PROVINCIAL STANDARDS & GUIDELINES

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# Conservative Care Pathway

Created November 2016; Updated November 2017
Approved by the BCPRA Kidney Care Committee

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**IMPORTANT INFORMATION**

This BCPRA guideline/resource was developed to support equitable, best practice care for patients with chronic kidney disease living in BC. The guideline/resource promotes standardized practices and is intended to assist renal programs in providing care that is reflected in quality patient outcome measurements. Based on the best information available at the time of publication, this guideline/resource relies on evidence and avoids opinion-based statements where possible; refer to www.bcrenalagency.ca for the most recent version.

**For information about the use and referencing of BCPRA provincial guidelines/resources, refer to http://bit.ly/28SFr4n.**


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**BC Provincial Renal Agency (BCPRA)**
700-1380 Burrard Street
Vancouver, BC
V6Z 2H3

Phone: 604-875-7340
Email: bcpra@bcpra.ca
Web: BCRenalAgency.ca

Facebook.com/BCRenalAgency
@BCRenalAgency
Youtube.com/BCRenalAgency

## 1.0 Scope & Rationale

Care provided in the Kidney Care Clinics (KCC) can be thought of in 5 phases. Phases 1a and 1b are similar for all patients irrespective of their selected modality. Phases 1c, 2, 3, 4 and 5 vary according to the patient's modality selection (PD, HD, transplant or conservative care).

This guideline reviews the phases of KCC care. It focuses specifically on patients choosing the conservative care pathway and includes a staff reference tool (Appendix 1) and a checklist (Appendix 2) with specific areas of activity important for the KCC team to consider when providing care to this patient population. This guideline is applicable to adults.

Close linkages with primary care providers is foundational to providing care to patients on the conservative care pathway. Appendix 3 shows the phases of KCC care and the alignment with the phases in BC's palliative care guideline and end-of-life module for primary care physicians (both were developed by the General Practice Services Committee or GPSC).

As of April 2017, 25% of BC's KCC patients with an eGFR<20 mL/min had selected the conservative care option over dialysis or transplant. This percentage has been increasing steadily over the past few years.

## 2.0 Recommendations

**Recommendation #1: Utilize a 5-phase framework in conceptualizing the provision of care to patients on the conservative care pathway.**

Care provided in the Kidney Care Clinics (KCC) can be thought of in 5 phases. Phases 1a and 1b are similar for all patients irrespective of their selected modality. The other 3 phases will vary according to the patient's modality selection (PD, HD, transplant or conservative care).

For patients on the conservative care pathway, the phases can be conceptualized as follows:

**ALL KCC PATIENTS**
**(irrespective of selected modality)**

**Phase 1a: CKD Stage 3 - 4 Care**
***(active KCC care) (eGFR >25)***

- Orientation to KCC; education about kidney disease, health maintenance and resources.
- KCC interdisciplinary team assessment; goal-setting and treatment planning.
- Introduction to advance care planning (ACP).
  - Where to find ACP documents/resources.[1]
- Information on substitute decision-makers (SDM)[2], representative agreements & advance directives.
  - Discussion on what is important to the patient (i.e., beliefs, values & treatment preferences).
  - Familiarization of the patient with the concepts of goals of care.
- Active monitoring, treatment and psychosocial/emotional intervention as required.

**Phase 1b: CKD Modality Selection**
***(CKD progressing &/or anticipated to progress & eGFR 15-25)***

- Education about modality options appropriate to the patient (PD, HD, transplant and conservative care).

[1]Refer patient to BC Advance Care Planning website & ACP Planning Guide, My voice at www2.gov.bc.ca.
[2]Required if patient wishes a substitute decision-maker that differs from the list of Temporary Substitute Decision Makers in the Health Care Consent & Care Facility Admission Act.

- Discussion re goals of care within the context of modality selection (illness trajectory, prognosis and expected outcomes).
- Selection of preferred modality and documentation in PROMIS.

**PATIENTS ON THE CONSERVATIVE CARE PATHWAY - refer to Appendices 1 and 2 for details**

**Phase 1c: CKD Stage 5 Care (ESKD)**
***(ongoing supportive care, eGFR <15)***

- Communication of patient's modality choice with patient's primary care physician (PCP).
- If patient open to same, continue review and discussion of an advance care plan.
- Continued discussion re goals of care, including continued desire for conservative care.
- Comprehensive symptom assessment and management (using the modified ESAS and symptom management algorithms).
- If patient in agreement, confirmation that referral sent to home care/home support, if required.
- Medication/blood work rationalization.
- Crises education and planning, as appropriate (in case of acute worsening of symptoms, caregiver overwhelmed, etc).

**Phase 2: Decompensation**
***(life expectancy: <8 months) (declining eGFR & symptoms that would otherwise have triggered RRT if the conservative care path had not been chosen)***

- Communication with PCP and other patient supports (e.g., home care and/or palliative care team) re significant changes in patient status.
- Continued discussion regarding current care plan, including goals of care and continued desire for conservative care.
- If patient in agreement, confirmation that referral sent to palliative care team and application submitted to BC Palliative Care Benefits Program.
- Comprehensive symptom assessment and management.
- Medication/blood work rationalization.
- Crises education and planning, as appropriate (in case of acute worsening of symptoms, caregiver overwhelmed, etc).

**Phase 3: Increased Symptoms**
**(life expectancy: <1 month)**

- KCC team available to PCP & hospice/palliative care teams for consultation (mostly symptom mgt).

**Phase 4: Decline/Last Days**

- KCC team available to PCP & hospice/palliative care teams for consultation (mostly symptom mgt).

**Phase 5: Death & Bereavement**

- Bereavement support.
- Reflecting upon the patient's death as a KCC team.

For a list of relevant terms, see Appendix 4.

**Recommendation #2:**
**Create ways to systematically review the care provided to patients on the conservative care pathway to ensure that specific activities and discussions occur at appropriate intervals. A Conservative Care Checklist is provided in Appendix 2 to guide these reviews.**

## 3.0 References


1. BC Provincial Renal Agency, Best Practices: Kidney Care Clinics, 2014. http://www.bcrenalagency.ca/resource-gallery/Documents/Best%20Practices-%20Kidney%20Care%20Clinic_0.pdf. Accessed Nov 6, 2015.
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## 4.0 Sponsors

This BCPRA guideline/resource was developed to support equitable, best practice care for patients with chronic kidney disease living in BC. The guideline/resource promotes standardized practices and is intended to assist renal programs in providing care that is reflected in quality patient outcome measurements. Based on the best information available at the time of publication, this guideline/resource relies on evidence and avoids opinion-based statements where possible; refer to www.bcrenalagency.ca for the most recent version.

**Developed by:**

- A Working Group of BCPRA KCC and BCPRA Palliative Care Committee multidisciplinary care providers from across BC. The group included: nephrologists, registered nurses, social workers, a palliative care nurse specialist, a researcher, a data coordinator, and a patient.

**Reviewed by:**

- BCPRA Palliative Care Committee
- BCPRA Medical Advisory Committee
- BCPRA Executive Committee

**Approved by:**

- BCPRA Kidney Care Clinic Committee

For information about the use and referencing of BCPRA provincial guidelines/resources, refer to **http://bit.ly/28SFr4n.**

## 5.0 Effective Date

July 2017. This guideline is based on scientific evidence available at the time of the effective date; refer to www.bcrenalagency.ca for most recent version.

# Appendix 1: Staff Reference Tool - CKD Patients on a Conservative Care Pathway

This Staff Reference Tool is intended to provide KCC staff with an overview of the phases of KCC care and the major activities at each phase. See Appendix 2 for additional detail and relevant resources

| CKD Patients on a Conservative Care Pathway (CKD Stage 5) | | | | | |
|---|---|---|---|---|---|
| **eGFR** | **< 15** | **< 15 & declining** | | | |
| **KCC Phase** | **1** | **2** | **3** | **4** | **5** |
| **Description** | **Supportive ongoing care** | **Decompensation; prognosis <8 mos** | **↑ symptoms; prognosis <1 mo** | **Decline/ last days** | **Death & bereavement** |
| PCP Communication | Communicate patient's choice with PCP. Confirm roles. | | KCC team available to PCP & other community supports, including hospice/ palliative care teams for consultation (mostly symptom mgt). | | Acknowledge death with phone call, letter or card to family.<br><br>Review grief & bereavement resources. |
| Advance Care Planning | Discuss ACP. Document in patient record & PROMIS | • Review desires at EOL (KCC team or via PCP/PC team).<br>• Encourage patient to update will, power of attorney & other relevant forms (e.g., organ donation, bequest forms) | | | |
| Goals of Care | Discuss goals of care, including continued desired for conservative care. | Provide information on palliative care services in local community.<br><br>Confirm BC Palliative Care Benefits Program Application submitted www2.gov.bc.ca/assets/gov/health/forms/349fil.pdf (HLTH 349).<br><br>As required, confirm:<br>• Referral(s) sent to appropriate palliative care service.<br>• No CPR form www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf (HLTH 302).<br>• Notification of Expected Death in the Home form www2.gov.bc.ca (HLTH 3987) (urban areas only).<br>• Compassionate care benefits form www.canada.ca/en/employment-social-development/programs/ei/ei-list/reports/compassionate-care.html | | | |
| Symptom Assessment & Management | Complete mESAS (My Symptom Checklist) Q6 mos & PRN. Enter results into PROMIS. www.bcrenalagency.ca/resource-gallery/Documents/My%20Symptom%20Checklist.pdf<br><br>Utilize symptom management algorithms & patient handouts. Communicate with PCP. | Continue with mESAS, symptom management algorithms & patient handouts. | | | |
| Medications | Discontinue non-essential medications. | Discontinue non-essential medications. | | | |
| Blood Work | Reduce frequency of testing, if appropriate. | Reduce frequency of testing, if appropriate. | | | |
| Crises Education | | Identify possible kidney-related crises (acute worsening of symptoms, caregivers overwhelmed etc) & develop management plan. Confirm who to contact and contact numbers. | | | |

# Appendix 2: Checklist- CKD Patients on a Conservative Care Pathway

This Checklist is intended to support the systematic review of care provided to patients on the conservative care pathway and to ensure that specific activities and discussions occur at appropriate intervals. This Checklist outlines activities for patients on KCC's Conservative Care Pathway (starts at Phase 1c). Phases 1a (CKD Stage 3 - 4 Care) and 1b (CKD Modality Selection) are not shown because they are the same for all KCC patients irrespective of the selected modality.

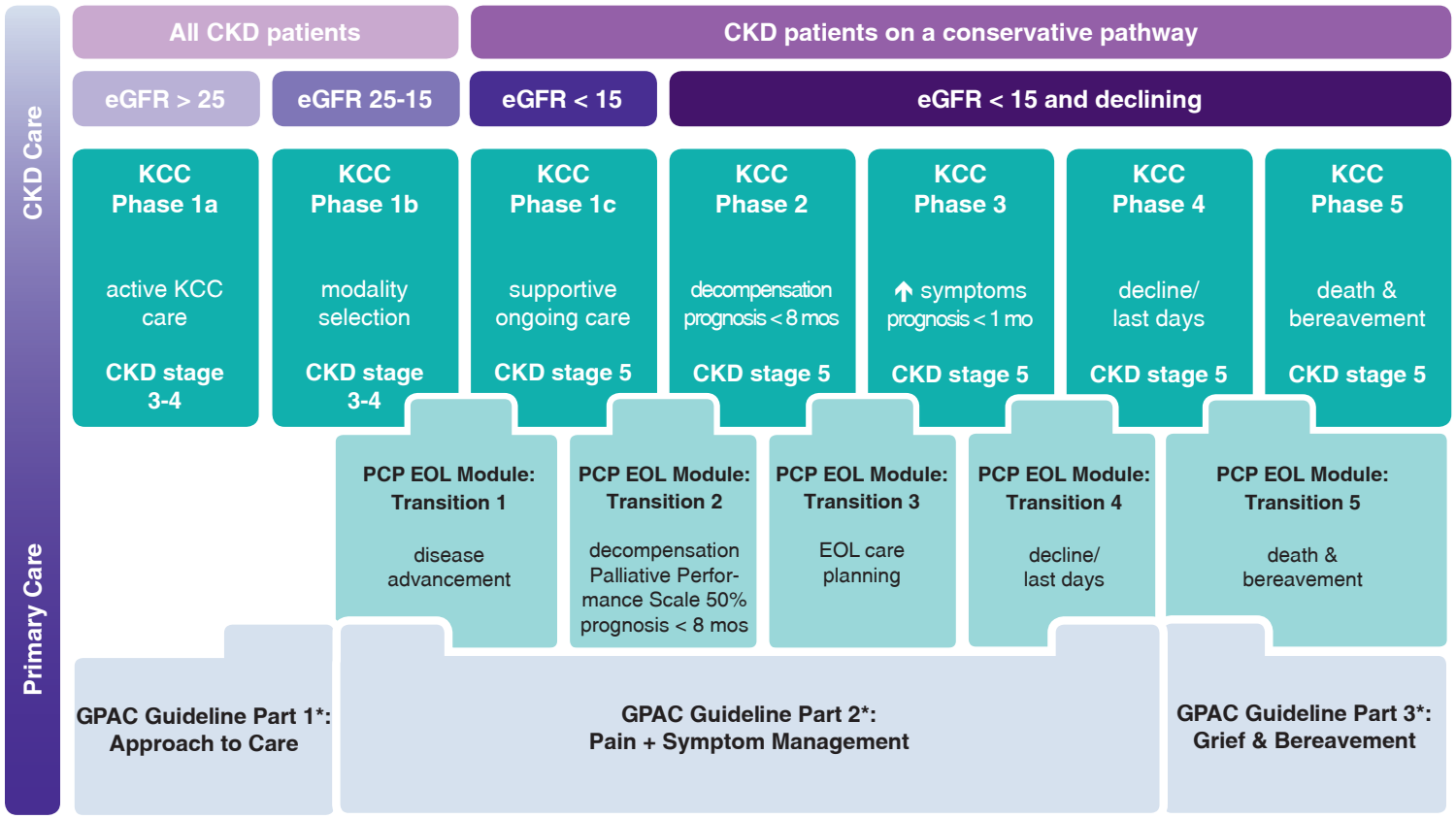
| Category | Activity | KCC Phase | | | | |
|---|---|---|---|---|---|---|
| | | 1c | 2 | 3 | 4 | 5 |
| | | Stage 5 CKD Care | Decompensation (<8 mos) | ↑ symptoms; Prognosis <1 mo | Last Days | Bereavement |
| PCP Communication | Communicate patient's modality choice &/or significant changes in status. Confirm roles of KCC & PCP. Recommend both verbal & written communication. | | | | KCC team available to PCP & other community supports, including hospice/ palliative care teams for consultation (mostly symptom mgt) | |
| ACP | Continue ACP discussion including:<br>• Educating patient about process of identifying SDM.<br>• Educating patient about process of developing representation agreement &/or advance directive, if desired.<br>• Discussing what is important to patient (e.g., beliefs, values, spiritual & cultural needs, treatment preferences). | | | | | |
| | If patient open to same &/or as appropriate, review desires at end of life, including place of death (done by KCC team or via PCP/palliative care team). | | | | | |
| | Document ACP discussion in patient record. | | | | | |
| | Update ACP documentation in PROMIS. | | | | | |
| | If available, place copy of ACP & related documentation in patient record (hard copy &/or electronic files). | | | | | |
| | When patient/family ready, encourage patient to update will, power of attorney & other relevant forms (e.g., organ donation, bequest forms). | | | | | |
| Goals of care | Continue goals of care discussion, including continued desire for conservative care. | | | | | |
| | Provide education on palliative care services available in local community. If needed & desired, confirm referral sent to appropriate service (by KCC or PCP). | | | | | |
| | Confirm BC Palliative Care Benefits Program Application form has been submitted (PCP/palliative care team or KCC team). www2.gov.bc.ca/assets/gov/health/forms/349fil.pdf (HLTH 349) | | | | | |
| | If no CPR desired, confirm completion of No CPR form. https://www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf (HLTH 302.1). | | | | | |
| | If home death desired, confirm "Notification of Expected Death in the Home" form has been signed by the patient if the patient/family opts for no pronouncement (PCP/ palliative care team or KCC team). www2.gov.bc.ca (HLTH 3987). (form used outside urban areas only). | | | | | |

Continued on next page...

| Category | Activity | KCC Phase | | | | |
|---|---|---|---|---|---|---|
| | | 1c | 2 | 3 | 4 | 5 |
| | | Stage 5 CKD Care | Decompensation (<8 mos) | ↑ symptoms; Prognosis <1 mo | Last Days | Bereavement |
| Goals of care (continued) | Ensure patient/family has copies of No CPR & "Notification of Expected Death at Home" forms, if relevant. | | | | See notes on previous page. | |
| | Provide information on compassionate care benefits as appropriate. www.servicecanada.gc.ca/eforms/forms/sc-ins5216b(2012-01-007)e.pdf (SC INS5216B). | | | | | |
| Symptom assessment & management[3] | Assess symptoms using the modified ESAS (My Symptom Checklist) q 6 months & more often if significant KCC-related symptoms. | | | | | |
| | Enter results of ESAS into PROMIS. | | | | | |
| | Develop/update symptom management plan, incorporating symptom management algorithms (bcrenalagency.ca) & other best practices. | | | | | |
| | Review symptom management plan with patient/family & provide relevant handouts. | | | | | |
| | Contact PCP to discuss kidney-specific symptoms, including providing copies of ESAS & relevant symptom management algorithms. | | | | | |
| | Assess need for home care/home support. If needed & desired, confirm referral has been sent (by KCC or PCP) & relevant information communicated. | | | | | |
| Medication review | Review medications with patient & discontinue any non-essential medications. | | | | | |
| Blood work rationalization | Review blood work with patient &, if appropriate, reduce the number or frequency of tests. | | | | | |
| Crises education (acute worsening of symptoms, caregivers overwhelmed, etc) | Identify possible kidney-related crises & develop management plans | | | | | |
| | Provide anticipatory education to patient/family re possible crises. | | | | | |
| | Confirm patient/family has contact numbers & knows who & when to call (e.g., GP, KCC team, nephrologist, home care, palliative care/hospice team, spiritual care). | | | | | |
| Bereavement support | Acknowledge death with phone call, letter or card to family. | | | | | |
| | As appropriate, offer brief grief & bereavement counselling to the family/caregiver & provide resources such as funeral packages, community supports & grief counselling resources. e.g., BC Bereavement Helpline (www.bcbereavementhelpline.com), local counselling/grief support resources, local hospice society & PCP. | | | | | |
| Reflections on patient's death as a KCC team | Discuss and reflect upon the patient's death as a kidney care team. | | | | | |

[3] Refer to symptom management protocols at: http://www.bcrenalagency.ca/health-professionals/clinical-resources/chronic-kidney-disease-(ckd)

# Appendix 3: Alignment of the Phases of KCC Care with the Phases in BC's Palliative Care Guideline & End-of-Life Module for Primary Care Physicians



## Appendix 4: Glossary

**Active KCC Care**: Actively monitors, treats, educates & provides psycho-emotional & social support for kidney disease (Best Practices: Kidney Care Clinics, 2014).

**Conservative Care Pathway**: Course of events initiated when a person with end-stage kidney disease chooses to receive kidney care but without dialysis treatments or transplant.

*The definitions below were developed by BCPRA's Palliative Care Committee. They are intended as "working definitions" are in the process of being reviewed.*

**Advance Care Planning (ACP)**: A process by which a capable adult talks over their beliefs, values and wishes for health care with their close family/friend(s) and a health care provider in advance of a time when they may be incapable of deciding for themselves. [BC Ministry of Health]

**Advance Care Plan**: A written summary of a capable adult's wishes or instructions to guide a substitute decision maker if that person is asked by a physician or other health care provider to make a health care treatment decision on behalf of the adult. [BC Ministry of Health]

**Advance Directive (AD):** A capable adult's written instructions that speak directly to their health care provider about the health care treatment the adult consents to, or refuses. It is effective when the capable adult becomes incapable and only applies to the health care conditions and treatments noted in the advance directive. [BC Ministry of Health]

**End-of-life Care**: is provided in the final stage of life. Care provided during this time may be called supportive care, palliative care or symptom management. End-of-life care addresses physical, psychological, and spiritual concerns and focuses on comfort, respect for decisions, and support for the family. It is provided by an interdisciplinary group of health care providers. [BC Ministry of Health]

**Goals of Care**: Describes people's goals for their care and should include treatment of the disease and/or symptom management. In some cases, it includes limits on the interventions that people want, such as "do not resuscitate" orders. [The Way Forward National Framework]

**Medical Orders for Scope of Treatment (MOST)**: A physician order based on an adult's Advance Care Planning conversations that details a variety of medical interventions that will or will not be initiated. [Fraser Health]

**Palliative Care/ Palliative approach to care**: An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [World Health Organization]

**Representative**: A person 19 years or older who is named by a capable adult, in a representation

agreement, to make health care treatment decisions on their behalf when they are incapable of deciding. [BC Ministry of Health]

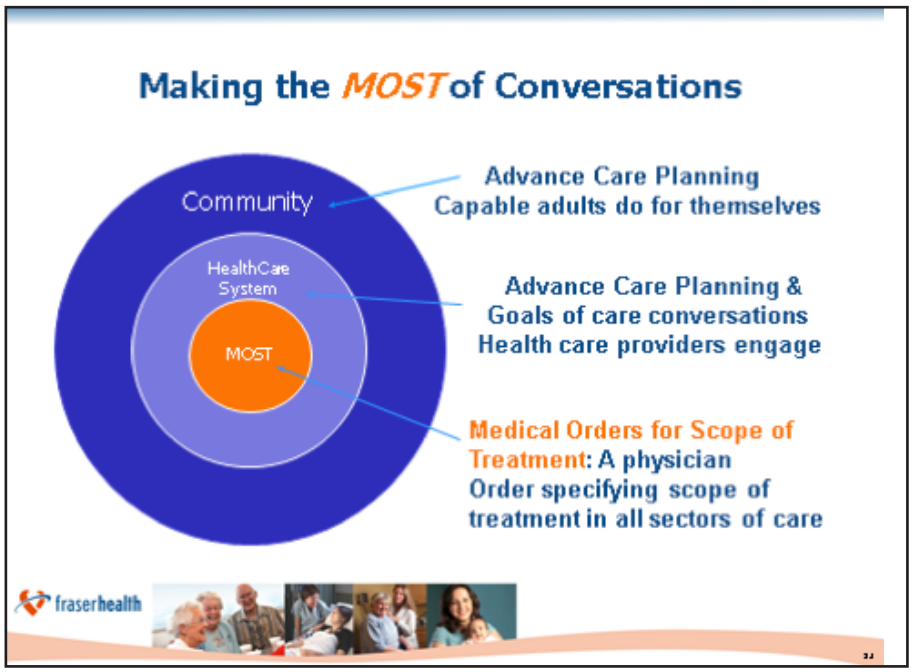
**Representation Agreement (RA)**: The document in which a capable adult names their representative to make health care and other decisions on his/her behalf when incapable.

There are two types:

1. Section 7 RA: Adult may authorize a representative to make decisions about the routine management of financial affairs, personal care and some health care decisions on behalf of the adult, excluding decisions about the refusal of life support and/or life-prolonging medical interventions.
2. Section 9 RA: Adult may authorize a representative to make personal care and health care decisions on behalf of the adult, including decisions about the acceptance or refusal of life support and life-prolonging medical interventions. [BC Ministry of Health]

**Substitute Decision Maker**: A capable person with the authority to make health care treatment decisions on behalf of an incapable adult, and includes a personal guardian (committee of the person), representative and/or temporary substitute decision maker. [BC Ministry of Health]

**Temporary Substitute Decision-Maker (TSDM)**: A capable adult chosen by a health care provider to make health care treatment decisions on behalf of an incapable adult when care is needed. The health care provider must choose a TSDM from the list in the Health Care Consent and Care Facility Admission Act in the order given. A TSDM is not chosen if the adult has an advance directive that addresses the care needed at the time, or if the adult has an available personal guardian or representative. [BC Ministry of Health]




*Courtesy of Fraser Health Authority*

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