# Provincial Clinical Knowledge Topic

## *Advance Care Planning and Goals of Care Designations, All Ages - All Locations*

## *V 1.1*

## Revision History

| Version | Date of Revision | Description of Revision | Revised By |
|---|---|---|---|
| 1.0 | March 26, 2018 | Completion of topic | Eric Wasylenko |
| 1.1 | September 13, 2018 | Revision to topic | Eric Wasylenko |

## Important Information Before You Begin

The recommendations contained in this knowledge topic have been provincially adjudicated and are based on best practice and available evidence. Clinicians applying these recommendations should, in consultation with the patient or Alternate Decision Maker (if the patient lacks capacity), use medical judgment in the context of individual clinical circumstances to direct care. This knowledge topic will be reviewed periodically and updated as best practice evidence and practice change.

The information in this topic strives to adhere to Institute for Safe Medication Practices (ISMP) safety standards and align with Quality and Safety initiatives and accreditation requirements such as the Required Organizational Practices. Some examples of these initiatives or groups are: Health Quality Council Alberta (HQCA), Choosing Wisely campaign, Safer Healthcare Now campaign etc. It is also in compliance with Alberta Legislation including the Personal Directives Act and the Adult Guardianship and Trusteeship Act.

Please refer to the following for more information and recommendations about this topic:

- Website: Conversations Matter
- AHS Policy: Advance Care Planning and Goals of Care Designation
- AHS Procedure: Advance Care Planning and Goals of Care Designation
- AHS Resource: Advance Care Planning / Goals of Care
- Website: Adult Guardianship and Trusteeship Act
- Website: Personal Directives Act

# Rationale

## Goals of Care Designations

Goals of Care Designations (GCD) are medical orders that describe the general and sometimes specific focus of a patient's desired care approach, harmonized with what is medically appropriate to provide. They also create awareness of a person's care choices in relation to the care sector they are living in or being cared for. They ideally arise from fully informed conversations between patients (or their alternate decision-maker) and health care providers. GCDs replace and expand upon previous "Do Not Resuscitate" (DNR) and "Full Code" designations that were increasingly seen as outdated and too binary considering the complexities of modern health care capabilities and the complex trajectories of patients' health conditions. This framework focuses on what can be usefully provided in service of the patient's goals and wishes.

There are three general categories of GCDs, and seven sub-categories. It is important to remember that the three general categories are not referred to as 'levels of care'. They do not imply more or less care. They specifically guide teams and patients to consider the most appropriate focus of care, or direction of care and interventions.

## Advance Care Planning

Along with GCD determinations, Advance Care Planning (ACP) in Alberta is a process of deliberation about future healthcare preferences. A person engages in ACP by learning about possible current and future health scenarios relevant to them, reflecting on values and wishes, communicating with their health care providers and members of their family, documenting decisions and, in the case of adults, naming an alternate decision-maker (ADM) in a Personal Directive. Note: in the legislation, the alternate decision-maker is referred to as the "Agent". Advance Care Planning helps people prepare for current and future, in-the-moment decision-making for health care encounters while they remain decisionally capable. ACP most importantly helps guide the alternate decision-maker and health care team with decision-making if the person becomes incapable of consenting to or refusing interventions. (www.conversationsmatter.ca).

## Impact of ACP/GCD

ACP conversations are valuable for many patients, not just for those nearing the end of their lives. The bulk of the research regarding ACP pertains to end of life care. Some of the findings are summarized here:

- It is known that without fulsome ACP conversations, patients receive more invasive care at the end of life – something that may or may not be desired by the patient.[1,2]
- Quality of death and bereavement adjustment have both been rated as poorer when such conversations have not been undertaken.[1,3]
- Patients are more likely to receive care that is consistent with their wishes, when they have had ACP conversations with their physicians.[3]

This mechanism of decision-making and communication of decisions helps make our system more patient-centred, improves continuity of care, supports care quality and safety for patients, reduces unwanted transfers and procedures, reduces decisional burden and moral distress for families and caregivers, and helps prevent inappropriate consumption of resources.

It is important to remember that ACP conversations can and should involve any member of the care team who are in a position to engage the patient on any elements of ACP discussions.

## Integration of ACP/GCD

While ACP and GCD are important for most patients of all ages, including children and adults, ACP discussions should be prioritized for those with chronic health conditions, those who are likeliest to encounter the health system, those who are in facility care, those who are frail and those who are at greater risk of health deterioration.

While ACP is an ongoing process of reflection and communication, a Goals of Care Designation order reflects the ACP conversations and decisions and places them within a shorthand mechanism for rapid communication when required. GCDs are foundational for health care encounters and decision-making. They communicate focus of care for that patient to the entire care team. They describe the general aims of care, potential locations of care and guidance on transfers in location, as well as describing the interventions to be applied and those to be avoided in the event of life-threatening deterioration in the patient's condition.

## Recording and Communicating ACP/GCD

The documentation and communication of GCDs and advance care plans occurs increasingly in the electronic record environment, where available. In paper health records, the documents that capture a patient's ACP/GCD are contained in a green plastic folder called a Green Sleeve. Patients keep their own Green Sleeves when they live in their own homes in the community. They are asked to store them on or near the refrigerator – a convention that paramedics are aware of so that they can be readily found during a paramedic response. The documents are meant to be brought to outpatient health encounters. Green Sleeves may be located:

- on or near the refrigerator in the patient's home
- in the patient's room if in a lodge or assisted living facility
- at the front of the patient health record, if presenting for a health service at a location where a health record is created for the purpose of that encounter

A GCD Order is reviewed when clinically important changes occur for a patient, when they transition to a new care environment, or at any time the patient or care team feels an update conversation is required.

The record of ongoing discussions, what was decided, who was involved in the discussions, and the changes in GCDs over time are captured in the ACP/GCD Tracking Record. This documentation:

- helps the next health care provider who sees the patient to understand the rationale for the current GCD Order
- provides clues about where to pick up the conversation if decisions about the focus of care need to be revisited or confirmed
- saves considerable time and avoids burdening patients with repeated, potentially lengthy, and challenging conversations

## Contextualizing GCDs in Clinical Decision Making

Patients are encouraged to have conversations about their values and wishes with their family members as well as their health teams. Any of those people in the patient's circle could be helpful key informants about a person's values and underlying motivations for their decision during a health crisis or at a time of emotional decision-making by everyone involved.

It is important to remember that GCDs guide care and are meant to reflect an understanding between the care team and the patient (or ADM) at a given time. If clinical circumstances or patient values change, the GCD Order should be confirmed or changed after review. In emergencies, where there may not be time for fulsome conversation, good clinical decision-making sometimes means that the GCD should be over-ridden in light of new and unexpected circumstances. This would not be a common occurrence, and must always be justifiable. Considering emergency circumstances, guidance should be sought from the patient, the ADM, colleagues, and family members where feasible.

For examples of clinical decision making scenarios, and to better understand the seven GCD categories, please refer to clinical scenarios below:

- Adult Decision Making Scenarios
- Pediatric Decision Making Scenarios
- Appendix C – Dementia Special Considerations

## Dispute Resolution Mechanisms

If agreement cannot be reached, the AHS dispute resolution mechanism helps care teams, patients, family and ADMs navigate decision making. Information about the dispute resolution mechanism can be found on AHS Insite: http://insite.albertahealthservices.ca/8738.asp

## Goals of Management

1. Goals of Care Designations are the shorthand mechanism by which health care professionals describe and communicate the general focus of care for a patient.
2. GCD Orders are reviewed when clinically important changes occur for a patient, when they transition to a new care environment, or at any time the patient or care team feels an update conversation is required.
3. In emergencies, good clinical decision-making sometimes requires acting outside the bounds of a given GCD Order in light of unexpected circumstances. While GCD Order are meant to be prescriptive, they can be overridden when necessary and when carefully justified.

## Decision Making

The GCD architecture contains three general foci of care that have been labeled comfort care, medical care and resuscitative care. Within each of the categories are two or three sub-categories. Care and interventions that should be considered and ones that should not be considered can be incorporated according to the chosen GCD category.

### Comfort Care Designations (C)

C designations encompass care and interventions for people approaching the end of their lives with predictably life-limiting condition or disease, and can include:

- supportive symptom management
- supporting best functioning possible for patients considering their disease trajectory

The first sub-category (C1) envisions care directed at the above goals for any length of time. Sometimes patients with a C1 Designation live a considerable length of time. Intercurrent illnesses can be treated if the patient wishes, especially when such treatment reduces symptom burden. But the primary end of life illness is not being cured or controlled.

In the second sub-category (C2) all actions are focused on preparing for imminent death – ie. death that is expected to occur within hours or days.

### Medical Care Designations (M)

M designations encompass care and intervention focusing on curing or controlling the patient's condition or disease or maintaining a person's health while they live with chronic medical conditions, without considering resuscitation or ICU as a care option.

The first sub-category (M1) indicates that the patient would agree to be cared for in, or transferred to, any health care facility that is best suited for their care goals.

The second sub-category (M2) tells the care team that even if the patient's condition deteriorates despite best available treatment where they live, such that death from their illness can be anticipated, they would not wish to be transferred to hospital for more sophisticated interventions and investigation. At the point of deterioration, rather, the goal of care would transition to comfort care (C) in their current location.

There are a few examples where emergency management might be suitable for limited intervention even if the patient has an M2 GCD Order, such as if a long term care patient sustains a fall and requires laceration repair or operative stabilizing of a painful hip fracture. This patient could be treated in an acute care facility and then returned to their current location of living as soon as is warranted. In this circumstance, GCD Order documentation should include a special notation that the GCD Order remains as M2, with specific limited emergency intervention for the purpose of managing the symptom.

## Resuscitative Care Designations (R)

R designations encompass agreement that admission to a critical care unit such as ICU or appropriate resuscitative interventions followed by ICU care will be undertaken should a patient experience a health deterioration that requires such measures to save their life.

The first sub-category (R1) tells the care team to respond with the full range of appropriate life-saving and life-sustaining interventions that are required.

The second sub-category (R2) tells the care team to avoid use of chest compressions, while still utilizing all other techniques to save and support life as appropriate.

The third sub-category (R3) tells the care team to avoid the use of both chest compressions and intubation/ventilation to save or sustain life while still allowing other appropriate critical care interventions.

These seven categories of actions cannot hope to cover every care situation, so the GCD Order form contains space to record specific patient requests or medical instructions. Some specific exceptions are encompassed in the following detailed category descriptions.

Patients should almost always be aware of their GCD Order and participate in the conversation leading to its determination. There are circumstances where the GCD Order will be assumed to be R1, and in which a conversation need not occur. Examples would include healthy, pregnant, labouring women and healthy children undertaking usually straightforward and low-risk surgical procedures. However, patients and their alternate decision-makers should still be made aware of the general architecture of GCDs during health care encounters, where feasible and appropriate to do so, along with the assumption about their R1 designation in such circumstances. Ideally this is best accomplished through general health system information that all patients could receive during health care encounters.

**Table 1. Intervention Considerations for Specific Goals of Care Designations**

| Goals of Care Designations | | Interventions | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Chest Compressions | Intubation | ICU Admit – Adult | ICU Admit - Pediatric | Surgery | Site Transfer | Symptom Control |
| R Resuscitative Care | 1 | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ |
| | 2 | ✘ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ |
| | 3 | ✘ | ✘ | ✔ | ✔ | ✔ | ✔ | ✔ |
| M Medical Care | 1 | ✘ | ✘ | ✘ | Can consider, if required for symptom control | ✔ | ✔ | ✔ |
| | 2 | ✘ | ✘ | ✘ | | | | ✔ |
| C Comfort Care | 1 | ✘ | ✘ | ✘ | | | | ✔ |
| | 2 | ✘ | ✘ | ✘ | | ✘ | ✘ | ✔ |

Table adapted from Alberta Health Services Advance Care Planning/Goals of Care Designation Pocket Card

Detailed Designation descriptions follow, reproduced from the Advance Care Planning and Goals of Care Designation Policy document[5]

## Goals of Care Designations – Guide for Clinicians

Please refer to Appendix A of the Advance Care Planning and Goals of Care Designation Policy

### R: May intervene with medical care, including Resuscitative Care if required.

Goals of Care: 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.

### R1: Medical care including ICU admission of required, with intubation and chest compressions

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.

- **General Guidelines:** 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.
- **Resuscitation:** is undertaken for cardio respiratory arrest or acute deterioration.
- **Life Support Interventions:** are usually undertaken.
- **Life Sustaining Measures:** are used when appropriate within overall goals of care.
- **Major Surgery:** 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.
- **Transfer from current location of care:** is considered if an alternative location is required for diagnosis and treatment.[5]

### R2: Medical Care including ICU admission if required, with intubation but without chest compressions

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.

- **General Guidelines:** 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.
- **Resuscitation:** is undertaken for acute deterioration, but chest compressions should not be performed.
- **Life Support Interventions:** may be offered, without chest compressions.
- **Life Sustaining Measures:** are used when appropriate within overall goals of care.
- **Major Surgery:** 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.
- **Transfer from current location of care:** is considered if an alternative location is required for diagnosis and treatment.[5]

### R3: Medical Care including ICU admission if required, without intubation or chest compressions

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.

- **General Guidelines:** 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.
- **Resuscitation:** is to be undertaken for acute deterioration but chest compressions or intubation should not be performed.
- **Life Support Interventions:** may be offered without intubation or chest compressions.
- **Life Sustaining Measures:** are used when appropriate within overall goals of care.
- **Major Surgery:** 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.
- **Transfer from current location of care:** is considered if an alternative location is required for diagnosis and treatment.[5]

## M: May intervene with medical care, excluding tertiary level ICU

Goals of care are 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.

### M1: Medical care with transfer to Acute care when required and without the option for life-saving ICU care

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.

- **General Guidelines:** 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.
- **Resuscitation:** is not undertaken for cardio respiratory arrest.
- **Life Support Interventions:** should not be initiated, or should be discontinued after discussion with patient or alternate decision-maker.
- **Life Sustaining Measures:** are used when appropriate within overall goals of care.
- **Major Surgery:** 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.
- **Transfer to another location of care:** is considered if that location provides more appropriate circumstances for necessary diagnosis and treatment.[5]

## M2: Medical care without transfer to Acute care and without the option for life-saving ICU care

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.

- **General Guidelines:** 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.
- **Resuscitation:** is not undertaken for cardio respiratory arrest or acute deterioration.
- **Life Support Interventions:** should not be initiated or should be discontinued after discussion with patient.
- **Life Sustaining Measures:** are used when appropriate within overall goals of care.
- **Major Surgery:** 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.
- **Transfer 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.[5]

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## C: Provide comfort care

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.

### C1: Symptom comfort care

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.

- **General Guidelines:** A diagnosis exists which is expected to cause eventual death. New illnesses are not generally treated unless control of symptoms is the goal.
- **Resuscitation:** is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.
- **Life Support Interventions:** should not be initiated, or should be discontinued after discussion.
- **Life Sustaining Measures:** can be used for goal directed symptom management.
- **Major Surgery:** 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.
- **Transfer:** 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.[5]

### C2: Terminal Care

Goals of care are aimed at preparation for imminent death (usually within hours or days), with maximal efforts directed at symptom control.

- **General Guidelines:** expert terminal care can be provided in any location.
- **Resuscitation:** is not to be undertaken in the event of cardio respiratory arrest/failure. Chest compressions or intubation should not be performed.
- **Life Support Interventions:** should not be initiated, or should be discontinued after discussion.
- **Life Sustaining Measures:** should be discontinued unless required for goal directed symptom management.
- **Major Surgery:** is not appropriate.
- **Transfer:** to another site is usually not undertaken due to risk of death during transport.[5]

## Adult Decision Making Scenarios - *The following scenarios are for illustrative purposes only and are not meant to limit specific clinical decision making.*

**Figure 1: R1 Adult Scenario - Sudden onset dyspnea, loss of consciousness, no pulse detected**

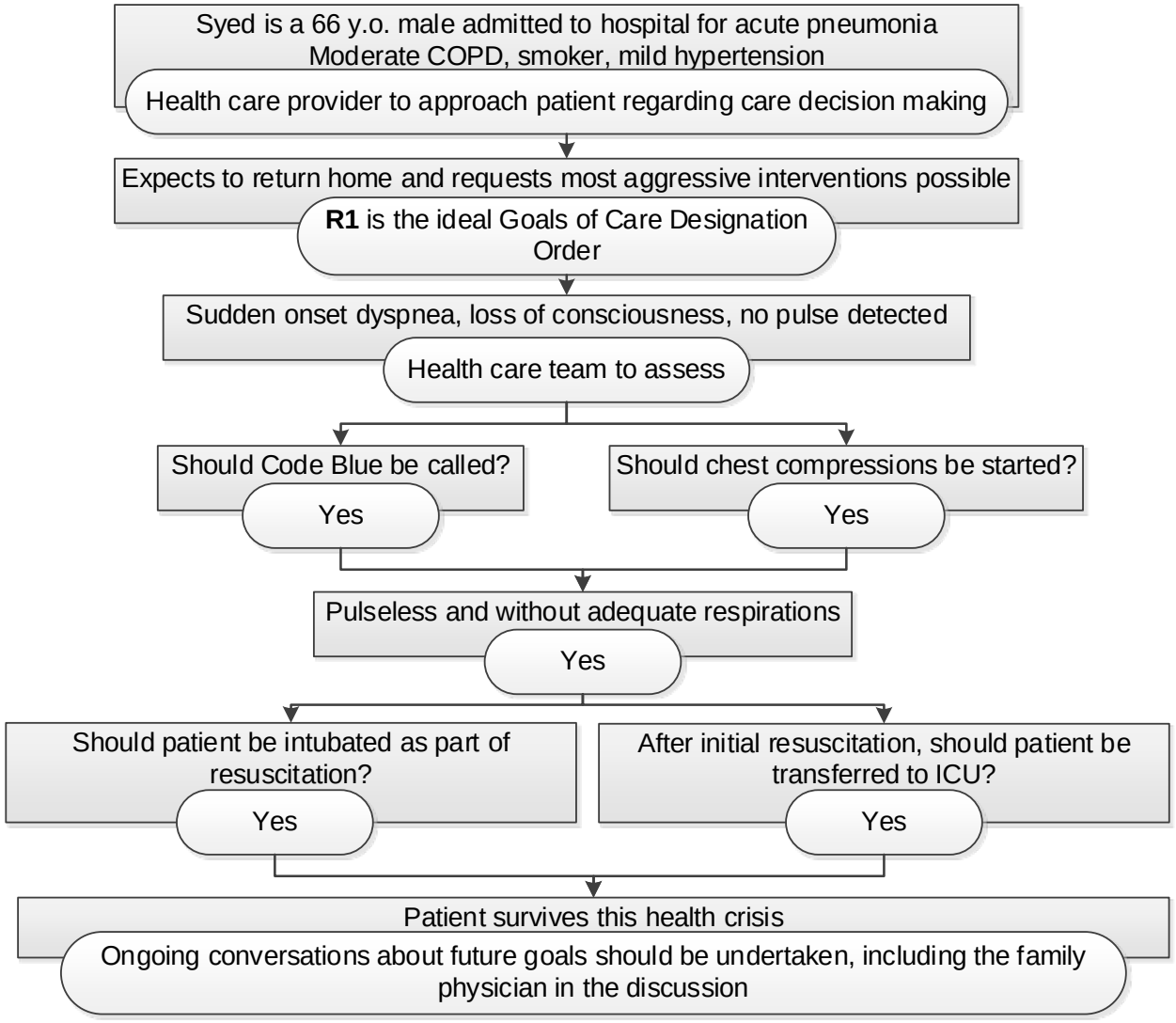


Figure 1 Discussion Points:

Hopefully this patient would have had an ACP/GCD discussion with his family doctor prior to becoming ill enough to require hospital admission. That conversation and decision about the appropriate GCD would be documented as a GCD Order, along with a notation on the ACP/GCD Tracking Record, with both forms placed in a Green Sleeve for the patient to own and produce at relevant health care encounters. In the future, such documents may be uploadable from the family physician's office into a provincial Clinical Information System.

**Figure 2: R1 Adult Scenario - Chest pain, tachycardia and dyspnea suspicious for acute MI during dialysis clinic visit**

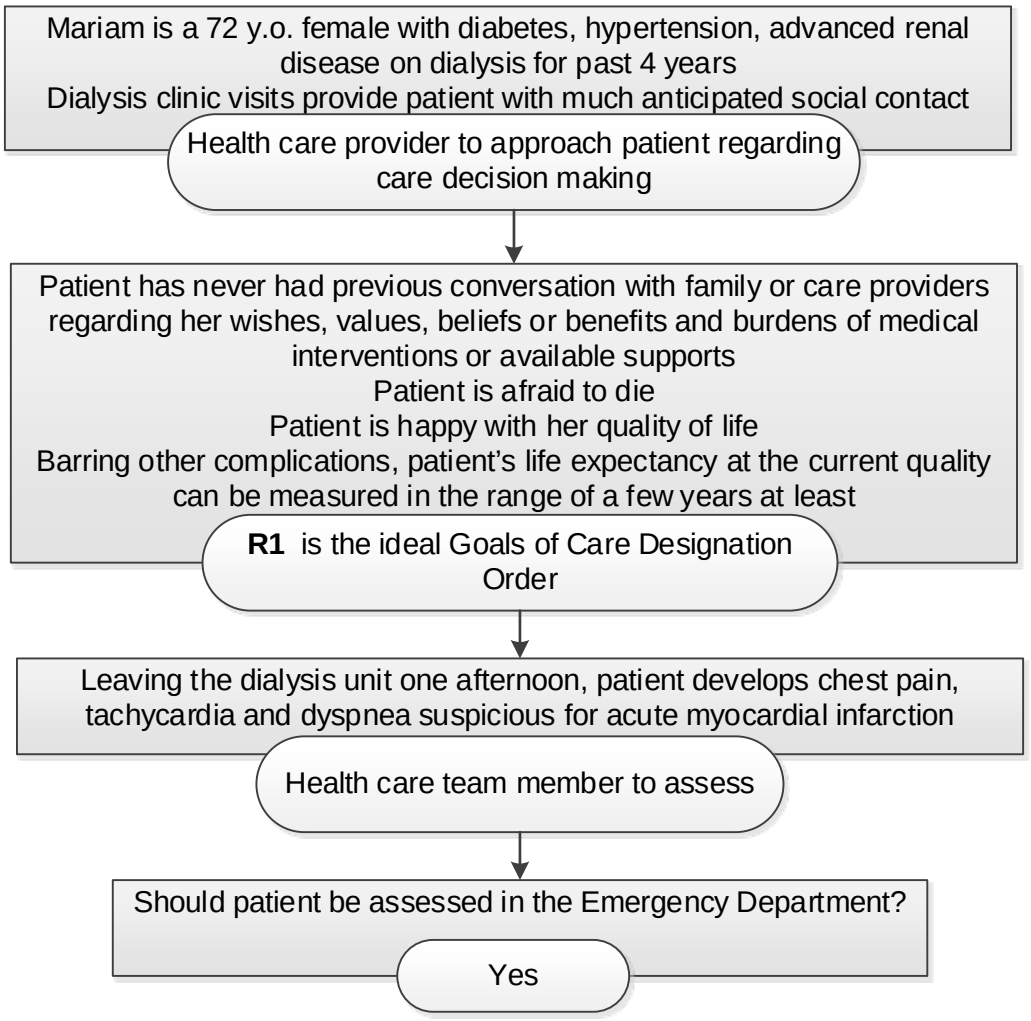


Figure 2 Discussion Points:

Having had the conversation leading to a GCD Order, any health care team will know what to do in service of her goals, in case of an acute health deterioration. The ACP/GCD conversation can be initiated by any member of any of her care teams, and should eventually include any members who can contribute usefully to a good decision. Conversations leading to a GCD Order should be documented on the ACP/GCD Tracking Record.

For this patient, the prior lack of an ACP/GCD conversation and the lack of a GCD Order would be considered unsafe and below the standard of care. It is every health care provider's responsibility, within their scope of practice, to initiate steps to correct the absence of an ACP conversation and a GCD Order. For non-physicians that could involve alerting a supervisor or the MRHP of this need.

**Figure 3: R1 Adult Scenario – Elderly patient with sudden onset massive GI hemorrhage**

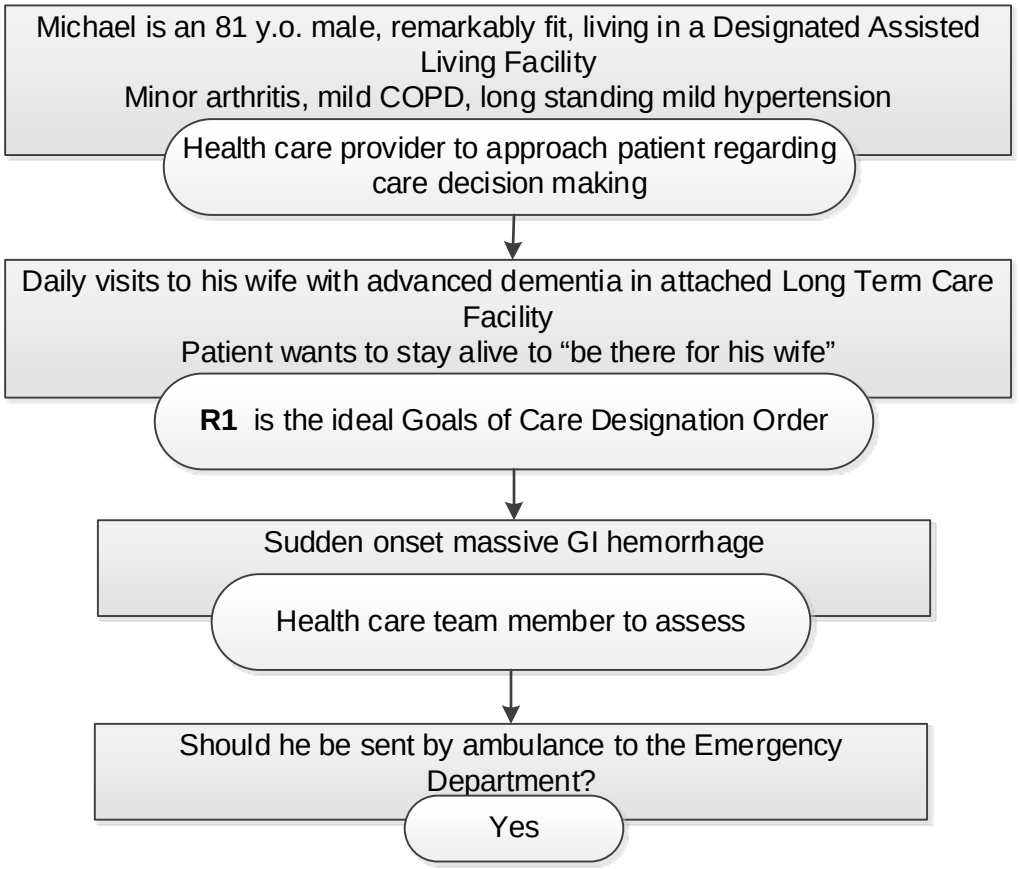


Figure 3 Discussion Points:

Age is not solely determinative of a specific GCD Order. In compliance with his important self-determined goals and considering what can be done medically in service of his goals, especially taking into account his relative absence of serious condition or disease prior to this episode, R1 designation could be appropriate. Document the conversation leading to the GCD Order on the ACP/GCD Tracking Record.

The actions taken to address his new health crisis are appropriate.

**Figure 4: R1 Adult Scenario – 28 year old patient with severe lupus**

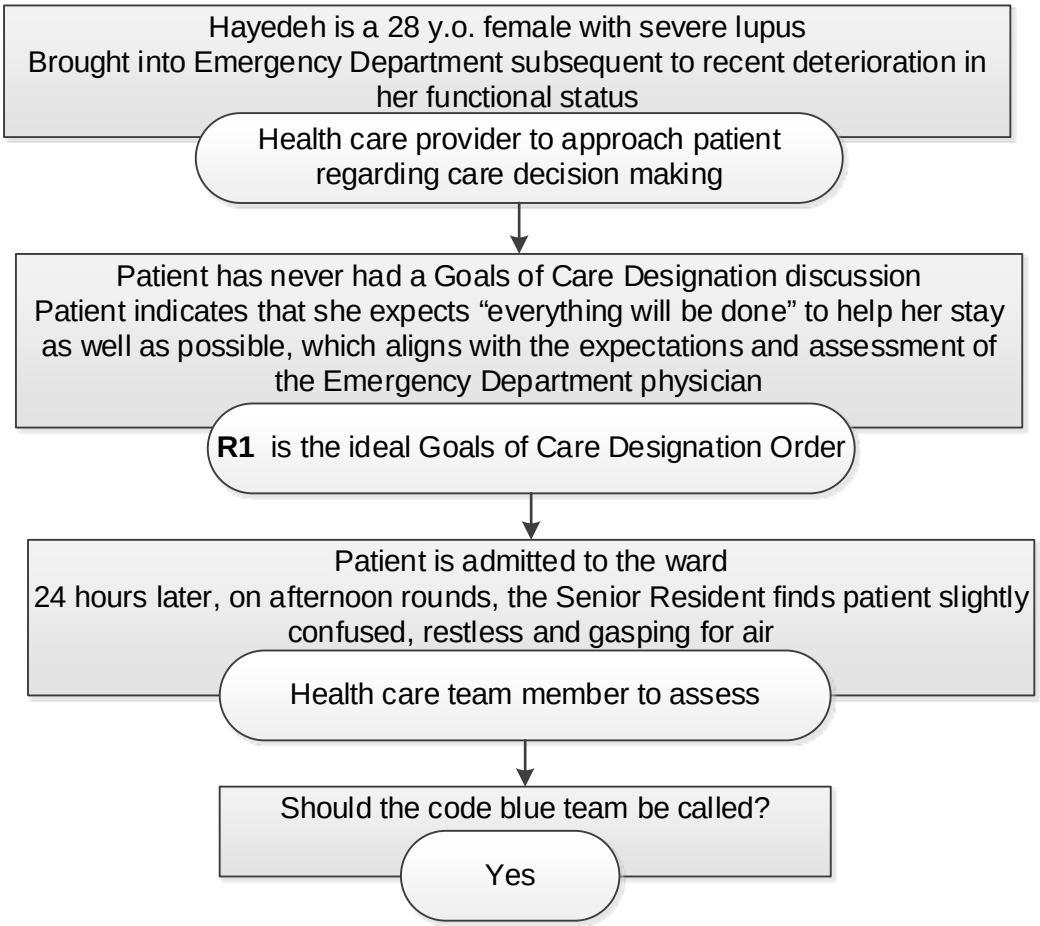


Figure 4 Discussion Points:

Ideally, as a young patient who has a serious condition or disease that could result in acute deterioration at any time, she would have had the benefit of a prior advance care planning/goals of care designation conversation, leading to a GCD Order that would be in her possession and documented in clinic notes (including her family physician and her rheumatologist) along with documentation describing the decisions, recorded on the ACP/GCD Tracking Record.

An R1 GCD offers her the benefits of intensive investigation and life-saving/life-sustaining measures as initial interventions.

**Figure 5: R2 Adult Scenario – Post-operative severe dyspnea & cyanosis**

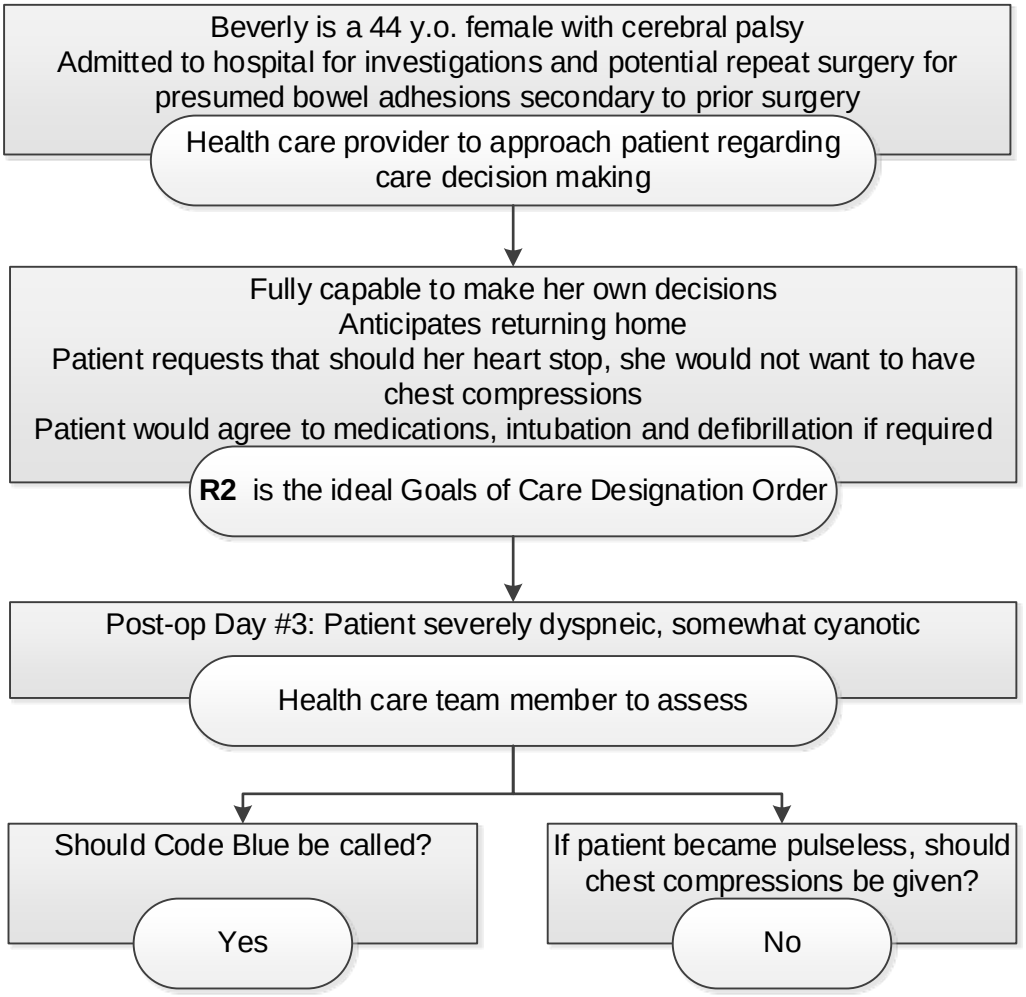


Figure 5 Discussion Points:

This patient is deciding to partially limit the extent of life-saving interventions should she encounter a life-threatening clinical situation.

She should be made aware that her decision will be honored. She should also be aware that without chest compressions, the chances of successful future resuscitation could be lessened. The conversation leading to the GCD Order should be documented on the ACP/GCD Tracking Record.

**Figure 6: R2 Adult Scenario – Conscious patient with ventricular tachycardia**

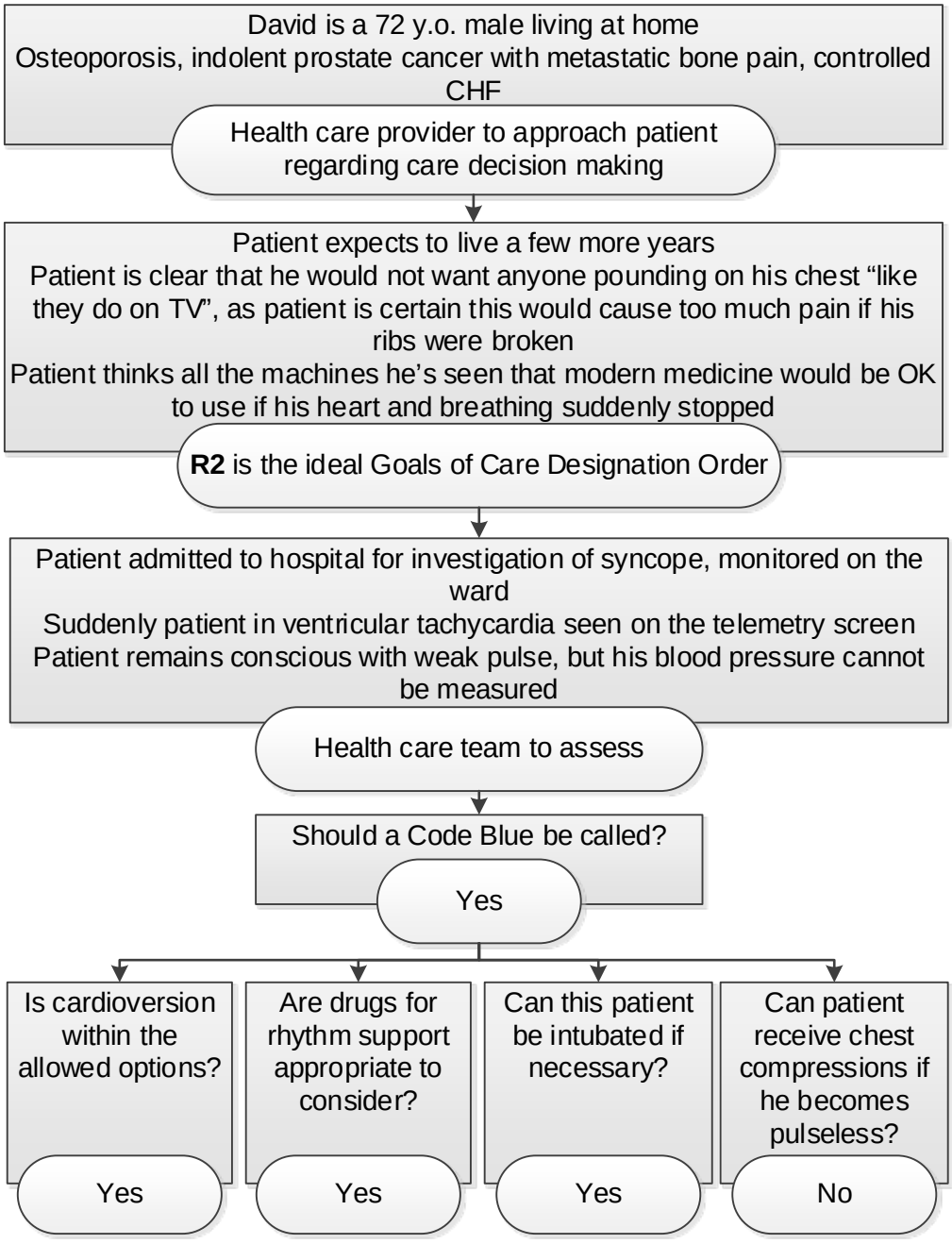

Figure 6 Discussion Points:

This patient has limited the extent of life-saving interventions that can be considered in the event of a cardio-respiratory collapse. He should be aware that this decision will be honored, and that other life-saving/life-sustaining interventions will be tried if they can be useful in helping him. Depending on his outcome, further conversations may be necessary to consider affirming or revising his GCD Order. These further conversations will be aided by documentation on the ACP/GCD Tracking Record about what was discussed.

**Figure 7: R3 Adult Scenario – Patient lacks decisional capacity, family member not in agreement with GCD Order**

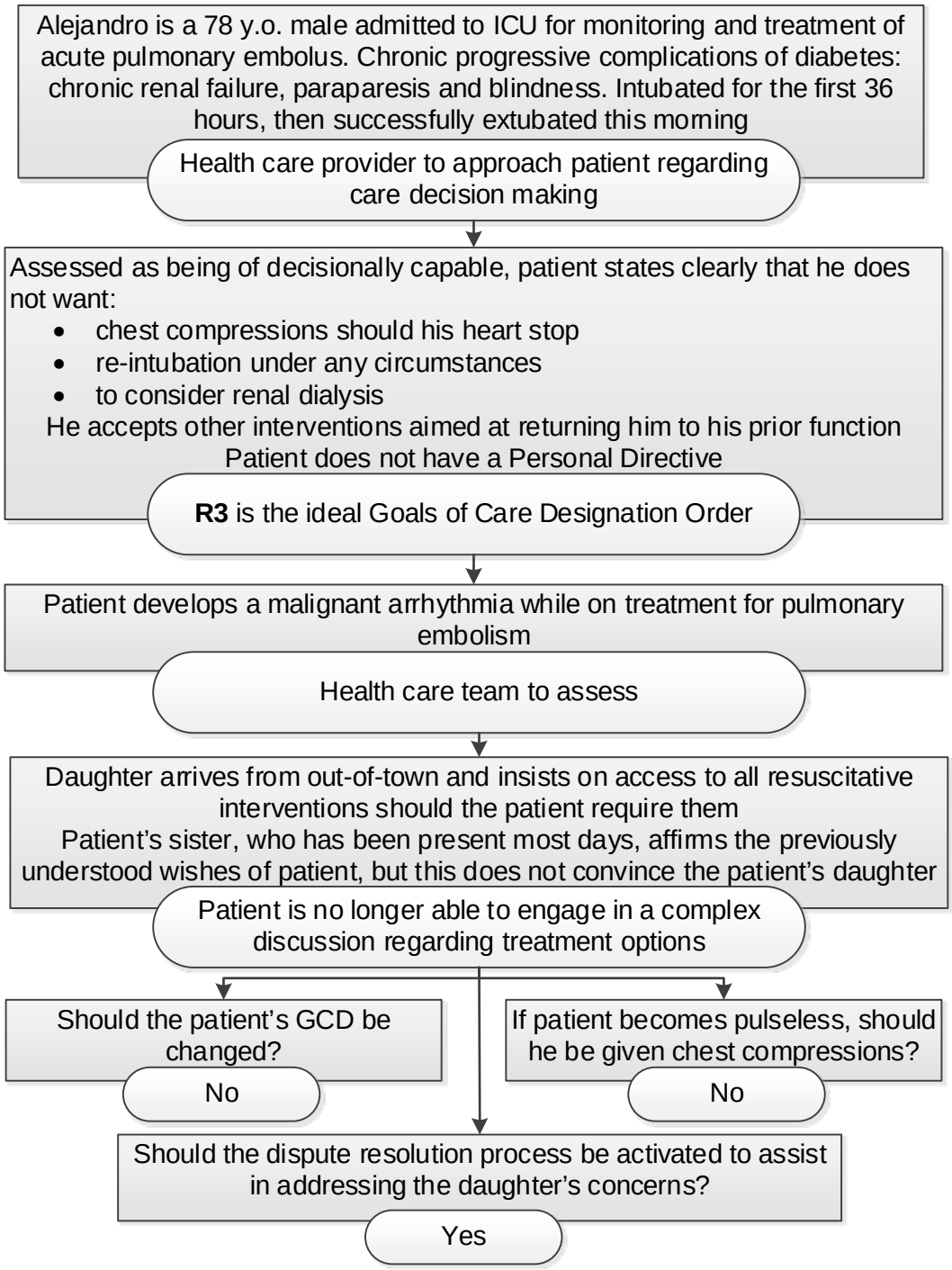

Figure 7 Discussion Points:

The patient's GCD Order is R3, and the special instructions that reflect his desire to also not have dialysis, should be noted prominently on his health record and in his Green Sleeve.

This scenario demonstrates the value of documenting the conversation and who was present during the conversation, within the ACP/GCD Tracking Record.

Despite his daughter's insistence, the health care team should honor the patient's wishes. However, the dispute resolution mechanism should be invoked in order to help the patient, the care team and the patient's family to have disagreement resolved constructively and in an open manner. This should be done as an emergency considering the patient's tenuous medical condition, and hopefully before a life-threatening change in his condition occurs. Of course, any of the resources triggered by the dispute mechanism can be used as helpful resources before the dispute resolution process is initiated. If there had been more time, the team could have considered the value of engaging any of the teams such as spiritual care, social work, ethics or palliative care to assist in decision-making. Information regarding the AHS dispute resolution mechanism can be found on AHS Insite: http://insite.albertahealthservices.ca/8738.asp

His daughter can apply to the Court for a Guardianship Order or other remedies to address her concerns. The health care team, with support from Clinical Legal, will decide appropriate clinical intervention in the circumstances of an unresolved dispute of such magnitude, pending an emergency Court action brought by either the patient's daughter or by AHS, for judicial intervention.

**Figure 8: R3 Adult Scenario – CCU Admission, patient hypotensive, hypoxic and unresponsive**

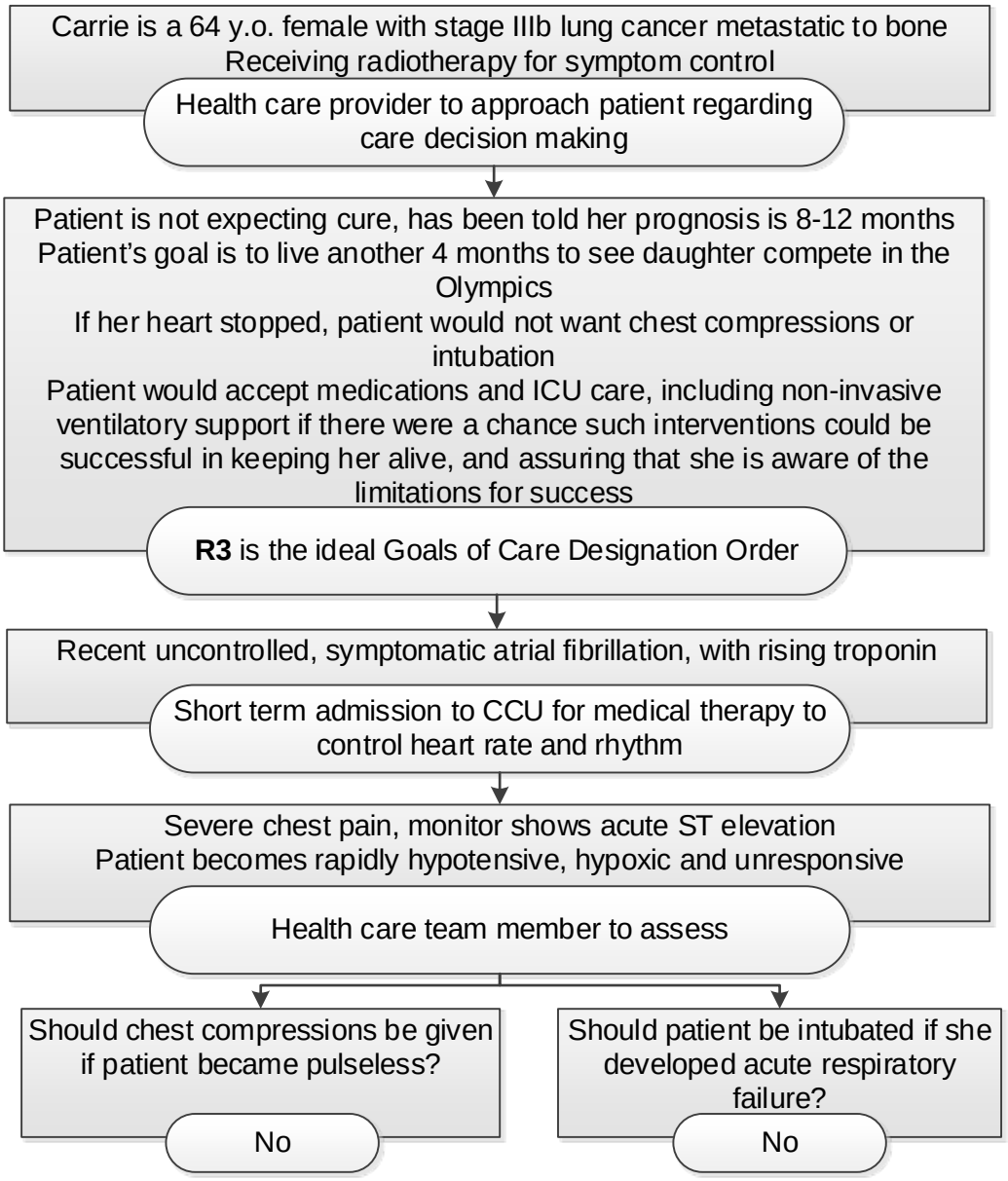


Figure 8 Discussion Points:
After a healthy and inclusive ACP/GCD discussion that outlines the benefits and limitations of various intervention approaches, this patient understands and accepts the limitations on successful resuscitation should she suffer cardio-respiratory collapse from any cause.
The care team will invoke intensive medical interventions (without chest compressions and intubation) to the degree that medical interventions can be useful to support her physiology, and will revert to comfort measures if her physiology cannot be adequately supported to keep her alive. The conversation details should be recorded on the ACP/GCD Tracking Record.

**Figure 9: M1 Adult Scenario – Hip fracture and post-operative ICU care**

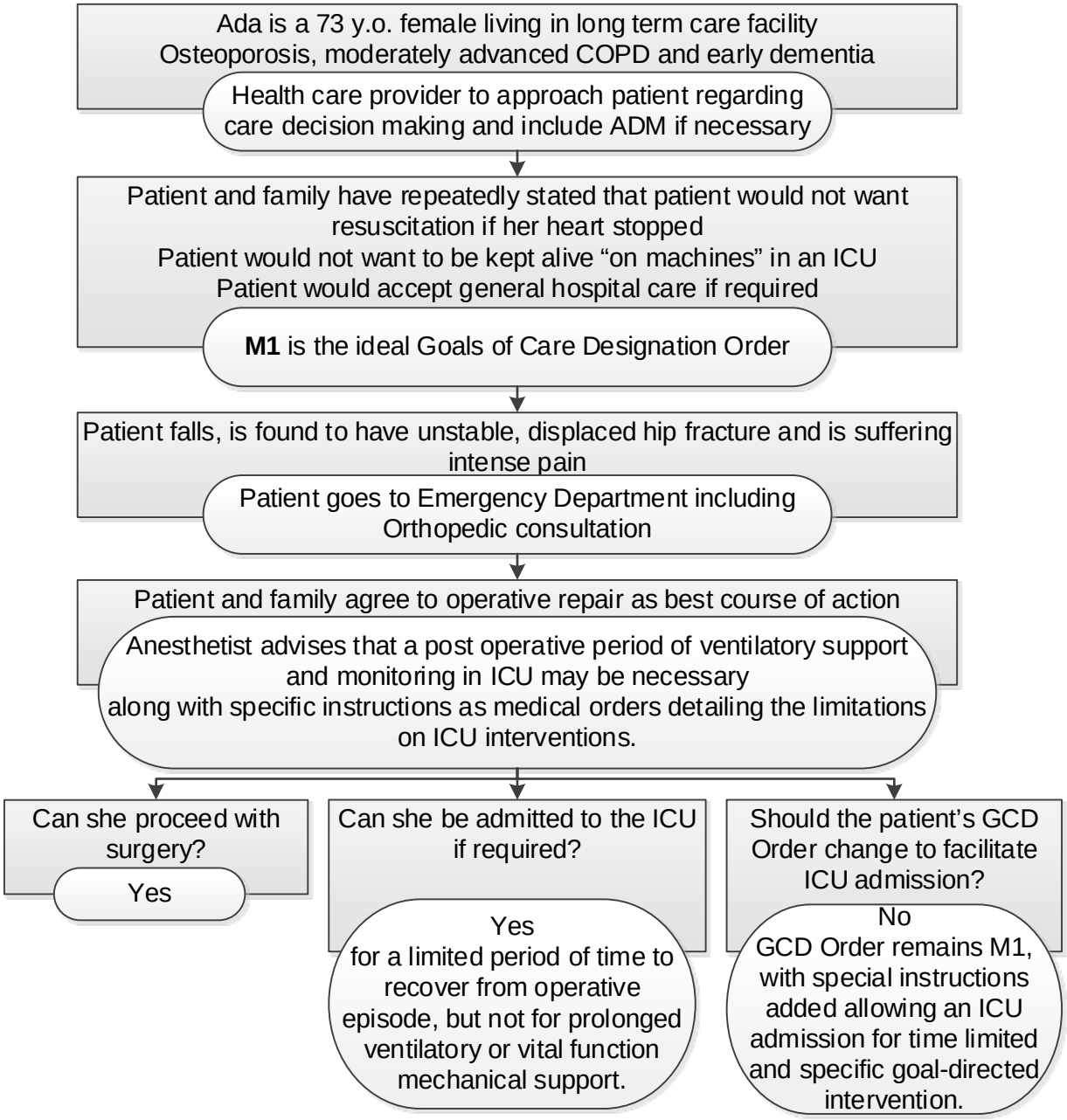

Figure 9 Discussion Points:

Full discussion with the patient and family regarding the care that might be required as part of the operative episode, and documentation of this conversation, is required. Summary instructions are to be placed in the appropriate location on the GCD Order, and the ACP/GCD Tracking Record should contain more complete details. Documentation also must include the special instructions for this patient that allows ICU care for a limited time, while retaining the M1 GCD Order.

Her M1 GCD Order does not limit the anesthetist from providing appropriate respiratory and circulatory support during the operative and peri-operative time, even if she unexpectedly deteriorates. During the time of operative and peri-operative intervention all measures to allow that intervention to be as successful as possible are considered to be legitimate as agreed to by the clinical teams, patient and family. This is why the GCD Order is not changed to R1 for the peri- and intra-operative period.

Her M1 GCD Order also expresses her desire to not have prolonged cardio-respiratory support in an ICU should her course of recovery not proceed as expected. Withdrawal of life-support measures in that circumstance, after appropriate conversations and consultations, would usually be seen as appropriate.

**Figure 10: M1 Adult Scenario - sepsis suspected secondary to indwelling catheter**

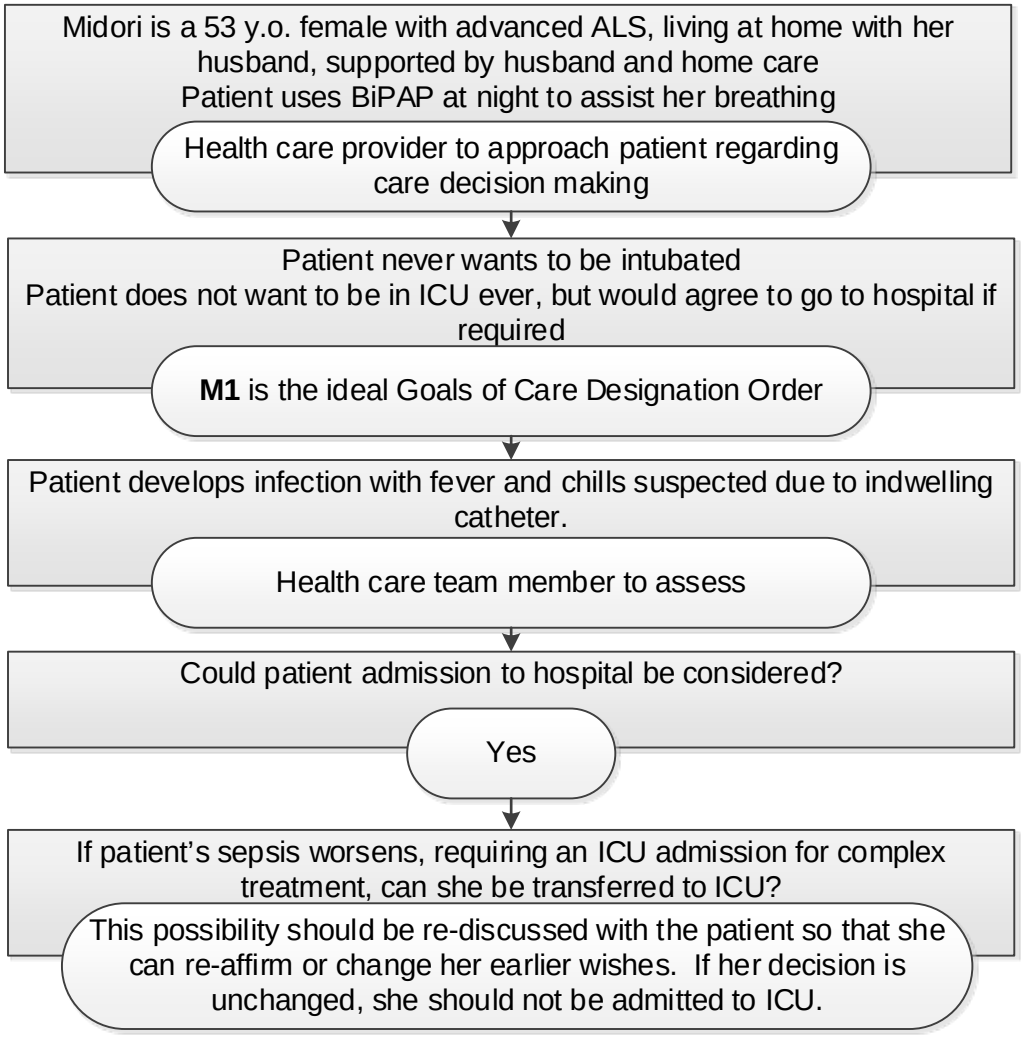


Figure 10 Discussion Points:

Addressing the new situation with the patient is required, so that she can either affirm her prior decision or change her mind. If she is no longer capable to make and communicate a decision, and if she does not have an Agent named in a Personal Directive who can speak for her, her previously stated wishes should be honored. It would be useful to include an ADM in discussions, although this is not required. Recognizing that the patient and the health care team may require use of the ADM to guide treatment decisions at some point, it is prudent to make the ADM aware of ACP conversations (with patient approval). Documentation on the ACP/GCD Tracking Record will assist all decision-makers and should be done.

If she is not admitted to an ICU, continued treatment outside of ICU is warranted, including exemplary symptom management. If her condition deteriorates, and treatment is no longer expected to help her to live, further discussion of her GCD Order may lead to a change to either C1 or C2 (depending on her proximity to death), along with the provision of ideal palliative care.

**Figure 11: M1 Adult Scenario – Long term care patient with pneumonia and deterioration of respiratory status**

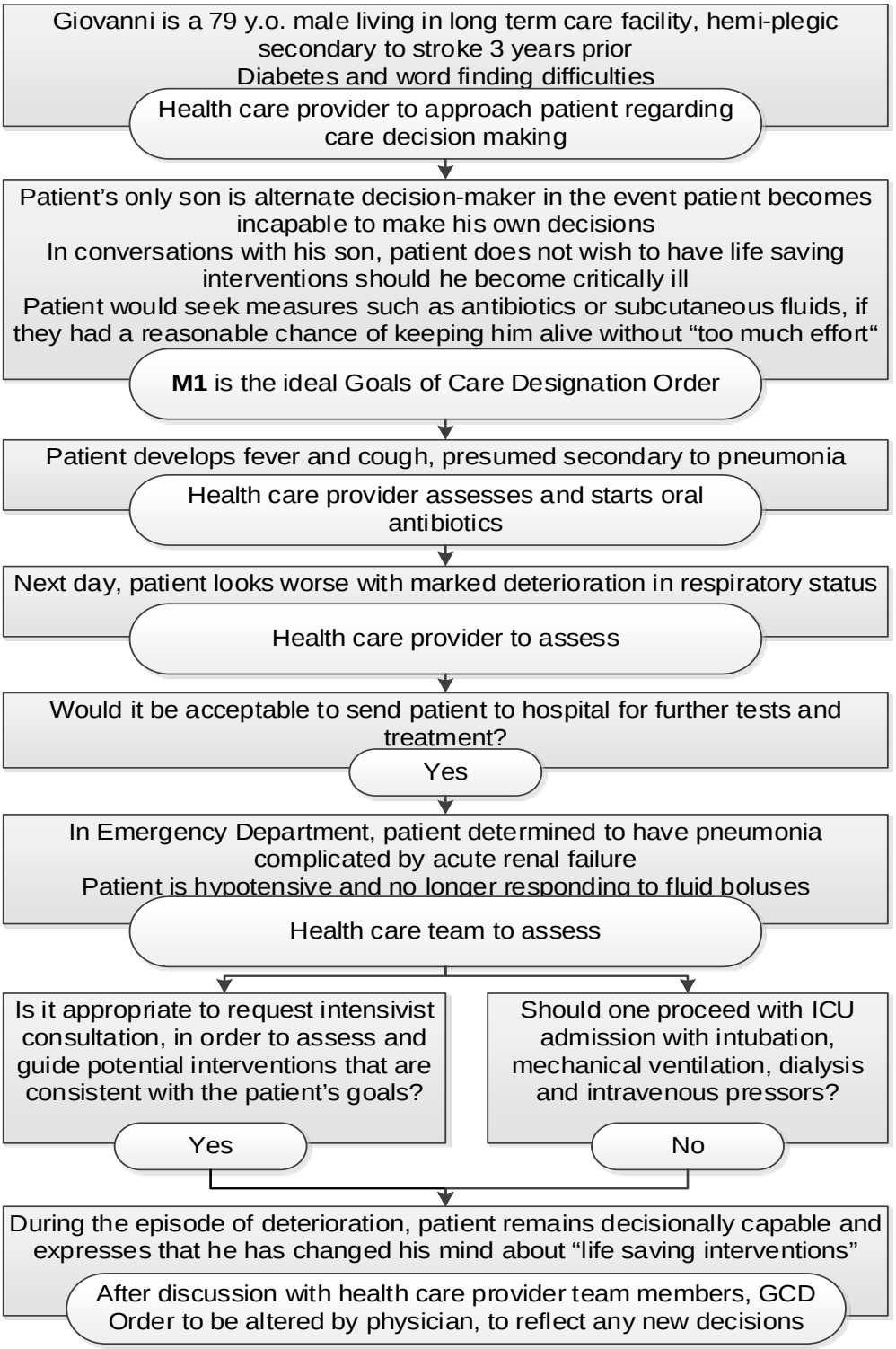

Figure 11 Discussion Points:

Patients sometimes change their mind in the midst of acute deterioration. Careful deliberation with the patient, family members (if the patient wishes them to be involved), ADM and relevant members of the health care team should be undertaken. The patient must be able to understand the relevant consequences of the decisions he is either affirming or wishing to change. If he is no longer capable of understanding and communicating the important impacts of his decisions, honoring the prior expressions of his wishes is appropriate. Keeping track of these important conversations and how the values underlying decision change over time is accomplished by documenting on the ACP/GCD Tracking Record.

**Figure 12: M2 Adult Scenario – Patient at home, suddenly critically ill**

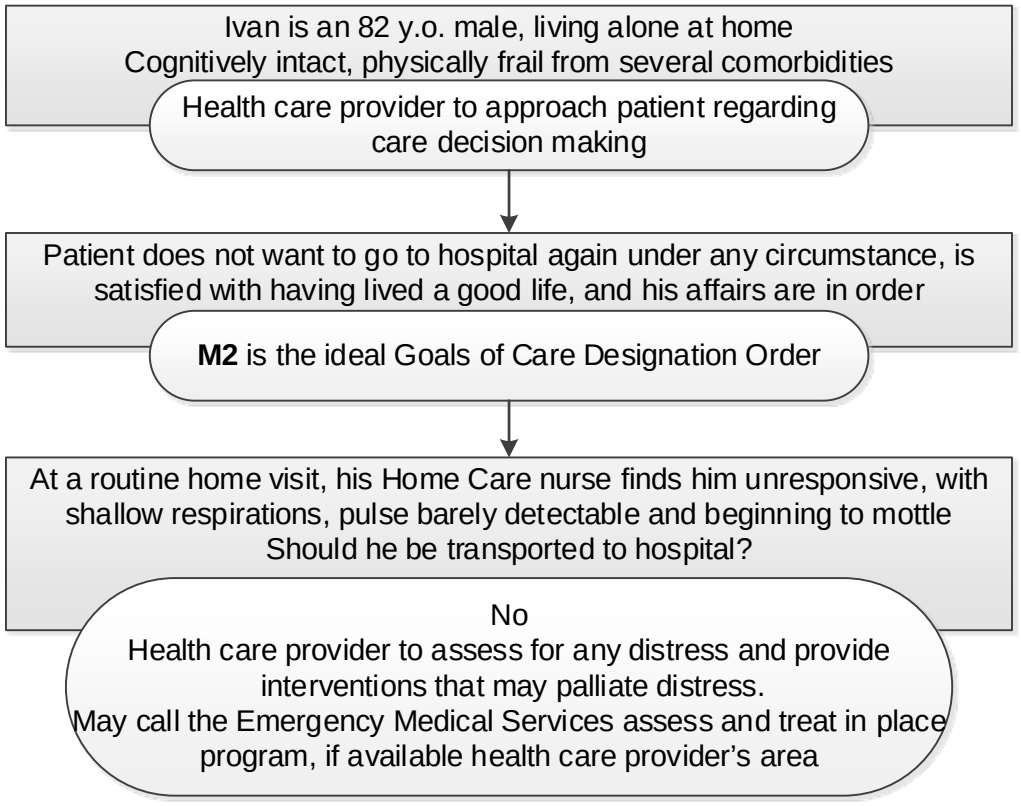


Figure 12 Discussion Points:

This patient is dying and maximum efforts to ease any symptoms should be undertaken. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 13: M2 Adult Scenario – Choking patient**

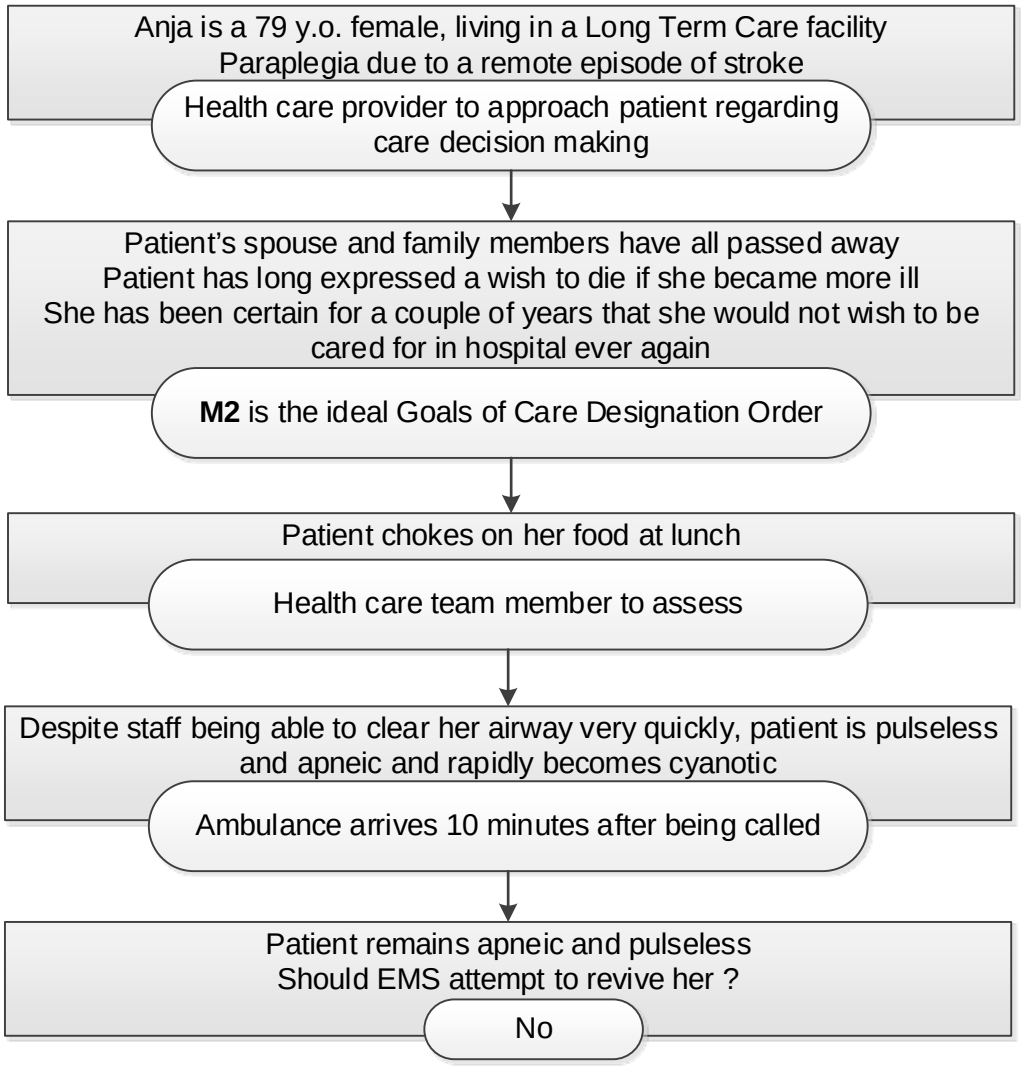


Figure 13 Discussion Points:

Even though the apparent cause of her acute deterioration and likely death is choking, she has died despite best efforts to respond quickly and clear her airway. Paramedics should not attempt to revive her, since such efforts would be counter to her clearly expressed wishes. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 14: C1 Adult Scenario – Impaired swallowing mechanism**

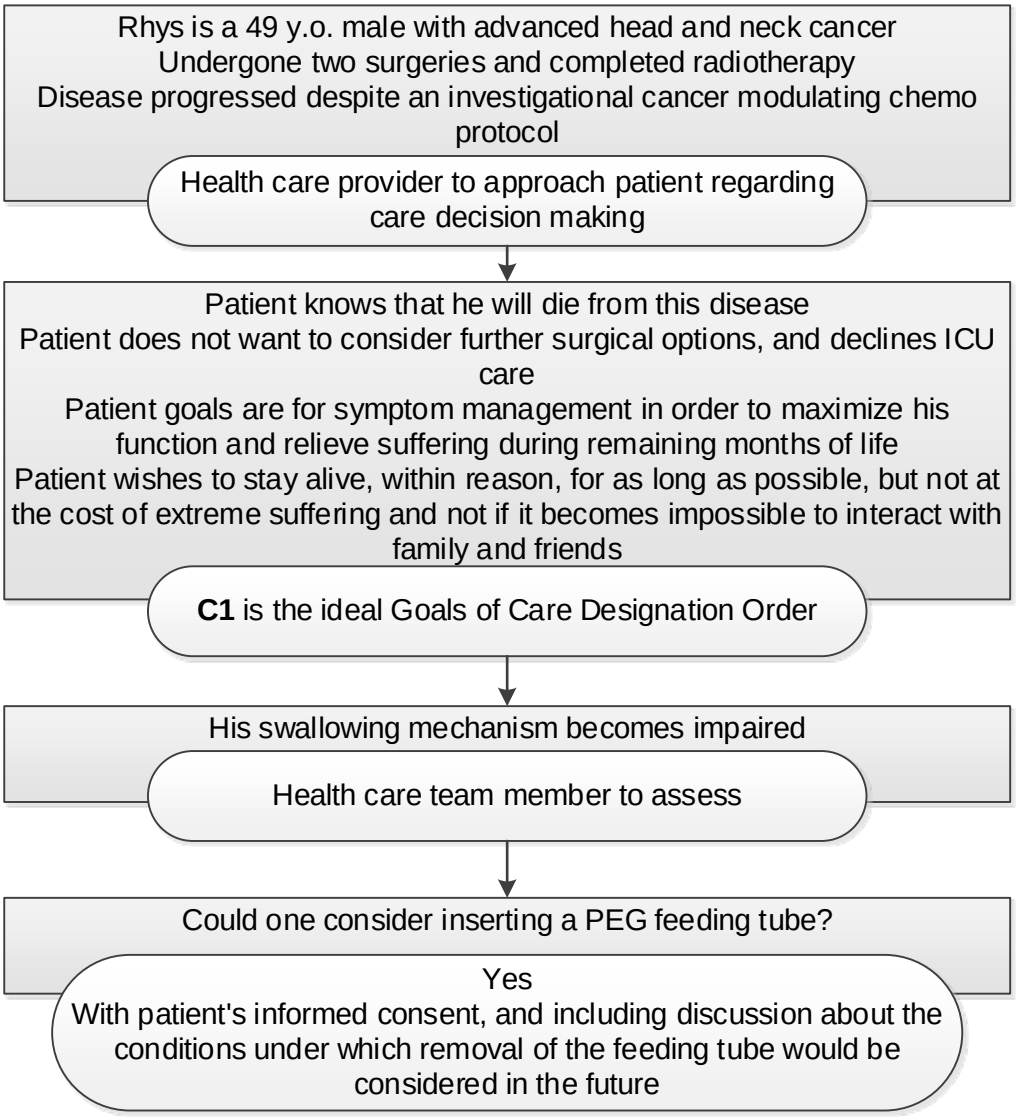


Figure 14 Discussion Points:

Managing symptoms and supporting function so that a patient can meet their goals during the time that their death approaches means that location-specific aggressive supportive interventions can still be considered after fulsome discussion with the patient, and deliberate consent for such a procedure. Documenting the conversations and decisions on the ACP/GCD Tracking Record should be done.

**Figure 15: C1 Adult Scenario – Surgery and post-operative ICU care**

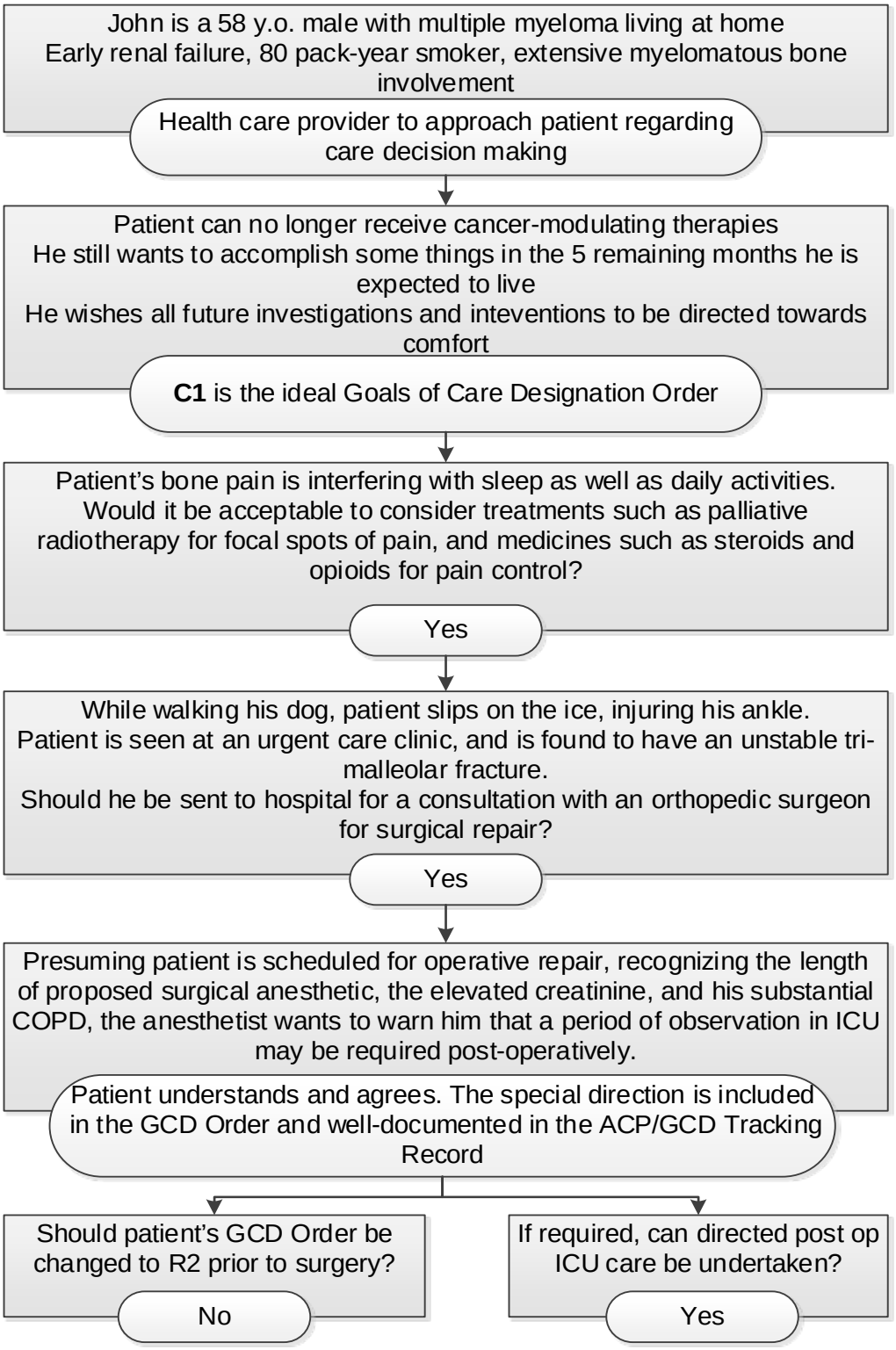

Figure 15 Discussion Points:

Full opportunities for intra-operative and peri-operative physiologic support should remain in the hands of the anesthetic and surgical team, in order for surgical goals to be met. ICU admission is also possible, within the limitations the patient has provided.

The GCD Order remains C1 during the peri-operative episode, along with clearly documented special instructions that chest compressions should not be used in the event of cardio-respiratory collapse. Further, if the patient cannot be extubated after a reasonable post-operative time in ICU, considering his underlying condition and his wishes, then life-support measures can be withdrawn subsequent to appropriate discussion and consultations. Further documentation of these conversations and special instructions on the ACP/GCD Tracking Record will aid in communication between all involved teams.

For hints on how to proceed with difficult conversations, please see the Serious Illness Conversation Guide.

**Figure 16: C2 Adult Scenario – Family request for O2 therapy for acutely dyspneic and restless patient**

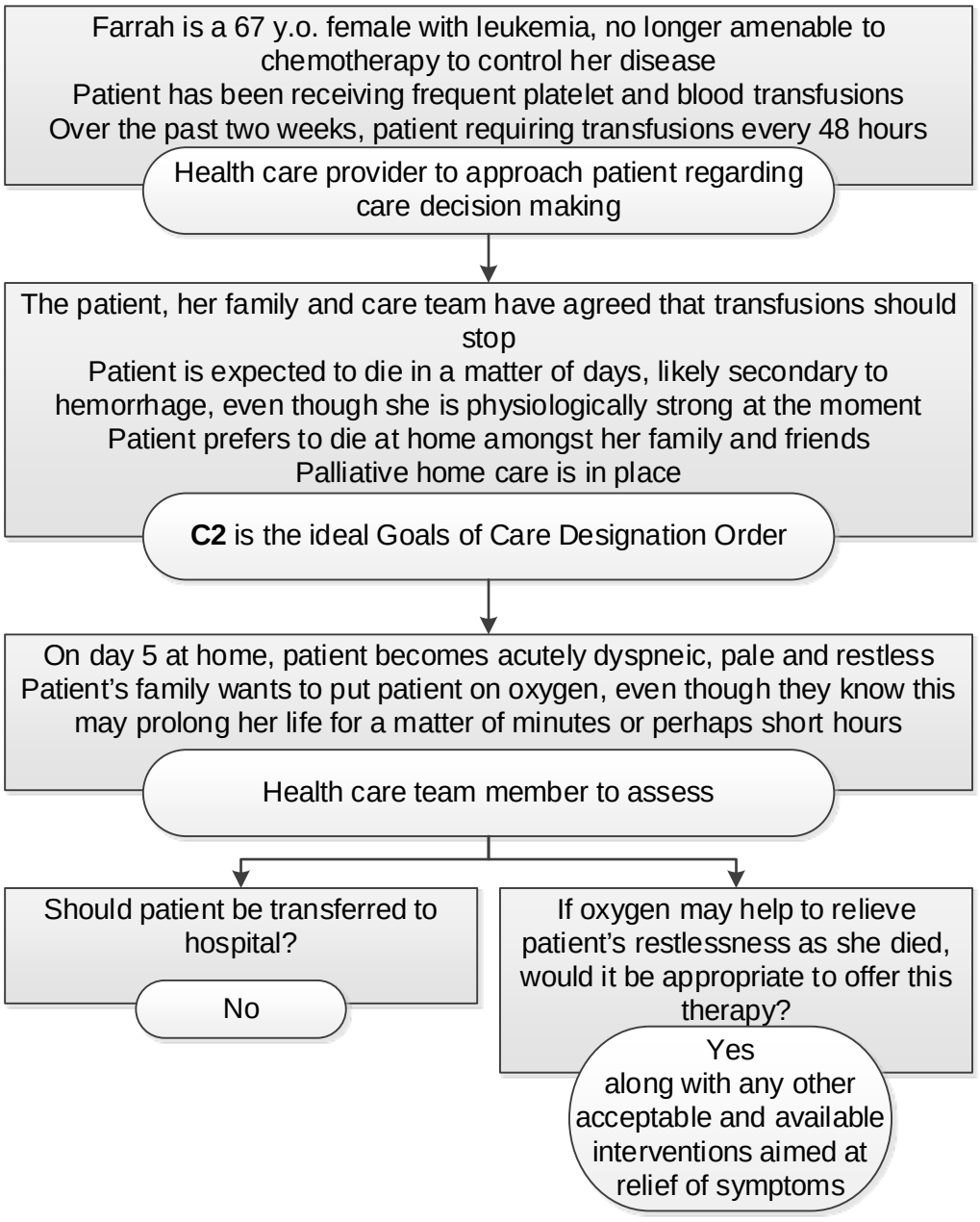

Figure 16 Discussion Points:

Measures aimed solely at prolonging life should not be undertaken, but measures that have a possibility to relieve distress can be utilized, even if these interventions might marginally prolong life – as long as their use does not cause other undue suffering that cannot be mitigated.

Other palliative interventions might better manage her dyspnea/restlessness, and should be considered. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 17: C2 Adult Scenario – Hospitalized imminently dying patient**

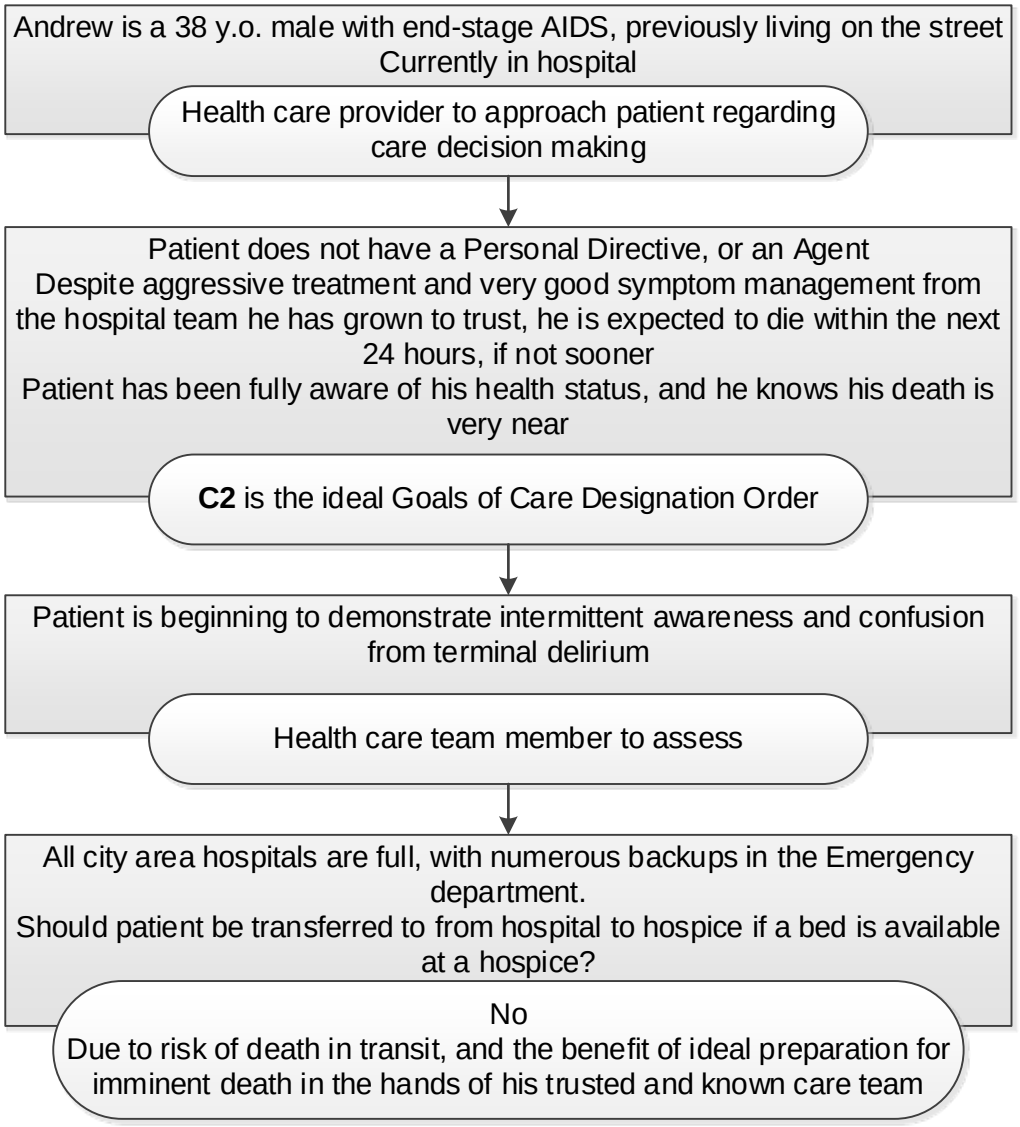


Figure 17 Discussion Points:

A C2 GCD Order asks all members of the team to be thinking about imminent death and to undertake actions that best support the patient in preparation for imminent death. Documenting the conversations on the ACP/GCD Tracking Record helps assure that all health care personnel understand and follow Andrew's wishes.

**Pediatric Decision Making Scenarios** - *The following scenarios are for illustrative purposes only and are not meant to limit specific clinical decision making.*

**Figure 18: R1 Pediatric Scenario – Previously healthy, collapse during sports**

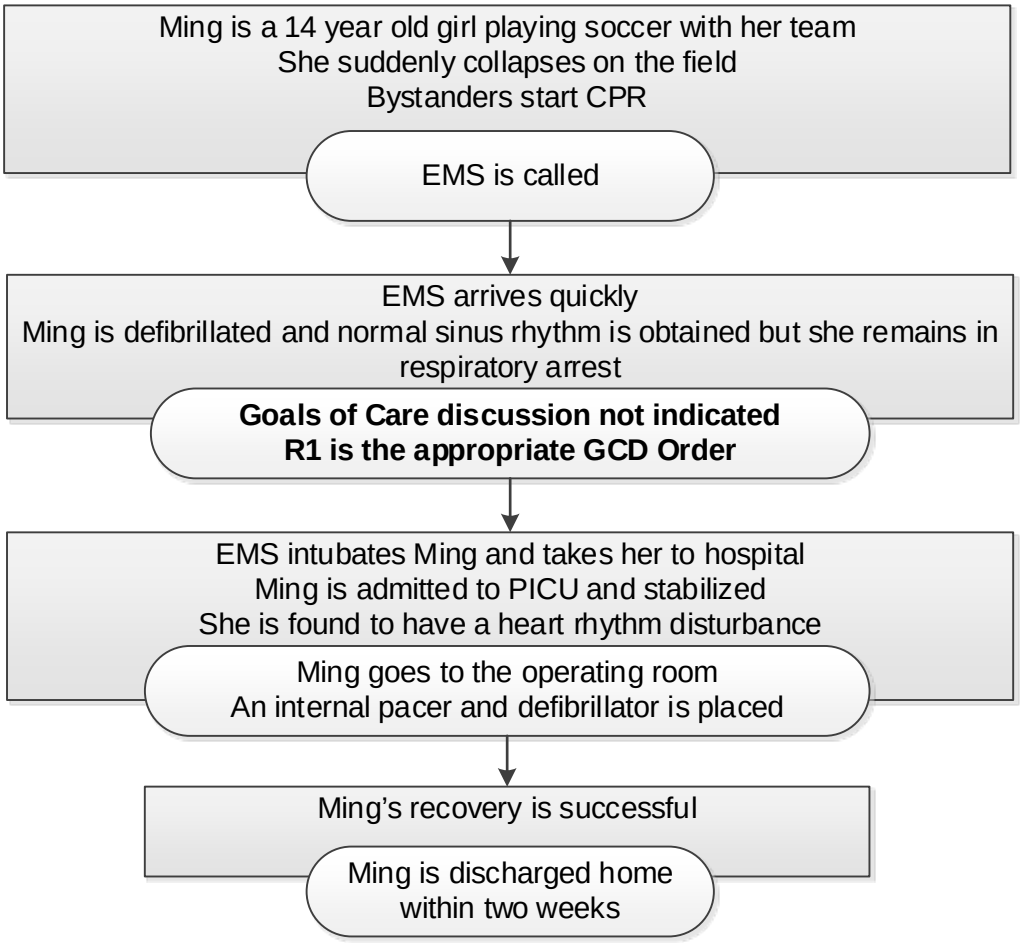


Figure 18 Discussion Points:

Healthy children will not have a GCD. It is assumed for children, or when there is no documentation, that the GCD is R1.

All resuscitative measures are performed even in the absence of an R1 GCD Order. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 19: R1 Pediatric Scenario – Child with Neurological Condition**

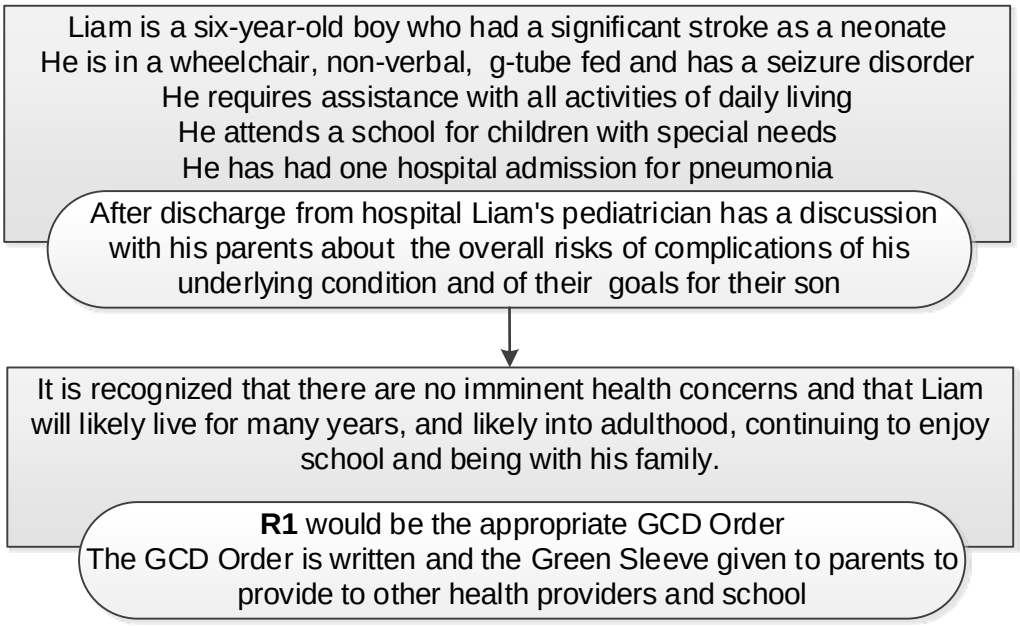


Figure 19 Discussion Points:

It is common for children who have severe or profound neurodevelopmental disabilities to have a GCD Order of R1. The benefit of explicitly documenting this GCD is to indicate that a conversation and decision have occurred to determine this GCD Order. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record. This helps all clinicians to understand the thinking that went into the eventual decision, including the clinical expertise of the team and the values expressed by Liam's parents.

**Figure 20: R2 Pediatric Scenario – Extremely premature infant (born at extremely low gestational age)**

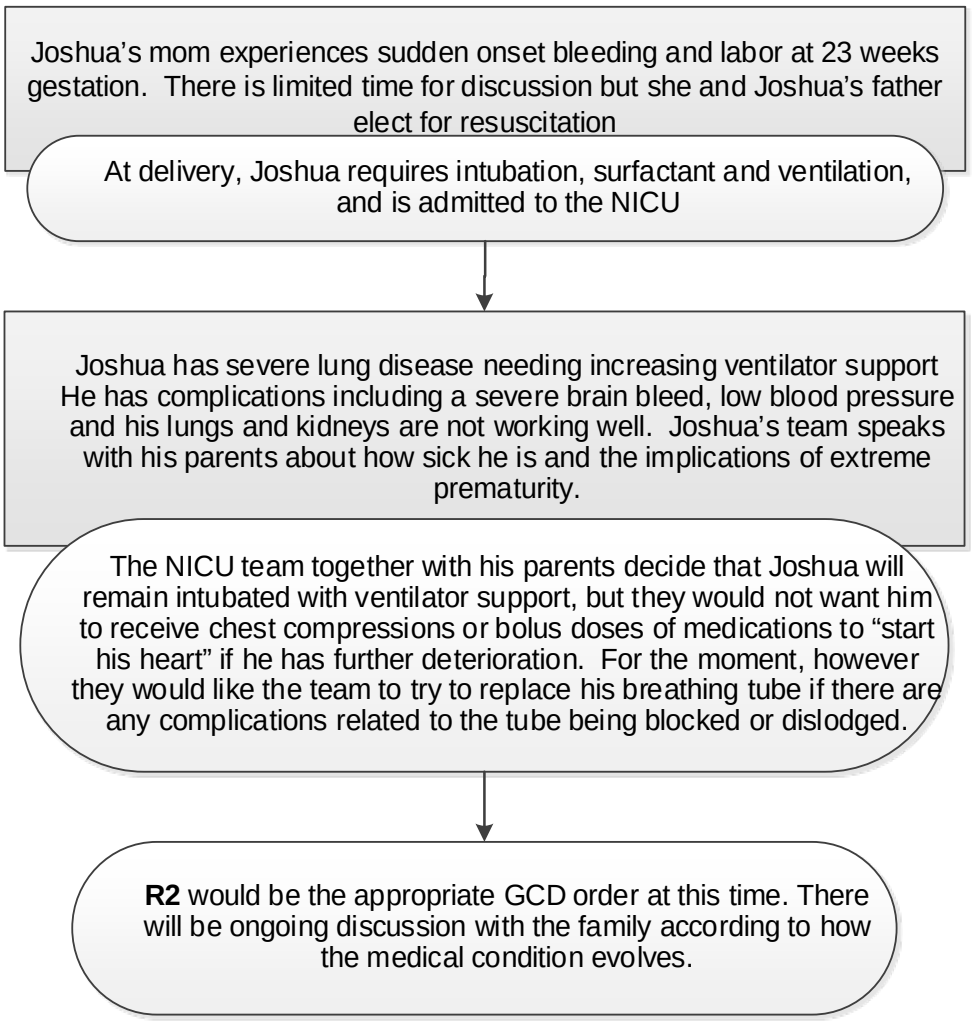


Figure 20 Discussion Points:

Any Goals of Care Designation may be appropriate in the NICU setting, depending on the patient's circumstances and how their conditions evolve over time. Advance Care

Planning/Goals Care Designation Tracking Record completion will help inform all future conversations.

**Figure 21: R2 evolving to C2 Pediatric Scenario – Hypoxic-ischemic encephalopathy (HIE)**

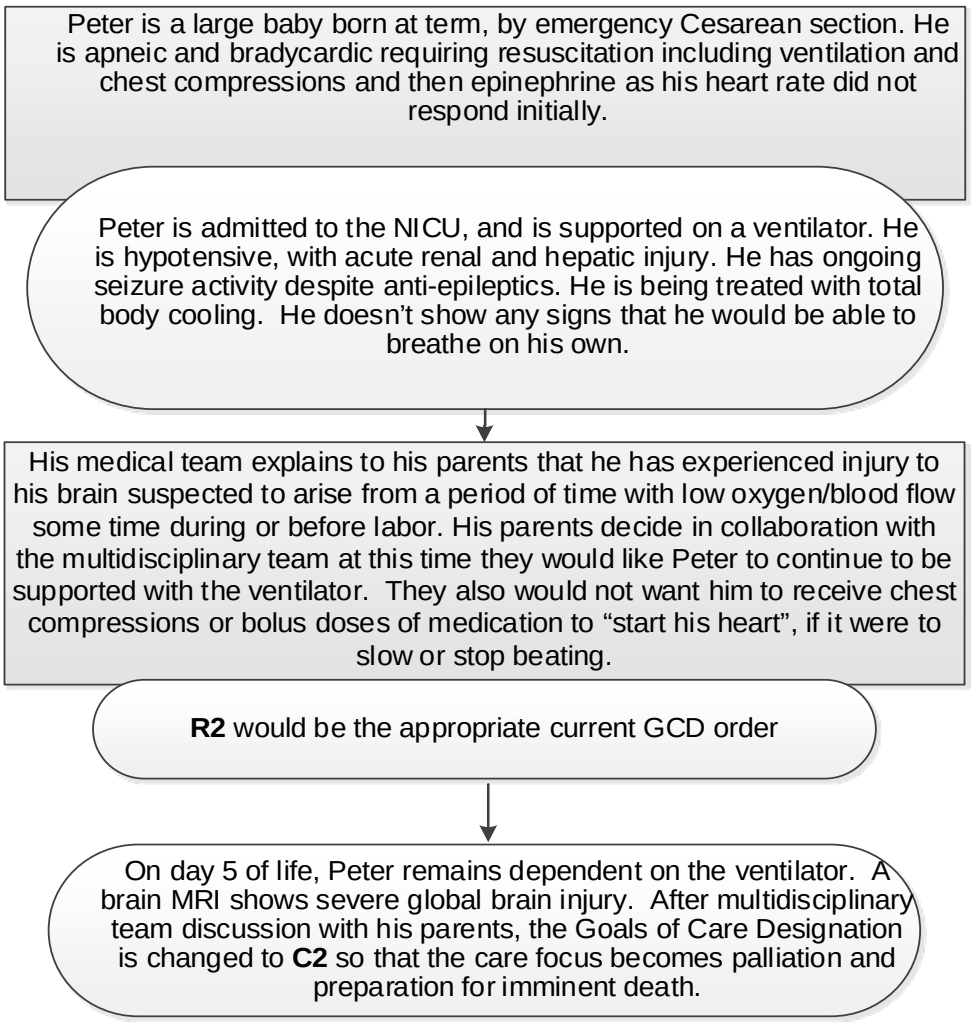


Figure 21 Discussion Points:

Any Goals of Care Designation may be appropriate in the NICU setting, depending on the patient's circumstances and how their conditions evolve over time. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 22: R3 Pediatric Scenario – Multiple abnormalities noted on antenatal ultrasound**

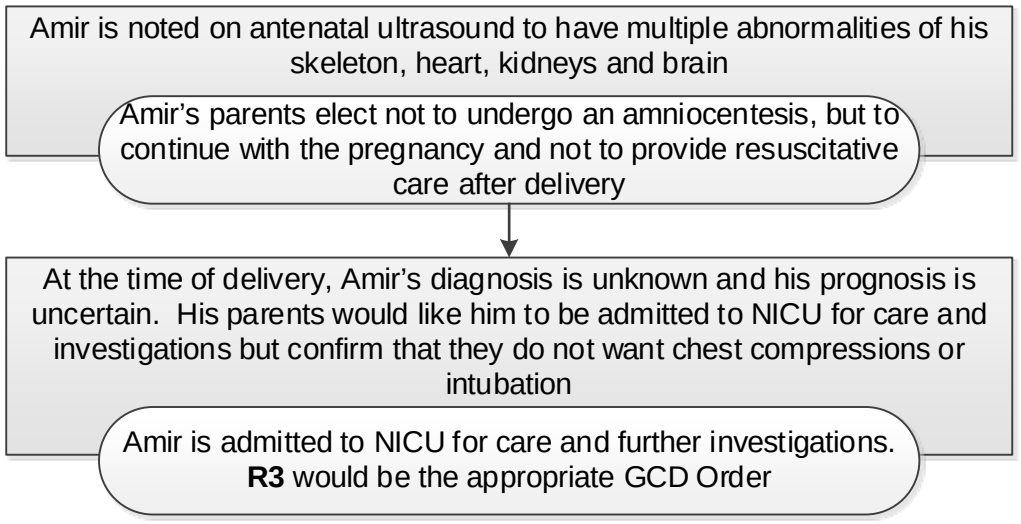


Figure 22 Discussion Points:

The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 23: M1 Pediatric Scenario – Complex congenital heart disease with frequent respiratory infections**

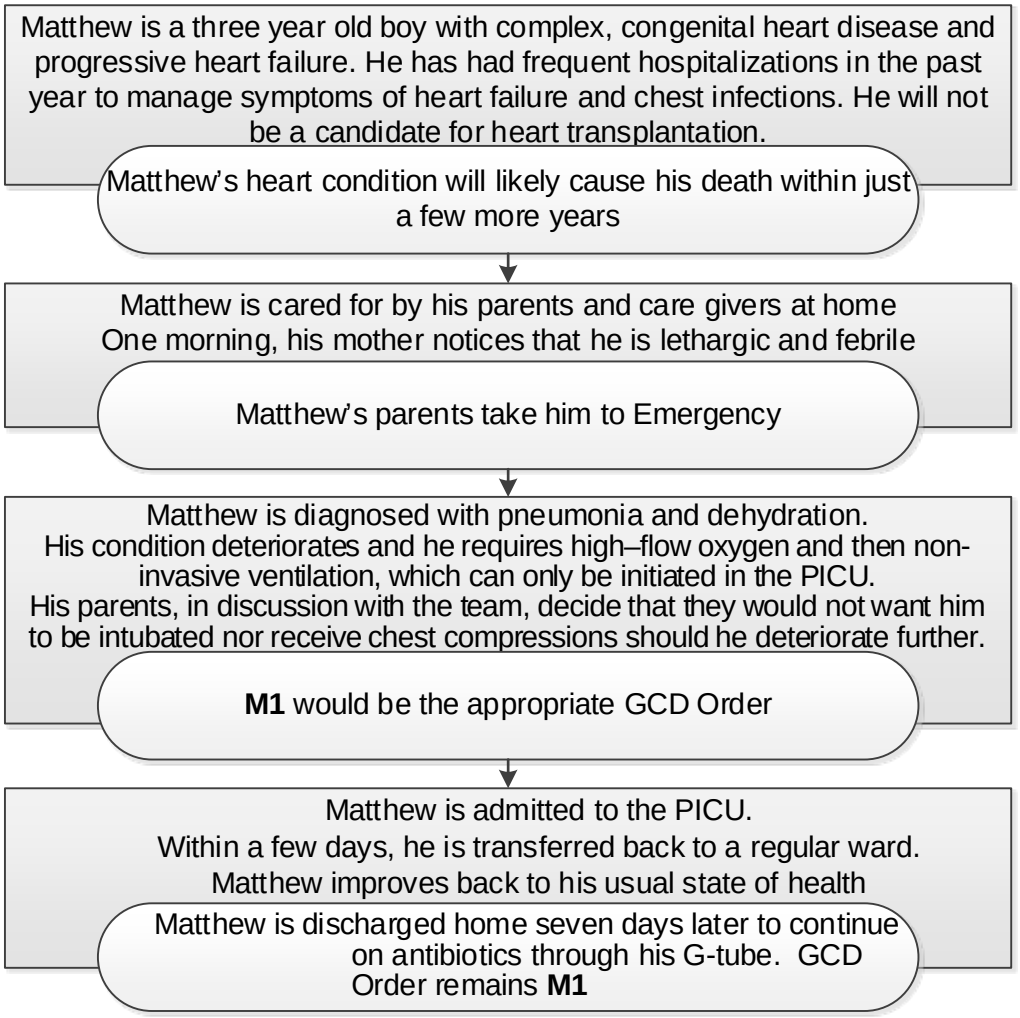


Figure 23 Discussion Points:

All GCDs include attention to control of symptoms. When symptom control for a child can best be provided in the PICU, then this location of care can be chosen. To support his care team in the community, an updated ACP/GCD Tracking Record should accompany the patient and family.

**Figure 24: M2 Pediatric Scenario – Congenital metabolic disorder resulting in neurodegeneration and liver failure**

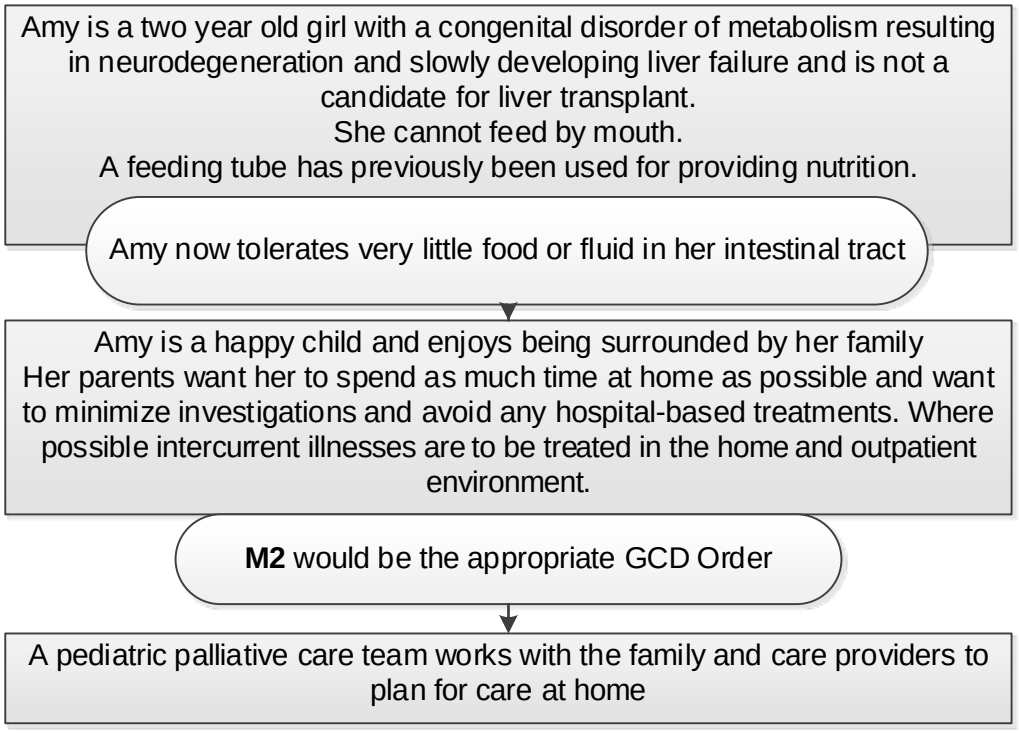


Figure 24 Discussion Points:

If circumstances change, then a relevant GCD order change could be considered along with a discussion about the impacts of a change in GCD. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

Typically for M2 – designated patients, care is provided outside of hospital.

**Figure 25: C1 Pediatric Scenario – Acute Myelogenous Leukemia, relapse post bone marrow transplant**

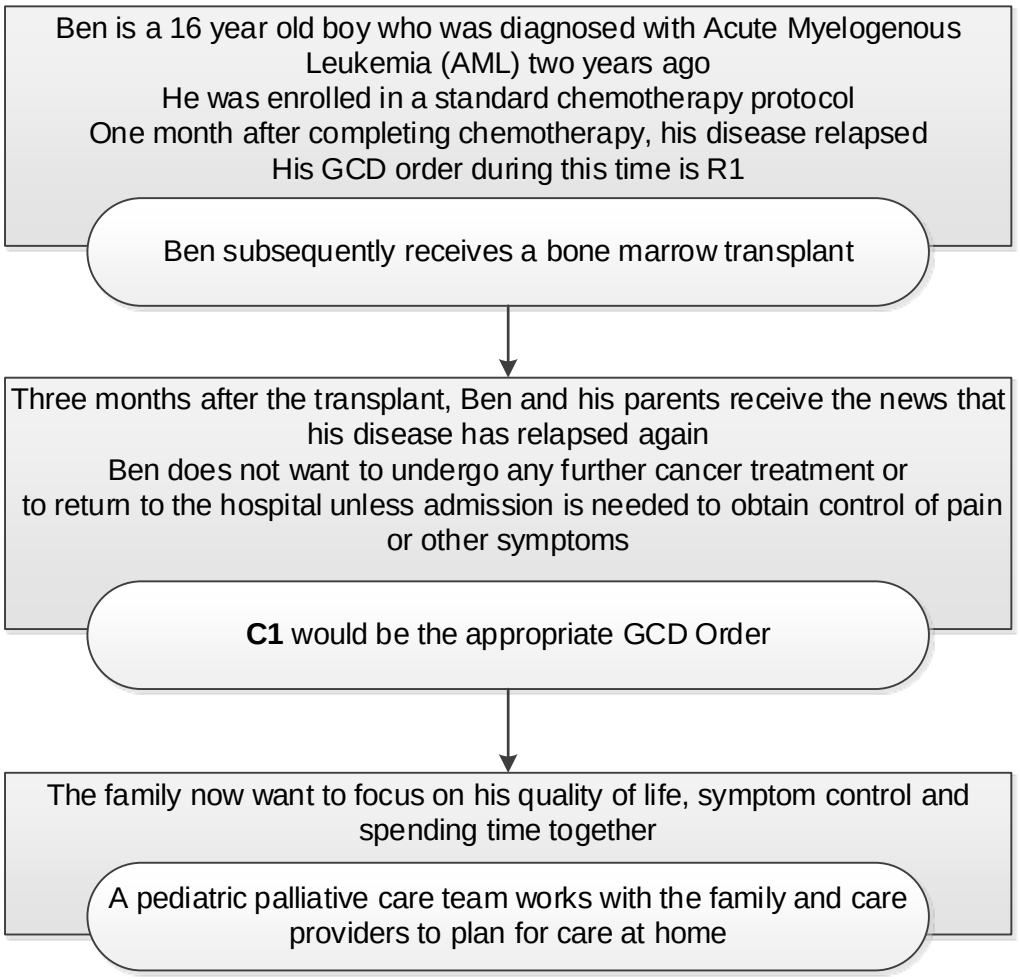


Figure 25 Discussion Points:

Comfort care designations encompass care and interventions focusing on supportive symptom management and optimizing function in patients who are approaching the end of their lives with a predictably life-limiting illness. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 26: C2 Pediatric Scenario – Complex patient with deteriorating baseline health status**

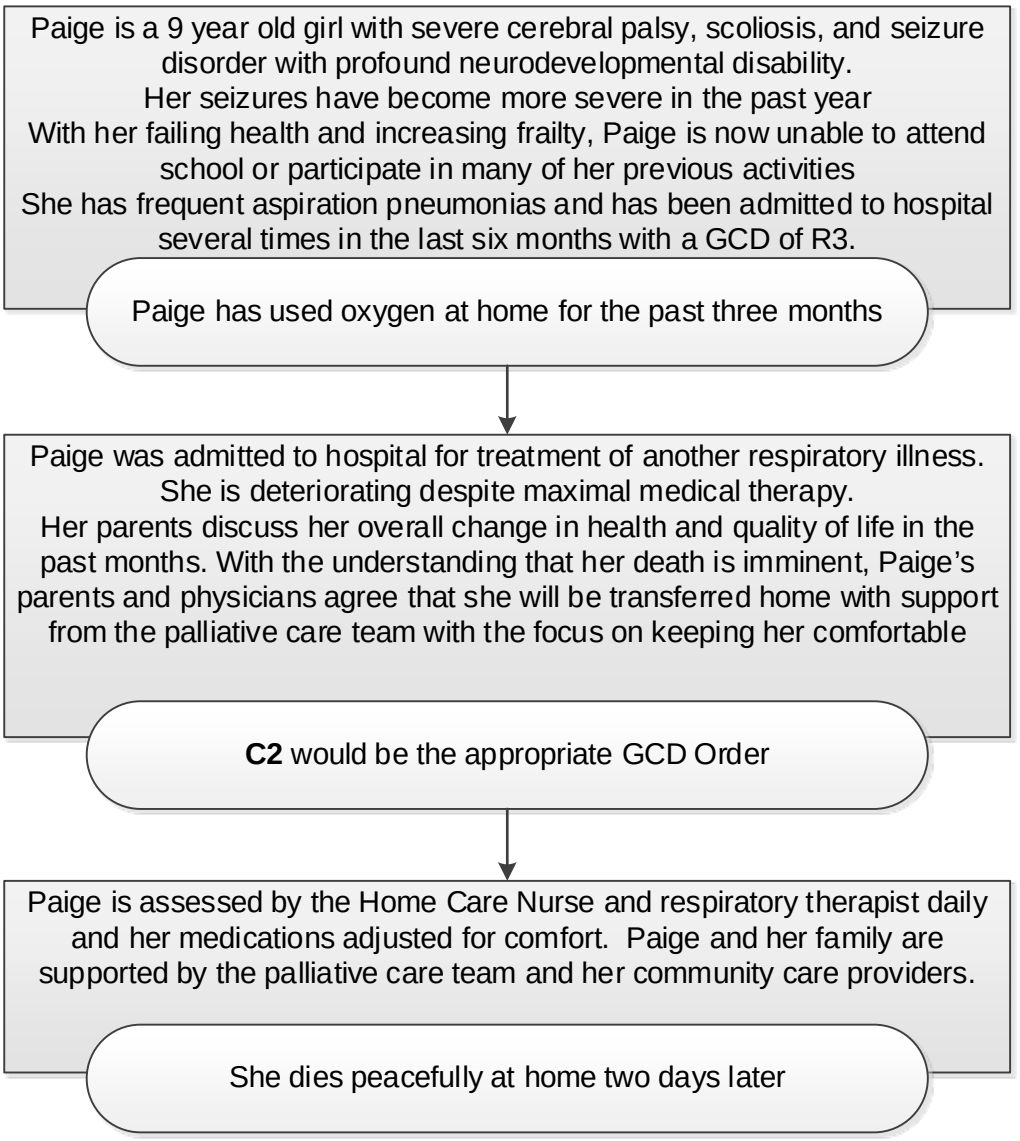


Figure 26 Discussion Points:

C2 designation is intended for when death is imminent. Despite children with profound neurodevelopmental disability being at risk of death at any time in childhood from complications of their condition, most will carry an R1 GCD. The change to C2 GCD for Paige reflects that the parents and health care providers understand that her baseline health has deteriorated such that she is unlikely to survive in the near term. Therefore, preparation is made for imminent death. A summary of the pertinent aspects of the conversation that went into the decision should be recorded in the ACP/GCD Tracking Record

**Figure 27: Pediatric Surgery Scenario – M1 patient with severe dental abscesses**

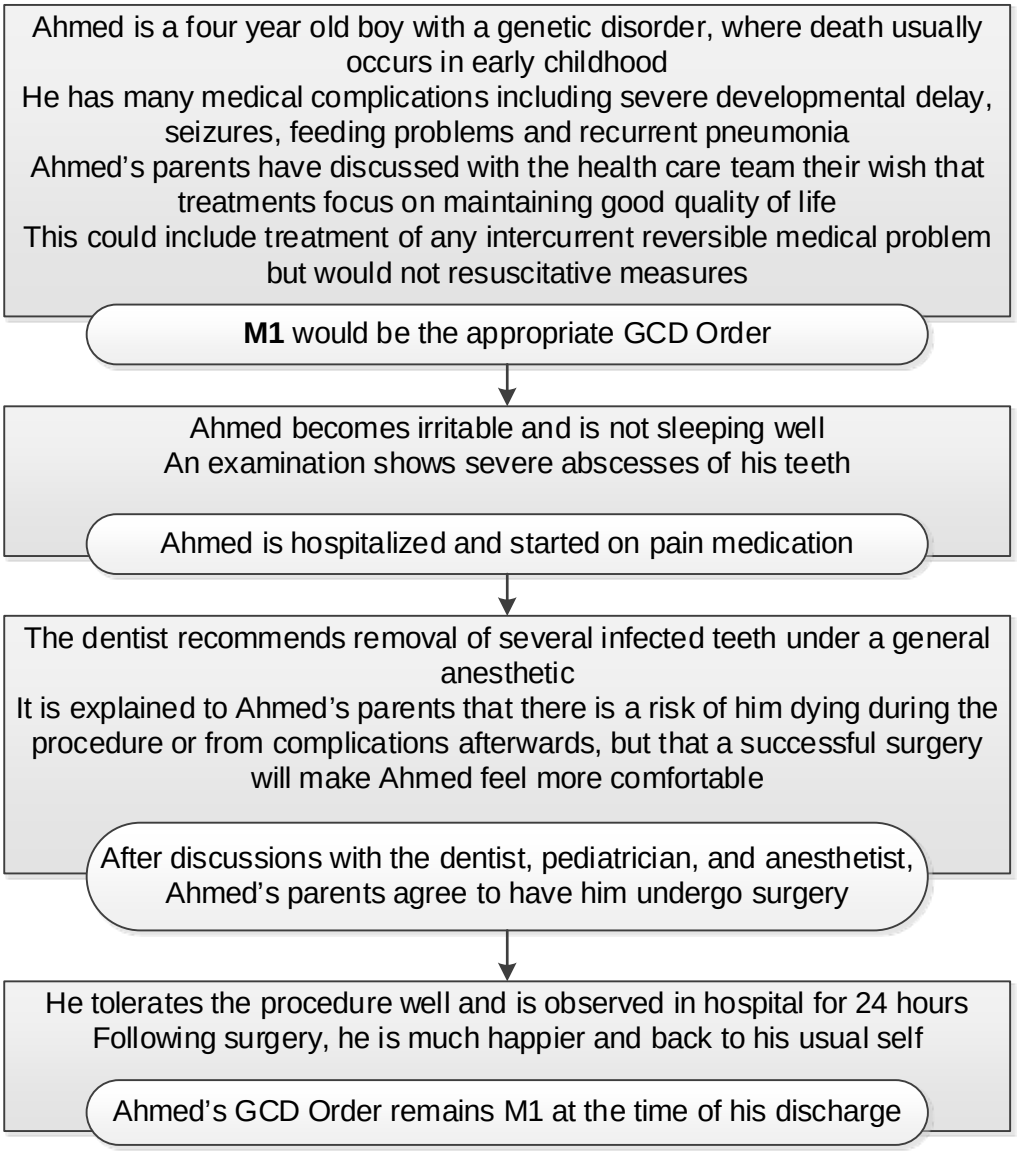

Figure 27 Discussion Points:

It is not true that an R1 GCD is automatic during and after surgery.

Full opportunities for intra-operative and peri-operative physiologic support should remain in the hands of the anesthetic and surgical team, in order for surgical goals to be met. ICU admission is also possible, within the limitations the patient has provided.

The GCD Order remains M1 during the peri-operative episode, along with clearly documented special instructions that chest compressions should not be used in the event of cardio-respiratory collapse. Further, if the patient cannot be extubated after a reasonable post-operative time in ICU, considering his underlying condition and his wishes, then life-support measures can be withdrawn subsequent to appropriate discussion and consultations. Further documentation of these conversations and special instructions on the ACP/GCD Tracking Record will aid in communication between all involved teams.

See Advance Care Planning and Goals of Care Designation Policy under M designation for surgery.

Considering his health challenges, Ahmed is for the most part stable and actually thriving in limited ways. Ahmed's parents have discussed with the health care team their wish that no heroic life-saving measures be used if his breathing or heart should stop. While they are focusing primarily on his comfort, they would likely agree to many interventions aimed at cure or control of current and future health challenges.

## Order Set - Goals of Care Designations, All Ages – All Locations

**Order Set Restrictions:**

General guidance for when it would not be clinically indicated or appropriate for a GCD 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).

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 also documented in the *Advance Care Planning/Goals of Care Designation Tracking Record*.

See the Advance Care Planning and Goals of Care Designation Procedure for documentation details

**Order Set Keywords:** ACP, GCD, Goals of Care, DNR

**Order form for Goals of Care Designation Orders located here**

## Goals of Care Designation Orders, All Ages – All Locations

*Note: this order set is intended to act as specifications for an order set within a clinical system. Any documentation or information that would normally be captured during ordering (such as the involvement of an ADM) will be part of the individual GCD Orders and documentation. For more information, please refer to the Clinical Knowledge Viewer, Foundational Knowledge under Advance Care Planning/Goals of Care: https://www.albertahealthservices.ca/cgv/Page15918.aspx*

**R: Medical Care and Interventions, Including Resuscitation**

*Goals of Care: 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.*

☐ Goals of Care Designation - R1

☐ Goals of Care Designation - R2

☐ Goals of Care Designation - R3

**M: Medical Care and Interventions, Excluding Resuscitation**

*Goals of care: 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.*

☐ Goals of Care Designation - M1

☐ Goals of Care Designation - M2

**C: Medical Care and Interventions, Focused on Comfort**

*Goals of care: 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.*

☐ Goals of Care Designation - C1

☐ Goals of Care Designation - C2

# Relevant Guidelines, Procedures, Protocols and Clinical Knowledge Topics

## Procedures

Advance Care Planning and Goals of Care Designation Procedure

## Policy

Advance Care Planning and Goals of Care Designation Policy

## Additional Guidelines

Canadian Pediatric Society Position Statements:

- Advance care planning for pediatric patients
- Counseling and management for anticipated extremely preterm birth

## Provider Education and Resources

### Personal Directives Act and Adult Guardianship and Trusteeship Act:

Advance care planning also provides an opportunity to inform and encourage patients to: i) write a personal directive, ii) designate an agent (or Alternate Decision Maker) to make personal decisions on their behalf, and iii) consider whether a supported decision-making arrangement would be helpful in making personal decisions.

For more information on writing advance instructions about personal matters:

- Website: Adult Guardianship and Trusteeship Act
- Website: Personal Directives Act

### Serious Illness Conversation Guide:

Developed by Ariadne Labs at the Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health, the Serious Illness Conversation Guide is a tool to assist clinicians in managing conversations with patients and their families.[4] This tool provides step-by-step guidance of how: a) to initiate conversations, b) to assess understanding and elicit information preferences, c) to share prognosis, d) to explore relevant topics, and e) to conclude and document conversations. The accompanying Reference Guide for Clinicians offers recommendations on: a) setting up the serious illness conversation, b) terminology used to communicate information, and c) suggestions on managing common patient scenarios. These are available through www.ariadnelabs.org.

- Serious Illness Conversation Guide
- Serious Illness Care Program – Reference Guide for Clinicians

There are, however, limitations on how these resources are applied in the context of this Knowledge Topic. Neither of these resources make reference to GCDs or the language used in describing changes to GCDs. These resources do not address the process by which a decision-maker is chosen, or the conversations surrounding patient preferences for location or transfer of care. The underlying assumption of both the Serious Illness Conversation Guide and the Reference Guide for Clinicians is that conversations are predicated upon the patient having a serious condition or disease.

Conversations regarding ACP/GCD can occur **at any time**; even young, healthy people can start thinking about and communicating their wishes and values to loved ones. In the event that one becomes ill, unable to communicate or make a decision, every person should consider who they would want to speak for them and make decisions on their behalf. Conversations should include any specific circumstances under which the person would wish to change location of care or initiate transfer of care. GCDs should not be referred to as being "lowered" or "reduced", but rather that the focus of patient care has changed.

It is also useful at any time to have written a Personal Directive, named an Alternate Decision Maker (ADM) and discussed with your ADM any relevant information that would assist them to make personal decisions on your behalf should you become incapable.

### Video series

- Advance Care Planning
- Goals of Care Designation
- Advance Care Planning: Topic Overview

### ACP/GCD learning modules

- Adult and Pediatric Modules (can be accessed via Conversations Matter)
- AHS employees can register through MyLearningLink

### Other Frequently Asked Questions

Questions about how to manage the Green Sleeves, the paper versions of the GCD Order form, and the use of the ACP GCD tracking record can be found in the FAQ for the Health Professional and the Advance Care Planning and Goals of Care Designation Policy documents:

- FAQ
- Advance Care Planning and Goals of Care Designation Policy

## Analytics

### Baseline Analytic – Outcome Measure

| | |
|---|---|
| **Name of Measure** | Order set Usage: Goals of Care Designations, All Ages – All Locations |
| **Definition** | For all patients, number of times orderset is being used. Overall, by region, by sites, and by units |
| **Rationale** | Intended to measure if the order set cited in the knowledge topic is being used and what % of time. May indicate areas with adoption issues or gaps in topic |
| **Notes for Interpretation** | Site capacity, rural considerations, roll out of provincial CIS |

### Clinical Analytics – Outcome Measure #1

| | |
|---|---|
| **Name of Measure** | Percentage of patients with a GCD Order anywhere in the health record. |
| **Definition** | This measure is used to assess the percentage of adult patients with a GCD Order in the health record. |
| **Rationale** | The priority aim addressed by this measure is to increase the completion of ACP documentation. ACP involves conversations among patients, families and clinicians about who should make decisions if the patient is unable, and what type of care the patient desires. As per AHS' Advance Care Planning and Goals of Care Designation Level 1 Procedure, "A Goals of Care Designation order shall be written by the most responsible healthcare practitioner (or designate) and documented on the patient's health record." |
| **Cited References** | Konrad Fassbender, Jayna M. Holroyd-Leduc, Malcena Stalker, Alex Potapov, Patricia Biondo, Jessica Simon & Neil Hagen. Identification and implementation of indicators to monitor successful uptake of Advance Care Planning in Alberta: a Delphi study. Palliative Medicine 2016; 30(6): NP192. |

## Clinical Analytics – Outcome Measure #2

| | |
|---|---|
| **Name of Measure** | Percentage of deceased patients who die having had an M1, M2, C1 or C2 GCD in the week prior to their death, who received resuscitative or life-support interventions in advance of death |
| **Definition** | This measure is used to assess the percentage of patients who received resuscitative or life support interventions that did not align with their GCD (i.e. patients with M or C GCDs who receive resuscitative or life support interventions). |
| **Rationale** | The ultimate goal of ACP is to help people get medical care that is consistent with their values, goals and preferences during serious and chronic condition or disease. However, miscommunication of patients' end-of-life preferences is unfortunately common, and can lead to the provision of unwanted end-of-life care. Discordance between a patient's care received and his or her wishes is increasingly being viewed as a consequential medical error, and a target for improving patient safety. |
| **Cited References** | Konrad Fassbender, Jayna M. Holroyd-Leduc, Malcena Stalker, Alex Potapov, Patricia Biondo, Jessica Simon & Neil Hagen. Identification and implementation of indicators to monitor successful uptake of Advance Care Planning in Alberta: a Delphi study. Palliative Medicine 2016; 30(6): NP192. |

## Clinical Analytics – Outcome Measure #3

| | |
|---|---|
| **Name of Measure** | Percentage of deceased long term care and home care patients with a C2 GCD who were transferred to acute care and/or ICU |
| **Definition** | This measure is used to assess the percentage of patients with a C2 GCD who were transferred to acute care and/or ICU. |
| **Rationale** | The ultimate goal of ACP is to help people get medical care that is consistent with their values, goals and preferences during serious and chronic condition or disease. However, miscommunication of patients' end-of-life preferences is unfortunately common, and can lead to the provision of unwanted end-of-life care. Discordance between a patient's care received and his or her wishes is increasingly being viewed as a consequential medical error, and a target for improving patient safety. |
| **Cited References** | Konrad Fassbender, Jayna M. Holroyd-Leduc, Malcena Stalker, Alex Potapov, Patricia Biondo, Jessica Simon & Neil Hagen. Identification and implementation of indicators to monitor successful uptake of Advance Care Planning in Alberta: a Delphi study. Palliative Medicine 2016; 30(6): NP192. |

## Keywords

- ACP
- GCD
- Goals of Care
- R1
- R2
- R3
- M1
- M2
- C1
- C2
- DNR

## References


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3. Detering K, Hancock A, Reade M, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. 2010; 340:c1345. doi: 10.1136/bmj.c1345.
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5. Alberta Health Services. Policy: Advance Care Planning and Goals of Care Designation. https://extranet.ahsnet.ca/teams/policydocuments/1/clp-advance-care-planning-hcs-38-policy.pdf. Revised August 16, 2016. Accessed January 9, 2018.

## Appendix A – Glossary of terms

| Table 2. Glossary of Terms | | |
|---|---|---|
| **ACP** | Advance Care Planning | 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 |
| **ACP/GCD Tracking Record** | Advance Care Planning/Goals Care Designation Tracking Record | A record to document the decisions/next steps/outcomes of discussions related to ACP and GCD |
| **ADM** | Alternate Decision Maker | 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, or '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, supported decision-maker, or a person designated in accordance with the Human Tissue and Organ Donation Act. ADM and substitute decision maker |
| **Agent** | | A person designated in a Personal Directive to make Personal Decisions on behalf of the patient |
| **AHS** | | Alberta Health Services |
| **AIDS** | Acquired Immunodeficiency Syndrome | A disease of the immune system caused by infection with human immunodeficiency virus (HIV), which attacks CD4 T lymphocytes (CD4 cells) and leaves the person vulnerable to life-threatening infections and cancers |
| **ALS** | Amyotrophic Lateral Sclerosis | A progressive disease of the nervous system that leads to disability through the destruction of nerve cells. Also known as Lou Gehrig's disease. |

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| **AML** | Acute Myelogenous Leukemia | A cancer of a person's blood and bone marrow that affects myeloid cells which are precursors to mature white blood cells. Also known as acute myeloid leukemia, acute myeloblastic leukemia, acute granulocytic leukemia or acute nonlymphocytic leukemia |
| **BiPAP** | Bilateral Positive Airway Pressure | A non-invasive positive pressure ventilation system which delivers air at an inspiratory positive airway pressure (IPAP) when the person inhales through a mask and tubing, and delivers air at an expiratory positive airway pressure (EPAP) when the person exhales |
| **CCU** | Coronary Care Unit | An inpatient unit specialized for the care, treatment and monitoring of people with acute cardiac conditions |
| **CHF** | Congestive Heart Failure | A cardiac condition in which a person's heart fails to pump blood with normal efficiency and is unable to keep up with the demands on it, thus leading to inadequate blood flow to other organs |
| **CKT** | Clinical Knowledge Topics | Clinical Knowledge Topics (CKTs) are provincial best practice/evidence-informed clinical guidance for defined diseases/conditions, specific patient populations or segments of a clinical pathway |
| **COPD** | Chronic obstructive pulmonary disease | A respiratory condition in which chronic obstruction of airflow in a person's lungs interferes with their normal breathing and is not fully reversible |
| **CPR** | Cardiopulmonary Resuscitation | An emergency life-saving procedure that is performed on a person in cardiac arrest or who is unresponsive with abnormal or no breathing, and that uses chest compressions and artificial ventilation in order to manually maintain brain function |
| **Decisional Capacity** | | The ability to understand the information that is relevant to the making of a Personal Decision and the ability to appreciate the reasonably foreseeable consequences of the decision. |
| **DNR** | Do Not Resuscitate status | Outdated nomenclature, GCDs replace and expand upon previous 'DNR' and 'Full Code' designations that were increasingly seen as outdated and too binary considering the complexities of modern health care capabilities and the complex trajectories of patients' health conditions |

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| **EMS** | Emergency Medical Services | |
| **GCD** | Goals of Care Designation | 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 |
| **GCD Order** | Goals of Care Designation order | A medical order that denotes the selected Goals of Care Designation |
| **GI** | Gastro-intestinal system | Referring to a person's internal abdominal organs, including the stomach, small and large intestine |
| **Green Sleeve** | | A folder containing a patient's GCD Order, along with an ACP/GCD Tracking Record, for the patient to own and produce at relevant health care encounters |
| **G-Tube** | Gastrostomy Tube | A tube that is inserted through a person's abdomen in order to deliver nutrition directly to the stomach |
| **ICU** | Intensive Care Unit | An inpatient unit that specializes in the care, treatment and monitoring of people with serious condition or disease |
| **MRHP** | Most Responsible Health Practitioner | 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 |
| **NICU** | Neonatal Intensive Care Unit | An inpatient unit that specializes in the care, treatment and monitoring of newborn infants who are ill or premature |
| **O2** | Oxygen therapy | The use of supplemental oxygen as a medical treatment, and that can be administered via nasal cannula, face mask, tracheal intubation or hyperbaric chamber |
| **Patient** | | All persons who receive or have requested health care or services from Alberta Health Services and its health care providers |

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| **PICU** | Pediatric Intensive Care Unit | An inpatient unit that specializes in the care, treatment and monitoring of infants, children or teenagers with a critical condition or disease |
| **UTI** | Urinary Tract Infection | A urinary tract infection is a general term for an infection anywhere between the kidneys and the urethra (where urine comes out). Most urinary tract infections are bladder infections. They often cause pain or burning when you urinate. They're caused by bacteria and can be cured with antibiotics. |

## Appendix B – The difference between a Goals of Care Designation and a Personal Directive

**Table 3. The difference between a Goals of Care Designation (Green Sleeve) and a Personal Directive – a resource for patients**

| | Goals of Care Designation Order (GCD) | Personal Directive (PD) |
|---|---|---|
| **What is it?** | A GCD is a **medical order** that specifies general care intentions, locations of care and transfer opportunities for current and future care. A GCD is determined by matching your values and beliefs with expert clinical advice regarding appropriate medical care that can take into account your wishes. | A **legal document** that you create while you are capable of making your own decisions. It allows you to **name a decision maker** (called an "agent") and provide written instructions in the event that you no longer have the capacity to make decisions for yourself. |
| **What does it cover?** | A Goals of Care Designation order covers **medical treatment only**. | **All Personal matters** – like where to live, medical treatments, personal activities, and legal decisions. A PD doesn't cover financial matters.<br>To leave instructions for managing your finances, you need to complete an enduring power of attorney (EPA). |
| **Who writes it?** | You may discuss your values and wishes with any member of your healthcare team, however the GCD is a physician order that must be signed by your "most responsible care provider" (usually your physician). Conversations you have with health care professionals about Advance Care Planning (ACP) should be documented on the ACP/GCD Tracking Form and kept with your GCD Order in your Green Sleeve. | Any capable adult can write his/her own personal directive.<br>**Go to the Government of Alberta website for a PD template.**<br>Talk to the person you want to appoint to be your agent to make sure they are willing to take this role.<br>If you are no longer capable of making your own decisions and you don't have a PD, your family or friends can apply to the courts to become your legal guardian or the government can appoint a public guardian for you or a referral can be made to the Office of the Public Guardian. The Public Guardian may make an application to the Court of Queen's Bench to be appointed legal guardian. |

| Table 3. The difference between a Goals of Care Designation (Green Sleeve) and a Personal Directive – a resource for patients | | |
|---|---|---|
| | **Goals of Care Designation Order (GCD)** | **Personal Directive (PD)** |
| **When is it used?** | Your GCD is used in all healthcare encounters, guiding the care team regarding appropriate categories of interventions. They are also used in situations in which you are unable to communicate your care wishes.<br>If you don't have a GCD, your physician will assess your situation and will assign a temporary designation until you or your alternate decision maker can confirm your wishes. | Your PD may be brought into effect after a capacity assessment has been completed and you are deemed unable to make personal decisions. When this happens, the person you named as your agent will be given the legal authority to make decisions on your behalf (based on the information in your PD). Your agent is meant to speak as if they were you expressing your own wishes. |
| **Where is it kept?** | The GCD Order will be given to you in a green sleeve. This is yours to keep.<br>**Keep it on or by your fridge.**<br>Healthcare professionals who are caring for you at your home, including paramedics providing you with emergency care know to look for it there. | **Give a copy to your agent.**<br>You can also register your PD online – the information in the registry includes the fact that you have a PD, your agent, and contact information for your agent.<br>A copy should be included in the Greensleeve, so that your Health Care Provider can access it if necessary. |
| **For more information** | www.conversationsmatter.ca | https://www.alberta.ca/personal-directive.aspx |

Adapted from Alberta Health Services Edmonton Zone Working Group, "What is the difference between a Goals of Care Designation (Green Sleeve) and a Personal Directive?", February 2015.

## Appendix C – Dementia Special Considerations

**Recommendations / considerations when applying the ACP/GCD principle for patients with dementia**

- Dementia is a progressive and irreversible condition associated with a gradual loss of cognitive ability, functioning, and language ability. As the disease progresses, there is an increasing incidence of medical complications such as dysphagia, pressure sores, malnutrition and dysphasia. Although dementia is in itself a terminal condition, death is usually precipitated by the development of one or more of its medical complications.
- Swallowing problems become increasingly common as the dementia progresses, resulting in difficulties with nutrition and hydration. The use of artificial forms of feeding (i.e. tube feeding) and hydration to overcome these issues has not been to shown to provide any benefit and thus, the use of artificial nutrition or hydration in end stage dementia is not recommended.
- Although dementia is associated with a gradual decline in verbal communication, other forms of communication should be utilized as necessary.
- As individuals with dementia and / or family members will often not initiate conversations about ACP and GCD, it is the responsibility of the healthcare professional to initiate such conversations. The number and duration of conversations, together with the level, content and style of communication used, should be tailored to the specific needs of the individual living with dementia and their situation, and their experiences, fears and previously expressed preferences should be incorporated into these conversations.
- When discussing the goals of care designation for individuals with dementia, it is important to take into consideration the individual's personhood and values in addition to their comorbidities and baseline level of physical functioning, functional capacity, and dementia severity, as these all impact the person's prognosis
- It is important to ensure that both the patient (where possible) and their family and caregivers have a clear understanding about the disease and its natural course and prognosis, so that they can have an informed discussion about ACP in dementia. It is always preferable to have these discussions at a time when the patient can participate and express their wish; however, this is not always possible.
- All individuals living with dementia should be assumed to have decision making capacity, and should be an active participant within the ACP process. If concerns arise regarding their decision making ability, all attempts should be made to maximize and support decision making before deciding to proceed with conducting a formal assessment of their decision making capacity. This support may involve using alternative forms of communication, supported decision making, etc. It is important to encourage involvement of significant others or family members early on in the ACP process.
- The process of ACP should be incorporated into daily clinical care for patients with dementia, with discussions around ACP and GCD being initiated as early as possible within the disease, and ideally at the time of their dementia diagnosis, so that they are able to participate in the process. These discussions are not standalone events however, and should be repeated over a period of time.

- ACP and end of life care are fluid concepts, and an individual's viewpoint may change as the disease progresses or problems / situations change. It is important to be aware of some of the potential milestones which may trigger repeat discussions about GCD and ACP, which includes transitions of care, during the process of formal documentation of future wishes (i.e. power of attorney) or at times of significant changes in the patients' health.
- Although an M1 GCD is a common GCD for individuals over 65 years of age, it is not the rule, and any discussions around the GCD needs to take into consideration the individual's age, co-morbidities (especially dementia), frailty, and level of functioning in addition to other factors.

**References:**


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2. The Irish Hospice Foundation. Advance care planning and advance healthcare directives with a person with dementia. 2017. Retrieved from: http://hospicefoundation.ie/wp-content/uploads/2016/07/Final-Guidance-Document-2-ACP-AHD.pdf
3. Piers R, Albers G, Gilissen J, De Lepeleire J, Steyaert J, Van Mechlen W, et al. Advance care planning in dementia: recommendations for healthcare professionals. BMC Palliat Care. 2018;17(1):88.


**Dementia scenarios and recommendations developed in collaboration with Dr. Frances Carr*

## Dementia Decision Making Scenarios - *The following scenarios are for illustrative purposes only and are not meant to limit specific clinical decision making.*

**Figure 28: R2 Early Dementia**

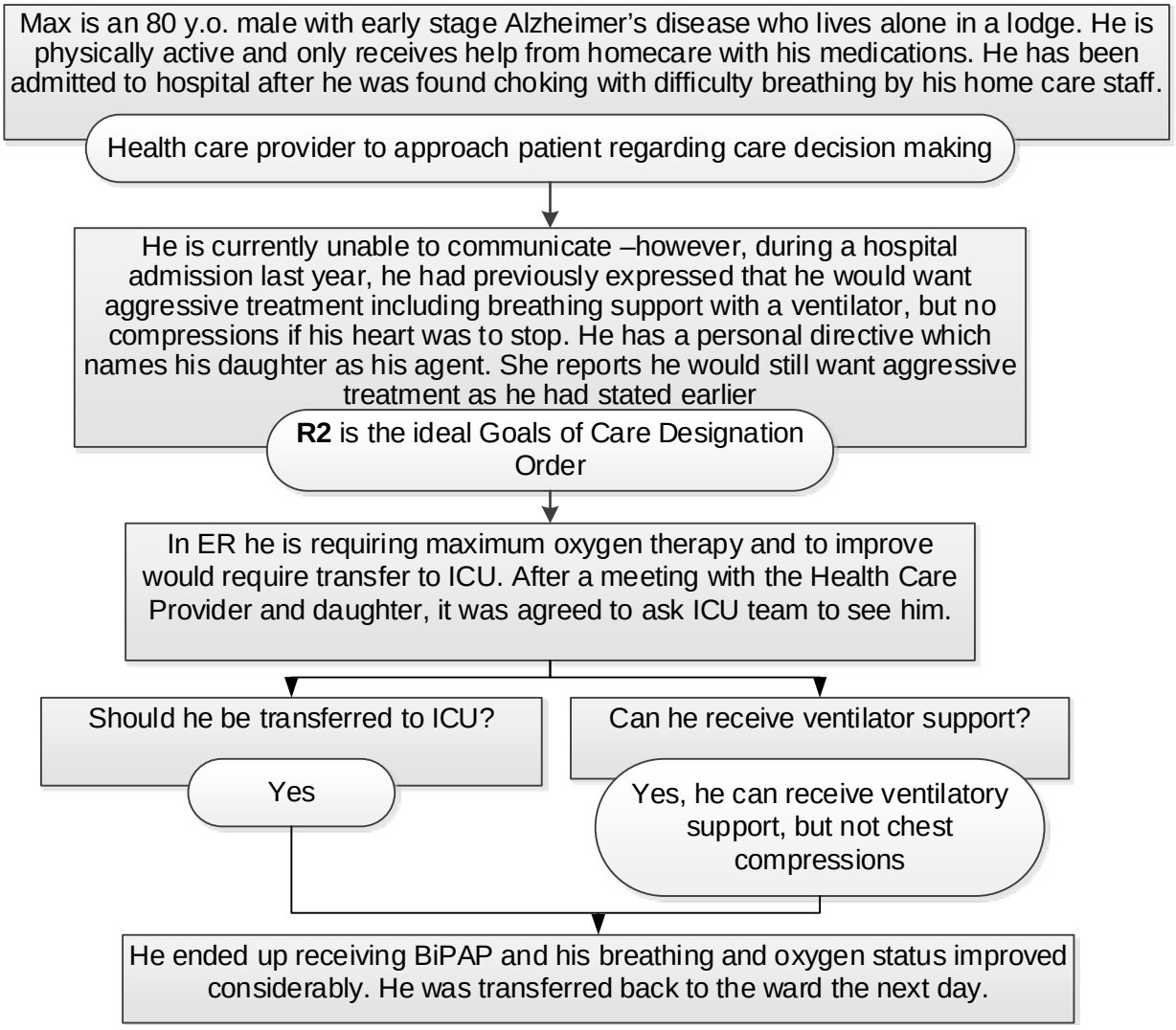


Figure 28 Discussion Points:

Max had previously stated that although he did not want chest compressions, he was willing to receive intubation / ventilator support. The care team felt they could offer interventions to successfully meet those goals and so R2 GCD is appropriate.

Although he ended up being transferred to ICU, he only required a brief amount of non-invasive ventilatory support before he clinically improved. This highlights the importance of advocating for the view that advanced age should not be a barrier to intensive medical treatment for appropriately healthy older adults, and especially for those individuals who experience a sudden acute medical decline due to an unforeseen event. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

**Figure 29: M1 Advanced Dementia**

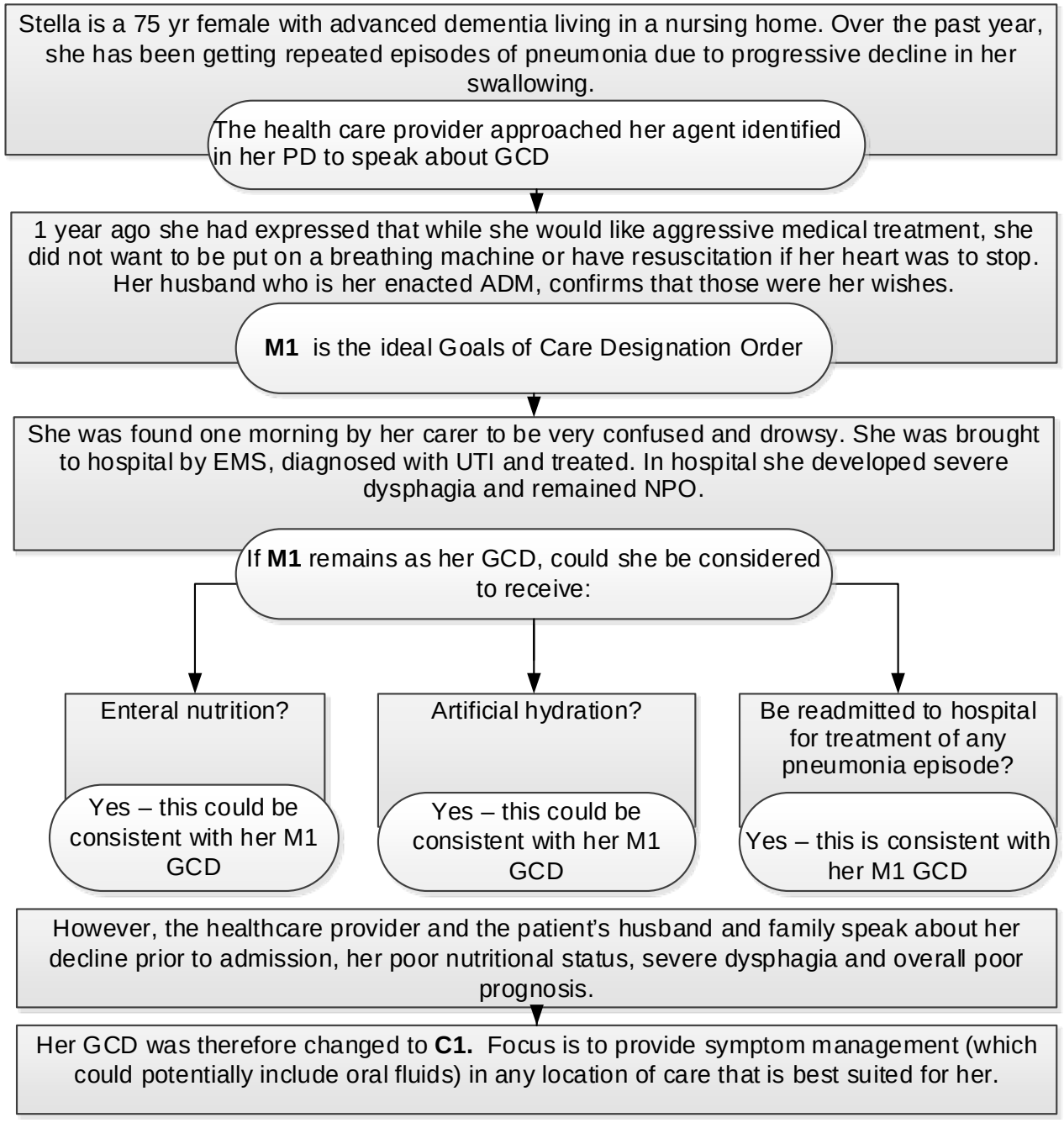


Figure 29 Discussion Points:

Consideration of the underlying prognosis, function and prior baseline of all patients with dementia is crucial when considering and discussing ACP and GCD for this population. The key conversation elements and decisions should be recorded on the ACP/GCD Tracking Record.

## Acknowledgements

We would like to acknowledge the contributions of the clinicians who participated in the development of this topic. Your expertise and time spent are appreciated.

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## Additional Contributors

*Thank you to the following clinicians who participated in the colleague review process or in some stages of topic development. Your time spent reviewing the knowledge topics and providing valuable feedback is appreciated. Claire Chapman, Cynthia Johnson, Shannon Morrison, Tracy Lynn Wityk Martin, Susan Bremner, Tony Truong, Frances Carr, Ayman Abou Mehrem, Amelie Stritzke, Amber Reichert, Derek Townsend, Alan Sobey, Catherine Patocka, Michael Bullard, Barb Martini.*

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