Goals of Care

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POLICY

The focus of this policy is on the Goals of Care. A patient centric approach that integrates patient`s values, wishes and goals in the context of medically appropriate treatment. It provides the framework and tools for clinicians to be able to meet the criteria of the policy. It provides resources for individuals and families to engage in advance care planning. The goals of care are based on Advance Care Planning conversations.

PURPOSE

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(es) that will be followed in cases of dispute in the determination of Goals of Care Designations

SCOPE

Compliance with this procedure is required by all Windsor Regional Hospital employees, members of the medical and midwifery staffs, students, volunteers, and other persons acting on behalf of Windsor Regional Hospital (including contracted service providers as necessary). This procedure does not limit any legal rights to which you may otherwise be entitled.

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 substitute decision-maker and their health care team; and record those choices.

Windsor Regional Hospital's setting means any environment where treatment/procedures and other health-care services are delivered by, on behalf of or in conjunction with Windsor Regional Hospitals.

Substitute 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 an advance directive, a co-decision-maker, a specific decision-maker or a person designated in accordance with Bill 58, the *Organ or Tissue Donation Statute Law Amendment Act, 2014.Human Tissue and Organ Donation Act.*

Capacity means

a) the patient understands the nature, risks, and benefits of the procedure and the consequences of consenting or refusing, and capacity is addressed *Health Care Consent Act 1996, section 4*.which states that a person is capable with respect to a treatment, admission to a care facility or a advance assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or advance assistance service , as the case may be, and able to appreciate the reasonable foreseeable consequences of a decision or lack of decision.
b) 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, Mental Health Act, section 33.

Goals of care means the intended purposes of clinically indicated health care interventions and support as recognized by a patient or substitute 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 substitute 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).

Guardian means, where applicable:

For a minor:
a) as defined in the Family Law Act;
b) as per agreement or appointment authorized by legislation (obtain copy of the agreement and verify it qualifies under legislation; e.g., agreement between the Director of Child and Family Services Authority and foster parent(s) under the Family Law Act; or agreement between parents under the Family Law Act; or as set out in the Family Law Act regarding guardians of the child to be adopted once the designated form is signed);
c) as appointed under a will (obtain a copy of the will; also obtain grant of probate, if possible;
d) as appointed in accordance with a advance directive (obtain copy of advance directive);
e) as appointed by court order (obtain copy of court order) (e.g., order according to the Family Law Act); and,
f) a divorced parent who has custody of the minor.

For an adult:
a) an individual appointed by the Court to make decisions on behalf of the adult patient when the adult patient lacks capacity.

Health record means the Windsor Regional Hospitals legal record of the patient's diagnostic, treatment and care information. ("PHI" Personal Health Information)

Legal representative means the following in relation to a minor, as applicable: a) guardian; b) nearest relative as defined in the Mental Health Act who has the authority to consent to treatment for a minor formal patient or minor who is subject to a Community Treatment Order.

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 Windsor Regional Hospitals 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 Windsor Regional Hospitals and its health services providers, or individuals authorized to act on behalf of Windsor Regional Hospitals. This term is inclusive of residents, clients and outpatients.

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

PROCESS

1. Goals of Care Conversations

1.1 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 advance 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.

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

a) conversations which could compromise health;
b) conversations which could delay emergency intervention; and/or,
c) conversations which are not relevant to the current clinical scenario or care pathway for the patient.

1.3 Conversations about goals of care are undertaken with:

a) the patient and whoever the patient, when capable, requests to be involved in the conversation;
b) the patient's **substitute decision-maker** if the patient lacks **capacity** to make health care decisions, or
c) where the patient lacks capacity and the substitute decision-maker cannot be contacted, or there is no substitute 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.

Note: If a specific decision-maker has already been selected to participate in a health care decision, then the goals of care conversation may occur with the specific decision-maker as part of that decision-making process.

1.4 Any member of a patient's health care team may initiate and undertake an advance care planning 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 advance care planning and 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
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 substitute decision-maker) if requested by the patient (or substitute decision-maker).

1.5 Attempts to reconcile any disagreement between the patient/substitute decision- maker and the most responsible health practitioner's decision regarding the Goals of Care Designation order shall follow the dispute resolution process (see Section 6).

1.6 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 substitute decision-maker is immediately available:

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

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.

1.7 Notwithstanding 1.6 above, where no Goals of Care Designation order exists but an advance directive exists that describes a person's wishes for initiation or withholding of life-saving interventions, emergency personnel should follow their current Medical Control Protocols.

2. Advance Directive or Patient Request

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

Note: An advance directive does not replace a Goals of Care Designation order.

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

Note: Wishes outlined in an advance directive that have not been brought into effect can inform the discussion, but where the patient is capable it is the discussion with the patient that would take precedence.

2.3 Where the adult patient lacks capacity but has previously expressed a wish to limit interventions that could be considered clinically indicated, whether directly or in a advance directive (which would be 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 substitute decision-maker, when writing a relevant Goals of Care Designation order.

2.4 Where an adult patient lacks capacity, an existing Goals of Care Designation order is not available, and a goals of care conversation cannot take place with the substitute decision-maker, the most responsible health practitioner shall comply with any request to restrict or limit specific treatment/interventions outlined in a advance directive that has been brought into effect or as expressed by the patient when previously capable when writing a relevant Goals of Care Designation order.

2.5 Where the adult patient expresses a wish, either directly (when capable) or in a advance directive that has been brought into effect, requesting interventions that are not clinically indicated, the treating physician should engage in a discussion with the patient/substitute decision-maker. If a mutually agreeable decision cannot be reached, the dispute resolution process as detailed in Section 6 should be followed.

2.6 Where the patient lacks capacity and the substitute decision-maker gives clear instruction requesting restriction or limits on intervention/treatment that are clinically indicated, the patient's wishes are otherwise not known, and when the most responsible health practitioner believes that such instructions are not clinically appropriate, the dispute resolution process shall be initiated. *(**Refer to Appendix C** Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations)*

2.7 When the patient is a minor, the legal representative is entrusted to make decisions in the child's best interests. Wishes expressed by the legal representative to 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 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 legal representative, the dispute resolution process should be triggered (see Section 6). Contact with the Director of Child and Family Services Authority may be required, depending on the situation.

2.8 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 6 should be followed. Contact with the Director of Child and Family Services Authority may be required, depending on the situation.

3. Documentation of Goals of Care Designation Order

3.1 A Goals of Care Designation order shall be written by the most responsible health practitioner (or designate) and documented on the patient's health record.

3.2 Pertinent details of advance care planning and goals of care discussions shall be documented in the patient's health record and the Windsor Regional Hospital *Advance Care Planning/Goals of Care Designation Tracking Record.*

3.3 The Goals of Care Designation order shall be placed in a prominent and consistent location on the patient's health record in a timely manner.

4. Goals of Care Designation across the Continuum of Care

4.1 When a patient is transferred between sectors of care or services within the Windsor Regional Hospital, the Goals of Care Designation order completed 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.

a) When a patient is transferred between sectors of care or services within Windsor Regional Hospitals, the original copy of the Goals of Care Designation order and Windsor Regional Hospitals *Advance Care Planning/Goals of Care*

Designation Tracking Record shall be included in the transfer documentation. A photocopy shall remain with the sending facility.

b) When a patient is discharged from an acute care facility, a photocopy of the Goals of Care Designation order and the Windsor Regional Hospitals *Advance Care Planning/Goals of Care Designation Tracking Record* completed during admission shall be included in the discharge summary and forwarded to the community physician (where known) and/or the receiving Continuing Care Living Option or to Home Care, where applicable. A photocopy shall remain with the sending facility.

Note: The original copy of the Goals of Care Designation order travels with the patient regardless of care or living environment and shall be kept in the patient health record, where available.

4.2 Resources for advance care planning and Goals of Care Designation information shall be made available in all Windsor Regional Hospital's 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.

5. Review of Goals of Care Designation Orders

5.1 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 substitute 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.

5.2 Changes in a patient's Goals of Care Designation order shall be discussed between the most responsible health practitioner (or designate) and the patient. In the event that the patient lacks capacity, changes in the Goals of Care Designation order shall be discussed with the substitute decision-maker.

6. Goals of Care Designation Decision Support and Dispute Resolution

6.1 When circumstances bring significant complexities, decision support may be required. In the event that there is uncertainty, distress, or disagreement regarding the appropriateness of life support interventions or the Goals of Care

Designation between:

a) the patient or substitute decision-maker and the most responsible health practitioner; or,
b) 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.

6.2 In cases where dispute regarding Goals of Care Designation occurs within a critical care setting, refer to Windsor Regional Hospitals Dispute Prevention and Resolution in Critical Care Settings Policy.

6.3 The most responsible health practitioner (or designate) shall ensure that the patient or substitute decision-maker is informed of, and has access to, the avenues of decision support and dispute resolution.

6.4 When the avenues of decision support and dispute resolution as set out in Appendix C Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations have been explored, including consultation with the designated medical administrator, and the disagreement or dispute regarding a patient's Goals of Care Designation remains, the most responsible health practitioner (or designate), in his/her professional judgement, may issue a clinically indicated Goals of Care Designation order.

SUBSTITUTE DECISION-MAKER QUICK REFERENCE GUIDE

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 substitute decision-makers would be appropriate to engage in the Goals of Care conversation with, or on behalf of, the patient:
The hierarchy according to the *Health Care Consent Act, 1996.*

APPENDIX A

If you have any questions or comments regarding the information in this procedure, please contact the Policy Department

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 B

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. When required, the most responsible health practitioner has a responsibility to ensure a patient is informed of, and has access to, any relevant decision support and dispute resolution resources necessary for their circumstances.

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 choice of a Goals of Care Designation order written by the most responsible health practitioner. Some members of the interprofessional 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 progress 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.

Decision Support Resources Available

The following identified services can be accessed using the current referral process: 1.1 Interprofessional 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.

1.1 Second Opinion

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/substitute decision-maker should be given the opportunity to request an additional opinion and assisted to obtain one.

1.2 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) Hospice Palliative Care Service provides support and information regarding symptom management during terminal illness and preparation for the end of life.

1.3 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 Windsor Regional Hospitals. These can include, but are not limited to:

a) Ethics Services – An ethics consultation provides a guided discussion for decision-makers, including patients, substitute decision-makers, families, and health care professionals, about ethical dilemmas in clinical practice.
b) Patient Relations/Legal Affairs – Will provide required support for dispute resolution and access to other services ie. The Consent/Capacity Board, support WRH staff on related legal matters.

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 consult with the designated medical administrator. It is not the role of the designated medical administrator to assist in the determination of a Goals of Care Designation, but rather to lend guidance and support for due process in making clinically and ethically sound decisions regarding care and Goals of Care Designations.

Goals of Care Designation Orders Following Dispute Resolution

If, after appropriate avenues of decision support and dispute resolution have been explored, including consultation with the designated medical administrator, the disagreement or dispute between the health care team and the patient regarding the patient's Goals of Care Designation remains:

a) the most responsible health practitioner (or designate) may issue, based on his/her professional judgment, a clinically relevant Goals of Care Designation order;
b) Windsor Regional Hospitals' support for this decision, including process consultation with the designated medical administrator, will be noted on the patient's health record; and appropriate application to the Consent and Capacity Board.
c) the most responsible health practitioner (or designate), or the designated medical administrator, shall advise the patient/substitute decision-maker that he/she may seek external legal counsel when required in advance of implementing or withdrawal of specific treatment.

REFERENCES

Health Care Consent Act, 1996.

Substitute Decision Act, 1992.

Family Law Act, 1990.

Alberta Goals of Care Designation

Mental Health Act, 2015.