Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Community Engagement

Community Engagement Report

Annual CEAN Forum:

Advance Care Planning

Event Date: March 27, 2010

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Community Engagement Advisory Network

Annual Forum: March 27, 2010

Advance Care Planning

Introduction

The Community Engagement (CE) department of Vancouver Coastal Health (VCH) is supported by a group of members of the public, the CE Advisory Network (CEAN), to enhance patient and public involvement in health service planning and decision-making. It is our collective goal to conduct a forum each year, providing an opportunity for members of VCH staff and leadership to meet with members of CEAN to discuss health service issues of concern to both VCH and the public. Past forums have covered topics such as emergency room wait times, cross-cultural health needs and transforming seniors' care in acute care facilities. Through meetings with both CEAN members and VCH leadership in December 2009, it was determined that the topic for this year's forum would be advance care planning.

What is *Advance Care Planning*, and why is this topic a priority for VCH?

Advance care planning (ACP) is the process of thinking, learning, talking and deciding what health care you want if you become very ill and can't communicate for yourself. It can include who you want to make decisions for you and what specific wishes, values and beliefs you want them to think about. Healthcare providers need support and training to work in partnership with patients and family members under these sometimes challenging circumstances.

VCH initiated strategic planning for ACP in 2008, exploring staff protocol and training to work with VCH patients. The BC Government is also considering legislation around 'advanced directives' in order to address similar end-of-life issues for patients, families, health care professionals and the health authorities. Because ACP is a potentially controversial topic, the ACP Strategy Team expressed interest in public input on the implementation of this strategy, including messaging to the public, and community groups' possible contribution to making ACP better understood.

Forum Planning, Agenda and Attendance

Meetings to plan the forum format and agenda were held with CEAN members and staff in January, February and March. It was agreed that the forum would be held at the Paetzold complex in Vancouver General Hospital, and combine short presentations and dialogue circles to allow participants to explore these issues.

The agenda for the day included a presentation from VCH President and CEO Dr. David Ostrow, a series of presentations on ACP, two rounds of small group discussions, and a plenary session and wrap up.

A total of 45 people attended the ACP forum, with strong representation from the CEAN membership, VCH staff and leadership, as well as partner organizations such as Providence Healthcare, the BC Cancer Agency, and the Council of Seniors Citizens of BC (COSCO).

Presentations

The presentation from Dr. David Ostrow focused on the increasing challenges faced by the health authority due to rising demand for health services, and the strategies VCH has adopted to meet this demand while operating on budget. Dr. Ostrow indicated the relevance of ACP to the health authority and emphasized the role the public can play in supporting the social change required for ACP implementation. (see Appendix 1)

Presentations from the ACP Strategy Team (see Appendices 2-4) included:

1. **What is Advance Care Planning and why do we need this?** Cari Hoffmann, Advance Care Planning Coordinator, Fraser Health Authority

2. **Legislation and Logistics:** Darren Kopetsky, Client Relations and Risk Management, Vancouver Coastal Health

3. **Advance Care Planning as a sign of social change:** Pat Porterfield, Palliative Care Services, Vancouver Coastal Health

4. **Stories of Advance Care Planning:** Douglas McGregor, Palliative Care Services, Vancouver Coastal Health

Following the presentations, event participants were invited to choose two of the following four topics for discussion, in two consecutive rounds:

1. Communication between VCH and the public: How can VCH facilitate acceptance and understanding of ACP in the public *for those who have never thought about advance care planning before.*

2. Communication between VCH and the public: How can VCH facilitate acceptance and understanding of ACP in the public *for those who may be mistrustful or worried about the intent / outcome of ACP.*

3. Communication between healthcare providers and VCH patients and their loved ones: What are some key messages for staff training?

4. Communication among families: how can patients and families support each other to have these conversations?

Each small group recorded the content of their discussion, and facilitators identified the top recommendations for action. Results of small group discussions have been combined by topic in the summaries below.

Topic 1: Communication between VCH and the public: How can VCH facilitate acceptance and understanding of ACP in the public *for those who have never thought about advance care planning before.*

Priorities from this group focused on the need for clarity of information, and 'de-mystifying' the issue. The topic of Advance Care Planning can sound quite overwhelming to the general public for many reasons, such as technological options for life support, the sensitivities of various groups around death and dying, and the possible documentation options.

Clarity in communication with the public was summarized as follows:

Concise guidelines for the public on how and when to approach ACP:

- **Where** can I get information about ACP? (from my health authority, from my GP, from a lawyer, etc.)
- **When** should I start thinking about ACP? (at what point in my health condition? At what age?)
- **Who** should I speak to when I'm making an ACP? (e.g. with family members, with friends, with health professionals)

Key aspects of public messaging were suggested:

- Use clear, straightforward, non-medical language
- Find ways to make the ACP message relevant and interesting to a range of target audiences
- Recognising that we live in a death-phobic society, find ways to 'normalise' ACP
- By using a range of media outlets (beyond VCH facilities), we contribute to the 'normalising' of ACP. In addition to traditional forms of media such as radio/newspaper/TV, VCH should consider providing information through community centres, pharmacies, libraries, banks, and public transit (such as HandyDART)

Several concerns arose in this discussion with regard to potential conflicts or obstacles that may arise for even the most determined and responsible patient. For example, family conflict may impede the patient's ability to express his wishes. Increasing numbers of people do not have a family doctor, or find that their family doctor has little skill or time to discuss ACP. Finally, some patients may not have sufficient knowledge about the complex decisions required near end-of-life (e.g. for chronic conditions such as renal disease or COPD) and therefore not understand the burden of decisions for family members. Participants in this discussion strongly suggested that VCH must acknowledge these common problems, yet still maintain positive and empowering messages:

- The benefits of ACP for family
- Starting the ACP conversation long before the 'moment of crisis' so that everyone is prepared
- Talk to friends and spiritual leaders, as well as family
- Learn and understand your specific health options (tube feeding, ventilator, etc.)
- VCH has a process in place to follow your wishes

Topic 2: Communication between VCH and the public: How can VCH facilitate acceptance and understanding of ACP in the public *for those who may be mistrustful or worried about the intent / outcome of ACP.*

This group was more concerned with how VCH would address the strong fear or cynicism that some members of the public could express. A variety of groups have already raised questions regarding

the intent of advance care planning (i.e. a veiled attempt to legalise euthanasia, a method of justifying service cuts to special needs populations, or a way to save money by denying life-saving services). Indeed, group members articulated a common response: "What's in it for VCH?"

This discussion of messaging for mistrustful groups is particularly important as VCH moves forward with planning and implementing an ACP strategy. By 'normalising' the ACP discussion in the public arena, and by introducing the topic of ACP long before a health crisis, we give patients sufficient time to learn about and understand ACP as a process of choosing options for themselves, instead of perceiving ACP as a set of decisions handed to them. Particularly for patients with chronic diseases or longer-term life-threatening illnesses, the timing and skill for introducing ACP must be considered carefully so that patients, families and even the care team do not associate the ACP discussion with loss of hope.

This group also discussed the potential lack of GP and/or family availability and lack of awareness about possible negative impacts of life-saving technology. Suggestions included providing clear information on the benefits of ACP (including information on the impact of technology), advising people on how to complete an advance care plan for filing with their healthcare provider, and to counter public fear by 'normalising' the ACP conversation, citing examples of ACP use in other countries and provinces.

Topic 3: Communication between healthcare providers (HCPs) and VCH patients and their loved ones: What are some key messages for staff training?

As acknowledged above, it is important that staff acquire sufficient skill and comfort in discussing ACP with patients and their family members. In preparing for this new area of healthcare decision-making, it was suggested that there be three levels of training for staff, establishing consistency of approach and language:

- Level one for all staff: what is ACP? Why VCH is embracing and supporting this approach; can refer patients who want more information to appropriate resources (perhaps included in VCH orientation for all staff)
- Level Two for more advanced skills
- Level Three training for staff specialists (social workers, case managers, etc.), with initial focus on those VCH staff involved with chronic disease management

Some specific aspects of staff training messages were discussed as well, including:

- The need for comprehensive description of the ACP process (instead of focusing on Do Not Resuscitate and/or other documents),
- The reasons for completing an ACP (e.g. the benefits to the person and the family)
- Sensitivity to patient and family readiness
- Consideration regarding the language used to describe ACP, for example, "Asking about future health care decisions"
- Understanding how an ACP fits within 'goals of care' conversations, and the steps required to move the ACP (the patient's wishes, values and beliefs) into a current plan of care
- Need to consider the timing of different aspects of ACP, e.g. when to inquire about whether the person has an ACP. This might be the responsibility of professional staff (not the Admitting clerk) during the hospital stay
- Discharge may be a good time to provide information and encourage person to discuss ACP with their family and their family doctor once they are back home
- Family doctor seen as important: they need resources and paid time to do this (i.e. ensure ACP can be billed). Might fit within toolkit that could address other aspects of 'prevention' work, e.g. a letter given to chronic disease patients each year that indicates the physician will

review the person's health status with them (like 'Patients as Partners'), discuss reducing risk factors, ACP, etc.

Topic 4: Communication among families: how can patients and families support each other to have these conversations?

Participants emphasised the death-phobic nature of mainstream society as a barrier to public acceptance of ACP, but they articulated a potentially powerful approach to overcoming such barriers. Citing the social change movements for other sensitive diseases, they related examples of formerly taboo topics such as HIV/AIDS and cancer that are now commonly discussed in families and media without the same alarm and fear of decades past.

People also acknowledged that, like these other changes in public opinion/response, the social change did not come about by medical or education system intervention, but instead by the general public taking charge of raising awareness and, as addressed numerous times in this forum, 'normalising' the topic. Participants felt that neither the education nor the healthcare system could be held ultimately responsible for ACP in our families and communities, but that we, as members of the public must take responsibility to 'start the conversation' and facilitate ACP in healthcare decision-making. The complexity of family dynamics particularly requires encouragement of early and frequent conversations. Diverse approaches to such topics will be needed, incorporating the beliefs and values of various populations, and short, simple information can guide people to take steps into this challenging new area of social change.

Next Steps

Feedback generated from this forum will be used by VCH's ACP Strategy Team in two ways:

- To inform the development of a regional public awareness plan regarding the initiation of ACP at VCH
- To inform development of 3 year work plans for ACP implementation across the VCH region.

Within a week of this event, VCH ACP Strategy staff received copies of all small group discussion notes and started integrating these contributions into program planning. The Community Engagement department will update forum participants with the progress of VCH's ACP strategy.

Evaluation

Forum evaluation forms were completed by 31 of 45 participants and indicated a high level of satisfaction for the event. Respondents particularly enjoyed the open discussion and encouragement of active participation, and all 31 thought this forum was a useful way to discuss ACP and public involvement. The brainstorming in small groups and opportunity to hear each other's ideas were specifically mentioned as positive aspects, and suggestions for future improvement included logistical details and opening events like these to the general public.

Appendix 1

CEO Update

Dr. David Ostrow
President & CEO
Vancouver Coastal Health
CEAN Forum
March 27 2010

Vancouver Health

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VCH Vision

To support **healthy lives in healthy communities** with our partners through care, education and research.

Vancouver Health

2

What distinguishes VCH?

1. **Culture of Innovation**
2. **Efficiency and Excellence**
3. **Communities of Care**

Vancouver Health

3

A Day in the Life of VCH*

- **914** emergency department patients
- **125** patients admitted through the emergency department
- **5** life/threatened organ cases/day
- **316** surgery patients in our operating rooms (5 days/wk)
- **2,065** ambulatory patients
- **1,961** inpatient days
- **891** home care nursing visits
- **175** community Occupational and Physical Therapy visits
- **5,121** home support hours
- **6,240** residential care clients
- **891** assisted living tenants
- **30%** of patient activity from outside our region

*Includes Providence Health Care

Vancouver Health

4

2 Realities:
1. Life Expectancy Increasing

1979	1989	1999	2006
75.1 Years	77.6 Years	79.0 Years	80.7 Years

OECD Life Expectancy
Total Population at Birth, Canada

Vancouver Health

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2 Realities:
2. Costs Are Increasing

1966	1976	1986	1996	2006
$195	$527	$1349	$2058	$3678

Total expenditures in Canada on health/capita
US$ purchasing power parity

OECD Health Data 2008

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Hospital Utilization by Seniors

- British Columbia 1971: inpatient hospital days

- British Columbia 1996: inpatient hospital days

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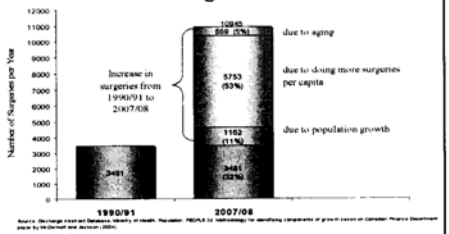
Surgery: population growth, aging, doing more



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VCH Summary of Performance 2002/03-2008/09

	2003/4	2008/9	% Change
Cases	72,872	81,034	↑ 11.2
Population Growth			↑ 5.9
Emergency Room Visits	286,077	323,461	↑ 13.1
Knee Replacements 26 weeks	28%	83%	↑196.4
Musculoskeletal Injury rate per 100 FTEs	6.3	3.9	↓ 38.1
VCH Funding	1,618.21	2,012.98	↑ 4.0
Other Health Authority Funding	4,399	6,377	↑ 5.0
VCH Share of Funding	26.9%	24.8%	↓ 2.1

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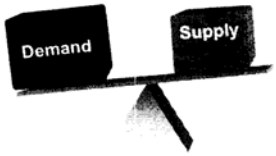
Among the challenges: VCH Funding

Total funding 10/11: $ 2.9B

Year	Deficit ($M)
06/07	45
07/08	35
08/09	19
09/10	0

Vancouver Health 10

How do we balance demand and supply?



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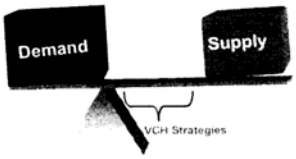
How we balance demand and supply



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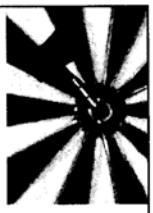
What we've achieved



- Balanced budget
- Reduced administration and support costs to under 10%
- Maintained service to patients
- Participating in Lower Mainland consolidation
- Integrated Vancouver's community and acute sectors

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5 Goals

1. Provide the best quality of care
2. Promote better health in our communities
3. Optimize our current workforce and prepare for the future
4. Use our resources efficiently
5. Sustain a viable health system

Vancouver Health

Aboriginal Patient Navigator Program

- Goal: improve health outcomes for Aboriginal people
- Bridges the gap between health care providers and Aboriginal patients
- Meet face to face with patients and families
- Help health care staff understand and accommodate Aboriginal health practices and beliefs
- Access through doctor or health care provider, or phone toll free: 1-877-875-1131

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Downtown East Side Clinical Housing Team

- Serves clients in Downtown Core and the Downtown Eastside who are housed in supportive low threshold housing and need more clinical interventions
- Supports +700 individuals in 11 sites
- Supports referrals from Community Court and other agencies
- Community housing partners:
  - Portland Hotel Community Services
  - Raincity Housing and Support Society
  - Lookout Emergency Aid Society

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Service Enhancements: Coastal

- Tobacco, harm reduction services initiated in coastal aboriginal communities
- Consultation, support for nursing support services extended to Bella Bella and Bella Coola
- Public Health Nursing services contracts, letters of agreement with aboriginal communities throughout Coastal
- Enhancement of Mental Health and Addiction services in the Pemberton Valley

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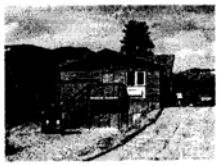
Burnaby Centre for Mental Health & Addiction

- BC's first residential treatment facility for medically stable adults with complex mental health and addiction needs opened July 2008
- Innovative strengths-based treatment program
- Clients referred from hospital, community and criminal justice system
- Referrals from across BC

Vancouver Health 19

The Crossing at Keremeos

- BC's first long-term residential centre for youth aged 14-18 with addiction (42 beds)
- Partnership with:
  - Central City Foundation
  - From Grief to Action
  - Portage
  - Interior Health
  - Fraser Health



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Public Involvement at VCH

The role of CEAN as we move forward

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CEAN since June 2009

- Public campaign for hand hygiene
- Dorothy's Story: seniors, families and professionals – partners in care
- Advance Care Planning

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Advanced Care Planning: How you can help

- Help us "start the conversation"
- Tell us what you would need in order to do Advance Care Planning
- Share with us the areas that still alarm you around ACP so we respond appropriately in our preparation and planning
- Be part of that social shift we need around death and dying

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Vancouver Health

Promoting wellness. Ensuring care.

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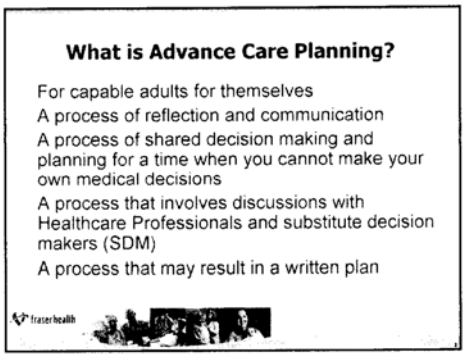
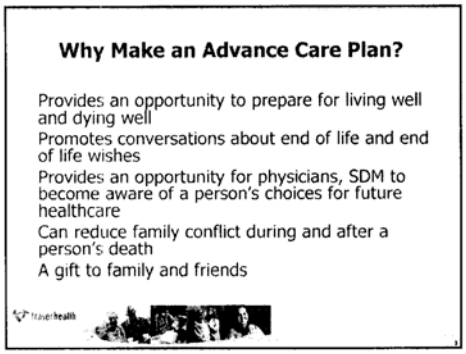
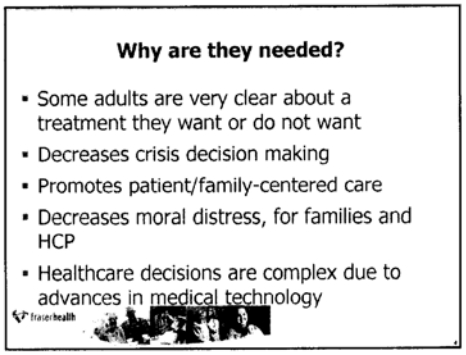
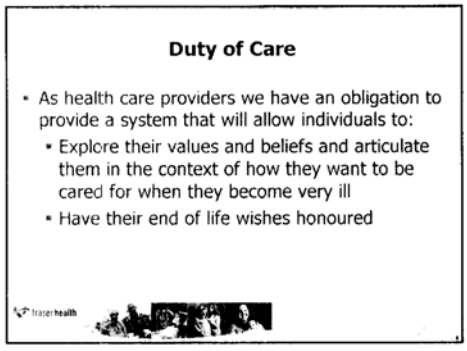
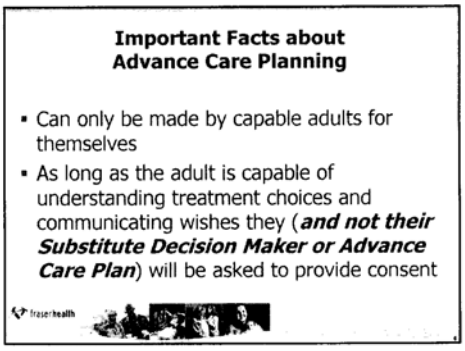
Appendix 2



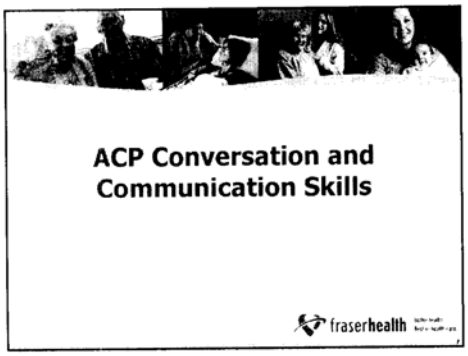








Fraser Health Advance Care Planning ~ 1-877-825-5034



Components of a good ACP conversation:

- Capable adult readiness to talk
- Healthcare Professional prepared to:
  - Initiate the conversations, Explore and clarify statements, Elicit beliefs, values and goals
- Understanding of what "living well" means to the person
- Realistic information about the benefits and burdens of treatments
- Where possible, a description of how this person's disease is likely to progress and what treatments he/she might face in the future

Because wishes can change over time...

- Focus on ACP conversations that occur over time, as opposed to a signed document
- Stress that as long as the person is capable of communicating their wishes and understanding treatment choices, they will be asked to provide consent
- Re-visit the conversation and the document routinely

Contact at Fraser Health

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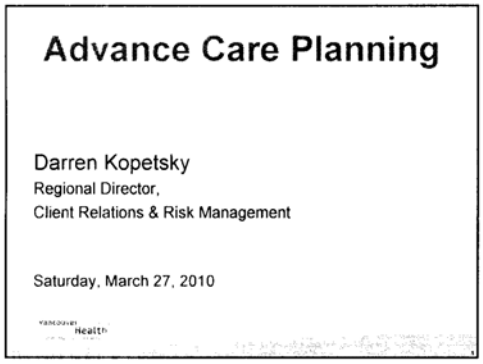
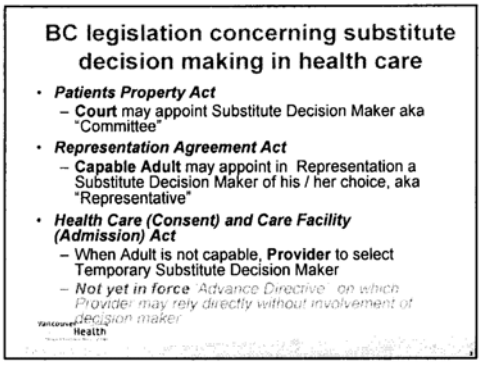
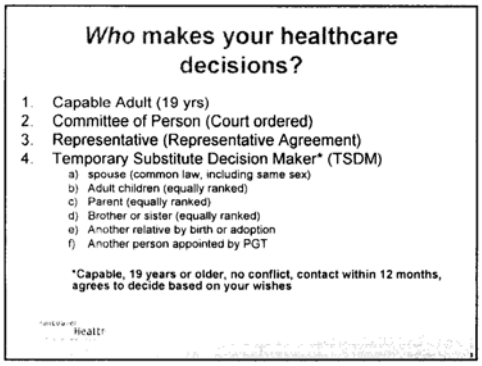
cari.hoffmann@fraserhealth.ca

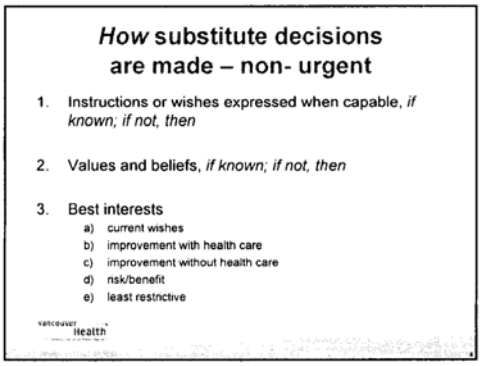
Fraser Health Advance Care Planning ~ 1-877-825-5034

Appendix 3


Advance Care Planning
Darren Kopetsky
Regional Director,
Client Relations & Risk Management
Saturday, March 27, 2010
Vancouver Health


BC legislation concerning substitute decision making in health care
• Patients Property Act
– Court may appoint Substitute Decision Maker aka "Committee"
• Representation Agreement Act
– Capable Adult may appoint in Representation a Substitute Decision Maker of his / her choice, aka "Representative"
• Health Care (Consent) and Care Facility (Admission) Act
– When Adult is not capable, Provider to select Temporary Substitute Decision Maker
– Not yet in force "Advance Directive" on which Provider may rely directly without involvement of decision maker
Vancouver Health


Who makes your healthcare decisions?
1. Capable Adult (19 yrs)
2. Committee of Person (Court ordered)
3. Representative (Representative Agreement)
4. Temporary Substitute Decision Maker* (TSDM)
a) spouse (common law, including same sex)
b) Adult children (equally ranked)
c) Parent (equally ranked)
d) Brother or sister (equally ranked)
e) Another relative by birth or adoption
f) Another person appointed by PGT
*Capable, 19 years or older, no conflict, contact within 12 months, agrees to decide based on your wishes
Health


How substitute decisions are made – non- urgent
1. Instructions or wishes expressed when capable, if known; if not, then
2. Values and beliefs, if known; if not, then
3. Best interests
a) current wishes
b) improvement with health care
c) improvement without health care
d) risk/benefit
e) least restrictive
Vancouver Health

How substitute decisions are made – urgent / emergency

No emergency health care contrary to wishes

12.1 A health care provider **must not provide health care** under section 12 if the health care provider has reasonable grounds to believe that the person, while **capable** and after attaining 19 years of age, **expressed an instruction or wish** applicable to the circumstances **to refuse consent** to the health care.

(Health Care (Consent) and Care Facility (Admission) Act)

Health

If 'heroic measures' are offered by the team

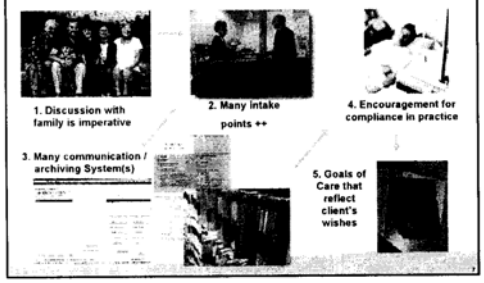
Legislation sets out that a Temporary Substitute Decision Maker may only refuse life supporting care and treatment if the following conditions are met:

a) the decision to refuse substitute consent is medically appropriate, and

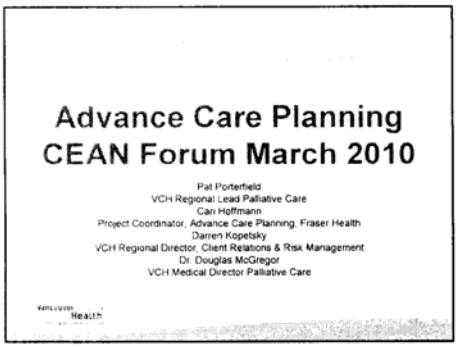
(b) the person has made the decision in accordance with
1) the adult's wishes, and if not known,
2) values and beliefs, and if not known
3) best interests

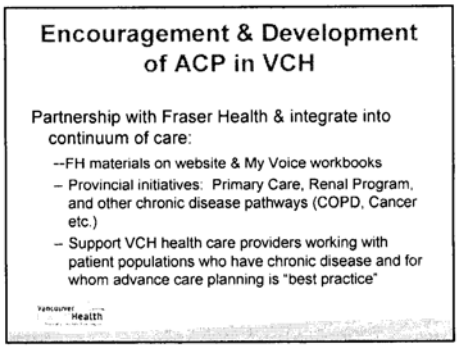
Health

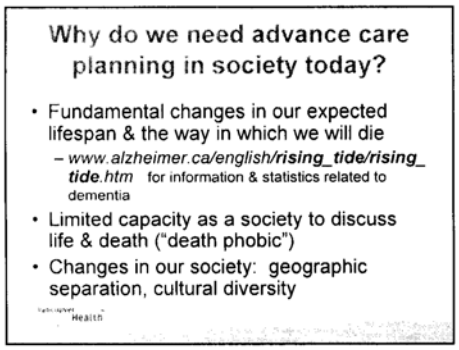
Advance Care Planning: Receipt & Management

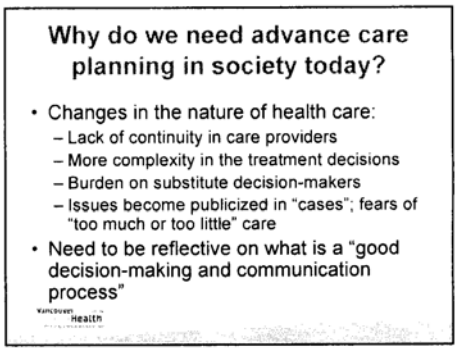


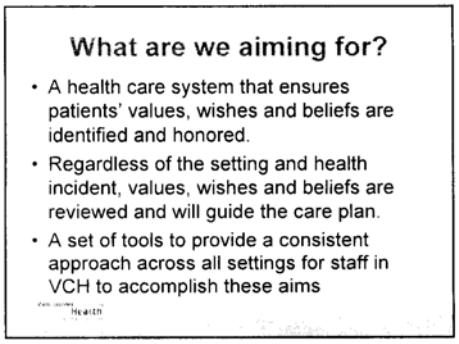
Appendix 4


Advance Care Planning
CEAN Forum March 2010
Pat Porterfield
VCH Regional Lead Palliative Care
Cari Hoffmann
Project Coordinator, Advance Care Planning, Fraser Health
Darren Kopetsky
VCH Regional Director, Client Relations & Risk Management
Dr. Douglas McGregor
VCH Medical Director Palliative Care
Health


Encouragement & Development of ACP in VCH
Partnership with Fraser Health & integrate into continuum of care:
--FH materials on website & My Voice workbooks
– Provincial initiatives: Primary Care, Renal Program, and other chronic disease pathways (COPD, Cancer etc.)
– Support VCH health care providers working with patient populations who have chronic disease and for whom advance care planning is "best practice"
Health


Why do we need advance care planning in society today?
• Fundamental changes in our expected lifespan & the way in which we will die
– www.alzheimer.ca/english/rising_tide/rising_tide.htm for information & statistics related to dementia
• Limited capacity as a society to discuss life & death ("death phobic")
• Changes in our society: geographic separation, cultural diversity
Health


Why do we need advance care planning in society today?
• Changes in the nature of health care:
– Lack of continuity in care providers
– More complexity in the treatment decisions
– Burden on substitute decision-makers
– Issues become publicized in "cases"; fears of "too much or too little" care
• Need to be reflective on what is a "good decision-making and communication process"
Health


What are we aiming for?
• A health care system that ensures patients' values, wishes and beliefs are identified and honored.
• Regardless of the setting and health incident, values, wishes and beliefs are reviewed and will guide the care plan.
• A set of tools to provide a consistent approach across all settings for staff in VCH to accomplish these aims
Health

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