



# **Advance Care Planning & Personal Directives: Recommendations for Legal Practice in Alberta**

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Covenant Health  
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# Introduction

This guide contains joint practice principles on advance care planning in Alberta that were developed collaboratively by members of the legal and health care sectors (the “Joint Practice Principles”), as well as companion recommendations for legal practice in Alberta (the “Recommendations for Legal Practice”).

The Joint Practice Principles describe key concepts and roles (including the role of the client/patient) and provide useful information about the respective practice contexts in health care and law. Their intent is to establish shared terminology and understanding of best practices, provide resources, lead professionals to evaluate and optimize the effectiveness of their practices, and further encourage collaborative approaches to advance care planning. They are not intended to create liability.

The Recommendations for Legal Practice are intended to increase the likelihood that advance care plans are followed in health care settings. They are derived from expert opinion<sup>1</sup>, advance care planning (ACP) policies<sup>2</sup> (Appendices A and B), frameworks<sup>3,4</sup>, joint practice principles<sup>5,6</sup> and guides<sup>6,7,8,9</sup> from various jurisdictions, and academic and legal literature.<sup>10,11,12,13,14</sup> These sources describe the current state (e.g. health care practices, complaints to the Office of the Public Guardian and Trustee (OPGT), gaps in the legislation, physician attitudes to personal directives) and prescribe principles and practices to strengthen lawyers’ understanding of and effectiveness in their ACP-related practices.

## Context

ACP is defined as “the process of preparing people and alternate decision-makers for communication and medical decision-making.”<sup>15</sup> The process is conceptualized as being five steps<sup>16</sup>:

1. Think about your values and goals;
2. Learn about your health;
3. Choose someone to make health and personal decisions for you;
4. Communicate your wishes to the people you trust and your healthcare team; and
5. Document your wishes in a personal directive.

The objectives of ACP include fostering individuals’ capacity for in-the-moment medical decision-making and achieving better concordance between health outcomes and the maker’s values, wishes and goals. There is compelling and high-quality evidence that ACP decreases surrogate grief, post-traumatic stress disorder and burden.<sup>17</sup>

Lawyers and health care providers (HCPs) have distinct roles in ACP. In Alberta, lawyers draft personal directives (PDs) (called “advance directives” in other jurisdictions) which may designate an agent or agents and may contain information and instructions respecting the maker’s personal and health matters (s. 7 of the Personal Directives Act RSA 2000, c P-6 (the PDA)). HCPs make treatment decisions, identify cognitive or functional decline and assess care needs. However, some of these professions’ roles overlap including eliciting goals and preferences, establishing care plans, assessing

capacity and addressing abuse and neglect.<sup>11,13</sup>

Despite the development of national frameworks, health care policies and education, and public-facing resources, completion rates of certain key ACP components remain low: 14% and 6% of Albertans have talked to their HCP and lawyer, respectively, about their wishes for health and personal care, compared to 55% who have talked to a family member.<sup>18</sup> This stagnancy has been attributed to an array of factors including the complexity of stakeholders and systems.<sup>15</sup> Experts in ACP argue that medical-legal collaboration is necessary to “take ACP to the next level.”<sup>11,13,15</sup>

In a survey published in 2018, Alberta lawyers identified barriers to ACP in their practices such as clients’ lack of preparedness (73% of respondents) and lawyers’ lack of knowledge about health sector policies and practices (49% of respondents).<sup>14</sup> They also rated resources that would be useful or very useful: client workbooks (81% of respondents), best practice guide (83%), information on how Goals of Care Designation orders (GCDs) and PDs function together (87%) and information on health policies (83%).<sup>14</sup> Collaborations between health, law and other stakeholders (e.g. OPGT, social work, patient advisors) in Alberta and elsewhere have revealed a lack of understanding about each other’s practice contexts. Significantly, lawyers may not be aware of how PDs are used in health care settings, which may lead them to misjudge their effectiveness and underestimate the importance of facilitating other ACP behaviours.

## **Development of Joint Practice Principles**

To address the above gaps, in 2023-2024 the Covenant Health Palliative Institute hosted focus groups comprised of legal, health care and social work professionals with roles in advance care planning. Invitations were circulated through professional associations and communities of practice,<sup>19</sup> and to others as they were identified by the Palliative Institute’s Advance Care Planning Advisory Committee, professional associations or team members. A total of four focus groups were attended by 26 unique participants. The first focus group reviewed and made recommendations based on the Joint Practice Principles on Advance Care Planning (2018) developed by the American Bar Association.<sup>6</sup> Using an iterative model of development, each subsequent focus group reviewed the most recently revised version of the Joint Practice Principles. Together we reached consensus on key elements of ACP, roles and coordinated approaches.

## **Development of Recommendations for Legal Practice**

The Recommendations for Legal Practice in Alberta augment the Joint Practice Principles. They were originally created for the Legal Education Society of Alberta’s course on advance care planning (“Aligning Practice to Reality: Understanding Advance Care Planning”, April 2024) by authors Maureen Douglas, Melanie Blackwell, Shelly Chamaschuk, Charlie Chen and Sara O’Dea. They contain six specific recommendations, additional rationale and examples from HCPs and the OPGT, precedent language and a list of resources.

# Alberta Medical- Legal Joint Practice Principles on Advance Care Planning



# Definitions

## **Advance care planning or ACP:**

The process of preparing people and alternate decision-makers for communication and medical decision-making. The process is conceptualized as being five steps:

1. Think about your values and goals;
2. Learn about your health;
3. Choose someone to make health and personal decisions for you;
4. Communicate your wishes to the people you trust and your healthcare team; and
5. Document your wishes in a personal directive.

## **Agent:**

A person designated in a personal directive to make personal decisions on behalf of the maker.

## **Alternate decision-maker:**

A person who is authorized to make decisions on behalf of an individual.

## **Maker:**

A person who makes a personal directive.

## **Public Guardian:**

The Public Guardian of Alberta appointed under the Adult Guardianship and Trusteeship Act SA 2008, c A-4.2.

## **Serious illness:**

A condition that carries a greater risk of mortality and negatively impacts a person's daily function or excessively stresses their caregivers.

Principle	Definition	Relevant Recommendations for Legal Practice
<p>1. Proxy Designation</p>	<p>The most important legal component of advance care planning is the careful selection and appointment of an agent and alternate agent(s) in a valid personal directive. It is important for the maker to confirm that their agent is willing to act and prepare their agent by sharing with them the maker's beliefs, values, wishes and goals for health and personal care.</p> <p>Individuals who cannot identify an agent may designate the Public Guardian as their agent by complying with the Personal Directives Act, as amended.</p> <p>For individuals who do not want to appoint an agent, it is especially important for them to record their beliefs, values, wishes and goals in a personal directive as a means of sharing these with alternate decision-makers.</p>	<p>See Recommendation #1:</p> <p>Strongly advise your client to appoint and equip their agent (page 11)</p> <p>Criteria to choose the best candidate(s) (page 11)</p> <p>Agent's authority and duty (page 11)</p> <p>Considerations regarding appointing multiple agents (pages 12-13)</p> <p>Naming the Public Guardian as agent (page 13)</p>
<p>2. Advance Care Planning as an Ongoing Process</p>	<p>Advance care planning takes place over a lifetime. It changes as one's goals and priorities in life change through different stages of life and health conditions. Ongoing reflection, discussion and communication with one's agent and health care team, along with family, friends and advisors, are essential to having one's beliefs, values, wishes and goals understood and honoured. These discussions should occur for all adults (over the age of 18), who have decision-making capacity, at all stages of life and health.</p>	<p>See:</p> <p>Revisiting advance care planning upon certain events (the "Six Ds") (page 16)</p> <p>Communication between individual and their health care provider (pages 15-16)</p> <p>Communication with agent and others (pages 11-12, 15)</p>
<p>3. Focus on Beliefs, Values, Wishes and Goals</p>	<p>In general, individuals should be encouraged to focus on their overarching personal beliefs, values, wishes and goals in the event of worsening health instead of specific treatment or clinical interventions for hypothetical situations.</p>	<p>See Recommendation #2:</p> <p>Encourage your client to identify and discuss their values with their agent(s), loved ones and health care providers, and thoughtfully and comprehensively document these in their personal directive (page 13)</p> <p>Questions and resources to elicit client's values (pages 13-14), sample clauses (pages 14-15)</p> <p>Reasonableness of predicting future wishes about specific limitations and treatments (page 16)</p>

Principle	Definition	Relevant Recommendations for Legal Practice
4. Advance Care Planning in Serious Illness Care	<p>If individuals are facing serious illness, the focus of advance care planning may then move to specific treatment preferences. In these cases, the individual is encouraged to meet with their primary/key health care provider to create a care plan that aligns with their beliefs, values, wishes and goals. Ongoing discussion between the individual, their agent, family, friends and advisors about the individual's beliefs, values, wishes and goals, and as acceptable to them, continue to be important.</p> <p>The health care provider should be informative and willing to educate the agent/alternate decision-maker of their responsibilities.</p>	<p>See:</p> <p>Advise client to have a goals of care discussion with their health care provider (page 16)</p> <p>Communication between individual and their health care provider (pages 15-16)</p>
5. Advance Care Planning Tools	<p>Advance care planning tools and guides can provide structure and guidance to inform the process of reflection and discussion, and help individuals identify their beliefs, values, wishes and goals. Such tools and guides may help ensure more authentic, compassionate and effective conversations, personal directives, and Goals of Care Designation orders so they better align with an individual's beliefs, values, wishes and goals for health care now and in the future.</p>	<p>See:</p> <p>Recommended resources (page 23)</p>
6. Role of Personal Directive	<p>A personal directive is the legal document that appoints a maker's agent and/or records the maker's beliefs, values, wishes and goals for personal matters, including health care, to guide decision-making if the maker loses capacity. The personal directive should result from a process of information sharing, reflection, discussion, and communication.</p> <p>Inclusion of values-based statements can help ensure enough flexibility in the personal directive to allow alternate decision-makers to respond to new personal and/or medical circumstances. Although instructions about specific interventions are generally discouraged, they may be justified in special circumstances by the maker's clinical and personal context. In such cases, the personal directive should provide an explanation of the context to assist those who may be interpreting the personal directive.</p>	<p>See: Recommendation #4:</p> <p>Guidance on drafting personal directives (page 17)</p> <p>Addressing potential concerns and confusion about validity of personal directive (page 17)</p> <p>Providing context for "unusual" wishes (pages 17, 21)</p> <p>Health care's difficulty in interpreting subjective language and decontextualized instructions (pages 17-19)</p> <p>Drafting to foster agent's flexibility (page 20)</p>

Principle	Definition	Relevant Recommendations for Legal Practice
7. Sharing Documents	Makers should share documentation of their beliefs, values, goals, and wishes in the form of a personal directive with their agent and health care team, and ensure the personal directive is part of the health record, so that they are adequately informed before a crisis arises. Makers should also be encouraged to consider sharing their personal directive with their family, trusted friends and advisors, as appropriate.	See: Recommendation #5: Guidance on storing personal directives (page 21) Sharing and uploading personal directives (page 21)
8. Health-Legal Collaboration	Joint initiatives on advance care planning between the legal and health care sectors benefit clients and patients. These initiatives aim to increase awareness of respective professional and practice contexts, identify issues, and develop and implement new approaches, such as joint education, congruent policies and practices, best practice guides and precedent documents.	
9. Role of Goals of Care Designation Order	<p>A Goals of Care Designation (GCD) order is a medical order that provides one set of short-hand instructions by which health care providers describe and communicate general care intentions, specifically indicated health interventions, transfer decisions and locations of care for a patient. A GCD order can only be written by a physician or nurse practitioner and does not require patient consent. A GCD order strives to harmonize a patient's values, wishes and goals for health care as it relates to their current health care status and clinically indicated care.</p> <p>Individuals should be directed to their health care team for more information about GCDs.</p>	See: Information and resources from the Government of Alberta, Alberta Health Services and Covenant Health Palliative Institute (pages 16, 23)



# Recommendations for Legal Practice and Sample Precedent Clauses

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# 1. Strongly advise your client to appoint and equip their agent(s).

Assuming your client has someone in their life who can act as their agent, a well-chosen and equipped agent is the best safeguard of your client's wishes.

## Advice to offer to your clients:

- a. Consider and apply the following criteria to choose the best candidate(s):
  - i. Willing to act.
  - ii. Knows you well and deeply understands what is important to you.<sup>4</sup>
  - iii. Trustworthy. Do you trust this person to make decisions about your life, comfort, and well-being? Will they endeavour to honour your values and beliefs instead of imposing their own beliefs? The PDA provides that, in the absence of clear instructions, the agent must base their decision on their knowledge of the maker's wishes, beliefs, and values (s. 14(3)(a)).
  - iv. Comfortable navigating health care situations, making decisions and advocating for your values and wishes to be followed.
  - v. Comfortable directing your family and friends. Can this person handle differing opinions of family members and come to a decision that reflects your wishes and discussions?
  - vi. Available and able to make the time commitment required. Does this person live nearby? Is this person healthy? Will they be available to attend medical and legal appointments to more thoroughly understand your condition, prognosis, treatment options and preferences?<sup>7</sup>
  - vii. Emotionally capable. Are they comfortable talking about sensitive and difficult issues?
  - viii. Will collaborate well with the attorney appointed on your financial matters under Enduring Power of Attorney.<sup>7</sup>
- b. Let your agent(s) know you've chosen them and ensure they agree to act.
- c. Help your agent(s) to understand their authority and duty (s. 14 and 17 of PDA). The Centre for Public Legal Education's (CPLEA) guide for agents is an excellent resource.<sup>8</sup> OPGT receives many complaints based on misunderstandings of the agent's role (e.g. the agent is NOT a caretaker responsible for meeting the maker's day-to-day needs, such as ensuring they have toiletries in their rooms, taking them to medical appointments, transportation, etc.). Also, the PD can give agent(s) authority in *all* personal matters or can give *domain-specific* authority (e.g. Mona has authority for health and Marlys has authority for accommodation) (s. 3 of the PDA). If you want to give domain-specific authority, make sure it's reflected in the PD and your agents are aware, as it can be confusing to them.
- d. If appropriate, give your agent(s) a copy of your PD and tell them where it's stored/uploaded. Ensure you update them when you execute a new PD. You may also provide them with a

summary of all your contacts and important documents using the Canadian Hospice Palliative Care Association's template.<sup>7</sup>

- e. Have early and ongoing high-quality conversations with your agent(s) about your values and wishes, health condition(s) and prognosis. Provide them with any ACP workbooks (e.g. My Wishes Alberta workbook<sup>20</sup>) or other tools you have used to describe and document your values and wishes.
- f. If appropriate, consider inviting your agent(s) to your medical and legal appointments so that all critical players (agent(s), health care, legal) are aware and understand the content and context of your advance care plans (e.g. GCDs). Involve your agent(s) early and throughout to foster informed decision-making and increase the likelihood that providers and agents will appreciate that quality ACP has occurred.
- g. Advise all others who may need to know or work with the agent(s) you have chosen. Anticipate circumstances or provisions that may cause potential conflict. Have you chosen an unexpected or controversial agent(s)? Are there others who may have expected to be your agent and may try to usurp your agent(s)? Have you remarried, and might your spouse have a different understanding of your health condition and wishes than your adult children? Are there some members of your family who do not communicate with each other? Are some of your values and preferences at odds with those of the others in your family?
- h. Consider whether anyone besides the agent(s) should have a copy of the PD. OPGT often receives complaints from family members who have concerns about the agent's decision-making but have not seen the PD. Some concerns may be alleviated if family members have the PD and can determine whether the agent is following your wishes. Conversely, you may have reasons *not* to provide the document to those who are not your agent.

### **Recommendations for lawyers:**

- a. A very common misconception is that the PD (and the agent's authority) comes into effect upon execution. Under the PDA, the PD (or, any part of the PD, if it addresses multiple health and personal matters) comes into effect only when the maker lacks capacity with respect to that matter (s.9(1)). If your client wants support with present decision-making, discuss whether a Supported Decision-Making Authorization, which comes into effect immediately, is indicated.<sup>21</sup>
- b. If the maker is considering multiple agent(s):
  - i. Consider whether they will be able to work together.
  - ii. Specify whether they must act unanimously or whether any of them may act alone.<sup>12</sup>
  - iii. Where an agent(s) is given domain specific authority under s. 3 of the PDA, (e.g. Mona is given authority for health and Marlys is given authority for accommodation), make sure this is clearly spelled out.
  - iv. If your client wants to name an even number of agents, keep in mind that the PDA provides "majority rules" (s. 16(2)). State clearly how disagreements will

be resolved, for example: "If Joe and Jane don't agree, Joe has the final say" (s. 16(2)(c)). Otherwise, the dispute must be resolved through the court process which, for most personal decisions, is impractical, time-consuming and expensive.

- v. If the maker wants anyone to be notified when the PD comes into effect and of decisions being made, this should be stated in the PD, and the agent should be made aware of this instruction. Conversely, the PD can name those who should *not* be notified of the PD coming into effect. (s. 7(1)(c)).
  - vi. If there is someone whom the client wishes to play no role in their health care decisions, consider adding a paragraph stating that such individual is disqualified from participating in health care decisions.<sup>12</sup>
- c. Be aware that OPGT can't be named as an agent without their consent (s.7(4)(c)). Also, the OPGT can't be named as an alternate agent (s.7(4)(a)).
  - d. If visitation is important to the maker, include a clear statement directing the agent. The OPGT has identified a trend in complaints against agents for refusing visitation to family members.

## 2. Encourage your client to identify and discuss their values with their agent(s), loved ones and health care providers, and thoughtfully and comprehensively document these in their PD.

Often, makers focus on instructions about specific healthcare interventions, which may not be relevant to their current or future health condition and risk paralyzing those who are attempting to interpret them. Many now advocate for PDs to include detailed statements of the maker's values (a.k.a. "values directive") to illustrate key considerations for the maker's medical decision-making and to guide agents and HCPs in a range of possible but unforeseen health situations.

- a. Before discussing specific wishes, and especially in the case of clients who do not have a life-limiting condition or are relatively young, begin by asking your client about their values. Then, ask how they would like these values to be honoured in their future care. For example:
  - i. What matters most to you (or, what makes your life meaningful)?<sup>7</sup>
  - ii. What does living well look like to you?
  - iii. How do you define quality of life?
  - iv. What beliefs do you hold that might impact your medical decision-making? (e.g. religious beliefs)
  - v. What values do you hold that impact your medical decision-making? (e.g. value being able to be active, living at home with a partner)

- vi. What life circumstances would you find most unbearable?<sup>7</sup> (e.g. “I’d rather be dead than be in a permanent state where I’m unable to communicate, be mobile, and care for myself.”)
  - vii. What do you worry about most (or fear) when you think about your future health? (e.g. cognitive decline)<sup>7</sup>
  - viii. What are your favourite activities, events, routines or ceremonies? (e.g. being outdoors)
- b. High-quality resources to help lawyers elicit and document values are: the My Wishes Alberta workbook<sup>20</sup> and the Nova Scotia Personal Directives Reflection Guide<sup>9</sup> - which lists more than 100 words to inspire descriptions of values and beliefs and includes prompts to help identify fears, worries and what gives life meaning.
  - c. Use examples and illustrations. Where possible, use limits; phrase in terms of what is acceptable and not acceptable to your client.

Sample language:

*#1: If I'm faced with an incurable progressive disease, my main goals as my health deteriorates would be to be able to speak and think as clearly as possible and be with my family.*

*I want to be able to listen to music and watch movies. I fear loss of cognitive capacity.*

*I'm not afraid of loss of independence, but value my intellect; highly critical functions to preserve, if possible, would be my hearing and cognitive functioning. I am an introvert and enjoy time alone and time with my partner and immediate family and close friends.*

*I love music and the arts. I love a great movie.*

*I love to think about big ideas and come up with innovative solutions for the world's ills, especially for healthcare and medical education.*

*If, due to illness or injury, I am left with profound cognitive deficits and am no longer able to engage in complex thinking and debate, or I'm permanently not able to make medical decisions anymore, I would not want life-prolonging treatments in that condition.*

*I would prefer palliative care and allowing the natural progression of disease and dying.*

*#2: My greatest joy is spending time with my spouse, my kids and their families. Being with them often, at our homes and at our cabin, for celebrations, to visit, share food, play games, and laugh gives my life meaning. It would be very hard for me if my health condition or treatment permanently kept me from living with my spouse or seeing my family...*

*#3: My Christian spirituality and membership in my community church is one of the most important values in my life. I supremely enjoy worshipping, fellowship, serving in various volunteer roles (like our food insecurity program) and receiving Pastoral Care from my Minister. Although I believe life is sacred and a gift from God, I would not undergo all treatments to preserve life. Rather, I am content knowing that God will take me when it's*

*my time. I do not want to suffer, so I've discussed my goals of care with my doctor and feel a "comfort" designation most aligns with my goals...*

*#4: I'm a driven person. It's very important to me to be intellectually and physically well. It's a point of pride that I've been the chair of the board of the company that I founded for 50 years into my 90s. I am a voracious reader of anything related to business, including politics and world affairs. As well, I push myself to eat nutritiously and exercise appropriately so that I can remain vital and continue to play tennis and golf weekly. It would be unacceptable to me to be kept alive by machines, to lose the ability to move around and be outdoors, and to be unable to communicate. My granddaughter is very like-minded, and I've had many conversations with her about my values and wishes for health care. If I am unable to make health care decisions, I trust her to make decisions relating to my care and interpret my values and wishes to the specific situation and decide what is best for me. I do not want any others to provide direction or question her decisions...*

*#5 Dignity and Dependence: I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. To me, quality of life is more important than quantity of life, and this philosophy should guide you in making your decisions.*

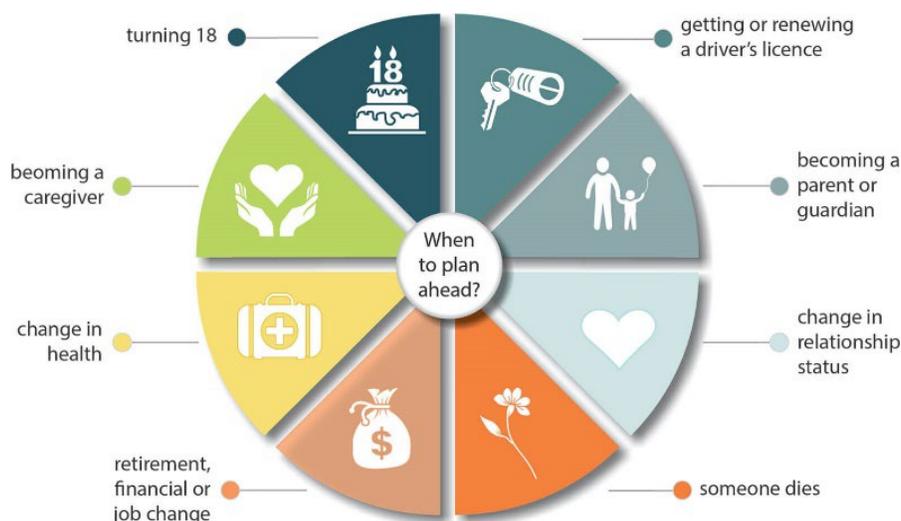
- d. Consider the audience. Those who may be seized with interpreting the PD are your client's agent(s), HCPs (s. 24(1) of PDA), and possibly the OPGT. What might be the circumstances when the PD comes into effect? For example, an HCP (who may not know your client) will want to know what they should understand about your client in order to give them the best possible care.
- e. Consider the limitations of subjective language. What might "maintain my independence" mean to different people? What about "don't want to become a burden to my family"? When possible, be descriptive and paint a picture rather than using words that can have different connotations or interpretations.
- f. Encourage your client to discuss their values and wishes for health care with family and friends who are not their agent(s). Having discussions ahead of time will alleviate tension between members of your client's "circle" when decisions need to be made and help them advocate for your client's wishes.

### 3. Facilitate active communication with your client's health care provider(s) to understand prognosis, possible interventions and to establish all parties' confidence in quality of ACP conversations and validity of PD.

As described in greater detail under "Guidance on drafting PDs" below, instructions about treatment are most effective when they are informed by discussions between the maker and their HCPs about their actual health condition and foreseeable trajectory. Also, research studies have found that physicians may be more likely to follow PDs - especially instructions that they do not agree with - if they have confidence that rigorous ACP conversations have occurred and

the maker has made informed choices.

- a. Advise your client to have a goals of care discussion with their provider and understand the role of a Goals of Care Designation order and Green Sleeve (Appendices C and D). The Government of Alberta, Alberta Health Services and Covenant Health Palliative Institute have various high-quality resources that prepare patients to have high-quality conversations:
  - [MyHealth Alberta: Advance Care Planning](#)
  - [Alberta Health Services: Advance Care Planning](#)
  - [Palliative Institute: Advance Care Planning](#)
- b. Especially for makers who do not have a life-limiting diagnosis and are relatively young, encourage them to talk to their HCP about the reasonableness of predicting future wishes about specific limitations and treatments. It is possible, when presented with a specific diagnosis, medical event and limitations, they will feel differently about what is acceptable and not acceptable. For example, some PDs state that the maker does not want pain medication, however, later in life they may want relief from extreme pain.
- c. Recommend revisiting ACP with their HCP and lawyers upon certain events (e.g. the "Six "Ds"<sup>6</sup>):
  - i. You reach a new DECADE in your age;
  - ii. You experience a DEATH of a loved one;
  - iii. You experience a DIVORCE;
  - iv. You receive a DIAGNOSIS of a significant health condition;
  - v. You experience a significant DECLINE in your functional condition; or
  - vi. You change your DOMICILE or someone moves in with you.
- d. The following figure similarly reminds individuals to update ACP upon certain life events.<sup>22</sup>



- e. With your client's consent, send their physician a copy of the PD and advise them about ACP discussions. Provide a short summary of the relevant legislation to address potential uncertainty about the PD's validity, operation and role. Finally, invite updates (e.g. upon new GCD, PD or changes to health).

Sample letter from lawyer to physician<sup>6</sup>:

*I am enclosing a Personal Directive (PD) signed by my client and your patient, Mr. Gerald McCormick. Mr. McCormick has consented to our offices communicating about his PD to ensure his advance care planning is accurately communicated and documented and increase the likelihood that it is ultimately honoured. Although we started advance care planning in my office, your role in explaining Mr. McCormick's conditions, care and treatment options is an important element for this ongoing, shared decision-making process. At the next office visit, please consider discussing and documenting his wishes as well as including his PD in the medical record...If, upon further discussion, you believe that Mr. McCormick's wishes do not match the declarations in the PD, please notify him and our office. If you complete an updated PD or GCD, please consider forwarding a copy to our office...*

## 4. Guidance on drafting PDs

- a. Ensure the PD revokes all previous PDs.
- b. Clear and concise PDs are preferred by physicians, especially considering that they may come into effect in a health emergency.<sup>6</sup>
- c. To address potential concerns and confusion about a PD's validity and when and how it comes into effect, clearly label it as "Personal Directive of [maker's name]." Consider attaching a brief summary of the relevant sections of the PDA (e.g. s. 9 Bringing personal directive into effect, s.11 Effect of agent's decisions and s.4 Agent's authority).<sup>4,10</sup>
- d. Physicians are hesitant to rely on a PD that is not recent, especially if there has been a new diagnosis or change in health circumstances. Given PDs are often done as part of an estate planning package, which might deter updating, consider offering to update existing clients' PDs as a piecemeal (i.e. "bang trim") service.<sup>6,10</sup>
- e. Include explanations of the personal context for wishes, especially if they are "unusual" or risk being interpreted as unreasonable or futile (e.g. "based on my previous treatment...", "having witnessed the pain and suffering of my husband..."). Physicians are more likely to honour wishes if they understand the reason or experience behind a preference.<sup>10</sup>
- f. Physicians are wary of following PDs that are not informed by and tailored to the patient's health condition.<sup>4,6,10,23</sup> When the PD includes specific instructions about treatment, ensure it is informed by the individual's health context. Ask: *What medical diagnoses do you have? What has your healthcare provider(s) shared with you about possible medical decisions that will need to be made in the future? Are there any treatment options that you have already thought about and know that you would never want in the context of your medical diagnosis?*

Sample precedent:

*I have ALS. I have talked to my doctors and my specialist, and I know that I very likely will lose my ability to swallow in the near future and may even lose my ability to breathe on my own. I don't want any support for artificial nutrition, nor do I want invasive ventilation.*

- g. Physicians and agents struggle to apply specific medical instructions that are based on hypothetical health situations. The following table illustrates the difficulty with applying legalistic language and decontextualized instructions to specific health conditions and limitations.

Language		Analysis from health care provider and/or OPGT
<i>"No drastic measures"</i>		Unclear. OPGT continues to see this language in PDs.
<i>"No life support by artificial means under any circumstances"</i>		No context; suggests individual has not considered different future situations; open to misinterpretation. Has this individual contemplated how this would apply to an event that they would survive with reasonable quality of life? Agents have interpreted this instruction to deny pain medication.
<i>"If I am not expected to recover to my previous level of function, independence and cognition..."</i>		Too vague. It would be more helpful if the wording were more definitive and descriptive of what that condition looks like i.e., minimally conscious state, or unresponsive wakefulness syndrome. Even so, the challenge is with all the gradations in between. This is why hypotheticals are so challenging. Best to ask the maker/patient what functions are critical to them to consider as decent quality of life.
<i>"Prolonging my life would be unacceptable to me if..."</i>	<i>...I am not able to communicate with my family and friends."</i>	In general, expressing wishes in terms of limits (or, what is acceptable and unacceptable), is relatively helpful. However, the realities (and nuances) of various conditions and treatments might still lead to uncertainty about what the maker intended in a specific situation. Does this mean simply not being able to talk? What about sign language or other forms of communication? What about aphasia when they can't communicate but have full understanding?
	<i>...I no longer have control of bodily functions."</i>	What if this statement is made in the PD of a 20-year-old who is in an accident resulting in quadriplegia?
	<i>...I am kept alive with machines but with no chance of survival if I am taken off the machines."</i>	Better
	<i>...I am declared brain dead and my primary organs may or may not be substantially affected."</i>	Better

<p><i>"If my health condition worsened in a way that my recovery is not expected..."</i></p>	<p>Difficult to interpret "recovery is not expected." Recovery to what level?</p>
<p><i>"If there is some hope that I will recover from my illness or injury such that my quality of life is not severely compromised..."</i></p>	<p>As above, "recover" and "quality of life is not severely compromised" might mean something very different to different people. Knowing more about the maker's values and beliefs would help readers understand what might be acceptable impacts on quality of life. Also, any illustration of a hierarchy of values or trade-offs might be helpful, e.g. <i>"I'd be willing to continue life-prolonging treatments even if I can no longer provide myself with personal care, as long as my cognitive ability remains intact so that I can converse, process emotions and reflect."</i></p>

h. It is helpful to distinguish between your client's wishes in circumstances of:

- i. serious illness; and
- ii. terminal illness or chronic illness when end of life is imminent.

Sample clauses:

1. *Serious illness*

1.1. *I direct my Agent to consider the following when making decisions in circumstances where I am seriously ill and I may die or I may recover:*

- 1.1.1. *I want access to all diagnostic and therapeutic treatments which are designed to improve my condition and may assist me to regain the capacity to make my own decisions.*
- 1.1.2. *I direct my Agent to make personal and medical decisions on my behalf having regard to the provisions herein and any more current similar writing(s) I have made after the date hereof setting out my personal wishes, beliefs and values regarding my personal and medical decisions.*
- 1.1.3. *When making decisions concerning life-sustaining treatment, I wish the following factors to be taken into account: the relief of suffering, the potential to restore functioning, the quality of my life, and the realistic extension of my life.*

2. *Terminal or end-of-life care*

2.1. *I direct my Agent to consider the following when making decisions in circumstances where I have been diagnosed with a terminal illness or a chronic illness and my end of life is imminent:*

- 2.1.1. *I do not want to receive treatments that artificially maintain a life-sustaining function of my body and are used only to prolong my life without improving the chances for cure or reversal of my condition.*

*I want comfort measures only, including surgery if needed, to relieve symptoms. I want the illness or conditions to be treated for relief of pain and distress, not to prolong life.*

2.1.2. *I do not want my Agent to prolong my life at all costs. I hereby give authorization for the withholding or withdrawal of treatment if my physicians and my Agent determine that my death is imminent with no reasonable medical expectation of recovery whether or not life-sustaining procedures are utilized. In these circumstances I also do not want to receive cardiopulmonary resuscitation.*

2.1.3. *I request that I receive comfort and care that relieves pain or distress, including palliative sedation. In case of severe pain, I request that drugs be mercifully administered to relieve pain.*

- i. If your client trusts their agent, draft in a way that gives the agent discretion to make the best decision at the relevant time. A document that is overly specific about how to act in certain circumstances may tie the agent's hands in making the decision that is truly most consistent with the client's wishes. If the PD specifies the client's health care preferences in certain circumstances, consider also including language giving the agent authority to override those specifications at the time of decision if the agent believes that doing so would be most consistent with the maker's best interests.<sup>12</sup>

Sample language:

*When making decisions concerning life-sustaining treatment, I wish the following factors to be taken into account: the relief of suffering, the potential to restore functioning, the quality of my life, and the realistic extension of my life.*

*I recognize that I cannot foresee everything that might happen or all options that may be available when I am incapable of making medical decisions for myself. My preferences stated in this [Section reference] are meant to guide my Agent and my health care providers in making decisions on my behalf. It is my intent that my Agent and my health care providers follow my stated preferences if my Agent and my health care providers believe that doing so is in my best interest, but my Agent shall have the discretion to make the decisions that my Agent believes to be in my best interest at the relevant time regardless of what is otherwise stated in this [Section reference].<sup>12</sup>*

*If this Personal Directive does not contain clear instructions that are relevant to the decision to be made, I direct my Agent to make the decision that my Agent believes I would have made in the circumstances, based on my Agent's knowledge of my wishes, beliefs and values. If my Agent does not know what my wishes, beliefs and values are in respect of such decision, I direct my Agent to make the decision that my Agent believes in the circumstances is in my best interests.*

- j. Anticipate that agent/family/loved ones may oppose wishes.<sup>10</sup> Consider adding a clause stating, "regardless of disagreement or opposition from my family, I still want my wishes to be carried out..." Include language that communicates to agent(s) and others that the maker has had fulsome conversations with HCPs.

- k. Anticipate physician may be inclined to apply clinical judgment and “best interest” approach to override wishes, especially if the maker’s instruction is, in their opinion, “unreasonable” or “unusual” (e.g. your client is a Jehovah’s Witness and has a religious objection to receiving a blood transfusion).<sup>10</sup> If the client has strong convictions and believes there is some risk that their agent/provider will have a different view of the maker’s best interest, consider using language addressing this and mandating the maker’s written wishes be followed.

Sample precedent clauses:

*Despite my age, co-morbidities, prognosis, likelihood of reversing the health situation...*

*It is my desire that my Agent and my health care providers follow my preferences stated in this [Section reference] exactly as written, even if my Agent and/or my health care provider believes that some alternative is better.<sup>12</sup>*

- l. As noted elsewhere, include language to demonstrate to physician(s) that rigorous ACP took place, especially if physicians might believe the patient’s treatment preferences are not in line with a reasonable medical course of action. Depending on the specific circumstances (e.g. maker’s ACP is informed by a recent life-limiting diagnosis), consider referring to discussions about goals of care that have occurred, specific GCDs, and tracing the definition of the specific designation they have chosen in conversation with their HCP (e.g. A “C1” designation is described as “...”).

Sample language:

*Based on ongoing and formal discussions with my physicians about my health, which I understand, and about my goals of care...*

## 5. Guidance on storing PDs

- a. As noted above, counsel your client to provide a copy of the PD and other ACP documents to their agent(s), HCPs and anyone else whom they want to be informed.<sup>4,10</sup>
- b. Advise clients to obtain a Green Sleeve, take it with them to medical appointments and store where their agent(s) and any emergency responders will be able to locate it.
- c. Advise clients to upload their PD to their electronic health records at [MyHealth Records](#).

## 6. Client interviews

The OPGT often receives calls and complaints when one family member takes the maker to a lawyer and a new PD is executed with that member appointed as agent, without the knowledge of the agent(s) named in the current PD. Others in the family allege that the maker did not have the capacity or was coerced.

The mental capacity to make a PD is relatively low. The maker must understand:

- their agent will make decisions about healthcare, where they will live, who can visit, and the programs they will participate in;

- the reasonably foreseeable consequences of appointing an agent; and
- that they can revoke the appointment as long as they have capacity.

Where there are competing PDs, or frequent revisions to PDs, there is often a combination of some mental decline as well as influence that may rise to the level of undue influence. It is difficult for HCPs to navigate this conflict, and determining capacity and influence issues are often impractical, time-consuming and expensive to engage the legal system.

Lawyers should follow optimal client interview techniques and exercise a healthy amount of suspicion when an adult child brings their aging parent in to sign a new PD appointing a different agent without a reasonable explanation for the change.

# Recommended Resources

## For clients:

1. My Wishes Alberta workbook (available in English, French, Arabic, Punjabi and Spanish):
  - a. [Electronic version](#)
  - b. [Print version](#)
2. [MyHealth Alberta: Advance Care Planning](#)  
Information and tools about ACP, Green Sleeves, GCDs and PDs
3. [Alberta Health Services: Advance Care Planning/Goals of Care](#)  
Videos, Conversations Matter guidebook in seven languages, ACP education sessions (on-line and in-person), and information about ACP, GCDs, and Green Sleeves
4. [Centre for Public Legal Education: Planning for Future Care](#)  
Guides for the public on being an agent, PDs and guardianship
5. [The Nova Scotia Personal Directives Reflection Guide](#). The Legal Information Society of Nova Scotia, 2023.

## For agents:

1. [Being an Agent](#). Centre for Public Legal Education Alberta, June 2025.

## For lawyers:

1. [Living Well, Planning Well: An Advance Care Planning Resource for Lawyers](#). Canadian Hospice Palliative Care Association, 2021.  
This 12-page guide for lawyers contains conversation starters; information on ACP, palliative care, CPR success rates and the “Life Planning Model”; questions to help clients select substitute decision-maker(s); questions to elicit values; sample precedent language, summary report form for SDM(s) and list of resources.
2. [Advance Care Planning in Canada: A Pan-Canadian Framework](#). Canadian Hospice Palliative Care Association, January 2020.
3. [Advance Directives: Counseling Guide for Lawyers](#). Commission on Law and Aging, American Bar Association, 2018.
4. [National Framework for Advance Care Planning Documents](#). Department of Health, Australian Government, May 2021.

# References

- <sup>1</sup> Dr. Charlie Chen, Palliative Care Physician Consultant and Medical Lead - Advance Care Planning and Goals of Care, Calgary Zone, Alberta Health Services; Shelly Chamaschuk, Partner, Reynolds Mirth Richards & Farmer LLP; Sara O’Dea, Executive Director and Melanie Blackwell, Capacity Assessment Policy Analyst and Complaints Officer, Office of the Public Guardian and Trustee; Sheila Killoran and Danica Hans, Education Leads, Covenant Health Palliative Institute; Jennifer Zelmer and Corinne Spronken, Education Consultants, Advance Care Planning and Goals of Care, Calgary Zone, Alberta Health Services.
- <sup>2</sup> [Advance Care Planning and Goals of Care Designation Policy](#), HCS-38, Alberta Health Services, effective date April 01, 2014, revised August 16, 2016; and [Advance Care Planning and Goals of Care Designation Procedure](#), HCS-38-01, Alberta Health Services, effective date April 1, 2014, revised May 18, 2018.
- <sup>3</sup> [Advance Care Planning in Canada: A Pan-Canadian Framework](#). Canadian Hospice Palliative Care Association, January 2020.
- <sup>4</sup> [National Framework for Advance Care Planning Documents](#). Department of Health, Australian Government, May 2021.
- <sup>5</sup> Alberta Joint Practice Principles on Advance Care Planning. Covenant Health Palliative Institute, 2023.
- <sup>6</sup> [Advance Directives: Counseling Guide for Lawyers](#). Commission on Law and Aging, American Bar Association, 2018.
- <sup>7</sup> [Living Well, Planning Well: An Advance Care Planning Resource for Lawyers](#). Canadian Hospice and Palliative Care Association, 2021, 12.
- <sup>8</sup> [Being an Agent](#). Centre for Public Legal Education Alberta, June 2025.
- <sup>9</sup> [The Nova Scotia Personal Directives Reflection Guide](#). The Legal Information Society of Nova Scotia, 2023.
- <sup>10</sup> Moore N, Detering KM, Low T, Nolte N, Fraser S, Sellars M. [Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study](#). BMJ Open 2019; 9(10): e032638.
- <sup>11</sup> Hooper S, Sabatino CP, Sudore RL. [Improving Medical-Legal Advance Care Planning](#). Journal of Pain and Symptom Management 2020; 60(2): 487-494.
- <sup>12</sup> Clapp AR, Lanzel AF. [Advance Directives Drafting and Implementation](#). American Bar Association, 2023.
- <sup>13</sup> Ries NM, Douglas M, Simon J, Fassbender K. [Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs](#). Healthcare Policy 2016; 12(2): 12-18.
- <sup>14</sup> Ries N, Douglas ML, Simon J, Fassbender K. [How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta](#). Alberta Law Review 2018; 55(3): 683-701.
- <sup>15</sup> Hickman SE, Lunn HD, Walling AM, Savoy A, Sudore RL. [The Care Planning Umbrella: The Evolution of Advance Care Planning](#). Journal of the American Geriatrics Society 2023; 71(7): 2350-2356.
- <sup>16</sup> [Advance Care Planning: Make a Plan in 5 Steps](#). MyHealth Alberta.
- <sup>17</sup> McMahan RD, Tellez I., Sudore RL. [Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review](#). Journal of the American Geriatrics Society 2021; 69(1): 234-244.

<sup>18</sup> [Albertans' Views on Advance Care Planning and Palliative Care: Public Poll Report](#). Covenant Health Palliative Institute, 2024.

<sup>19</sup> Canadian Bar Association, Alberta sections of Elder Law, Health Law, and Wills, Estates and Trusts; Alberta Health Services Palliative Care Grand Rounds, Provincial ACP GCD Community of Practice and Provincial Palliative and End-of-Life Care team.

<sup>20</sup> [My Wishes Alberta workbook](#). Covenant Health Palliative Institute.

<sup>21</sup> [Supported Decision-Making](#). Government of Alberta.

<sup>22</sup> [Advance Care Planning](#). Covenant Health Palliative Institute.

<sup>23</sup> Periyakoil VS, Gunten CFV, Arnold R, Hickman S, Morrison S, Sudore R. [Caught in a Loop with Advance Care Planning and Advance Directives: How to Move Forward?](#) Journal of Palliative Medicine 2022; 25(3): 355-360.



# Appendices

- A. Advance Care Planning and Goals of Care Designation Policy, HCS-38, Alberta Health Services, effective date April 01, 2014, revised August 16, 2016.
- B. Advance Care Planning and Goals of Care Designation Procedure, HCS-38-01, Alberta Health Services, effective date April 1, 2014, revised May 18, 2018.
- C. Goals of Care Designation Order, Form #103547, Alberta Health Services, revised April 2025.
- D. Advance Care Planning/Goals of Care Designation Tracking Record, Form #103152, Alberta Health Services, revised June 2018.

## TITLE

**ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION****SCOPE**

Provincial

## DOCUMENT #

HCS-38

## APPROVAL AUTHORITY

COEC

## INITIAL EFFECTIVE DATE

April 01, 2014

## SPONSOR

Seniors Health

## REVISION EFFECTIVE DATE

August 16, 2016

## PARENT DOCUMENT TITLE, TYPE AND NUMBER

Not Applicable

## SCHEDULED REVIEW DATE

August 16, 2019

**NOTE:** The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

If you have any questions or comments regarding the information in this document, please contact the Policy & Forms Department at [policy@ahs.ca](mailto:policy@ahs.ca). The Policy & Forms website is the official source of current approved policies, procedures, directives, standards, protocols and guidelines.

**OBJECTIVES**

- To guide **health care professionals, patients** and **alternate decision-makers** regarding the general intentions of clinically indicated health care, specific interventions, and the service locations where such care will be provided.
- To provide guidance for health care professionals to assist in rapid decision-making in the clinical environment.

**PRINCIPLES**

- Alberta Health Services respects human dignity by providing care that is clinically indicated and ethically appropriate and seeks to understand patient values regarding care provision.
- Within Alberta Health Services, **Advance Care Planning** will be the process by which health care professionals and patients and/or alternate decision-makers consider the clinically indicated future care for a patient. These conversations allow for respectful understanding of patient's wishes concerning general care focus as well as initiation, continuation and limits of specific interventions. This process will include communication between health care professionals, patients and when appropriate, alternate decision-makers.
- **Goals of Care Designations** (R-M-C) are the mechanisms by which health care professionals describe and communicate the general focus of care for a patient.
- Goals of Care Designations include direction about the general focus of care and some specific actions within that focus of care.
- Goals of Care Designations incorporate the values and wishes of a patient, as well as guide medically indicated interventions in service of those values and wishes.

## APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

## ELEMENTS

Detailed descriptions of Goals of Care Designations, and important clinical features embedded in them, are included in Appendix A: *Goals of Care Designations* of this policy.

### 1. Advance Care Planning and Goals of Care Designations

- 1.1 All adults should be given the opportunity to participate in Advance Care Planning as a part of routine care, started early in a longitudinal relationship with a healthcare provider and revisited when the health or wishes of an adult changes.
- 1.2 Goals of Care Designations shall be utilized throughout Alberta Health Services to establish and communicate general care directions, locations of care and transfer opportunities for current and future care for patients.
- 1.3 A **Goals of Care Designation order** is prescriptive but is also subject to clinical judgement of the current **most responsible health practitioner**.
- 1.4 Any member of a patient's health care team may initiate and undertake an Advance Care Planning and or Goals of Care Designation conversation. However, the most responsible health practitioner is ultimately responsible for ensuring that a clinically indicated Goals of Care Designation order has been discussed, established and documented.
  - a) It is understood that the patient and/or alternate-decision maker shall be engaged in all related discussions and decisions.
  - b) While conversation with the patient and/or alternate decision-maker are crucial, the Goals of Care Designation order form itself is a medical order and, as such, does not require a patient or alternate decision-maker's signature.
- 1.5 Once a Goals of Care Designation conversation has been held and if clinically indicated, a Goals of Care Designation order shall be created by the most responsible health practitioner and documented in the *Advance Care Planning/Goals of Care Designation Tracking Record*.
- 1.6 Reviewing, validating or altering a Goals of Care Designation order occurs (in conjunction with the patient):
  - a) when new circumstances or health issues arise;
  - b) when patients are accepted into a new location of care;

- c) at the request of the patient or alternate decision-maker; and/or
  - d) if the patient and/or alternate decision-maker disagrees with the designation.
- 1.7 All patients and all alternate decision-makers (when applicable) shall be made aware of Advance Care Planning and the Goals of Care Designation structure.
- 1.8 Where a Goals of Care Designation has been ordered, patients or their alternate decision-makers should be made aware of their specific Goals of Care Designation.
- In a situation where it is determined that providing such information may negatively impact the health or safety of the patient, it may not be appropriate to inform the patient of his/her Goals of Care Designation. In this case, it is recommended that the most responsible health practitioner consider consulting with, but not limited to:
- a) colleagues;
  - b) Clinical Ethics Service;
  - c) College of Physicians and Surgeons of Alberta;
  - d) Canadian Medical Protective Association; and/or,
  - e) Clinical and Regulatory Team.
- 1.9 If a patient's most responsible health practitioner changes, the previous Goals of Care Designation order remains applicable unless changed by the new most responsible health practitioner.
- 1.10 When a Goals of Care Designation is not documented on a patient's **health record**, then clinically appropriate **life support interventions** are provided if required. If it is known that the adult patient or alternate decision-maker has previously expressed the refusal of such interventions that refusal should be followed except in unusual circumstances where it would be clinically and ethically inappropriate to do so.
- 1.11 Where the patient and/or alternate decision-maker and the most responsible health practitioner disagree on a Goals of Care Designation, a dispute resolution process will be invoked (refer to *Alberta Health Services Advance Care Planning and Goals of Care Designation Procedure*).

## DEFINITIONS

**Advance Care Planning** means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their alternate decision-maker and their health care team; and record those choices.

**Alternate decision-maker** means a person who is authorized to make decisions with or on behalf of the patient. These may include: a minor's legal representative, a guardian, a 'nearest relative' in accordance with the *Mental Health Act*, an agent in accordance with a personal directive, a co-decision-maker, a specific decision-maker or a person designated in accordance with the *Human Tissue and Organ Donation Act*.

**Goals of Care Designation** means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker.

**Goals of Care Designation order** means the documented order for the goals of care designation as written by the most responsible health practitioner (or designate).

**Health care professional** means an individual who is a member of a regulated health discipline, as defined by the *Health Disciplines Act* or the *Health Professions Act*, and who practices within scope or role.

**Health record** means the Alberta Health Services legal record of the patient's diagnostic, treatment and care information.

**Life support interventions** means interventions typically undertaken in the Intensive Care Unit but which occasionally are performed in other locations in an attempt to restore normal physiology. These may include chest compressions, mechanical ventilation, defibrillation and physiological support.

**Most responsible health practitioner** means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s) within the scope of his/her practice.

**Patient** means an adult or child who receives or has requested health care or services from Alberta Health Services and its health care providers or individuals authorized to act on behalf of Alberta Health Services. This term is inclusive of residents, clients and outpatients.

## REFERENCES

- Appendix A: *Goals of Care Designations*
- Alberta Health Services Governance Documents:
  - *Advanced Care Planning and Goals of Care Designation Procedure* (#HCS-38-01)
  - *Consent to Treatment/Procedure(s) Policy suite* (#PRR-01)
  - *Dispute Prevention & Resolution in Critical Care Settings Policy suite* (#PRR-03)
- Alberta Health Services Forms:
  - *Advance Care Planning/Goals of Care Designation Tracking Record* (#103152)

TITLE  
**ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION**

EFFECTIVE DATE  
**August 16, 2016**

DOCUMENT #  
**HCS-38**

**VERSION HISTORY**

<b>Date</b>	<b>Action Taken</b>
August 16, 2016	Revised

## APPENDIX A

## Goals of Care Designations

The Goals of Care Designation order provides direction regarding specific health interventions, transfer decisions, locations of care, and limitations on interventions for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker where appropriate.

<p><b><u>R</u></b></p> <p><b>Medical Care and Interventions, Including Resuscitation</b></p>	<p><b><u>R - May intervene with medical care, including Resuscitative Care if required</u></b></p> <p><b>Goals of Care:</b> directed at cure or control of a patient's condition. The patient would desire ICU care if it was required, and would benefit from ICU if their medical condition warranted it.</p> <p><b>R1 = Medical Care including ICU admission if required, with intubation and chest compressions</b></p> <p>Goals of care are directed at cure or control of a patient's condition. Treatment of illness may include transfer to an acute or tertiary care facility with admission to the ICU if indicated. Intubation or chest compression may be provided.</p> <p><b><u>GUIDE:</u></b></p> <p><b>i) General guidelines</b> – this designation is for patients who would benefit from, and are accepting of, any appropriate investigations and interventions that the health system can offer, including physiological support in an ICU setting if required. All appropriate supportive therapies are offered, including intubation. Chest compressions and intubation are performed during a resuscitative effort when clinically indicated.</p> <p><b>ii) Resuscitation</b> – is undertaken for cardio respiratory arrest or acute deterioration.</p> <p><b>iii) Life Support Interventions</b> – are usually undertaken</p> <p><b>iv) Life Sustaining Measures</b> – are used when appropriate within overall goals of care.</p> <p><b>v) Major surgery</b> – is considered when appropriate. The possibility of intra-operative complications including death and the requirement for physiological support post operatively should be addressed with the patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</p> <p><b>vi) Transfer</b> from current location of care – is considered if an alternative location is required for diagnosis and treatment.</p>
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<p style="text-align: center;"><b>R</b></p> <p style="text-align: center;"><b>Medical Care and Interventions, Including Resuscitation</b></p>	<p><b>R2 = Medical Care including ICU admission if required, with intubation but without chest compressions</b></p> <p>Goals of care are directed at cure or control of a patient's condition. Treatment of illness may include transfer to an acute or tertiary care facility with admission to the ICU if required. Intubation can be considered when indicated but chest compressions are not performed.</p> <p><u>GUIDE:</u></p> <ul style="list-style-type: none"> <li><b>i) General guidelines</b> – this designation is for patients who would benefit from, and are accepting of, any appropriate investigations and interventions that the health system can offer, including physiological support in an ICU setting if required, but excluding chest compressions.</li> <li><b>ii) Resuscitation</b> - is undertaken for acute deterioration, but chest compressions should not be performed.</li> <li><b>iii) Life Support Interventions</b> – may be offered, without chest compressions.</li> <li><b>iv) Life Sustaining Measures</b> – are used when appropriate within overall goals of care.</li> <li><b>v) Major surgery</b> – is considered when appropriate. The possibility of intra-operative complications including death and the requirement for physiological support post operatively should be addressed with patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li><b>vi) Transfer</b> from current location of care – is considered if an alternative location is required for diagnosis and treatment.</li> </ul>
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<p style="text-align: center;"><b><u>R</u></b></p> <p style="text-align: center;"><b>Medical Care and Interventions, Including Resuscitation</b></p>	<p><b>R3 = Medical Care including ICU admission if required, without intubation or chest compressions</b></p> <p>Goals of care are directed at cure or control of a patient's condition. Treatment of illness may include transfer to an acute or tertiary care facility with admission to the ICU if required, but chest compressions or intubation should not be performed.</p> <p><b>GUIDE:</b></p> <ul style="list-style-type: none"> <li><b>i) General guidelines</b> – this designation is for patients who would benefit from, and are accepting of, any appropriate investigations and interventions that the health system can offer, including physiological support in an ICU setting if required, but excluding intubation and chest compressions.</li> <li><b>ii) Resuscitation</b> -is to be undertaken for acute deterioration but chest compressions or intubation should not be performed.</li> <li><b>iii) Life Support Interventions</b> - may be offered without intubation or chest compressions.</li> <li><b>iv) Life Sustaining Measures</b> – are used when appropriate within overall goals of care.</li> <li><b>v) Major surgery</b> – is considered when appropriate. The possibility of intra-operative complications including death and the requirement for physiological support post operatively should be addressed with patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li><b>vi) Transfer</b> from current location of care – is considered if an alternative location is required for diagnosis and treatment.</li> </ul>
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<p style="text-align: center;"><b><u>M</u></b></p> <p style="text-align: center;"><b><u>Medical Care and Interventions, Excluding Resuscitation</u></b></p>	<p><b><u>M - May intervene with medical care, excluding tertiary level ICU</u></b></p> <p><b>Goals of care:</b> directed at cure or control of a patient's condition. These patients either choose to not receive care in an ICU or would not benefit from ICU care.</p> <p><b>M1 = Medical care with transfer to Acute care when required and without the option for life-saving ICU care</b></p> <p>The goals of care are aimed at cure or control in any location of care, without accessing a tertiary level ICU. Treatment of illness may include transfer to an acute or tertiary care facility without admission to a tertiary level ICU.</p> <p><b><u>GUIDE:</u></b></p> <ul style="list-style-type: none"> <li><b>i) General guidelines</b> – all active medical and surgical interventions aimed at cure and control of conditions are considered, within the bounds of what is clinically indicated, and excluding the option of admission to a tertiary level ICU for life-saving interventions. If a person deteriorates further and is no longer amenable to cure or control interventions, the goals of care designation should be changed to focus on comfort primarily.</li> <li><b>ii) Resuscitation</b> – is not undertaken for cardio respiratory arrest.</li> <li><b>iii) Life Support Interventions</b> – should not be initiated, or should be discontinued after discussion with patient or alternate decision- maker.</li> <li><b>iv) Life Sustaining Measures</b> – are used when appropriate within overall Goals of Care.</li> <li><b>v) Major surgery</b> – is considered when appropriate. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li><b>vi) Transfer</b> to another location of care – is considered if that location provides more appropriate circumstances for necessary diagnosis and treatment.</li> </ul>
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<p style="text-align: center;"><b><u>M</u></b></p> <p style="text-align: center;"><b><u>Medical Care and Interventions, Excluding Resuscitation</u></b></p>	<p><b>M2 = Medical care without transfer to Acute care and without the option for life-saving ICU care</b></p> <p>The goals of care are aimed at cure or control, almost always within the patient's current care environment. Treatment of illness may be undertaken in the current location without transfer to acute or tertiary care should that condition deteriorate.</p> <p><b>GUIDE:</b></p> <ul style="list-style-type: none"> <li><b>i) General guidelines</b> – all interventions that can be offered in the current location of care are considered. If a person deteriorates further and is no longer amenable to cure or control interventions in that location, the goals of care designation should be changed to focus on comfort primarily.</li> <li><b>ii) Resuscitation</b> – is not undertaken for cardio respiratory arrest or acute deterioration.</li> <li><b>iii) Life Support Interventions</b> – should not be initiated or should be discontinued after discussion with patient.</li> <li><b>iv) Life Sustaining Measures</b> – are used when appropriate within overall goals of care.</li> <li><b>v) Major surgery</b> – is not usually undertaken, but can be contemplated for procedures aimed at symptom relief. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with the patient/family in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li><b>vi) Transfer</b> to another location of care – is not usually undertaken, but can be contemplated if symptom management or diagnostic efforts aimed at understanding symptoms can best be undertaken at that other location.</li> </ul>
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<p style="text-align: center;"><u>C</u></p> <p style="text-align: center;"><b>Medical Care and Interventions, Focused on <u>C</u>omfort</b></p>	<p><b><u>C - Provide comfort care</u></b></p> <p><b>Goals of care:</b> directed at symptom control rather than at cure or control of a patient's underlying condition that is expected to result in death. All interventions are for symptom relief.</p> <p><b>C1 = Symptom Comfort Care</b></p> <p>Goals of care are for maximal symptom control and maintenance of function, without cure or control of the underlying condition. A diagnosis exists which is expected to cause eventual death.</p> <p><b><u>GUIDE:</u></b></p> <ul style="list-style-type: none"> <li><b>i) General guidelines</b> – A diagnosis exists which is expected to cause eventual death. New illnesses are not generally treated unless control of symptoms is the goal.</li> <li><b>ii) Resuscitation</b> – is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.</li> <li><b>iii) Life Support Interventions</b> - should not be initiated, or should be discontinued after discussion.</li> <li><b>iv) Life Sustaining Measures</b> – can be used for goal directed symptom management.</li> <li><b>v) Major Surgery</b> – is not usually undertaken, but can be contemplated for procedures aimed at symptom relief. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with the patient/family in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li><b>vi) Transfer-</b> should be contemplated if symptom management or diagnostic efforts aimed at understanding symptoms can best be undertaken at another location. Transfer to an ICU is warranted if ICU is deemed to be the best location for palliation, especially in the Pediatric environment.</li> </ul>
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<p style="text-align: center;"><u>C</u></p> <p style="text-align: center;"><b>Medical Care and Interventions, Focused on <u>C</u>omfort</b></p>	<p><b>C2 = Terminal care</b></p> <p>Goals of care are aimed at preparation for imminent death (usually within hours or days), with maximal efforts directed at symptom control.</p> <p><u>GUIDE:</u></p> <ul style="list-style-type: none"> <li>i) <b>General guidelines</b> – expert terminal care can be provided in any location.</li> <li>ii) <b>Resuscitation</b> – is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.</li> <li>iii) <b>Life Support Interventions</b> – should not be initiated, or should be discontinued after discussion.</li> <li>iv) <b>Life Sustaining Measures</b> – should be discontinued unless required for goal directed symptom management.</li> <li>v) <b>Major Surgery</b> – is not appropriate.</li> <li>vi) <b>Transfer</b> to another site is usually not undertaken due to risk of death during transport.</li> </ul>
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TITLE

**ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION**

SCOPE

Provincial

DOCUMENT #

HCS-38-01

APPROVAL AUTHORITY

Clinical Operations Executive Committee

INITIAL EFFECTIVE DATE

April 01, 2014

SPONSOR

Seniors Health

REVISION EFFECTIVE DATE

May 18, 2018

PARENT DOCUMENT TITLE, TYPE AND NUMBER

Not Applicable

SCHEDULED REVIEW DATE

August 16, 2019

**NOTE:** The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

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## OBJECTIVES

- To standardize the process for determination of **Goals of Care Designations**.
- To standardize the process for documentation of Goals of Care Designations and **Advance Care Planning**.
- To enhance and promote communication of advance care planning and **goals of care** decisions.
- To identify the process(s) that will be followed in cases of dispute in the determination of Goals of Care Designations.

## APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

## ELEMENTS

### 1. Advance Care Planning conversations

- 1.1 All adults who have **capacity** should be given the opportunity to participate in Advance Care Planning as a part of routine care, started early in a longitudinal relationship with a healthcare provider and revisited when the health or wishes of an adult changes.
- 1.2 Any member of a **patient's** health care team may initiate and undertake an Advance Care Planning conversation. In collaboration with other members of the

health care team, the **most responsible health practitioner** (or designate) should ensure that advance care planning conversations include the steps involved in Advance Care Planning:

- a) Think about – think about your values and wishes;
- b) Learn – learn about your own health;
- c) Choose – Choose someone to make decisions and speak on your behalf;
- d) Communicate – Communicate your wishes and values about healthcare; and
- e) Document – Document your plan in a **personal directive**.

1.3 Patient wishes and values may change over time or with changes in their health; it is important to keep the conversation open and to discuss these changes.

## 2. Goals of Care Conversations

2.1 Goals of care conversations shall take place, where clinically indicated with the patient, as early as possible in a patient's course of care and/or treatment. These discussions explore the patient's wishes and goals for clinically indicated treatment framed within the therapeutic options that are appropriate for the patient's clinical condition.

**Note:** A personal directive may exist and a reasonable effort shall be made to obtain it in order to inform conversations regarding goals of care in the event that the patient becomes incapable.

2.2 General guidance for when it would not be clinically indicated or appropriate for a goals of care conversation to take place include, but are not limited to:

- a) conversations which could compromise health;
- b) conversations which could delay emergency intervention; and
- c) conversations which are not relevant to the current clinical scenario or care pathway for the patient (e.g. low risk visit/intervention for an otherwise well patient).

2.3 Conversations about goals of care are undertaken:

- a) with the patient and/or the **alternate decision-maker** (see Appendix A: *Alternate Decision Maker Quick Reference Guide*);
- b) where the patient lacks capacity and the alternate decision-maker cannot be contacted, or there is no alternate decision-maker, the most responsible health practitioner may have the goals of care conversation with a family member with whom the patient has a significant relationship

as long as that discussion would not be in conflict with any previously expressed wishes by the patient regarding the release of information to that family member in accordance with the *Adult Guardianship and Trustee Act* (Alberta).

- 2.4 Any member of a patient's health care team may initiate and undertake a goals of care conversation. However, the most responsible health practitioner is ultimately responsible for ensuring that a clinically indicated **Goals of Care Designation order** has been discussed, established and documented. In collaboration with other members of the health care team, the most responsible health practitioner (or designate) should ensure that goals of care conversations include:
- a) the patient's prognosis and the anticipated outcomes of current treatment;
  - b) exploration of the patient's values, understanding, hopes, wishes and expected outcomes of treatment;
  - c) the role of **life support interventions** and/or **life sustaining measures** and their expected degree of benefit (see Appendix B: *Degree of Clinical Benefit*);
  - d) information regarding comfort measures; and
  - e) if appropriate, an offer for involvement of resources such as, but not limited to, palliative care, social work, clinical ethics consultation, or spiritual care to provide support and guidance to the patient (or alternate decision-maker) if requested by the patient (or alternate decision-maker).
- 2.5 Once a Goals of Care Designation conversation has been held, and if clinically indicated, a Goals of Care Designation order shall be created and documented in the *Advance Care Planning/Goals of Care Designation Tracking Record*.
- 2.6 Attempts to reconcile any disagreement between the patient and/or alternate decision-maker and the most responsible health practitioner's decision regarding the Goals of Care Designation order shall follow the dispute resolution process as detailed in Section 7.
- 2.7 Where no Goals of Care Designation order exists, and in a health emergency, if:
- a) the patient lacks capacity;
  - b) there are no expressed wishes by the patient in regard to a Goals of Care Designation; and
  - c) no alternate decision-maker is immediately available.
    - (i) The most responsible health practitioner, in consultation with members of the health care team, shall assess the potential benefits and harms of the proposed interventions and write the most clinically relevant Goals of Care Designation order.

OR

- (ii) If the most responsible health practitioner is not available to provide a Goals of Care Designation order, the patient will receive available life support interventions, including transportation to a facility that can provide assessment to determine appropriate care.

2.8 Notwithstanding paragraph 2.7 above, where no Goals of Care Designation order exists but a personal directive exists that describes a person's wishes for initiation or withholding of life-saving interventions, emergency medical services personnel are encouraged to contact the EMS Online Medical Control (OLMC) physician to discuss care and treatment options and the existing Medical Control Protocols.

### 3. Personal Directive or Patient Request

3.1 Where an adult patient's personal directive is known to exist, a reasonable effort shall be made to obtain a copy for placement on the **health record**.

**Note:** A personal directive does not replace a Goals of Care Designation order.

3.2 Where the adult patient has expressed a wish to limit interventions that could be considered clinically indicated, whether directly or in a personal directive, the most responsible health practitioner has a responsibility to comply with the patient's health care wishes, after discussing those limitations with the patient, when writing a relevant Goals of Care Designation order.

**Note:** Wishes outlined in a personal directive that have not been brought into effect can inform the discussion, but it is the discussion with the patient that would take precedence.

3.3 Where the adult patient expresses a wish, either directly or in a personal directive that has been brought into effect, requesting interventions that are not clinically indicated, the most responsible health practitioner should engage in a discussion with the patient. If a mutually agreeable decision cannot be reached, the dispute resolution process as detailed in Section 7 should be followed.

3.4 Where the patient lacks capacity but has previously expressed a wish to initiate, continue or limit interventions that could be considered clinically indicated, whether directly or in a personal directive (which is in effect), the most responsible health practitioner has a responsibility to comply with the patient's health care wishes, after discussing those limitations with the alternate decision-maker, when writing a relevant Goals of Care Designation order.

- a) In situations where the most responsible health practitioner has reason to believe that the patient may have provided instruction without contemplating the beneficial possibilities of the current clinically indicated interventions, then further discussion with the members of the health care

team and the alternate decision-maker should ensue, including invoking the dispute resolution process if necessary (Refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*).

- 3.5 When writing a relevant Goals of Care Designation order and where a patient lacks capacity, an existing Goals of Care Designation order is not available, and a goals of care conversation cannot take place with the alternate decision-maker, the most responsible health practitioner shall comply with any request to initiate, continue, restrict or limit specific treatment/interventions outlined verbally or in a personal directive.
- a) In situations where the most responsible health practitioner believes that compliance with the request to initiate, continue, restrict or limit specific treatment/interventions is clinically and/or ethically inappropriate, then further consultation and dispute resolution process shall be activated (refer to Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings Policy*).
- 3.6 When the patient is a minor, the guardian is entrusted to make decisions in the child's best interests. Wishes expressed by the guardian to initiate, continue or limit treatments will be reflected in the Goals of Care Designation order where provision of those treatments would not be in the best interests of the child. Where initiation, continuation, or limitation of treatment is requested but not in the best interest of the child, and there is dispute between the most responsible health practitioner and the guardian, the dispute resolution process should be triggered as detailed in Section 7. Contact with the Director of Child and Family Services Authority may be required, depending on the situation.
- 3.7 When the patient is a **mature minor**, the most responsible health practitioner shall discuss Goals of Care Designation orders directly with the patient. If a dispute arises, the dispute resolution process as detailed in Section 7 should be followed. Contact with the Director of Child and Family Services Authority may be required, depending on the situation.

#### 4. Documentation of Goals of Care Designation Order

- 4.1 A Goals of Care Designation order shall be written by the most responsible health practitioner (or designate).
- 4.2 The Goals of Care Designation order and goals of care discussions are documented on the Alberta Health Services' *Goals of Care Designation (GCD) Order Form*.
- 4.3 Pertinent details of advance care planning and goals of care discussions shall be documented on the Alberta Health Services *Advance Care Planning/Goals of Care Designation Tracking Record* and in the patient's health record.

- 4.4 Original documentation of a patient's Goals of Care Designation is provided to the patient and is placed in a Green Sleeve (a green-coloured folder provided to patients specifically to contain documents related to Advance Care Planning and Goals of Care Designations).
- a) The use of the Green Sleeve allows for recognition of the contents by all members of the health care team in all areas of Alberta Health Services.
  - b) If a health care provider must make a copy of the original Goals of Care Designation Order for any purpose, the health care provider should add a notation to the copy stating "true copy of the current Goals of Care Designation order for this patient" with the staff member's signature, date and printed name.
- 4.5 When the patient presents for a health service and a health record is created for the purpose of that encounter, after verifying it is the most recent Goals of Care Designation, the Goals of Care Designation order shall be placed within the Green Sleeve which resides in the first section of the patient's health record in a timely manner.
- 4.6 When the patient moves throughout the system, the Green Sleeve accompanies the patient so that health care providers always know about the previous discussions and the patient's current Goals of Care Designation.
- 4.7 If a patient does not have the original Goals of Care Designation order with them, and there is no other reasonable access to the original order in the circumstances, then a photocopy, fax, or scanned copy of the most recent Goals of Care Designation order may be relied upon to guide treatment.

## 5. Goals of Care Designation across the Continuum of Care

- 5.1 The current Goals of Care Designation order travels with the patient regardless of care or living environment and shall be kept in the Green Sleeve, where available.
- 5.2 When a patient transitions between sectors of care or services within Alberta Health Services, the Goals of Care Designation order in effect at the sending location of care shall remain in effect until reviewed by the most responsible health practitioner (or designate) in the receiving location of care.
- 5.3 When a patient attends outpatient care or services at the same location on a regular basis (e.g., dialysis, chemotherapy), the patient's health care professional should obtain the original Goals of Care Designation order from the patient on the first day of treatment and verify with the patient that it is the most recent order. The health care professional should photocopy the order and add a notation "true copy of the current Goals of Care Designation order for this patient" with the staff member's signature, date and printed name. The copy should remain in the patient's health care record at that location.

- 5.4 When a patient is transferred between sectors of care or services within Alberta Health Services, the original Goals of Care Designation order and Alberta Health Services *Advance Care Planning/Goals of Care Designation Tracking Record* shall be included in the Green Sleeve in the transfer documentation. A photocopy (with the notation “true copy of the current Goals of Care Designation for this patient”, staff member’s signature, date and printed name) shall remain with the sending facility.
- a) Prior to transport, EMS staff should confirm with the sending facility or the patient (or their alternate decision-maker, if applicable) that the Goals of Care order provided to EMS reflects the most recent Goals of Care Designation.
- 5.5 When a patient is discharged from a facility, the discharge summary should communicate the Goals of Care Designation and pertinent details of the conversations.
- 5.6 Resources for advance care planning and Goals of Care Designation information shall be made available in all **Alberta Health Services settings**.
- a) Clinical providers and teams will have the resources available to facilitate advance care planning and Goals of Care Designation conversations.
- b) Education literature regarding advance care planning and Goals of Care Designations will be available and provided for patients and family.

## 6. Review of Goals of Care Designation Orders

- 6.1 A patient’s Goals of Care Designation order shall be reviewed by the most responsible health practitioner:
- a) at the request of the patient or alternate decision-maker;
- b) after transfer; and/or
- c) if there is a significant change in the patient’s condition or circumstances that may be relevant to the choice of Goals of Care Designation.
- 6.2 Changes in a patient’s Goals of Care Designation order shall be discussed between the most responsible health practitioner (or designate) and the patient, or in the event that the patient lacks capacity, with the alternate decision-maker.
- 6.3 Out of date Goals of Care Designation records should have a line drawn through them with VOID, the date and initials or signature on it and then filed at the back of the chart/green sleeve.

## 7. Goals of Care Designation Decision Support and Dispute Resolution

- 7.1 When circumstances bring significant complexities, decision support may be required (refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*).
- 7.2 In the event that there is uncertainty, distress, or disagreement regarding the appropriateness of life support interventions or the Goals of Care Designation between either the patient or alternate decision-maker and the most responsible health practitioner; or among the members of the patient's health care team, refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*.
- 7.3 Where uncertainty, distress, or disagreement may escalate to a dispute, the principles and processes outlined in the Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* policy suite shall be adhered to.
- 7.4 Where all efforts to reach consensus regarding appropriate interventions and/or a Goals of Care Designation have failed, and an impasse is reached, the most responsible health practitioner shall, in accordance with the Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* Procedure:
- a) write a Goals of Care Designation order, including notification of the date and time the order shall come into effect;
  - b) provide a written copy of the order to the patient and/or alternate decision maker, with reasonable advance notice; and
  - c) inform the patient and/or alternate decision maker of their right to seek legal advice.
- 7.5 Where the patient lacks capacity and their expressed wishes, values and beliefs specific to the situation at hand are not known; the Dispute Resolution Process shall be initiated if:
- a) the alternate decision-maker gives clear instruction to request, withhold, withdraw or limit intervention/treatment; and
  - b) the team strongly believes that the alternate decision-maker's instruction is not clinically indicated and is contrary to the patient's best interest and;
    - (i) there is disagreement regarding what constitutes the patient's best interest; or
    - (ii) there is disagreement regarding whether the patient's prior expressed wishes, values and beliefs are applicable or relevant to the particular situation at hand.

- 7.6 In the event of a time critical medical emergency, when the patient lacks capacity and there is not time to complete the steps of the dispute resolution process, the most responsible health practitioner may need to initiate specific interventions necessary to address the emergency need, even if contrary to the alternate decision-maker's position.

**NOTE:** Overriding the alternate decision maker would be the exception to the norm, supportable only in those emergency situations where:

- (i) the patient's relevant wishes, values and beliefs are unknown; and
  - (ii) there is disagreement regarding best interests; or
  - (iii) where there is earnest disagreement about the applicability of the patient's prior expressed wishes, values and beliefs.
- 7.7 Following any emergency treatment, initiate the dispute resolution process as required (Refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*).
- 7.8 Where no legal proceedings have been initiated by the patient or alternate decision maker prior to the date and time of effect of the Goals of Care Designation order, the most responsible health practitioner and the health care team may proceed with treatments and interventions consistent with the Goals of Care Designation order at that date and time of effect (refer to Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings Procedure*).

## DEFINITIONS

**Advance Care Planning** means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their alternate decision-maker and their health care team; and record those choices.

**Alberta Health Services setting** means any environment where treatment/procedures and other health-care services are delivered by, on behalf of or in conjunction with Alberta Health Services.

**Alternate decision-maker** means a person who is authorized to make decisions with or on behalf of the patient. These may include: a minor's legal representative, a guardian, a 'nearest relative' in accordance with the *Mental Health Act*, an agent in accordance with a personal directive, a co-decision-maker, a specific decision-maker or a person designated in accordance with the *Human Tissue and Organ Donation Act*.

**Capacity** means 1) the patient understands the nature, risks, and benefits of the procedure and the consequences of consenting or refusing, and 2) the patient understands that this explanation applies to him/her. In the context of treatment of a formal patient or a person subject to a Community Treatment Order under applicable mental health legislation, capacity is addressed in section 26 of the *Mental Health Act* which states that a person is mentally

competent to make treatment decisions if the person is able to understand the subject matter relating to the decisions and able to appreciate the consequences of making the decisions.

**Goals of care** means the intended purposes of clinically indicated health care interventions and support as recognized by a patient or alternate decision-maker, health care team, or both.

**Goals of Care Designation** means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker.

**Goals of Care Designation order** means the documented order for the goals of care designation as written by the most responsible health practitioner (or designate).

**Health record** means the Alberta Health Services legal record of the patient's diagnostic, treatment and care information.

**Life support interventions** means interventions typically undertaken in the Intensive Care Unit but which occasionally are performed in other locations in an attempt to restore normal physiology. These may include chest compressions, mechanical ventilation, defibrillation and physiological support.

**Life sustaining measures** means therapies that sustain life without supporting unstable physiology. Such therapies can be used in many other clinical circumstances. When viewed as life sustaining measures, they are offered in either a) the terminal stages of an illness in order to provide comfort or prolong life, or b) to maintain certain bodily functions during the treatment of intercurrent illnesses. Examples include enteral tube feeding and intravenous hydration. These measures should be clinically relevant and congruent with the patient's goals.

**Mature minor** means a person aged less than 18 years, who has been assessed and determined as having the intelligence and maturity to appreciate the nature, risks, benefits, consequences, and alternatives of the proposed treatment/procedure, including the ethical, emotional and physical aspects.

**Most responsible health practitioner** means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s), within the scope of his/her practice.

**Patient** means an adult or child who receives or has requested health care or services from Alberta Health Services and its health services providers, or individuals authorized to act on behalf of Alberta Health Services. This term is inclusive of residents, clients and outpatients.

**Personal directive** means a written document in accordance with the requirements of the *Personal Directives Act* in which an adult names an agent(s) or provides instruction regarding his/her personal decisions, including the provision, refusal and/or withdrawal of consent to treatments/procedures. A personal directive (or part of) has effect with respect to a personal matter only when the maker lacks capacity with respect to that matter.

**REFERENCES**

- Appendix A: *Alternate Decision-maker Quick Reference Guide for Advance Care Planning and Goals of Care*
- Appendix B: *Degree of Clinical Benefit*
- Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*
- Alberta Health Services Governance Documents:
  - *Consent to Treatment/Procedure(s) Policy suite (#PRR-01)*
  - *Dispute Prevention and Resolution in Critical Care Settings Policy (#PRR-03)*
  - *Dispute Prevention and Resolution in Critical Care Settings Procedure (#PRR-03-01)*
- Alberta Health Services Forms:
  - *Advance Care Planning/Goals of Care Designation Tracking Record (#103152)*
  - *Goals of Care Designation (GCD) Order Form (#103547)*
- Non-Alberta Health Services Documents:
  - *Adult Guardianship and Trusteeship Act (Alberta)*
  - *Child, Youth and Family Enhancement Act (Alberta)*
  - *Family Law Act (Alberta)*
  - *Personal Directives Act (Alberta)*

**VERSION HISTORY**

Date	Action Taken
August 16, 2016	Revised
May 18, 2018	Revised

## APPENDIX A

### Alternate Decision-maker Quick Reference Guide for Advance Care Planning and Goals of Care

Goals of Care conversations ideally take place with the patient and whomever the patient chooses to be a part of the conversation. When a patient lacks capacity, or has significantly impaired capacity, the following alternate decision-makers would be appropriate to engage in the Goals of Care conversation with, or on behalf of, the patient:

- a) Agent identified in a personal directive;
- b) Guardian, where the patient is a minor but not a mature minor;
- c) Court-appointed guardian;
- d) Specific decision-maker – (a specific decision-maker can only engage in a goals of care conversation if he/she has already been selected to make a health care decision and the goals of care conversation is relevant to that process);
- e) Court-appointed co-decision-maker (where the patient does not lack capacity but has significantly impaired capacity, and the Court has appointed someone to make decisions in conjunction with the patient); and
- f) Supported decision-maker (where the patient is capable and has selected someone to support him/her in decision making. Decisions are made solely by the patient).

With agreement from the patient or alternate decision-maker, the input and support of family members assists in the discussion prior to reaching consensus or a decision regarding Goals of Care Designation.

**Note:** Unless designated as a specific alternate decision-maker outlined above, family members do not have legal authority to make decisions which involve informed consent for the patient.

## APPENDIX B

### Degree of Clinical Benefit

Degree of Clinical Benefit has three categories:

a) Likely to Benefit:

In the opinion of the most responsible health practitioner, there is a reasonable chance that cardiopulmonary resuscitation, physiological support and life support interventions will restore and/or maintain organ function. The likelihood of the person being discharged from an acute care hospital is high.

b) Benefit is Uncertain:

It is unknown or uncertain whether cardiopulmonary resuscitation, physiological support and life support interventions will restore functioning. The subsequent prognosis or the likelihood of adverse consequences is also unknown or uncertain.

c) Certainly will not Benefit:

There is no reasonable chance that the person will benefit clinically from cardiopulmonary resuscitation, physiological support, and life support interventions.

## APPENDIX C

### Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations

#### Preamble

Decision-making by patients and the health care professionals who provide care to them is an integral component of health care. When circumstances bring significant complexities, including disagreement in what care is to be provided, additional decision support may be required. This Appendix details the decision support and dispute resolution resources available. The most responsible health practitioner has a responsibility to ensure a patient is informed of, and has access to, the decision support and dispute resolution resources referenced below.

#### Focus

The *Advance Care Planning and Goals of Care Designation* Policy advocates that patients and health care professionals engage in conversations that inform and lead to the determination of a Goals of Care Designation order written by the most responsible health practitioner.

The principles and processes of the Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* Policy suite shall be adhered to where uncertainty, distress, or disagreement surrounding a Goals of Care Designation decision is present.

Some members of the inter professional team have received advance care planning skills training, have been introduced to available resources, and are knowledgeable about the details of the goals of care designations. These staff and physicians may act as resources to their colleagues to provide support and knowledge about the advance care planning process and the Goals of Care Designations.

The role of health care professionals offering decision support or dispute resolution is to assist patient, families, physicians, and staff:

- a) who require additional information, time, and conversation related to advance care planning and decision-making; and
- b) with reaching consensus on a Goals of Care Designation.

#### 1. Decision Support Resources Available

The following identified services can be accessed using the current referral process:

##### 1.1 Inter professional Health Care Teams

Generally, staff and physicians providing care to a patient have the required knowledge and experience with advance care planning and Goals of Care Designations.

1.2 Second Opinion (refer to Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* Procedure)

The most responsible health practitioner (or designate) shall expeditiously seek a second opinion from a physician with knowledge and skills relevant to the circumstances of the patient's condition.

If not already undertaken, the patient/alternate decision-maker shall be given the opportunity to request an additional opinion and assisted to obtain one.

1.3 Programs

Additional professionals are available on a consult basis, such as but not limited to:

- a) *Social Work* provides information and support regarding a patient's and family's social, emotional, economic, and environmental issues.
- b) *Spiritual Care Services* provides information and support regarding whole-person spiritual care, which may involve questions of identity, meaning, and fundamental issues of life and death.
- c) *Palliative and End-of-Life Care Service* provides support and information regarding symptom management during terminal illness and preparation for the end of life.

1.4 Specialized Services

Other specialized services can provide information and support with regard to specific issues. Clinical decision support resources vary depending on the Zone and sector of care within Alberta Health Services. These can include, but are not limited to:

- a) *Ethics Service* – An ethics consultation provides a guided discussion for decision-makers, including patients, alternate decision-makers, families, and health care professionals, about ethical dilemmas in clinical practice.
- b) *Capacity Assessment Team* – The Capacity Assessment Team provides multidisciplinary cognitive capacity assessments for patients within urban acute care facilities.
- c) *Healthy Diverse Populations* – This service provides expert perspectives regarding diverse cultural and religious issues to programs, services, and case consultation teams.
- d) *Legal Services* – Alberta Health Services Legal Services' Clinical Counsel provides legal advice to Alberta Health Services staff on matters related to the care provided to patients.

TITLE	EFFECTIVE DATE	PROCEDURE
ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION	May 18, 2018	DOCUMENT # HCS-38-01

## 2. Avenues for Dispute Resolution

In the event that a dispute or disagreement regarding a patient's treatment plan and/or Goals of Care Designation remains after appropriate avenues of decision support have been pursued, the most responsible health practitioner shall refer to the Alberta Health Services Dispute *Prevention and Resolution in Critical Care Settings* Policy suite to guide further actions.

Last Name <i>(Legal)</i>		First Name <i>(Legal)</i>	
Preferred Name <input type="checkbox"/> Last <input type="checkbox"/> First		DOB <i>(dd-Mon-yyyy)</i>	
PHN	ULI <input type="checkbox"/> Same as PHN	MRN	
Administrative Gender <input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Non-binary/Prefer not to disclose (X) <input type="checkbox"/> Unknown	

## Goals of Care Designation (GCD) Order

Date <i>(dd-Mon-yyyy)</i>	Time <i>(hh:mm)</i>
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### Goals of Care Designation Order

To order a Goals of Care Designation for this patient, check the appropriate Goals of Care Designation below and write your initials on the line below it. *(See reverse side for detailed definitions)*

Check Initials	▶ <input type="checkbox"/> R1	<input type="checkbox"/> R2	<input type="checkbox"/> R3	<input type="checkbox"/> M1	<input type="checkbox"/> M2	<input type="checkbox"/> C1	<input type="checkbox"/> C2
	_____	_____	_____	_____	_____	_____	_____

Check  here  if this GCD Order is an interim Order awaiting the outcome of a Dispute Resolution Process. Document further details on the ACP/GCD Tracking Record.

Specify here if there are specific clarifications to this GCD Order. Document these clarifications on the ACP/GCD Tracking Record as well.

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**Patient's location of care where this GCD Order was ordered** *(Home; or clinic or facility name)*

**Indicate which of the following apply regarding involvement of the Patient or alternate decision-maker (ADM)**

- This GCD has been ordered after relevant conversation with the patient.
- This GCD has been ordered after relevant conversation with the alternate decision-maker (ADM), or others. *(Names of formally appointed or informal ADM's should be noted on the ACP/GCD Tracking Record)*
- This is an interim GCD Order prior to conversation with patient or ADM.

### History/Current Status of GCD Order

Indicate one of the following

- This is the first GCD Order I am aware of for this patient.
- This GCD Order is a revision from the most recent prior GCD *(See ACP/GCD Tracking Record for details of previous GCD Order)*.
- This GCD Order is unchanged from the most recent prior GCD.

Name of Physician/Designated Most Responsible Health Practitioner who has ordered this GCD	Discipline
Signature	Date <i>(dd-Mon-yyyy)</i>

**Goals of Care Designations – Approach to Care Guide for Clinicians**

<p><b>R1: Medical Care, Including Resuscitative Care, if Required</b> Goals of care are directed at cure or control of the patient's condition. The patient would desire ICU care if it was required and would benefit from ICU if their medical condition warranted it.</p> <p><b>R2: Goals of care are directed at cure or control of a patient's condition. Treatment of illness may include transfer to an acute or tertiary care facility with admission to the ICU if indicated. Intubation or chest compressions may be provided.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> for patients who would benefit from, and are accepting of, any appropriate investigations and interventions that health systems can offer, including physiological support in an ICU setting if required. All appropriate supportive therapies are offered, including intubation. Chest compressions and intubation are performed during a resuscitative effort when clinically indicated.</li> <li>• <b>Resuscitation:</b> is undertaken for cardio respiratory arrest or acute deterioration.</li> <li>• <b>Life Support Interventions:</b> is undertaken for cardio respiratory arrest or acute deterioration.</li> <li>• <b>Life Sustaining Measures:</b> are used when appropriate within overall goals of care.</li> <li>• <b>Major Surgery:</b> is considered when appropriate. The possibility of intra-operative complications including death and the requirement for physiological support post-operatively should be addressed with the patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li>• <b>Transfer from current location of care:</b> is considered if an alternative location for is required for diagnosis and treatment.</li> </ul> <p><b>R3: Goals of care are directed at cure or control of a patient's condition. Treatment of illness may include transfer to an acute or tertiary care facility with admission to the ICU if required, but chest compressions or intubation should not be performed.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> for patients who would benefit from, and are accepting of, any appropriate investigations and interventions that the health system can offer, including physiological support in an ICU setting if required, but excluding intubation and chest compressions.</li> <li>• <b>Resuscitation:</b> is undertaken for acute deterioration but intubation and chest compression should not be performed</li> <li>• <b>Life Support Interventions:</b> may be offered without intubation or chest compression.</li> <li>• <b>Life Sustaining Measures:</b> are used when appropriate within overall goals of care.</li> <li>• <b>Major Surgery:</b> is considered when appropriate. The possibility of intra-operative complications including death and the requirement for physiological support post-operatively should be addressed with the patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li>• <b>Transfer from current location of care:</b> is considered for diagnosis and treatment, if required.</li> </ul>	<p><b>M1: The goals of care are aimed at cure or control in any location of care, without accessing a tertiary level ICU. Treatment of illness may include transfer to an acute or tertiary care facility without admission to a tertiary level ICU.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> all active medical and surgical interventions aimed at cure and control of conditions are considered, within the bounds of what is clinically indicated, and excluding the option of admission to a tertiary level ICU for life-saving interventions. If a person deteriorates further and is no longer amenable to cure or control interventions, the goals of care designation should be changed to focus on comfort primarily.</li> <li>• <b>Resuscitation:</b> is not undertaken for cardio respiratory arrest.</li> <li>• <b>Life Support Interventions:</b> should not be initiated or should be discontinued after discussion with the patient or alternate decision-maker.</li> <li>• <b>Life Sustaining Measures:</b> are used when appropriate within overall goals of care.</li> <li>• <b>Major Surgery:</b> is considered when appropriate. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with patient in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li>• <b>Transfer to another location of care:</b> is considered if an alternative location for is required for diagnosis and treatment.</li> </ul> <p><b>M2: The goals of care are aimed at cure or control, almost always within the patient's current care environment. Treatment of illness may be undertaken in the current location without transfer to acute or tertiary care should that condition deteriorate.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> all interventions that can be offered in the current location of care are considered. If a person deteriorates further and is no longer amenable to cure or control interventions in that location, the goals of care designation should be changed to focus on comfort primarily.</li> <li>• <b>Resuscitation:</b> is not undertaken for cardiorespiratory arrest.</li> <li>• <b>Life Support Interventions:</b> should not be initiated or should be discontinued after discussion with the patient.</li> <li>• <b>Life Sustaining Measures:</b> are used when appropriate.</li> <li>• <b>Major Surgery:</b> is not usually undertaken but can be contemplated for procedures aimed at symptom relief. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with the patient/family in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li>• <b>Transfer to another location of care:</b> is not usually undertaken, but can be contemplated if symptom management or diagnostic efforts aimed at understanding symptoms can best be undertaken at that other location.</li> </ul>	<p><b>C1: Medical Care and Interventions, Focused on Comfort</b> Goals of care are directed at symptom control rather than at cure or control of a patient's underlying condition that is expected to result in death. All interventions are for symptom relief.</p> <p><b>C2: Goals of care are aimed at preparation for imminent death (usually within hours or days) with maximal efforts directed at symptom control.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> expert care can be provided in any location.</li> <li>• <b>Resuscitation:</b> is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.</li> <li>• <b>Life Support Interventions:</b> should not be initiated or should be discontinued after discussion.</li> <li>• <b>Life Sustaining Measures:</b> should be discontinued unless required for goal directed symptom management.</li> <li>• <b>Major Surgery:</b> is not appropriate.</li> <li>• <b>Transfer:</b> to another site is usually not undertaken due to risk of death during transport.</li> </ul> <p><b>C3: Goals of care are for maximal symptom control and maintenance of function, without cure or control of the underlying condition. A diagnosis exists which is expected to cause eventual death.</b></p> <ul style="list-style-type: none"> <li>• <b>General Guidelines:</b> A diagnosis exists which is expected to cause eventual death. New illnesses are not generally treated unless control of symptoms is the goal.</li> <li>• <b>Resuscitation:</b> is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.</li> <li>• <b>Life Support Interventions:</b> should not be initiated or should be discontinued after discussion with the patient.</li> <li>• <b>Life Sustaining Measures:</b> can be used for goal directed symptom management.</li> <li>• <b>Major Surgery:</b> is not usually undertaken but can be contemplated for procedures aimed at symptom relief. Resuscitation during surgery or in the recovery room can be considered, including short term physiological and mechanical support in an ICU, in order to return the patient to prior level of function. The possibility of intra-operative death (option: life-threatening intra-operative deterioration) should be discussed with the patient/family in advance of the proposed surgery, and general decision-making guidance agreed upon.</li> <li>• <b>Transfer:</b> should be contemplated if symptom management or diagnostic efforts aimed at understanding symptoms can best be undertaken at another location. Transfer to an ICU is warranted if ICU is deemed to be the best location for palliation, especially in the pediatric environment.</li> </ul>
<p>Please review the <i>Advance Care Planning and Goals of Care Designation Clinical Knowledge Topic</i> and/or <i>Advance Care Planning/Goals of Care Designation AHS policy</i> for additional guidance.</p>		

Affix patient label within this box

## Advance Care Planning/Goals of Care Designation Tracking Record

- Purpose: to document the content of Advance Care Planning (ACP)/Goals of Care Designation (GCD) conversations and/or decisions.

**Benefits:**

- Assists healthcare providers in being aware of previous conversations and to understand the reasons underlying the current GCD order.
- Gives clues about where to pick up the conversation if decisions need to be reviewed or confirmed.
- The ACP GCD Tracking Record is a continuous record that goes in the Green Sleeve. Documenting on both Tracking Record and progress note may be necessary to ensure transfer of critical information.
- The original form is kept in the patient’s Green Sleeve. When the patient moves to a new care setting, including home, a copy remains with the sending facility.

Date (yyyy-Mon-dd)	Site/ Attendees	Conversation Summary Notes	
			<b>Required Documentation</b>
			Any member of the healthcare team can record conversations on this form.
			Include who was involved in today’s discussions (i.e. patient, family, healthcare provider Include name and relationship/discipline)
			Summarize conversation and/or key decisions from today’s discussion
			<b>It helps to document responses to the following speaking prompts.</b>
			■ Have you completed a Personal Directive?
			■ Have you selected an alternative decision maker? If so do they know your wishes?
			■ What is your understanding now of where you are with your illness?
			■ If your health situation worsens what are your important goals?
			■ Do you know if you have a Green Sleeve?
			■ Do you know if you have a Goals of Care Designation (GCD) order?

