"MEMENTO MORI"

Medicine at the End of Life

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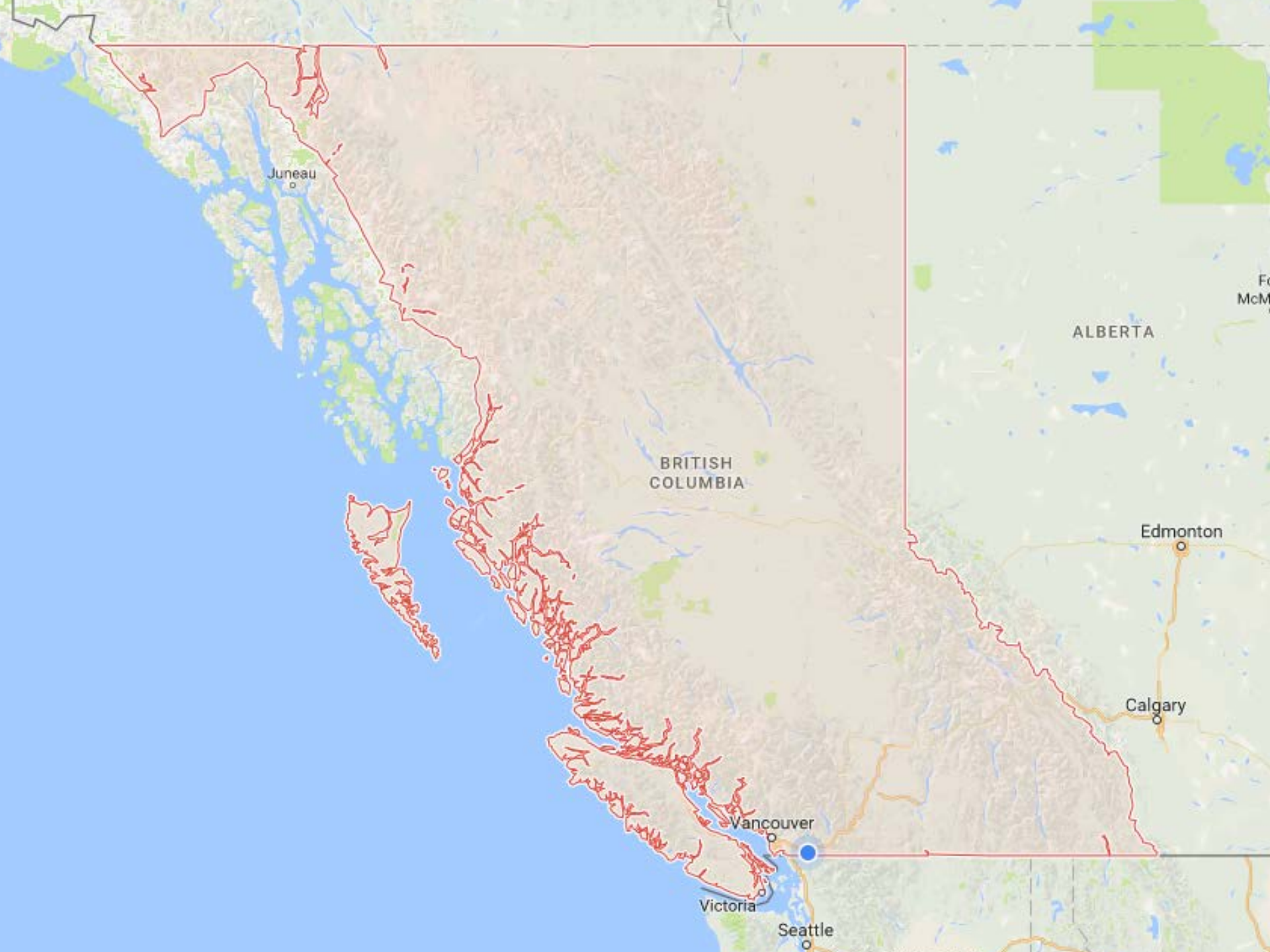
Van Gogh, 1886

First… What does “Memento Mori” mean?

Second… who is this random guy giving me a lesson in Latin & Roman history?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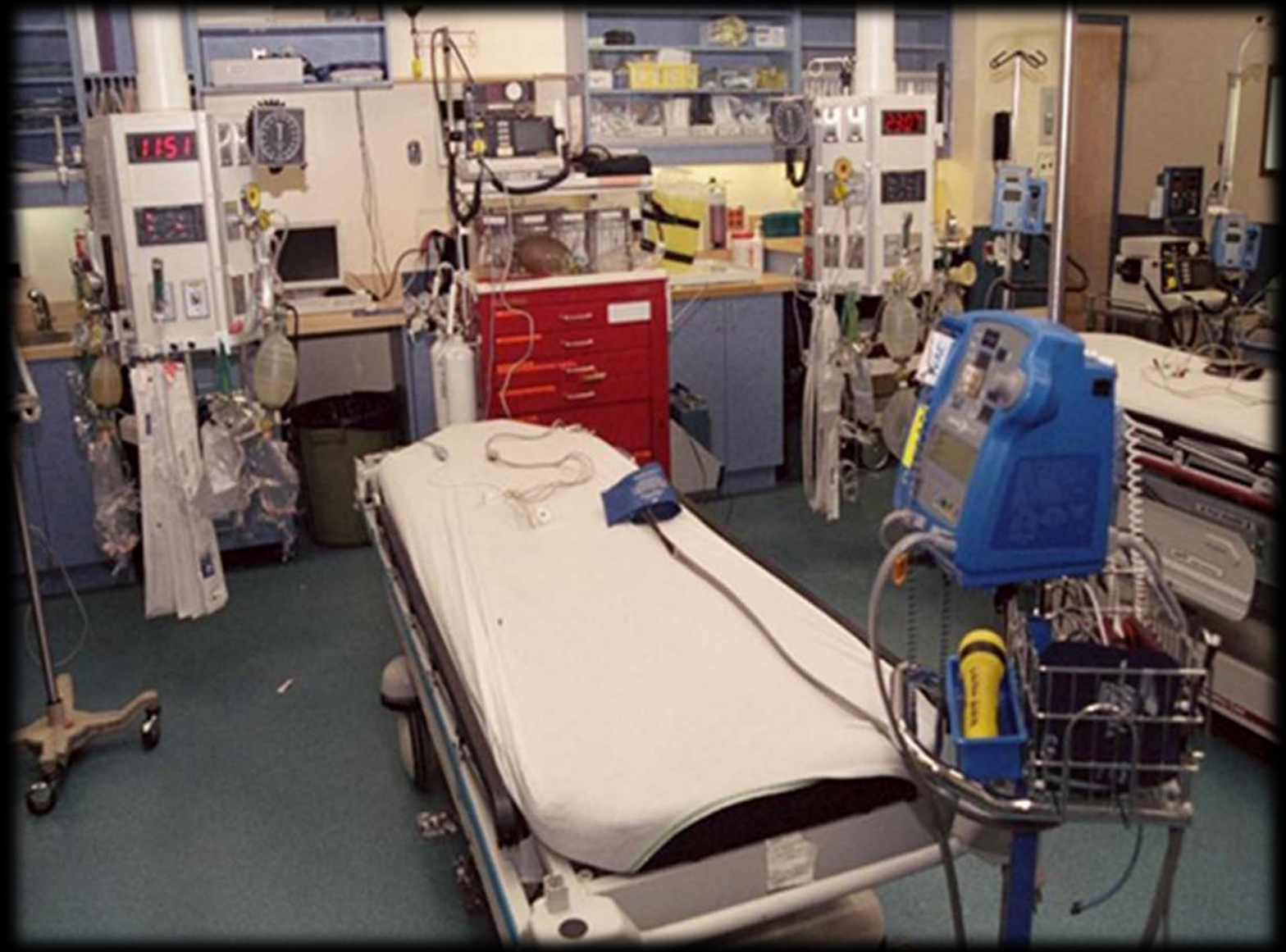
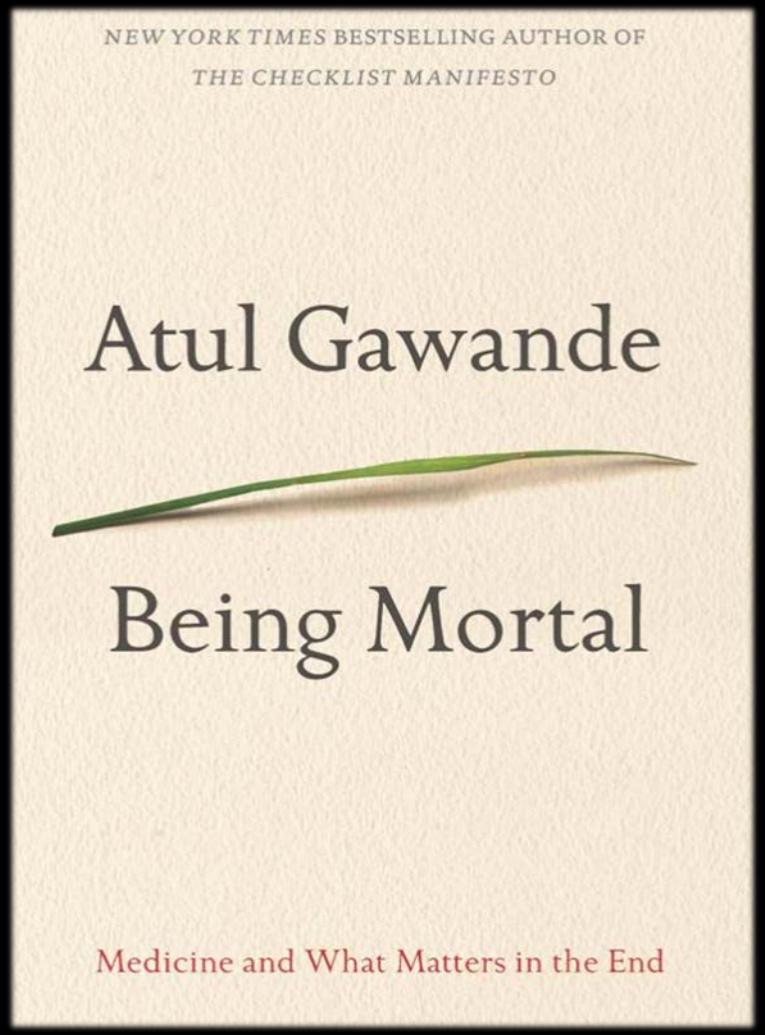
Disclaimers & Disclosures…

Why am I talking about this?



https://idiopathicmedicine.wordpress.com/2011/06/24/where-trauma-meets-tragedy/



"Our ultimate goal, after all, is not a good death but ***a good life to the very end***."

Outline

1. Advance Care Planning
   - Making decisions around “goals of care”
   - Documenting your choices
2. End of Life Care
   - Different levels of care at the end of life
   - Palliative Care

PART 1: Preparing for a Crisis – Advance Care Planning

*Advance Care **Planning***

"Medicine is a science of uncertainty and an art of probability."
– Sir William Osler (1849-1919)

Advance Care Planning

- A medial crisis can occur at any age, at any time.
- Advanced care planning is a process that **allows your voice to guide your physicians before a critical situation occurs.**

Advance Care Planning

- In the absence of explicit direction, doctors and the medical team are required to **assume you agree** to all medical treatments.
- There are advantages and disadvantages to this assumption…

Advance Care Planning

- Advance care planning is about creating a **making your voice independent of your ability to speak or make decisions.**
- The record of your voice (**written**, audio, video) is the definition of an **"Advance Care Plan."**

Advance care planning pieces:

- **Who** do you want making your health care decisions?
- **What** recommended medical treatment(s) do you agree to, or refuse?
- **Would you accept or refuse** life support and life-prolonging medical interventions for certain conditions?
- **What are your preferences** should you need residential care and not be able to be cared for at home?

How do you make these decisions? The first step is to <u>reflect</u>:

- What do you **<u>cherish</u>**?
- What do you **<u>fear</u>**?
- Who **<u>knows you</u>** the best?
- What would you want your physicians to know if you couldn't speak?

"By three methods we may learn wisdom: First, by reflection, which is noblest; Second, by imitation, which is easiest; and third by experience, which is the bitterest." – Confucius

Advance Care Planning

- Reflection and ***communication*** is key!
- ***Documenting*** these choices makes your wishes clear to your family members and doctor.

Have a discussion with your **loved ones** and **family doctor!**

REMEMBER – As life and circumstances change, ***your advance care plan can change!***

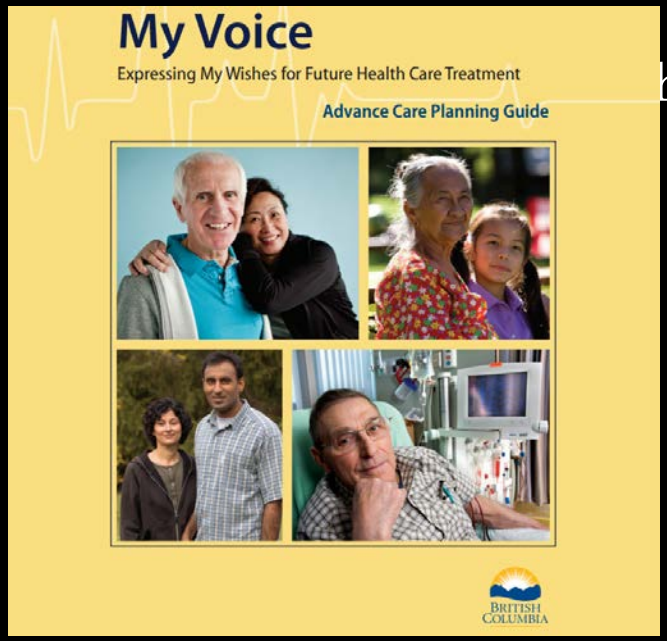
Why talk about it?

- When well-intentioned family members try to help with decision-making, **they often have differing opinions**.
- Leads to stress, confusion, fights and even **legal battles** – at an already stressful time.
- **Having a plan, communicating it, and writing it down removes doubt** and alleviates this added stress for everyone involved.

The Details of YOUR Advance Care Plan

"My Voice"

- Tool to guide people through the advance care planning process
- BC-Wide Resource
- Explains options of how to enact care wishes
- Able to name representatives:
  - To make health care decisions
  - To make financial decisions
  - To make end-of-life care decisions



WARNING – LEGAL ISSUES AHEAD,
there be dragons…

SUBSTITUTE DECISION MAKER

- If you are suddenly unable to make medical decisions for yourself, due to illness or medical incapacity and **you have not named someone, others will be approached to *decide for you***.
- That person is called a **temporary substitute decision maker (TSDM).**
- ***Unless you have an advance care plan stating otherwise the default order in which people are approached is set down by BC Law.***

Substitute Decision Maker Default Hierarchy

1. Your **spouse** (married, common-law, same sex - time living together doesn't matter)
2. A **son or daughter** (19 or older - birth order doesn't matter)
3. A **parent** (either, may be adoptive)
4. A **brother or sister** (birth order doesn't matter)
5. A **grandparent**
6. A **grandchild** (birth order doesn't matter)
7. Anyone else **related** to you by birth or adoption
8. A **close friend**
9. A person immediately related to you by marriage (in-laws, step-parents, step-children, etc.)

Substitute Decision Maker

- The only way to change who you would like to represent you is to **name a person legally as your representative.**
- Eg. If you would prefer to have a child or sibling represent you rather than a spouse.
- This requires **a representation agreement** and can be done through the ‘My Voice’ document.

Enhanced Representation Agreement

- Allows you to name a representative if you become incapable to make decisions.
- Covers personal care and all health care treatments, including life support and life-prolonging medical interventions.
- NOTE -> ***A separate document is needed for someone to make decisions about your finances….***

POWER OF ATTORNEY

- Allows you to appoint another person (called your attorney) to **make decisions about your financial and legal affairs.**
- The "attorney" is authorized to act when you become incapable.
- Attorneys may not make health care treatment decisions. You need a representation agreement for this (see previous slide).
- Power of Attorney & Medical Decision Maker are Different Roles!

Power of Attorney SCOPE

- The powers provided to the attorney can be tailored to suit your needs.
- For example, this may range from the ability to deposit cheques into your chequing account to complete access to all of your assets.

Medical Advance Directive

- Allows you to clearly state decisions about accepting or refusing specific health care treatments in advance.
- Your advance directive must be followed as long as it addresses the health care treatment you need at the time.
- If it does not cover your current care and you are incapable of making a decision your representative or appointed decision maker will be consulted.

Medical Advance Directive - MOST Form

- "**M**edical **O**rders for **S**cope of **T**reatment"
- A form that is REQUIRED if you are admitted to hospital – preferably in place beforehand!
- Allows doctors to know your wishes with level of care and CPR/breathing tubes

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MEDICAL ORDERS for SCOPE of TREATMENT (MOST)
End of Life Care Program

ADDI105016A New: Oct 03/12 Page: 1 of 1

DRUG & FOOD ALLERGIES

SECTION 1: CODE STATUS: *Note: CPR is not attempted on a patient who has suffered an unwitnessed cardiac arrest.*

Attempt Cardio Pulmonary Resuscitation (CPR). *Automatically designated as C2. Please initial below.*

Do Not Attempt Cardio Pulmonary Resuscitation (DNR)

SECTION 2: MOST DESIGNATION based on documented conversations ***(Initial appropriate level)***

Medical treatments excluding Critical Care interventions & Resuscitation	
M1	**Supportive care, symptom management & comfort measures. *Allow natural death.*** *Transfer to higher level of care only if patient's comfort needs not met in current location.*
M2	**Medical treatments available within location of care. Current Location:** _____ *Transfer to higher level of care only if patient's comfort needs not met in current location*
M3	**Full Medical treatments excluding critical care**
Critical Care Interventions requested. NOTE: Consultation will be required prior to admission.	
C1	**Critical Care interventions excluding intubation.**
C2	**Critical Care interventions including intubation**

http://mcithedoctorsoffice.ca/patients/43-clinic-First-Canadian-Place

CPR:

CARDIO - PULMONARY RESUSSITATION

- Can include the medical team:
  - Pressing on the chest to pump blood through your heart to your body
  - Forcing air into your lungs to get oxygen to your brain
  - Giving medicine to try and restart your heart
  - Using electric shock from a machine to try and re-start your heart
- These actions can cause broken ribs, damage to the brain, throat, voice, lungs and kidneys

RESUSITATION IS NOT RESURRECTION

The Reality of CPR

- In adults of ALL AGES:
- **In hospital** 2-3 of 20 are likely to survive (10-15%)
  - Of these only **1 out of 20** will recover well enough to go home
- **Out of hospital** – if response within 10 minutes 6% survive at 1 year

The Reality of CPR

- In people older than 65 years old these numbers are likely **even smaller**
- **52%** of people over 65 years old **who survive** to discharge will have **moderate to severe brain injury**
- **CPR doesn't fix medical problems** that caused the heart to stop!!!

Statistics to keep in mind when having discussions about CPR:

- Survival rate of CPR on television shows: --> 66%
- Actual in-hospital survival rates for CPR:

All hospital patients: ----------> 15%
Frail elders*: ----------> <5%
Individuals with advanced chronic illness**: -> <1%

* An older person that has troubles performing activities of daily living because of weakness or fatigue is more vulnerable to acute illness due to low activity level.

**Advanced chronic illness such as Alzheimer's, Parkinson's or end-stage heart, lung or kidney disease.

From compassionandsupport.org

DNR – Do Not Resuscitate

- **DNR does NOT equal "Do Not Care"**
- Requesting that CPR be withheld does not change the **quality of your medical care** – our goal is to provide you with care that **respects your wishes.**
- It is important to let your wishes be known.
- BC Ambulance Paramedics will provide CPR **unless it is clearly stated otherwise.**
- If you wish for no CPR there is a 'No CPR' form that can be completed and kept in your home to record your wishes.

PART 2: Living Well 'till Natural Death - End of Life Care

End of Life Care

- Home Care
- Assisted Living
- Long Term Care
- Palliative Care
- Hospice

Home Care

- Provides **support in your home** to recover from illness and injury, manage chronic conditions or live out your final days
- Philosophy is "**home is best**"
- There are both short term and long-term services
- Helps people **maintain independence** in their home

Home Care

- There is a wide range of services
  - Examples include: Home Nursing, support for caregivers, wound care treatment etc.
- Some services are free of charge and others have a cost dependent on your tax income
- Generally **you are referred from the hospital or your doctor's office**

Assisted Living

- Appropriate when someone is **no longer coping** well at home
- Provides:
  - An independent apartment with some meals (typically lunch and dinner)
  - Housekeeping
  - Social and recreation opportunities
  - 24 hour response system

Assisted Living

- There are both public and private pay assisted living homes
- Generally people still have a **degree of independence – no personal care provided**
- **Must be safe to make their own decisions and able to use an emergency response system if needed**

Residential Care

(aka Nursing Homes)

- 'Long Term Care'
- For adults who can **no longer live safely or independently at home** because of complex health care needs
- 24 hour nursing care
- Personal care and all meals

Palliative Care

Palliative 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*

Palliative Care

- provides **relief from pain** and other distressing symptoms;
- **affirms life** and regards dying as a normal process;
- ***intends neither to hasten or postpone death;***
    - Principle of Double Effect

Palliative Care

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to **help patients live as actively as possible** until death;
- offers a support system to **help the family cope** during the patients illness and in their own bereavement;

Palliative Care

- uses a **team approach** to address the needs of patients and their families, including bereavement counselling, if indicated
- will **enhance quality of life, and may also positively influence the course of illness**

Palliative Care

• is applicable **early in the course of illness**, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative Medicine Physicians

- Specialists in Palliative care in BC are mostly family doctors with interest and/or extra-training in management of symptoms of severe disease
- They are specialists in pain management, in organ function, in helping people meet their goals at end of life.

Hospice Care

- Hospice is an **alternative medical care setting** which is appropriate when people are thought to be in a terminal phase of illness
  - Usually less than 6 months of life left
- **Palliative Care continues throughout the life course**

Hospice in Chilliwack

- Not for profit charitable organization
- Care from the Chilliwack Hospice Society is available to individuals and families either:
  - In their home
  - At the hospital
  - At Cascade Hospice Residence
  - At a Care Facility

•There is a palliative care team in the Chilliwack community!

Cascade Hospice

Mission Statement:

- Hospice is not a place; it is a philosophy.
- We provide sensitive support to individuals in need of our services.
- Hospice philosophy emphasizes comfort, dignity and quality of life, it affirms life and neither hastens nor postpones death. People deserve to experience hope, wonder and joy.

Benefits of Hospice

- Beautiful 10 bed facility
- Room for guests, kitchen, social area
- More “home-like” atmosphere
- Excellent nursing to patient ratio, your family doctor can even continue to care for you there!

Chilliwack Hospice

- Bereavement services programs for family of all ages.
  - One on One Support
  - Bereavement and grief follow-up
  - Teen groups
  - Children's expressive art groups
  - Pregnancy/Infant Loss support

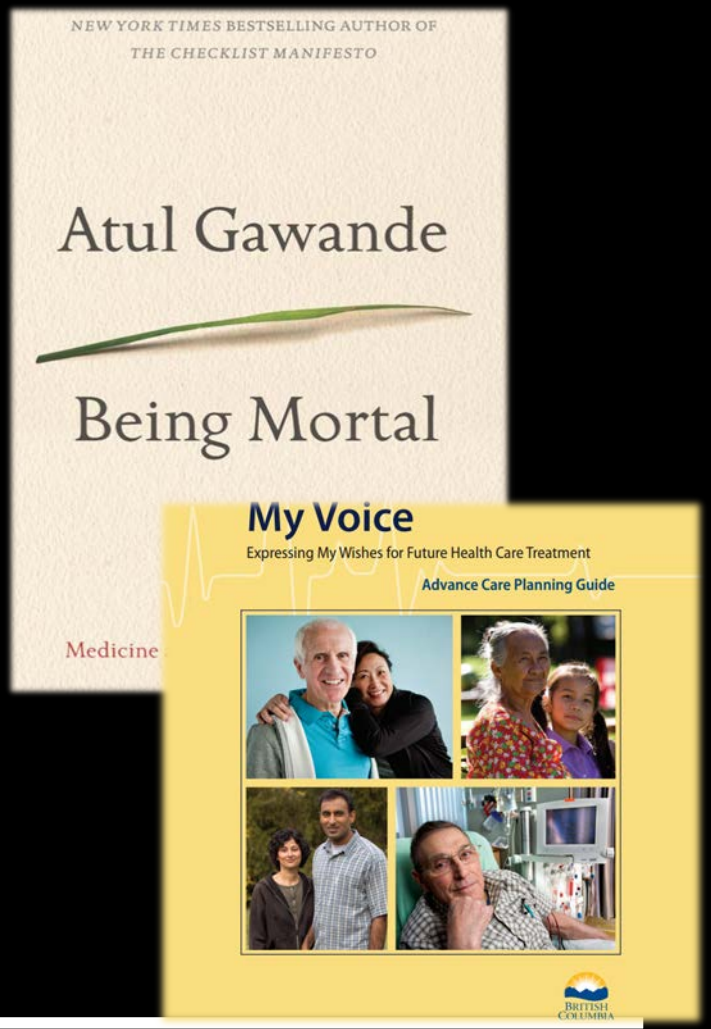
The Linchpin: COMMUNICATION around GOALS OF CARE

*(**beyond** the MOST form and legal documents….)*

GOALS of CARE

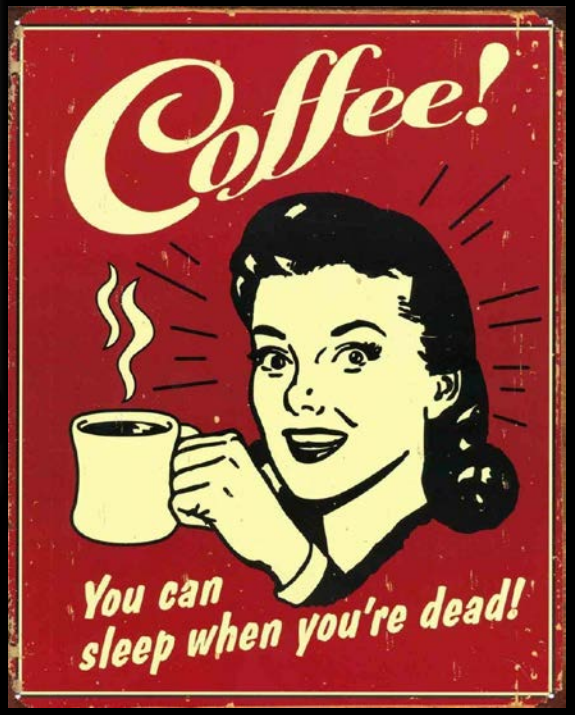
- Communication with your physicians and medical team will ensure your advanced directives are respected.
- Ask your physician questions – about the disease, the course, the natural history, how end of life manifests.
- Ask how your needs may be met in treatment – curative and palliative.

Resources



1. My Voice website: can read/download the document – google 'My Voice BC Advance Care'
2. How to assign a power of attorney (enduring): www.ag.gov.bc.ca/incapacityplanning/pdf/Enduring_Power_of_Attorney.pdf
3. BC Transplant Agency: http://www.transplant.bc.ca/index.asp
4. Cascade Hospice website
5. Fraser Health website
6. "Being Mortal" by Dr. Atul Gawande

Question / Discussion / Coffee Time



Bonus Topic(s)

What is organ donation?

- Giving away one's organs after death to provide life-saving transplant operations to others after death.
- One donor can save as many as 8 lives.
- It is not against any major religious affiliation, and is considered a selfless act
- A person must have died to be eligible to donate organs.* Two physicians uninvolved in organ transplantation must declare death before a person is considered a candidate

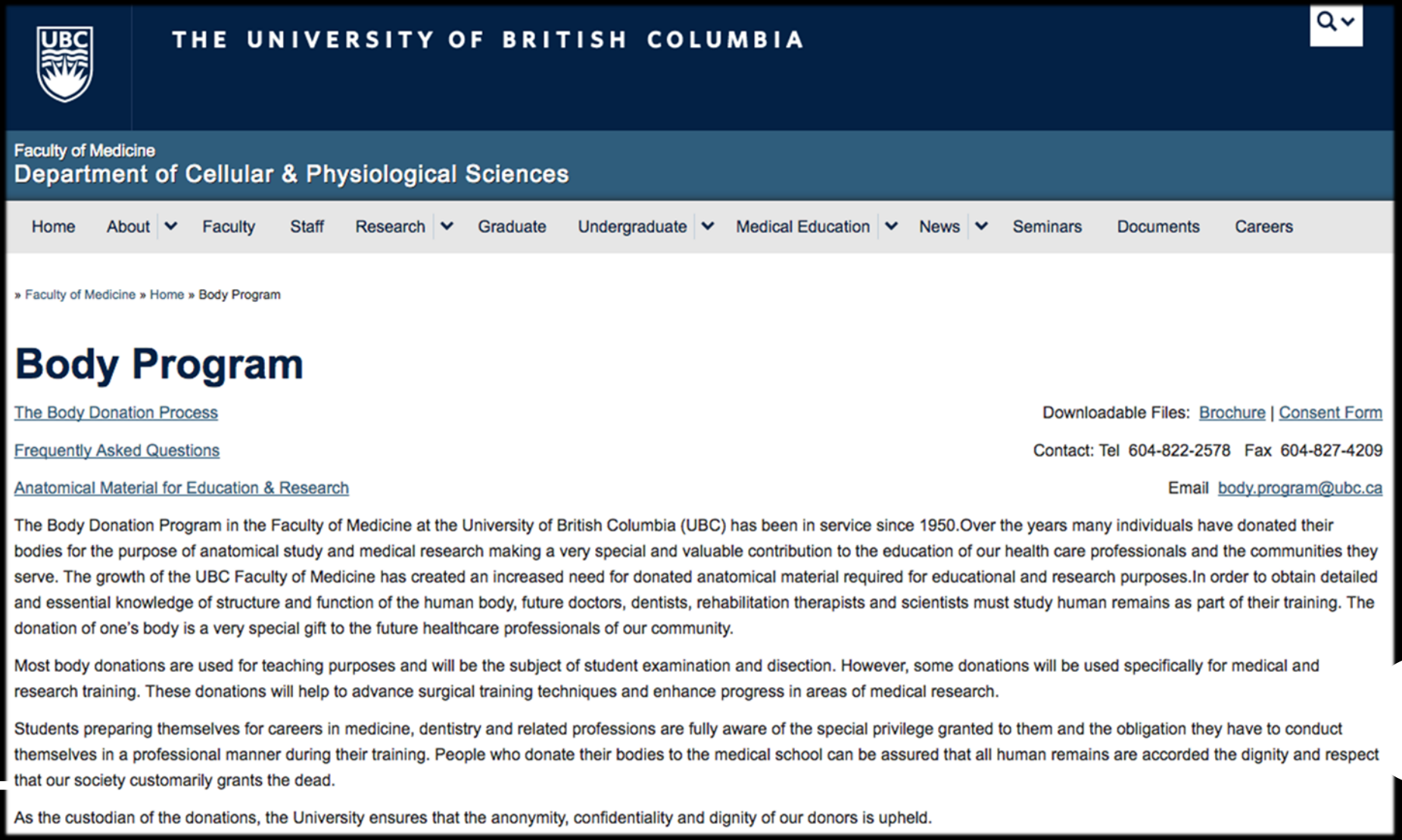
Why consider donation?

- Thousands of Canadians await transplants and many die on the waiting list.
- Although there are many people who have opted to be organ donors, very few are able to because of their cause of death.
- Average wait times are 3 to 45 months for a suitable donor.

Want to know more?

- You need to opt-in.
- You can put a decal on your care card, but you have to verify registration with the BC Transplantation services via e-mail or by phone.
- You need to tell your loved ones, especially your representative or substitute decision maker, so they know your wishes.
- In Canada, most organs can only be donated from someone who had died from a brain injury (1-2% of causes of death).

Body Donation Program @ UBC



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Body Program

The Body Donation Process

Frequently Asked Questions

Anatomical Material for Education & Research

Downloadable Files: Brochure | Consent Form

Contact: Tel 604-822-2578 Fax 604-827-4209

Email body.program@ubc.ca

The Body Donation Program in the Faculty of Medicine at the University of British Columbia (UBC) has been in service since 1950.Over the years many individuals have donated their bodies for the purpose of anatomical study and medical research making a very special and valuable contribution to the education of our health care professionals and the communities they serve. The growth of the UBC Faculty of Medicine has created an increased need for donated anatomical material required for educational and research purposes.In order to obtain detailed and essential knowledge of structure and function of the human body, future doctors, dentists, rehabilitation therapists and scientists must study human remains as part of their training. The donation of one's body is a very special gift to the future healthcare professionals of our community.

Most body donations are used for teaching purposes and will be the subject of student examination and disection. However, some donations will be used specifically for medical and research training. These donations will help to advance surgical training techniques and enhance progress in areas of medical research.

Students preparing themselves for careers in medicine, dentistry and related professions are fully aware of the special privilege granted to them and the obligation they have to conduct themselves in a professional manner during their training. People who donate their bodies to the medical school can be assured that all human remains are accorded the dignity and respect that our society customarily grants the dead.

As the custodian of the donations, the University ensures that the anonymity, confidentiality and dignity of our donors is upheld.