Is there such thing as a good death?

Ensuring that your needs and those of your loved ones are met

"Dying is more than just a physical event, it is a process that includes one's whole being – physical, psychological, and spiritual"

David Kuhl – What Dying People Want

Outline

1. Advanced Care Planning
   - Making decisions for the future
   - Documenting your choices
2. End of Life Care
   - Different levels of care at the end of life
   - Palliative Care

Advanced Care Planning

- No one knows what the future holds - health care crises can happen at any time and age
- Advanced care planning is a process that allows your values, beliefs and desires to be reflected in your healthcare

Advanced Care Planning

- Without specifying your desired care; health care providers are required to assume you agree to all medical treatments
- There are advantages and disadvantages to this assumption and it needs to be individualized

Advance Care Planning

- Advance care planning is about individualizing your healthcare to reflect your values and beliefs should you be unable to make your own decisions
- Writing these values and beliefs down is an advance care plan

Advanced care planning

Addresses:

- Who do you want making your health care decisions?
- What health care treatment(s) do you agree to, or refuse, if a health care provider recommends them?
- 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?

Reflection

- What do I value?
  - Spending time with loved ones?
  - Ability to do a certain pleasurable activity?
  - Longevity?
- What do I fear?
  - Pain?
  - Difficulty breathing?
  - Being alone?

Advance Care Planning

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

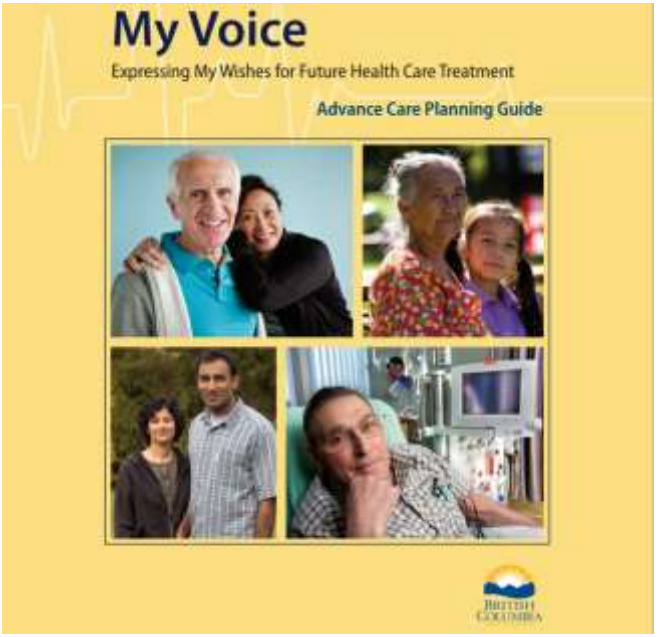
• A good first step is to have a discussion with your loved ones and family doctor

Why talk about it?

- When well-intentioned family members try to help with decision-making when their loved one is sick, they may 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 alleviates this

“My Voice”

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



Why should I speak with others about my wishes?

- 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

One person on the list below will be approached in this order:

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
- 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 person (attorney) is authorized to act when you become incapable.
- Attorneys may not make health care treatment decisions. You need a representation agreement for this

Power of Attorney

- 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 Advanced 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

Hospital Care - MOST Form

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

CPR

- Stands for:
- **C**ardio (heart)
- **P**ulmonary (lung)
- **R**esuscitation

- If the heart stops it is used to try and restart blood circulating and breathing

CPR

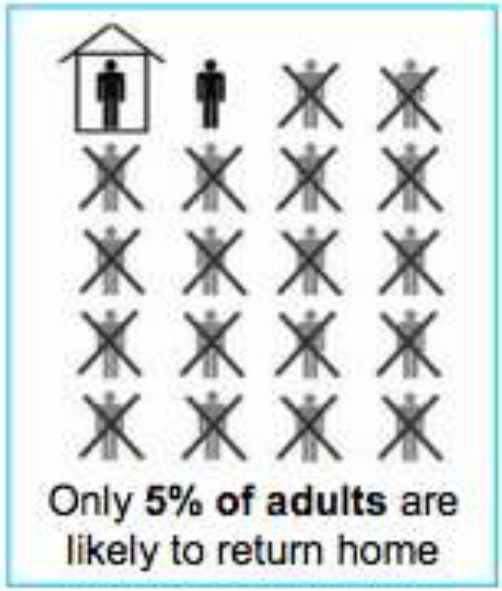
- Can include someone:
  - Pressing on the chest to pump blood through your heart to your body
  - Forcing air into your lungs to get oxygen to your brain
  - Giving medicine to try and restart your heart
  - Using electric shock from a machine to try and re-start your heart
- These actions can cause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

CPR – Miracles and Misconceptions

- Not quite what it looks like on television!
- Many studies have shown the public has unrealistic expectations of the effectiveness of CPR
- One study showed 80% of people age 70 or older believed they had a 50% or better chance of surviving CPR and leaving hospital

CPR – In reality

- 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



CPR – In reality

- 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

- CPR is not usually effective for:
  - Adults with medical conditions that have already caused damage to their heart, lungs, kidneys or brain
  - Adults who are at the natural end of their life
- CPR doesn't fix the medical condition that caused the heart to stop

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

CPR

- It is important to let your wishes be known
- In general in BC ambulance first responders 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

Hospital MOST Form

Covers level of care:

- Comfort Care Only
- Medical treatment within current hospital (no transfers)
- Full Medical Treatment (including transfers)
- Intensive Care Unit

Hospital MOST Form

Covers:

- Intubation – breathing tube
- Other interventions: dialysis, blood products, feeding through tubes

Appendix 1

fraserhealth

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

ADDI105015A 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.**

SECTION 3: SPECIFIC INTERVENTIONS *(Optional. Complete Consent Forms as appropriate)*

Blood products ☐ YES ☐ NO Enteral nutrition ☐ YES ☐ NO Dialysis ☐ YES ☐ NO
Non-invasive ventilation ☐ YES ☐ NO
Other Directions:

SURGICAL RESUSCITATION ORDER

☐ WAIVE DNR for duration of procedure and peri-operative period. Attempt CPR as indicated.
☐ Do Not Attempt Resuscitation during procedure.

SECTION 4: MOST ORDER ENTERED AS A RESULT OF *(check all that apply)*

☐ **CONVERSATIONS/CONSENSUS** ☐ Capable Adult	NAME:	DATE: (dd/mm/yr)
☐ Representative	NAME:	DATE:
☐ Temporary Substitute Decision Maker	NAME:	DATE:

☐ **PHYSICIAN ASSESSMENT** and ☐ Adult/SDM Informed and aware ☐ Adult not capable/SDM not available

☐ **SUPPORTING DOCUMENTATION** *(Copies placed in **Greensleeve** and sent with patient on discharge)*

☐ Previous MOST ☐ Provincial *No CPR*	☐ FH ACP Record ☐ Advance Directive	Representation Agreement ☐ Section 9 ☐ Section 7	☐ Other:

Date (dd/mm/yr)		**Print Name**		**Physician Signature:**
MSP #		**Contact #**		

Advance Directives and MOST Form

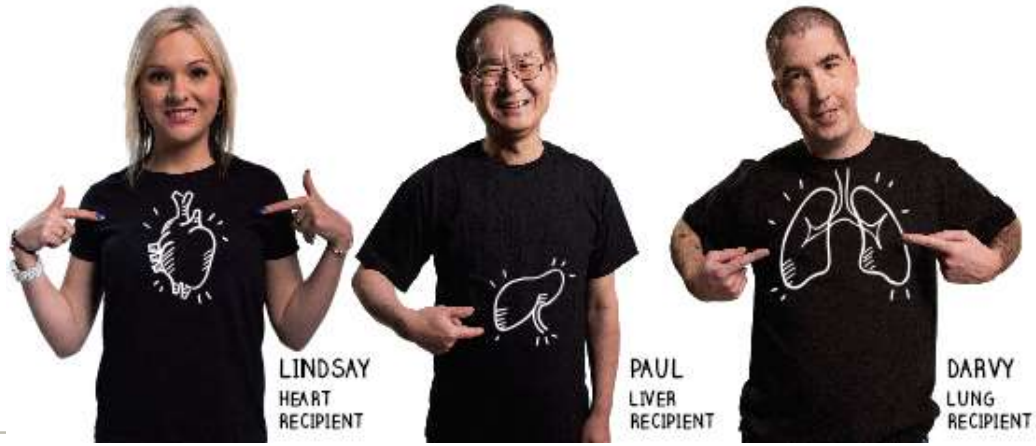
- Can always be changed as needed or as appropriate
- Often may change as person's disease progresses

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)

Summary – Advance Care Planning

- What is it? Why is it important?
- ‘My Voice’ document
- Substitute decision makers, representatives, power of attorney
- Medical Advance Directives
- CPR/DNR and levels of care in hospital
- Organ donation

Outline

1. Advanced Care Planning
   - Making decisions for the future
   - Documenting your choices
2. End of Life Care
   - Different levels of care at the end of life
   - Palliative Care

End of Life Care

- Homecare
- 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

- ‘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

- Aims to relieve suffering and improve quality of life
- Helps patients and families:
  - Address physical, psychological, social, spiritual and practical issues
  - Prepare and manage life closure and the dying process

- Total care of the person's body, mind and spirit

Palliative Care

- Is appropriate for any patient living with a life-threatening illness with:
  - Any diagnosis (not only cancer)
  - Any prognosis
  - Any time they have unmet needs or expectations

Palliative Care

- Is about living with a diagnosis, not dying with an illness
- Does not accelerate death
- Does not mean that medical care is no longer important or has stopped
- Accounts for the patient's values, family, friends, illness and beliefs into treatment plan
- Aims to provide for patient's and their families needs at the end of life.

Palliative Care

- Works best with a team!
- Multiple people will be involved in care including:
  - Nurse
  - Doctor
  - Social Worker
  - Spiritual Care
  - Pharmacist
  - Your family and loved ones
- Care can be given in the hospital, long-term care, hospice or at home

Palliative Care

- 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,
- They are specialists in organ function
- They are specialists 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
- 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

CHILLIWACK Hospice SOCIETY
Heartfelt support during dying and grieving

•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!

Grief and Spiritual Support

- It is okay and normal to have anticipatory grief
- Possible stages of grief: denial, anger, bargaining, depression, and acceptance

• Often when given a life-altering prognosis, some people value having time to spend with loved ones and the chance to mend relationships or say goodbye

• Spiritual support and religious practice is important and available

Chilliwack Hospice

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

Summary – End-of-Life

- Home Care
- Assisted Living
- Long term Care
- Palliative care
- Hospice Care

Communication

- Communication with your health care professional will ensure your advanced directives are respected.
- Ask your health care provider questions – about the disease, the course, the natural history, how end of life manifests.
- If you don't understand something ask more questions!
- Ask how your needs can be met in treatment.

Communication

- Having a difficult situation in hospital? There is help from ethicists and mediators
- You are not alone!

Communication

- Death and the end-of-life is not an easy topic – but it is so critically important to talk about ahead of time
- Reflection and communication is key!
- Talking with loved ones and healthcare providers is key to having your wishes followed

Is there such thing as a good death?

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

Pictures Credits

- http://www.hospiceofyancey.org/
- http://uthmag.com/10-amazing-life-lessons/
- http://www.medpagetoday.com/PublicHealthPolicy/Ethics/34181
- http://theamateursguide.com/?p=197