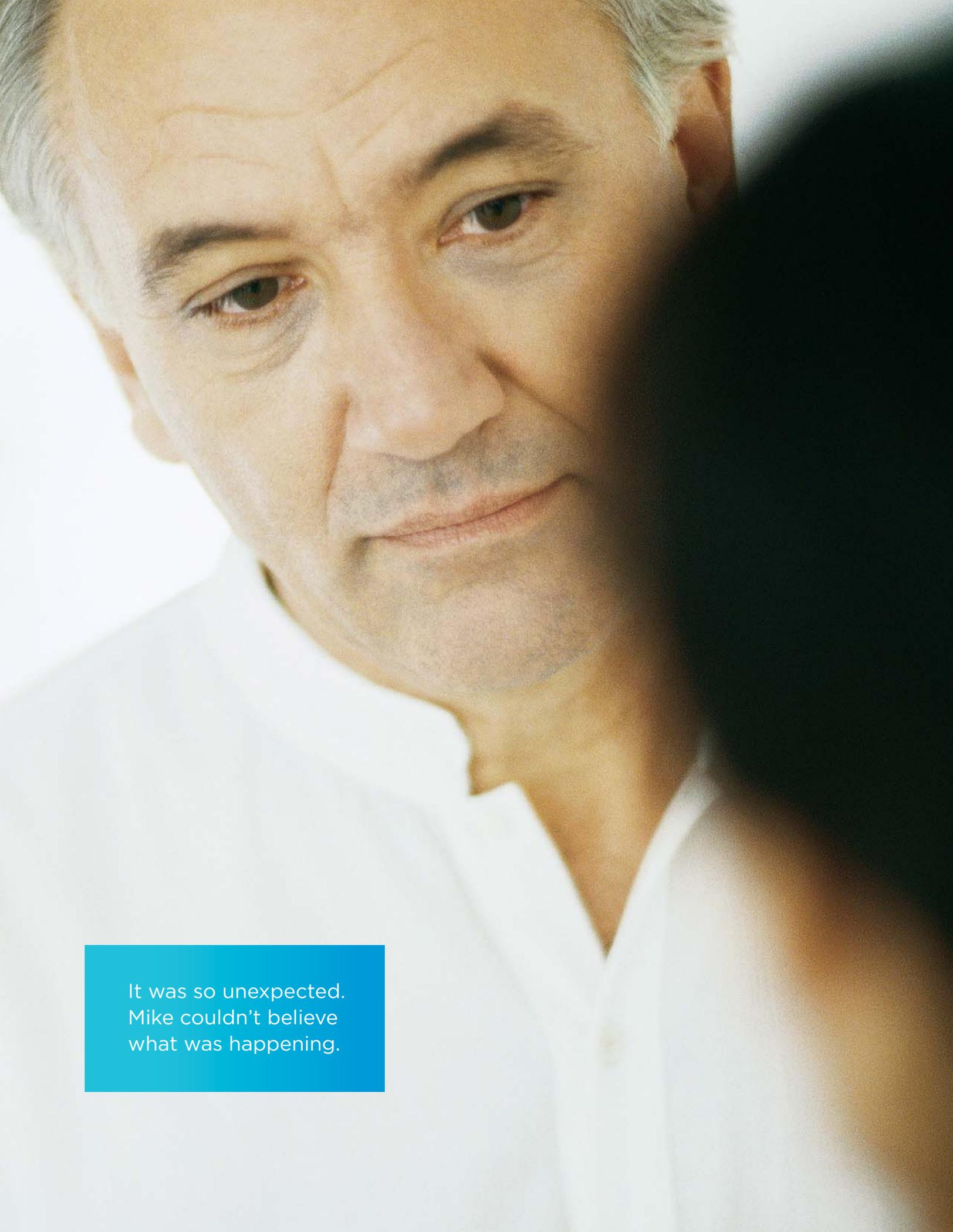
A trip to the emergency department, followed by a referral to an oncologist, confirmed that Susan had adenocarcinoma of the lung. The prognosis wasn't good. To maximize the amount of time Susan would have, the oncologist recommended surgery followed by chemotherapy and radiation.

The aggressive treatment made Susan weak. Despite feeling tired and overwhelmed himself as they rushed between doctor visits, Mike kept a brave face for Susan.

Susan and Mike had always been planners. They had followed a financial plan and had used a lawyer to prepare wills and powers of attorney, yet they had never talked about their wishes or goals for end-of-life care. Trying to stay positive, Mike didn't want to ask Susan about her end-of-life wishes, but decided he would do so when they had some time to slow down after the next round of chemotherapy.

Suddenly, Susan's condition deteriorated and Mike rushed her to emergency. Despite heroic measures, Susan died. It was so unexpected that Mike couldn't believe what was happening. It felt as though one moment they had been planning their future and now Mike was planning Susan's funeral.

In addition to his grief, Mike was wracked with questions and guilt. He wondered whether, instead of spending all their time in doctors' offices, they should have just spent these last weeks together at home. Mike would never know if that's what Susan would have wanted.



It was so unexpected.
Mike couldn't believe
what was happening.

1. Introduction

Susan and Mike's story is like that of many British Columbians. Without discussing end-of-life care goals, wishes, or values, Susan's family was left unprepared.

Advancements in medical treatment have profoundly prolonged life expectancy. As the population of BC is increasing, it is also aging. Life expectancies are projected to reach an average of 83 years by 2036.¹ This will result in larger numbers of British Columbians facing chronic disease and/or life limitations in the years before their death.

Many people avoid the process of advance care planning even when they are faced with a life-limiting illness. Discussing death and dying can be challenging for health care providers who must balance sensitivity for patients and families with pragmatic discussions about prognosis, symptom management, treatment, and quality of life. However, without early planning, many patients and families are forced to make difficult decisions in a time of crisis and without the time to consider all the options.

Without advance care planning, there is a real risk that patients will undergo interventions or care that is contrary to their beliefs, values, and wishes.

2. What is Advance Care Planning?

Like Susan and Mike, most British Columbians consider a will and power of attorney sufficient for end-of-life planning. The distinctions between the various documents available for estate planning and advance care planning can be difficult to comprehend, for both patients and physicians.

A will takes effect *after* a person passes, and an enduring power of attorney reflects a capable adult's appointment of a person to look after their legal and financial affairs should they become incapable of managing their affairs themselves during their lifetime. Neither a will nor an enduring power of attorney provides direction with respect to health care treatment.

In its guide, *My Voice: Expressing my wishes for future health care treatment*,² the BC Ministry of Health outlines various options related to health care planning.

- a) **Advance care planning** is a process by which a capable adult talks over their beliefs, values, and wishes for health care with their close family/friend(s) and a health care provider in advance of a time when they may be incapable of deciding for themselves.
- b) An **advance care plan** is a written summary of a capable adult's wishes or instructions to guide a substitute decision-maker* if that person is asked by a physician or other health care provider to make a health care treatment decision on behalf of the adult. It may include additional legal documents including:
- i. An **advance directive** is a legal document that sets out a capable adult's written instructions to their health care provider about the health care treatment the adult consents to, or refuses. It is effective when the capable adult becomes incapable, and only applies to the health care conditions and treatments noted in the advance directive.
 - ii. A **representation agreement** is a legal document in which a capable adult names their representative to make health care and other decisions on their behalf when incapable. There are two types of representation agreements:
 - Section 7: May authorize a representative to make decisions about the routine management of financial affairs, personal care, and some health care decisions on behalf of the adult, excluding decisions about the refusal of life support and/or life-prolonging medical interventions.
 - Section 9: May authorize a representative to make personal care and health care decisions on behalf of the adult, including decisions about the acceptance or refusal of life support and life-prolonging medical interventions.

As people's needs and wishes will vary over time and as their health status changes, advance care plans should be adapted as necessary.

* In *My Voice: Expressing my wishes for future health care treatment*, the BC Ministry of Health defines a substitute decision-maker as a capable person with the authority to make health care treatment decisions on behalf of an incapable adult, and includes a personal guardian (committee of the person), representative, and/or temporary substitute decision maker.

The planning process and the associated documents can be developed at any point in a person’s life, whether young or old, healthy or ill, or entering palliative, end-of-life, or terminal care.

A patient’s lifestyle also directs their need for an advance care plan. For instance, young people travelling to high-risk regions or engaging in dangerous activities should understand that an advance care plan is an important tool for their families should they be involved in an accident. As a person’s needs and wishes will vary over time and as their health status changes, the plan should be adapted and revised as needed.

The following table describes various life stages and elements of advance care planning that should be considered. The plan should be enhanced when individuals transition to new life stages, or experience major health or lifestyle changes. These events can be a trigger for physicians to suggest updating plans. Ideally, everyone should have — regardless of age, life stage, or health status — completed an advance care plan and shared it with family members and providers.

Advance Care Planning Elements by Life Stage		
Life stage	Physician-initiated advance care plan elements	Considerations to enhance plan elements
Young healthy adult	<ul style="list-style-type: none"> • Discussion with and identification of substitute decision-maker 	<ul style="list-style-type: none"> • High-risk lifestyle • Travelling
Adult	<ul style="list-style-type: none"> • Discussion with and identification of substitute decision-maker 	<ul style="list-style-type: none"> • Risk of complex or chronic illness • Co-morbidities • General poor health
Adult first diagnosed with complex or chronic illness	<ul style="list-style-type: none"> • Discussion with and identification of substitute decision-maker • Advance care plan 	<ul style="list-style-type: none"> • Co-morbidities • Rapidly declining health
Adult nearing the end of life or diagnosed with terminal illness	<ul style="list-style-type: none"> • Discussion with and identification of substitute decision-maker • Advance care plan • Discussion with family members 	<ul style="list-style-type: none"> • Family discord or lack of communication • Co-morbidities • Rapidly declining health

3. Policy Problem and Opportunity

Physicians who are aware of a patient's end-of-life care goals are better able to support patient and family decision-making.

The BC government reports that nearly 300,000 copies of the advance care planning guide *My Voice: Expressing my wishes for future health care treatment* have been distributed.³ Despite considerable interest in the subject and the numerous planning resources and options available, according to a 2012 Ipsos Reid Poll,⁴ few Canadians are adequately engaging in the process.

The lack of engagement in advance care planning may be attributable to a variety of factors, including:

- Few age- and life-stage appropriate materials for all patients.
- Advance care planning is not currently promoted as something to be done across a patient's lifespan as a standard of care.
- Inadequate support for health care providers in the provision of ongoing planning for patients and their families.

There is an opportunity to create and implement policies that address these issues, improve patient, family, and provider experience at the end of life, and ease the bereavement process.

Despite media interest in the subject and wide availability of quality advance care planning resources, few Canadians are engaging in the process.

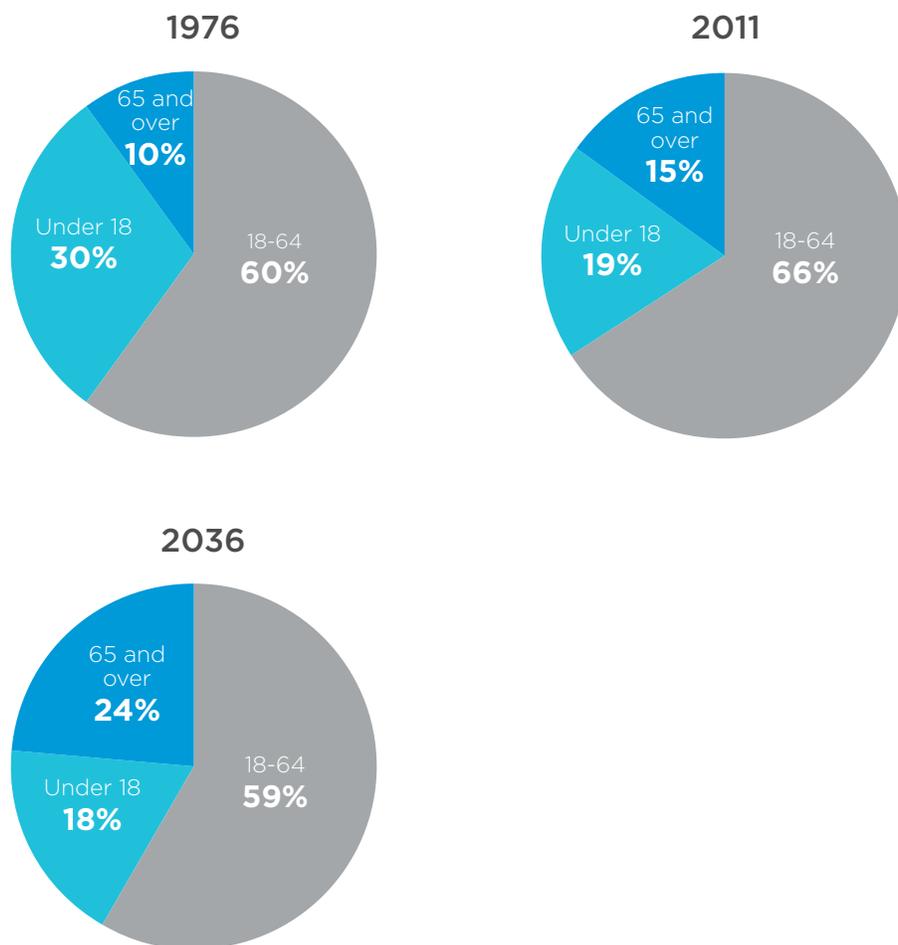
4. Advance Care Planning in BC and Canada

While British Columbians have access to many advance care planning resources, the number of British Columbians who engage in the process is low.

BC Demographics

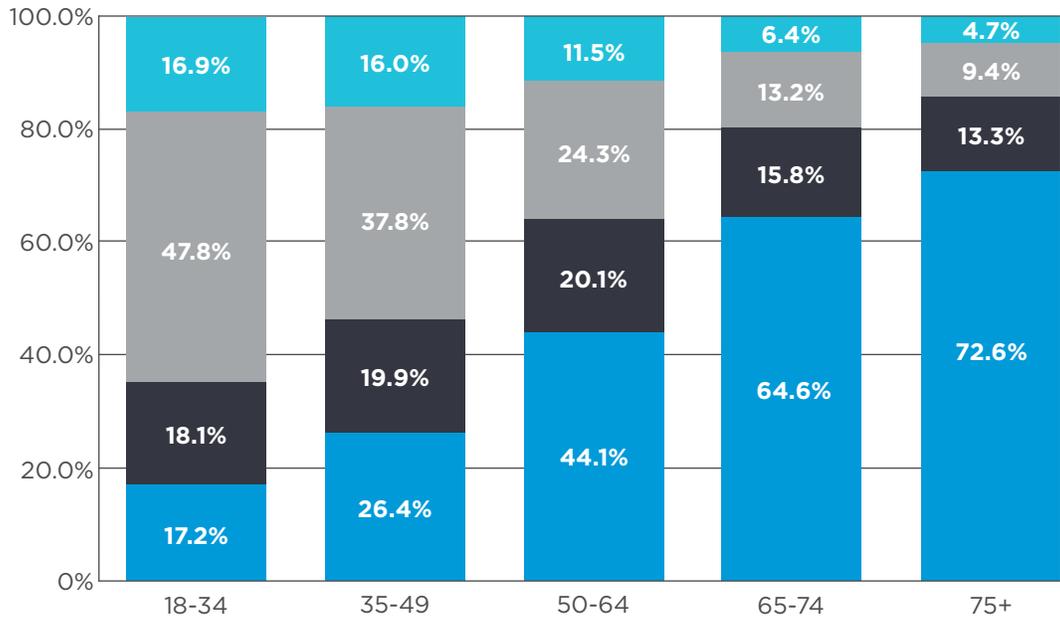
As baby boomers age, the population mix in BC is changing. As illustrated below, since the 1970s, there has been a tremendous increase in the number of people aged 65 and over. Meanwhile, the percentage of the total population under age 18 has decreased. These trends are predicted to continue.

BC population mix by age group: year 1976, 2011, and 2036.¹



As illustrated in the figure below, by age 65, over 80% of the population in BC has accessed the health care system due to a confirmed or possible chronic condition. This percentage increases to over 85% by age 75.

Distribution of chronic conditions by age group



Adapted from: Broemeling, Anne-Marie, Diane Watson, and Charlyn Black. *Chronic conditions and co-morbidity among residents of British Columbia*. Centre for Health Services and Policy Research, University of British Columbia, 2005.

- Non users
- Non-chronic service use
- Chronic conditions (possible)
- Chronic conditions (confirmed)

Along with changes in BC's demographics, there is a shift in the kinds of care that BC's population will need. With longer life, there is also an increased risk of life-limiting illnesses, chronic conditions, and co-morbidities, which increase the need for, and use of, health care resources. Risk of a significant number of illnesses increases with age — for example, cancer, arthritis, cardiovascular disease, diabetes, and chronic respiratory diseases.

Support for Health Care Providers

Physicians are well positioned to assist patients and their families with advance care planning. As family physicians provide longitudinal care to patients, they are able to initiate planning discussions early, have knowledge of transitions in a patient's health care status, and revise plans as appropriate. However, physicians need support in order to provide this care.

Alberta

In addition to other resources for health care providers, Alberta Health Services has created the "Goals of Care Designation Order" (Appendix A). The Order outlines a patient's specific goals of care at the end of life with respect to admission to the intensive care unit, resuscitation, and comfort. In addition to the Order, providers have access to a simple pocket card that lists appropriate interventions for each patient's selected "Goals of Care Designation."

The Order and pocket card assist providers and patients with communication of goals of care, as well as values and wishes, thereby reducing undesired or aggressive treatment at the end of life. Identifying and communicating broad patient wishes in a simplified way allows for succinct and clear communication and increases the likelihood that the patient's wishes will be reflected in the care provided.

British Columbia

The BC Ministry of Health has developed a number of initiatives for patients, including advance care planning guides and physician training programs, aimed at encouraging physicians to assist patients with their planning.

Patient Resources

As previously referenced, in 2013 the BC Ministry of Health developed a guide, *My Voice: Expressing my wishes for future health care treatment*,² an advance care planning resource intended for patients of all ages. The guide thoroughly explains the legal aspects of the process and provides a workbook that facilitates discussion between individuals and their families.

While British Columbians are fortunate to have access to many quality resources, some patients may feel that components are not relevant to them as they may not reflect the patient's own age, life stage, or health status. While the existing materials are very useful for older patients or those with a life-limiting illness, they may lack relevance for those wishing to engage in advance care planning earlier.

KEY FINDING

There are many patient resources available to support advance care planning but there is a general lack of awareness of their existence, or patients are not aware that they are applicable to them.

Physician Resources

Advance care planning resources have been developed by various areas of the health care system including government, health authorities, joint committees, and the Medical Services Commission.

In March 2013, the BC Ministry of Health published the *Provincial End-of-Life Care Action Plan for British Columbia*.⁵ This plan identifies key priorities and commitments from government to ensure that patients at the end of life, as well as their families, have the best care available.

At the health authority level, the Fraser Health Authority has implemented an initiative similar to that of Alberta Health Services. The Fraser Health Authority has replaced “Do Not Resuscitate” orders with “Medical Orders for Scope of Treatment” (Appendix B) and advance care planning forms (Appendix C). The Medical Orders for Scope of Treatment form is a physician order in the “greensleeve” of a patient’s chart to set out the code status and various other decisions regarding the scope of medical interventions for inpatients. In addition to providing guidelines for use of the forms, the Fraser Health Authority has further integrated care by collaborating with the BC Ambulance Service to ensure that paramedics honour these records of patient wishes.

The Ministry of Health and Doctors of BC work in partnership on collaborative committees to optimize health care in BC. Two of these committees, the Shared Care Committee and the General Practice Services Committee, have developed the Practice Support Program as a joint initiative to improve patient care and provider experience.

The Practice Support Program has worked to improve end-of-life care by developing a training module to support providers to enhance their skills in the provision of advance care planning. Approximately 1,000 physicians have taken the training module to date and have used this training to help patients throughout BC. The collaborative committees have encouraged patient planning by introducing fee codes that allow family and specialist physicians to bill for providing these services in some circumstances.

The BC Ministry of Health has developed initiatives, including advance care planning guides and physician training programs, aimed at encouraging advance care planning in the province.

The Medical Services Commission guidelines for BC physicians outline clinical problems and preferred approaches to treatment and management. These guidelines suggest advance care planning as the standard of care for the following groups: elderly patients with cognitive impairment, patients with congestive heart failure, and patients with cancer. While advance care planning is important regardless of age or health status, including it as a standard of care at least in these circumstances serves as a good reminder for providers that it is an important component of health care treatment and management.

5. Challenges in Advance Care Planning

By its nature, planning for end of life is challenging for patients, family members/caregivers, and health care providers.

Susan's story illustrates how many patients and families do not consider advance care planning until faced with a serious health crisis, at which point they may be reluctant to engage in the discussion.

Low Rates of Advance Care Planning

Despite the availability of the resources noted above, most people do not outline their wishes for care. According to a 2012 Ipsos Reid Poll:⁴

- Only 14% of Canadians have heard of advance care planning.
- Of those who have heard of advance care planning, only 20% have a written plan.
- Only 9% of Canadians have discussed their end-of-life care goals with a health care provider.

Challenges for Patients

Even when facing significant illness or death, patients and their families focus on life. There is a reluctance to face mortality. Therefore, despite access to planning guides and resources, there is generally an avoidance of discussing and planning care goals, values, and wishes for the end of life.

Planning Avoidance

Research has demonstrated that people are more comfortable with physician-initiated end-of-life and advance care planning discussions⁶ Most people report having avoided the process because they either associated the process with planning for euthanasia or feared that their preferences would change but their physician or family would be legally bound by the plan.⁷

Poor Communication

In the absence of an open discussion about end of life, patients and their families may be unaware of their prognosis and the nature of their illness; this is particularly true for older patients.⁸ Family members who reported a negative experience related to the death of a loved one attributed it to a lack of information about the dying process.⁹ In some circumstances, hospital patients are referred to palliative care without ever having had a frank discussion with their primary physician about their prognosis. Without discussion about prognosis and ensuring availability of that information, patients may feel abandoned by their primary care physician if they hear this information from another provider.¹⁰ Avoiding a sense of abandonment and optimizing patient autonomy are important elements in quality care at the end of life.^{10, 11}

Challenges for Providers

Health care culture is founded on the preservation of life. From early in their medical education, physicians begin associating patient survival with “success,” so it is not surprising that physicians may have difficulty discussing death and dying with patients.

In a systematic review, Hancock et al.¹² identified issues that prevent health care providers from discussing end of life with patients, even in the advanced stages of a life-limiting illness. These include:

- Perceived lack of training.
- Stress.
- Lack of time to attend to the patient’s emotional needs.
- Fear of a negative impact on the patient.
- Uncertainty about prognostication.
- Requests from family members to withhold information.
- A feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment.

Physician-Patient Communication

Many patients believe that informally sharing their wishes with family members is sufficient. Research indicates, however, that despite family members’ efforts to advocate for their loved ones, if plans are not explicit or shared with providers, these wishes are not implemented.^{13, 14}

Physicians report their reluctance to “prematurely” discuss death and dying because they fear that dispelling hope is bad for patients.¹² Evidence suggests however, that discussing and planning for end of life does not dispel hope or negatively impact patients, even for those patients who are terminally ill.¹⁵⁻¹⁷ An advance care plan developed between patient, provider, and extended family allows the physician to gain a better understanding of the individual and family’s cultural background, family dynamics, and decision-making process that will influence patient wishes as well as the end-of-life experience.

To promote advance care planning discussions between physicians and patients, there are resources available in the form of training modules and scripts in peer-reviewed journals, (see Appendix D).¹⁸ While these exist, there is not sufficient awareness of their existence, ease of use, or applicability for all physicians.

KEY FINDING

Despite the quantity and quality of advance care planning resources available to BC physicians, there are still opportunities to increase training uptake and to disseminate information more widely.

Physician-Physician Communication

The ability of primary care physicians to provide patient care is often limited by the information provided to them. Without normalizing discussions about death by implementing advance care planning early on, it can be difficult for physicians to initiate discussions. This difficulty is compounded when family physicians lack a clear understanding of a patient's prognosis. A shared care model can ensure that each member of the care team has the information necessary to appropriately initiate and engage in planning with their patients. A firm understanding of their patient's prognosis ensures that family physicians are able to guide their patient in their decision-making as it relates to the likely outcomes of their condition as well as the patient's values and goals.

Even when an advance care plan exists, physicians unexpectedly treating a patient, such as in emergency departments, often have little access to information about a patient's end-of-life goals and wishes beyond organ donation status. As the number of general practitioners with hospital privileges decreases, it is important to find ways to ensure patient wishes are upheld even if the primary care physician is not available. Providers who are unaware of a patient's values and beliefs are less able to counsel family members or others in appropriate decision-making related to care at the end of life.¹⁹

Challenges for the Health Care System

At the end of life, physicians may need to act as facilitators, assisting patients and their families with decision-making. Where there has been no explicit plan or discussion, family discord may direct life-prolonging care regardless of the patient's wishes.¹⁹ Without documented plans, families and caregivers have limited ability to uphold patient autonomy. In emergency situations, treating physicians without access to a documented advance care plan have no clear direction about the patient's wishes and must defer to emergency department protocols that are focused on patient survival to discharge. Currently, BC providers can access some information, including organ donation status,

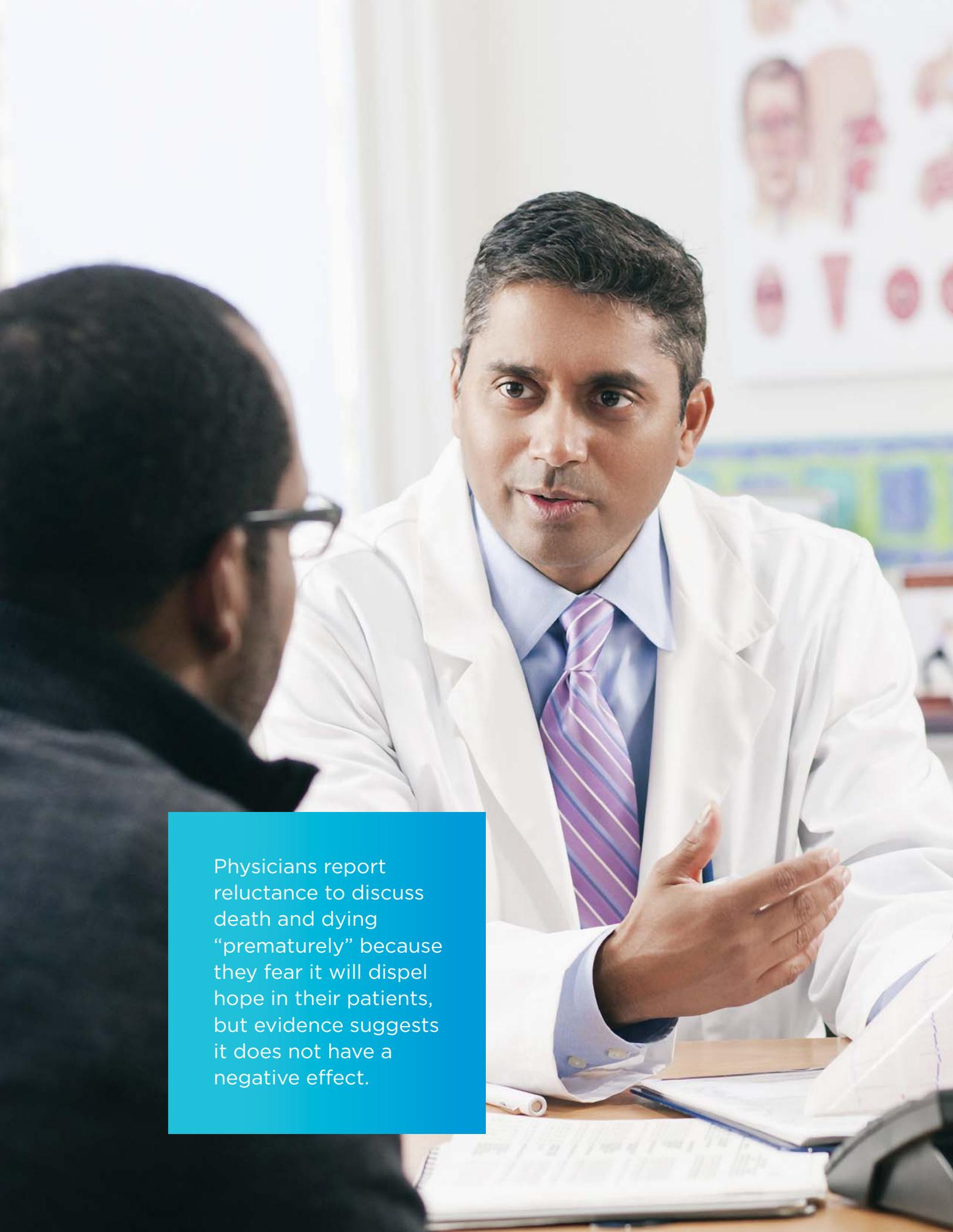
on a patient's BC Services Card/CareCard. Enhancing available information to include advance care plans would improve the patient, family, and provider experience.

BC Transplant is an excellent example of successful integration of services whereby people can register for the organ donation registry using various public services (online, driver service centres, doctors' offices, etc.). Once registered, the information is connected to the individual's BC Services Card and accessible to potential providers including physicians and emergency services. In contrast, with respect to advance care plans, there is little integration of services or access to information with the exception of Fraser Health Authority and BC Ambulance Service as noted above. Thus, while there are great resources created by government and other initiatives, their impact is limited by the level of awareness of the existence of plans among patients, families, and providers.

Other jurisdictions have begun pilot projects including "Coordinate My Care," a program by England's National Health Service. The project provides patients with a mobile phone application that outlines values and goals for end-of-life care, including preferences for dying at home, and makes the information easily accessible to all potential providers.²⁰ If BC patients are being encouraged to create plans, then there must be accessibility to, and integration of, services to ensure their wishes are available to others.

KEY FINDING

As lack of advance care planning among British Columbians has an effect on the entire health care system, BC must work to integrate services and access to information across the system.



Physicians report reluctance to discuss death and dying “prematurely” because they fear it will dispel hope in their patients, but evidence suggests it does not have a negative effect.

6. Benefits of Advance Care Planning

Advance care planning can contribute to a “good” death. Communication of patient wishes is at the centre of the process and may contribute to improved patient, family, and provider experience.

Benefits for Patients

In the past, there has been a perception that discussions of death should be avoided because such discussions increase “death anxiety” and are potentially traumatic.¹⁰ However, current research demonstrates that advance care planning can actually reduce death anxiety.²¹ In fact, patients report that engaging in educational discussions empowers them and helps sustain hope for the future.¹⁵ Engaging family members early in the process can also improve the eventual bereavement process.²² Patients can overcome their feelings of resistance or avoidance of discussing death if they understand that having a plan improves the bereavement process for family members.⁶

Perhaps most importantly, advance care planning is a social process in which patients and their family members engage with the physician and build a relationship.²³⁻²⁵ Advance care plans are highly personal, and reflect a patient’s personal needs and experiences as well as their desires surrounding end of life.²³ A patient’s cultural background will also drive his or her desires for an advance care plan.²⁶

Normalizing discussions about death early in the physician-patient relationship allows both parties to engage in discussions to ensure that the patient is able to make informed decisions and that the physician understands their patient’s values and goals with respect to treatment at end of life.

Benefits for Providers

Physicians are now caring for larger numbers of patients with complex or chronic illness.²⁷ For physicians, the advance care planning process is as important as the plan itself because it informs the delivery of quality care as well as improves the patient and family experience.

The support physicians need in order to assist patients with their planning varies depending on their experience and the focus of their practice. For instance, medical students may require more mentorship and opportunities to observe the process in order to gain the confidence to initiate these discussions.

Patient Care

Advance care planning with patients can give physicians confidence that they understand their patients’ wishes and have the information necessary to provide care. Planning can help reduce in-hospital deaths²⁷ and overly aggressive medical interventions.

When caring for patients and their family members during a stressful time, physicians who are aware of their patients' advance care goals are better equipped to focus on immediate patient needs,²⁸ which contributes to a positive provider experience.

Empowered Decision-Making

The advance care planning process gives providers an indication of how individual patients respond to various treatment options. Because no plan can outline specific wishes for every eventuality, a broad understanding of a patient's wishes provides a guide in case the patient cannot be consulted. With a plan, physicians are more familiar with a patient's values and can therefore speak with families about the types of decisions a patient would likely make.

Open and informed discussions about a patient's wishes and values can align the physician's, patient's, and family's understanding of the patient's goals and wishes and subsequently ease the sense of guilt that can accompany the bereavement process. At some point, family members may be included in advance care planning discussions that can provide physicians with insight into family dynamics and assist with future decision-making interactions with family members.^{23, 28} Given that family inclusion is linked to patient satisfaction, communication between providers, patients, and family/caregivers may lead to greater patient satisfaction and provider experience.^{24, 29}

Benefits for the Health Care System

As outlined throughout this paper, research has identified many benefits of advance care planning, particularly related to improving provider, patient, and family experience. In addition, research has also looked at advance care planning and cost avoidance.

Cost Avoidance

To date, research regarding advance care planning and cost avoidance has been contradictory.

Evidence suggests that patients who discuss advance care planning with their providers have lower medical costs in their final week of life due to less intensive interventions.³⁰ Conversely, other research claims this is an illusion because associated savings are only a reflection of reduced hospital days.³¹ Nonetheless, it is widely accepted that patients with advance care plans choose less aggressive treatment at the end of life, have fewer unnecessary readmissions to hospital, and fewer hospital days overall, all of which have an associated cost reduction.

Cost avoidance from reduced hospital days is only of benefit if it is a true reflection of a patient's wishes to avoid or reduce in-hospital stay. Using advance care planning to improve continuity of care upon discharge and subsequently reduce hospital readmission or hospital days overall is a cost benefit that should be examined further.



Research shows patients who discuss their wishes for end of life report feeling empowered and having a sense of sustained hope for the future.

7. Conclusion

Susan had a great life. This should not be minimized by focusing on the few weeks at the end of life when she and her family faced challenges.

She was fortunate to have had access to, and support from, the great physicians and services available in BC. Nonetheless, reviewing some of the challenges she and her family faced reveals the simplicity of advance care planning and the value it provides. Advance care planning could have:

- Encouraged Susan and Mike to share their values and goals for end of life early on.
- Empowered providers to better guide Susan and Mike in their decisions about treatment.
- Provided a framework for Susan's providers to follow.
- Clarified Susan's and Mike's wishes regarding hospital versus home care when Susan's condition deteriorated.
- Eased Mike's sense of guilt following Susan's death.

Talking about death is difficult for most people. For patients and family members, discussion of mortality can be overwhelming. Normalizing discussions of death and outlining care goals for end of life can help overcome this fear. Advance care planning that reflects the particular health status and life stage of all patients can help shift the culture of care. Physicians can provide the support patients need to articulate their overall goals for their end of life into a plan that promotes autonomy and a respectful death. Improving communication about patients' planning and initiating the discussion earlier can ensure that family members, caregivers, and health care providers are prepared to support them in their last days.

An advance care plan can articulate patient wishes for the end of life and ensure that loved ones, caregivers, and health care providers are prepared to meet their needs.

References

1. BC Stats. British Columbia Population Projections: 2010 to 2036: BC Stats2010. August 2010.
2. BC Ministry of Health. My Voice: Expressing my wishes for future health care treatment. Victoria: BC Minsitry of Health; 2012.
3. McQuillen K. BCMA draft policy paper on advance care planning [email correspondence with D. Viccars]. 2013.
4. Hanvey L. Overview of ACP in Canada. Canadian Foundation for Healthcare Improvement [webinar]. 2013. Available from: <http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/ACP/ACPWebinar.aspxf>.
5. British Columbia Ministry of Health. The Provincial End-of-Life Care Action Plan for British Columbia. 2013.
6. Kemp E, Kopp SW. Resistance and risk: Examining the effects of message cues in encouraging end-of-life planning. *Public Policy Marketing* 2011;30:100-109.
7. Seymour J, Gott M, Bellamy G, et al. Planning for the end of life: The views of older people about advance care statements. *Soc Sci Med* 2004;59:57-68.
8. Barnes S, Gardiner C, Gott M, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: A critical review of the literature. *Pain Symptom Manage* 2012;44:866-879.
9. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88-93.
10. Field MJ, Cassel CK. Approaching death: Improving care at the end of life: National Academies Press; 1997.
11. Back AL, Young JP, McCown E, et al. Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: Loss of continuity and lack of closure. *Arch Intern Med* 2009;169:474.
12. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: A systematic review. *Palliat Med* 2007;21:507-517.
13. Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. *N Engl Med* 1991;324:882-888.
14. Chai E MDE. Identifying the effective components of palliative care: Comment on “the optimal delivery of palliative care”. *Arch Intern Med* 2011;171:655-656.
15. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: Qualitative interview study *BMJ* 2006;333:886.
16. Robinson CA. “Our best hope is a cure.” Hope in the context of advance care planning. *Palliat Supportive Care* 2012;10(02):75-82.
17. Robinson CA. Advance care planning: Re-visioning our ethical approach. *Can Nursing Res* 2011;43:18-37.
18. Aitken PV. Incorporating advance care planning into family practice. *Am Fam Physician* 1999;59:605-612.

19. Winter L, Parks SM. Family discord and proxy decision makers' end-of-life treatment decisions. *Palliat Med* 2008;11:1109-1114.
20. Cross M. Delivering a digital death. *BMJ* 2013(Apr 24);346.
21. Emanuel EJ, Fairclough DL, Wolfe P, et al. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: Is it stressful? Is it helpful? *Arch Intern Med* 2004;164:1999.
22. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med* 2006;166:493.
23. Singer PA, Martin DK, Kelner M. Quality end-of-life care: Patients' perspectives. *JAMA* 1999;281:163-168.
24. Heyland DK, Groll D, Rocker G, et al. End-of-life care in acute care hospitals in Canada: A quality finish? *Palliat Care* 2005;21(3)A:142-150.
25. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Ann Internal Med* 2010;153:256.
26. True G, Phipps E, Braitman L, et al. Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med* 2005;30:174-179.
27. Heyland DK, Lavery JV, Tranmer JE, et al. Dying in Canada: Is it an institutionalized, technologically supported experience? *Palliat Care* 2000;16:S10.
28. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:634-641.
29. Lorenz K, Lynn J, Morton SC, et al. End-of-life care and outcomes. *Evid Rep Technol Assess (Summ)* 2004;Dec:1-6.
30. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: Associations with end-of-life conversations. *Arch Intern Med* 2009;169:480-488.
31. Emanuel EJ, Emanuel LL. The economics of dying — the illusion of cost savings at the end of life. *N Engl J Med* 1994;330:540-544.

Appendix A: Alberta Health Services Goals of Care Designation Order

	Alberta Health Services	Site: _____	
Goals of Care Designation Order			
Physician to initial in the box beside the chosen designation (Please choose only ONE) ↓			
R		R1	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care and resuscitation.
Medical Care and Interventions, including Resuscitation followed by Intensive Care Unit		R2	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care and intubation, but excluding chest compression.
		R3	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care, but excluding intubation and chest compression.
M		M1	Goals of Care and interventions are for cure or control of illness, excluding the option of ICU care. For non-hospital patients, transfer to an Acute Care facility is considered if required for diagnosis and treatment.
Medical Care and Interventions, excluding Resuscitation		M2	Goals of Care and interventions are for cure or control of illness, excluding the option of ICU care. For non-hospital patients, transfer to an Acute Care facility or surgical intervention, are not generally undertaken for an acute deterioration but may be considered in special circumstances to better understand or control symptoms.
C		C1	Goals of Care and interventions are for maximal symptom control and maintenance of function without cure or control of underlying condition. Transfer may be undertaken in order to better understand or control symptoms. Surgery may be undertaken in special circumstances to better understand or control symptoms.
Medical Care and Interventions, focused on Comfort		C2	Goals of Care and interventions are for physical, psychological and spiritual preparation for imminent death (usually within hours or days). Maximal efforts directed at compassionate symptom control. Transfer is usually not undertaken.
_____ Physician (Print Name)			_____ Signature
_____ Current Location of Care (name the specific facility/service/office)			_____ Date (yyyy/mm/dd)

Appendix B: Fraser Health Medical Orders for Scope of Treatment

 fraserhealth	<h2 style="margin: 0;">MEDICAL ORDERS for SCOPE of TREATMENT (MOST)</h2> <h3 style="margin: 0;">End of Life Care Program</h3>  <p style="font-size: small; margin: 5px 0;">ADD1105016A New: Oct 03/12 Page: 1 of 1</p>
DRUG & FOOD ALLERGIES	
SECTION 1: CODE STATUS: <i>Note: CPR is not attempted on a patient who has suffered an unwitnessed cardiac arrest.</i> <input type="checkbox"/> Attempt Cardio Pulmonary Resuscitation (CPR). Automatically designated as C2. Please initial below. <input type="checkbox"/> Do Not Attempt Cardio Pulmonary Resuscitation (DNR)	
SECTION 2: MOST DESIGNATION based on documented conversations (<i>Initial appropriate level</i>)	
Medical treatments excluding Critical Care interventions & Resuscitation	
_____ M1	Supportive care, symptom management & comfort measures. Allow natural death. <i>Transfer to higher level of care only if patient's comfort needs not met in current location.</i>
_____ M2	Medical treatments available within location of care. Current Location: _____ <i>Transfer to higher level of care only if patient's comfort needs not met in current location</i>
_____ M3	Full Medical treatments excluding critical care
Critical Care Interventions requested. NOTE: Consultation will be required prior to admission.	
_____ C1	Critical Care interventions excluding intubation.
_____ C2	Critical Care interventions including intubation.
SECTION 3: SPECIFIC INTERVENTIONS (<i>Optional. Complete Consent Forms as appropriate</i>) Blood products <input type="checkbox"/> YES <input type="checkbox"/> NO Enteral nutrition <input type="checkbox"/> YES <input type="checkbox"/> NO Dialysis <input type="checkbox"/> YES <input type="checkbox"/> NO Non-invasive ventilation <input type="checkbox"/> YES <input type="checkbox"/> NO Other Directions: _____	
SURGICAL RESUSCITATION ORDER <input type="checkbox"/> WAIVE DNR for duration of procedure and peri-operative period. Attempt CPR as indicated. <input type="checkbox"/> Do Not Attempt Resuscitation during procedure.	
SECTION 4: MOST ORDER ENTERED AS A RESULT OF (<i>check all that apply</i>)	
<input type="checkbox"/> CONVERSATIONS/CONSENSUS <input type="checkbox"/> Capable Adult	NAME: _____ DATE: (dd/mm/yr) _____
<input type="checkbox"/> Representative	NAME: _____ DATE: _____
<input type="checkbox"/> Temporary Substitute Decision Maker	NAME: _____ DATE: _____
<input type="checkbox"/> PHYSICIAN ASSESSMENT and <input type="checkbox"/> Adult/SDM Informed and aware <input type="checkbox"/> Adult not capable/SDM not available	
<input type="checkbox"/> SUPPORTING DOCUMENTATION (<i>Copies placed in Greensleeve and sent with patient on discharge</i>)	
<input type="checkbox"/> Previous MOST <input type="checkbox"/> Provincial No CPR	<input type="checkbox"/> FH ACP Record <input type="checkbox"/> Advance Directive
Representation Agreement <input type="checkbox"/> Section 9 <input type="checkbox"/> Section 7	<input type="checkbox"/> Other: _____
Date (dd/mm/yr) _____	Print Name _____
MSP # _____	Physician Signature: _____
Contact # _____	_____

Stores # 430438
Copyright © Fraser Health Authority 2012. All rights reserved.

ADVANCE CARE PLANNING (ACP) RECORD Cont'd

Back of Page 1

GUIDELINES FOR USE

- The purpose of the ACP Record is to document the outcomes of **conversations** related to Advance Care Planning and scope of treatment.
- This form is to be used by all members of the health care team (e.g., physicians, nurse practitioners, nurses, social workers, respiratory therapists) in all program areas (medicine, residential, renal etc) as a written communication tool.
- **This is a reference and may not reflect the most up to date conversations.**
- Before initiating conversations please ask if a My Voice Guide was previously provided. Ask to obtain copies of a previous MOST, Provincial No CPR, ACP Record, Advance Care Plan, Advance Directive, Representation Agreement. Review and place in the **GREENSLEEVE**.
- **Conversations** with the adult, or substitute decision maker(s) are documented, along with the **Key Outcomes** and subsequent plan of action to be implemented (e.g., Physician notified, or My Voice Guide introduced, completed) and who was involved.
- This form is placed in the **GREENSLEEVE** (green page protector) behind the physician order forms.
- **On transfer the GREENSLEEVE contents accompanies the adult.**
- On hospital discharge, retain the chart copy, give a copy of the ACP record to the adult. With consent from the adult or substitute decision maker, fax a copy to family physician.
- In primary care, give a copy of ACP record to the adult.

CORE ELEMENTS:

ACP conversations are ongoing and may include any combination of the five [5] Core Elements.

1. S.P.E.A.K. to adult about Advance Care Planning

Determine if the adult has:

- Chosen a **Substitute Decision Maker** (Representative appointed or TSDM)
- Thought about **Preferences** for treatment options.
- Any previously **Expressed wishes** (e.g. Advance Care Plan, Living Will)
- Written an **Advance Directive**. (instructions) appointed or (Representative

Then assess the adult and/or SDM's:

- Level of **Knowledge** regarding diagnosis, treatment options, risks and benefits.

2. Learn about & understand the adult & what is important to them. Involve Substitute Decision Maker(s).

Possible questions to ask:

- What does it mean to **live well**? What gives your life meaning?
- What does quality of life mean to you? Tell me your thoughts about quantity of life
- What fears/concerns do you have?
- How has your changing health status impacted you and your family? What is acceptable risk?
- Who or what gives you support in times of difficulty?

3. Clarify understanding & provide medical information about the disease progression, prognosis & treatment options.

What is the medical assessment?

- Diagnosis and implications now and in the future.
- Expected prognosis: Months to years? Weeks to months? Days to weeks? Hours to days?
- How might this disease progress (include discussion regarding resuscitation (CPR) and other life prolonging treatments (dialysis, tube feeds, ventilation support, etc.)
- What are the expected benefits and burdens of treatment?

4. Ensure interdisciplinary involvement and utilize available resources

- Ensure process is interdisciplinary. Utilize available resources and expertise including MD, NP, Social work, Palliative Care; Community resources (Alzheimer's, Parkinson's or Hospice Society)
- If treatment is not available in current location, does the adult wish to be transferred from their current location? Options may include acute care, hospice residences, residential care, and home.

5. Define goals of care, document & create plan.

- Discuss specifics of plan to ensure understanding of possible complications and how to manage them.
- If goal may not be attainable, what are the alternatives?

WHO MAKES MEDICAL DECISIONS?

(1) **Capable Adult (19 years of age or older): ALWAYS first if adult is able to provide consent.**

(2) Personal Guardian/Committee of Person (court-appointed) under the *Patients Property Act*

ONLY IF the adult is no longer able to provide informed consent then BC's hierarchical healthcare decision making list as dictated by provincial law for substitute consent applies. **To obtain substitute consent** to provide major or minor health care to an adult, a health care provider must choose the first, in listed order, of the following who is available and qualifies as dictated by BC provincial law for substitute consent.

(3) Representative: under the Representation Agreement Act (Section 9 agreement required for life sustaining consent)

(4) Advance Directive (if no Representative is appointed)**

(5) Temporary Substitute Decision Maker: If there is no Representative or Committee of Person, under the Adult Guardianship and Planning Statutes Amendment Act a health care provider must choose the nearest relative as ranked below:

- (a) The adult's spouse (common law, same sex);
- (b) The adult's children (equally ranked);
- (c) The adult's parents (equally ranked);
- (d) The adult's brothers or sisters (equally ranked);
- (e) The adult's grandparent (equally ranked)
- (f) The adult's grandchild (equally ranked)
- (g) Anyone else related by birth or adoption to the adult
- (h) A close friend of the adult
- (i) A person related immediately to the adult by marriage
- (j) Another person appointed by Public Guardian and Trustee

Duties of a substitute decision maker: A person chosen to give or refuse substitute consent to health care for an adult must be 19 years of age or older, have had communication within the last 12 months with the adult and not be in dispute with the adult, be capable of giving, refusing or revoking substitute consent. **Before giving or refusing substitute consent, the SDM(s) must comply with any instructions or wishes the adult expressed while he or she was capable.**

When no one from the ranked list of substitute decision makers is available or qualified, or there is a dispute between two equally ranked substitutes that cannot be resolved by the health care provider, the health care provider must contact a Health Care Decisions Consultant at the Public Guardian and Trustee at 1.877.511.4111

Appendix D: Advance Care Planning Discussion Script

Mrs. Jones has come in for a routine examination:

“Mrs. Jones, I’d like to talk with you about something I try to discuss with all of my patients. It’s called advance care planning. In fact, I feel that this is such an important topic that I have done this myself, with my own physician. Are you familiar with advance care planning?...”

“Have you thought about the type of medical care you would like to have if you ever became too sick to speak for yourself? That is the purpose of advance care planning, to ensure that you are cared for the way you would want to be, even in times when communication may be impossible....”

“There is no change in your health that we have not already discussed. I am bringing this up now because it is prudent for everyone, no matter what their age or state of health, to plan for the future....”

“Advance care planning will help both of us to understand your values and goals for health care if you were to become critically ill. Eventually, we may put your choices into a written document that I would make part of your patient record. We call this document an advance directive, and it would only be used if you were to lose the capacity to make decisions on your own, either temporarily or permanently....”

“Would you like to talk further about the kind of care you would want to have if you were no longer able to express your own wishes?”

“I also like to ask my patients if they have someone that they would like to identify to act on their behalf in the event that they are unable to express their own wishes. This person could be a relative or a friend. Is there someone whom you would want to be part of our discussion and whom you might want to have act on your behalf?...”

“Here is a copy of the form that I would like to use to structure our conversation. We will talk about it in more depth the next time we meet. Please think about it, talk with your family, and write down any questions you have. Also, next time please bring anyone with you whom you want to include in our discussion....”

Next visit:

Ask questions about specific scenarios. Start by asking about a persistent vegetative state.

“Mrs. Jones, I suggest we start by considering a few examples as a way of getting to know your thinking. I will use examples that I use for everyone. Let’s try to imagine

several circumstances. First, imagine you were in a coma with no awareness. Assume there was a slight chance that you might wake up and be yourself again, but it was not likely. Some people would want us to withdraw treatment and let them die, others would want us to attempt everything possible, and yet others would want us to try to restore health, but stop treatment and allow death if it were not working. What do you think you would want under these circumstances?”

Then ask Mrs. Jones similar questions about three other scenarios:

- Onset of coma from which there is a chance of recovery, but with significant disability.
- Onset of dementia when there is already an advanced life-threatening illness.

If she is already experiencing a significant illness, ask Mrs. Jones questions specific to her current illness:

“We should also consider the situations that your particular illness can cause; that way you can be confident we will do what you want. For sure, all people are different and you may never face these circumstances. Nevertheless, let’s imagine...”

“People sometimes think about circumstances they have seen or heard about. Some may seem worse than death. Do you ever think about such circumstances?”

Finally, ask Mrs. Jones about how she would like to handle a sudden critical life-threatening illness.

At the end of these scenarios, recap what you understand:

“Well, we’ve gone through several scenarios now. It seems to me that you feel particularly strongly about.... Indeed, you move from wanting intervention to wanting to be allowed to die in peace at the point when.... Do I speak for you correctly if I say that your personal threshold for deciding to let go is ...?”

Conclude by inquiring about broader values and beliefs:

“I think you have given a good picture of particular decisions you would want. Can you also say something about the values or beliefs that you hold? Understanding your more general views can be an important part of getting specific decisions right.”

Next visit:

“Mrs. Jones, have you and [your proxy/family member] had a chance to continue the discussion we started 2 weeks ago? I see you have a completed statement now. Let’s review your preferences.”

“I am glad we went through this planning process together. I have a much better idea of what matters to you than I did before, and that will help me to be a good physician for you — in general, as well as in case of serious illness.”

“If you feel ready, we can write down your preferences, and all three of us can sign this document and make it official. Then we will put it into your medical record and give you copies to take home.”

After a change in health status (such as relapse), after allowing time to adjust to the new reality:

“Mrs. Jones, we have had some changes in your health since we completed your advance care plans. People sometimes change their wishes, so let’s review the wishes you wrote down before.”

If the patient seems unsure of decisions:

“Your choices have changed on a couple of your earlier decisions when we reviewed your statement. You have also said that you want [proxy/family member] to be your proxy. Would you prefer to give these few decisions over to him/her to decide according to what he/she thinks would be in your best interests?”

“For the remaining decisions, about which you are clear and firm, would you like [proxy/family member] to stick closely to them, or would you prefer to give him/her room to make changes if he/she thinks your best interests would be better served by a different decision?”

115 - 1665 West Broadway
Vancouver BC V6J 5A4
doctorsofbc.ca

 [@doctorsofbc](https://twitter.com/doctorsofbc)

doctors
of bc 
Better. Together.