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Chapter 1- Meet Ritesh

Rationale: Understanding and accessing palliative care can be difficult for some individuals. They may be afraid of the term or be unfamiliar with the health system, so it is important to explain Palliative Care and how it will support their quality of life through their life-limiting illness.

Resources: Palliative care - Covenant Health

Palliative & End-of-Life Care - Health Professionals | Alberta Health Services

References:

Alberta Health Services. (2024). Palliative & End-of-Life Care (PEOLC).

 $\frac{https://www.albertahealthservices.ca/info/Page14559.aspx\#:\sim:text=Palliative\%20care}{\%20aims\%20to\%20improve,interdisciplinary\%20assessments\%20and\%20appropriate}{\%20interventions}$

Covenant Health. (2024). Palliative care. https://covenanthealth.ca/services/palliative-care

Covenant Health Palliative Institute. (2024). Palliative care.

https://cvh-web.prod.opwebops.dev/about/centres-and-institutes/palliative-institute/about

Rationale: Assessment is a priority in palliative care. The person's subjective experience is key to symptom management and can be captured through palliative self-assessment tools.

Resource: Symptom Assessment Tools | Alberta Health Services

Reference:

Alberta Health Services (n.d.), Symptom Assessment Tools: Palliative & End of Life Care (PEOLC), Info for Health Professionals, Retrieved March 4, 2024, from https://www.albertahealthservices.ca/info/page14546.aspx

Rationale: The Edmonton Symptom Assessment Scale Revised (ESAS-r) allows for daily self-reporting of symptom intensity and symptom development in people receiving palliative care. It provides a way to measure the physiological and psychological distress being experienced in 10 common symptoms. The higher the score, the more concerning the symptom. It is one example of an assessment tool being used in Alberta and is available in Connect Care. The ESAS-r has been widely adopted worldwide to guide interdisciplinary clinical care.

Resource: Edmonton Symptom Assessment System Revised (ESAS-r) Form (albertahealthservices.ca)



References:

Alberta Health Services, Symptom Assessment Tools: Assessment Approaches: The Edmonton Symptom Assessment System - Revised (ESAS-r), Retrieved March 4, 2024, from https://www.albertahealthservices.ca/info/page14546.aspx

Watanabe, S. M., Nekolaichuk, C., Beaumont, C., Johnson, L., Myers, J. & Strasser, F. (2011). A multi-centre comparison of two numerical versions of the Edmonton Symptom Assessment System in palliative care Patients. *Journal of Pain Symptom Management*, 41, 456-468.

Rationale: Access to the consult teams may vary based on location. Learn how to access this in your area. The Palliative Consult Team works with the person's Primary Health Care Provider to support:

- Symptom assessment and management recommendations (e.g., pain, nausea, anxiety, dyspnea, psychosocial and emotional distress.)
- Complex conversations and goals of care discussions.
- Education about disease progression and care needed for end of life.

Resources: Palliative Care Consult Team (Inpatient) | Alberta Health Services

Palliative Community Consult Team | Alberta Health Services

References:

Alberta Health Services, Programs and Services: Palliative Care Consult Team (Inpatient), Retrieved March 4, 2024 from https://www.albertahealthservices.ca/findhealth/Service.aspx?id=4151

Alberta Health Services, *Programs and Services: Palliative Community Consult Team*, Retrieved March 4, 2024 from

https://www.albertahealthservices.ca/findhealth/service.aspx?ld=6085

Chapter 2- Advanced Care Planning / Goals Of Care Designation:

Rationale: It is important to clarify that the goals of care designation (GCD) is a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care. It is kept with other advance care planning documents in a green sleeve.

Resource: Goals of Care Designation (GCD) Order; 103547 (albertahealthservices.ca)

References:

Alberta Health Services. (2023) *Goals Of Care (GCD) Order*, Retrieved March 4, 2024 from https://www.albertahealthservices.ca/frm-103547.pdf

Alberta Health Services. (2024). *Advance Care planning/Goals of care*. https://www.albertahealthservices.ca/info/page9099.aspx

Rationale: Advance care planning involves healthcare decisions and legal decisions. Depending on the interdisciplinary team members available at your site, identify someone who may be able to help patients take next steps when it comes to advance care planning. This may be a social worker, a lawyer, or a physician for example.

Resource: Advance Care Planning Goals of Care | Alberta Health Services

Reference:

Alberta Health Services. (2024). *Advance Care planning/Goals of care*. https://www.albertahealthservices.ca/info/page9099.aspx

Rationale: Less than one in five Canadians have completed advance care planning (ACP). As a health care provider, it is important to understand the ACP process so you can help people have these discussions. Encourage them to "Think, Learn, Choose, Communicate and Document" ACP as early as possible in their illness trajectory. Depending on the interdisciplinary team members available at your site, identify someone who may be able to help patients take next steps when it comes to advance care planning.

Resources: Advance Care Planning | Alberta Health Services

My Wishes Alberta Workbook | Compassionate Alberta

References:

Alberta Health Services. (2024). *Advance Care Planning*. https://www.albertahealthservices.ca/info/page12585.aspx

Covenant Health Palliative Institute. (2024). *My Wishes Alberta Workbook*. Compassionate Alberta. https://compassionatealberta.ca/plan-ahead/my-wishes-alberta-workbook

Rationale: A personal directive is a legal document that outlines your medical wishes. Exploring wishes and determining who will make decisions on the person's behalf can help to empower family and caregivers. You should inform people they can follow an online template to draft personal directives such as on the Alberta Government website or they can seek guidance from a lawyer. A lawyer can also help draft an Enduring Power of Attorney document for financial decisions. It can be helpful to point the person to a resource directory or offer the support of a social worker to assist with these tasks.

Resources: Plan Ahead | Compassionate Alberta

Plan Ahead Resource Directory | Compassionate Alberta

References:

Covenant Health Palliative Institute. (2024). *Plan Ahead*. Compassionate Alberta. https://compassionatealberta.ca/plan-ahead

Covenant Health Palliative Institute. (2024). *Plan Ahead Resource Directory*. Compassionate Alberta. https://compassionatealberta.ca/plan-ahead/plan-ahead-resource-directory

Rationale: Create opportunities to engage in ongoing advance care planning conversations. It's important to seek agreement from the person receiving care to discern if they are open to discussing their goals of care.

Resource: Serious-Illness-Conversation-Guide.2023-05-18.pdf (ariadnelabs.org)

Reference:

Ariadne labs. (2023). *Serious Illness Conversation Guide*. https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf

Rationale: GCD is about all three levels of care. Comfort care is for the time near death, and it is about keeping the person comfortable, not treating the disease. Medical care is about treating the disease and there are choices you can make about where and how that happens. Resuscitative care is about what you want in terms of life saving measures in an emergency.

Resources: Goals of Care Designation Order | Compassionate Alberta

Advance Care Planning: Learn about the Goals of Care Designation order (alberta.ca)

References:

Alberta Health Services. (2024). Learn About the Goals of Care Designation order. My Health Alberta.

https://myhealth.alberta.ca/HealthTopics/Advance-Care-Planning/Pages/Learn-about-GCD-order.aspx

Covenant Health Palliative Institute. (2024). *Goals of Care Designation order.* Compassionate Alberta. https://compassionatealberta.ca/plan-ahead/advance-care-planning/goals-care-designation-order

Chapter 3 Physical / Psychosocial:

Rationale: Ritesh wants to know more about the things he can do on his own to make himself feel more comfortable. You explain that besides pharmacological management a fan, cool cloth, dim lights, distraction techniques, conserving energy, relaxation music or relaxation and

imagery scripts, and counselling strategies can provide relief. You also share that interprofessional team members such as OT, PT, RT, Psychologist, Spiritual Care Provider, Music Therapist can help.

Resources: Palliative Care Tip - Issue #4: Dyspnea/Breathlessness - April 20, 2018 (albertahealthservices.ca)

Palliative Care - Symptom Management - Shortness of Breath (alberta.ca)

References:

Alberta Health Services. (2018, April 20). *Palliative Care Tip- Issue#4: Dyspnea/Breathlessness*. https://www.albertahealthservices.ca/assets/info/peolc/if-peolc-palliative-care-tips-issue4.pdf

Alberta Health Services. (2019, January 4). Symptom management-Shortness of Breath. My Health Alberta. https://myhealth.alberta.ca/HealthTopics/Palliative-Care/Pages/Shortness-of-Breath.aspx

Rationale: Regardless of professional role, we all can offer a supportive presence and listen with respect and sensitivity. Any team member can explore with the person their priorities, preferences, values, beliefs, fears and hopes regarding death and dying. Depending on the available resources at your site, you can refer to the spiritual care provider, social worker, or therapist if you think the person would benefit from additional support.

Resource: Grief Training: Building Better Health Care Professional Capacity <u>Learning Hub</u> (<u>virtualhospice.ca</u>)

Reference:

Canadian Virtual Hospice. (2021). *Grief Training: Building Better Health Care Professional Capacity.* The Learning Hub. https://www.virtualhospice.ca/learninghub/

Rationale: A referral to a Psychologist or a Spiritual Care provider would be appropriate. Depending on the available resources at your site, both can provide psychosocial support to patients and families. Spiritual Care providers work with any patient regardless of if they are religious or not and can support them with questions of meaning and the struggles of living with a life-limiting illness.

Resources: Spiritual Care | Alberta Health Services

Psychologists' Association of Alberta (psychologistsassociation.ab.ca)

References:

Covenant Health. (n.d.) *Spiritual Care*. https://cvh-web.prod.opwebops.dev/services/spiritual-care

Alberta Health Services. (n.d.). Spiritual Care. My Health Alberta.

https://www.albertahealthservices.ca/findhealth/Service.aspx?id=4828

Psychologist Association of Alberta. (n.d.). *Psychologist Association of Alberta*. https://psychologistsassociation.ab.ca/

Chapter 4 - Impact on the Family:

Rationale: A child old enough to love is old enough to grieve. It is common to see regressive behaviors from children and toddlers who are bereaved or experiencing separation due to illness.

Resources: www.dougy.org

www.kidsgrief.ca

www.youthgrief.ca

References:

Canadian Virtual Hospice. (2020). KidsGrief.ca. https://www.kidsgrief.ca/

Canadian Virtual Hospice. (2020). Youth Grief.ca. https://youthgrief.ca/

The Dougy Center. (2024). The right place when nothing feels right. https://www.dougy.org/

Rationale: Books are good resources to use with children facing anticipatory grief or who are bereaved. Choose a book that matches the age and understanding of the child. Books can aid caregivers and adults in supporting bereaved children. You tell them that the team psychologist is also available for support and offer to make a referral.

Resource: Amazon.ca: the invisible string book

When A Parent is Sick 2nd Edition: Hamilton, Joan: 9781895900910: Books - Amazon.ca

References:

Hamilton, J. (2021). When A Parent Is Sick (3rd ed.). Pottersfield Press Ltd.

Karst, P. (2018). The Invisible string. Little, Brown Books for Young Readers.

Alberta Health Services. (2024). Psychologist

https://www.albertahealthservices.ca//info/Page8494.aspx

Rationale: A referral to a Certified Music Therapist is appropriate. Music Therapists are trained to provide emotional support and enhance coping through music and counselling. Music can help children and youth process their feelings in an accessible way. If a Music Therapist is not available in your area, identify other team members (psychologist, counsellor, spiritual care) who may be able to help and encourage the family to use music and creative arts with the children.

Resource: www.mtaa.ca Music Therapy Association for Alberta- Find A Music Therapist

References:

Music Therapy Association for Alberta. (n.d.). Find a therapist. https://www.mtaa.ca/find-a-music-therapist

The Children's Grief Foundation of Canada. (2024). *Grief Support for every child*. https://childrensgrieffoundation.org/

Rationale: A referral to a dietician is appropriate. Dieticians can offer assessment and suggestions about how to bring in preferred foods, and how to eat safely. Dieticians can also educate about nutritional needs during serious illness. Remind the person to never force eating and to never feed someone who is sleepy, drowsy, or not alert.

Resources: Physical and Emotional Changes as Death Approaches (alberta.ca)

Nutrition Services HP | Alberta Health Services

Topics - Lack of Appetite and Loss of Weight - Canadian Virtual Hospice

References:

Alberta Health Services. (2023). *Physical and Emotional Changes as Death Approaches*. My Health Alberta.

https://myhealth.alberta.ca/Health/Pages/conditions.aspx?hwid=aa150174&lang=enca

Alberta Health services. (2024). Nutrition Services.

https://www.albertahealthservices.ca/nutrition/Page16404.aspx

Canadian Virtual Hospice. (2024). Lack of appetite and loss of weight.

https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Symptoms+ +Health+Concerns/Lack+of+Appetite+and+Loss+of+Weight.aspx

Rationale: Referral to a social worker would be appropriate in this situation. The social worker can help patients and families determine which income support benefits they may be eligible for and help them to apply, if desired. If there is no social worker on your service, other team members can help her apply.

Resource: Compassionate Care benefits <u>Caregiving benefits and leave - Canada.ca</u>

References:

Alberta Health Services. (2024). Social Worker.

https://www.albertahealthservices.ca/info/Page8497.aspx

Government of Alberta. (2024). *Compassionate Care Leave*. https://www.alberta.ca/compassionate-care-leave

Government of Canada. (2023, December 29). *El caregiving benefits*. https://www.canada.ca/en/services/benefits/ei/caregiving.html

Chapter 5 - Discharge Planning & Going Home:

Rationale: Depending on your role, your setting and your relationship with the person you may want to share different information with the team. The information you share can contribute to the patient and the family receiving appropriate palliative care based on their culture, needs and understanding. Take time to acknowledge the person, the family and the team, for the opportunity to work together to provide good care.

References:

Alberta Health Services. (2024). Careers.

 $\frac{\text{https://www.albertahealthservices.ca/medstaff/page7071.aspx\#:} \sim : \text{text=General\%20Pr}}{\text{actitioners\%20\%26\%20Family\%20Physicians\%3A\%20are, care\%20within\%20a\%20spe}}{\text{cific\%20discipline}}.$

Alberta Health Services. (2024). *Occupational therapist (OT)*. https://www.albertahealthservices.ca/info/Page8493.aspx

Alberta Health Services. (2024). *Pharmacist*. https://www.albertahealthservices.ca/careers/Page11743.aspx

Alberta Health Services. (2024). *Physiotherapist (PT)*. https://www.albertahealthservices.ca/info/Page8489.aspx

Alberta Health Services. (2024). *Registered Nurse (RN)*. https://www.albertahealthservices.ca/info/Page8605.aspx

Alberta Health Services. (2024). Social Worker. https://www.albertahealthservices.ca/info/Page8497.aspx

Alberta Health Services. (n.d.). Spiritual Care. My Health Alberta. https://www.albertahealthservices.ca/findhealth/Service.aspx?id=4828

Alberta Health Services. (2024). Transition Services. https://www.albertahealthservices.ca/shc/Page14842.aspx

Music Therapy Association for Alberta. (n.d.). Find a therapist. https://www.mtaa.ca/find-a-music-therapist

Rationale: Depending on the available disciplines in your area, various team members can participate in discharge planning. It's important to include interprofessional team members that will address each person's specific needs when they go to their next care location. In Ritesh's case he will need support from a Respiratory Therapist to set up home oxygen. Family physicians will take over care in the community and follow ups may be necessary.

Resource: Respiratory Therapy https://www.albertahealthservices.ca/info/Page8496.aspx

Reference:

Alberta Health Services. (2024). *Respiratory Therapist (RT)*. https://www.albertahealthservices.ca/info/Page8496.aspx

Rationale: The interprofessional team can collaborate to facilitate a safe and smooth transition of care for the person and their family. Tasks are assigned based on staff roles and available resources. The goas is for the team to work together to provide care in the person's preferred location when possible.

Reference: Hospital Discharge Planning (alberta.ca)

Resource:

Alberta Health Services. Hospital Discharge Planning, MyHealth Alberta, Retrieved March 4, 2024 from https://myhealth.alberta.ca/Health/pages/conditions.aspx?hwid=ug5158

Alberta Palliative Care Competency Frameworks

Competency References:

Alberta Health Services. (2024). *Alberta Palliative Care Competency Frameworks*. https://www.albertahealthservices.ca/info/Page17398.aspx

Covenant Health Palliative Institute. (2024). Resources for healthcare providers. Covenant Health. https://covenanthealth.ca/about/centres-and-institutes/palliative-institute/resources/healthcare-providers

Covenant Health Palliative Institute. (2023). Alberta Interprofessional Palliative Care Competency Framework. https://covenanthealth.ca/sites/default/files/2023-10/interprofessional-palliative-care-competency-framework.pdf