Advance Care Planning

Specialized Seniors Clinics 2013

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Contributors & Special Thanks

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- Special *Thank You* to the FHA Residential Program

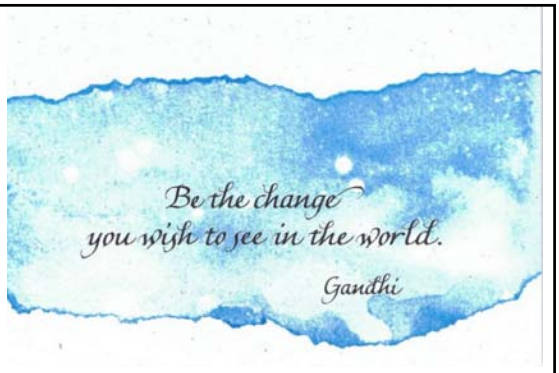
Goal

- To improve quality of life for people living with chronic diseases such as dementia by increasing our capacity to provide exceptional care through to death focusing on issues unique to caring for these people and their families.
- Increase our confidence, knowledge and skill in caring for a person with dementia.

By the end of the workshop we hope you will:

- Develop further skills in:
  - conversations; information sharing; supporting decision making
  - developing care plans
  - engaging, guiding and supporting families.
- Have basic understanding of the Provincial Legislation around incapacity planning tools & consent
- Understand dementia as it relates to ACP
- Decide as a team the roles and responsibilities, and process for Advance Care Planning in the Specialized Seniors Clinics

Identify challenges to engaging in advance care planning



The change we hope to see…

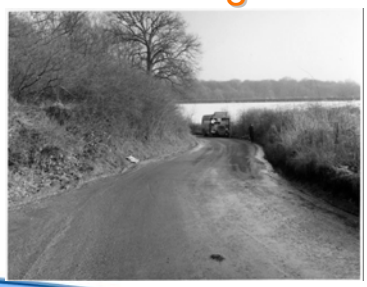
- Standardized System will remind staff to engage in conversations again and again.
- Staff will use language which supports a Client and Family Centered approach
- Families will be prepared for the progression of the Chronic Disease process

ADKAR Change Model

Awareness
Desire
Knowledge
Ability
Reinforcement

- One: Advance Care Planning
- Two: ACP approach for people with dementia and their family
- Three: Legal aspects
- Four: Team's roles and responsibilities

One: Advance Care Planning



What is Advance Care Planning:
Health Care Provider Perspectives

View video clip:

How to talk End of Life Care with a Dying Patient – Atul Gawande

What is Advance Care Planning?

- An ongoing process of shared decision making and planning, reflection and communication
- Involves discussions with Healthcare Professionals (HCP) and substitute decision makers (SDM) about the client's expressed wishes or instructions.
- May have resulted in a written plan (*So SPEAK*)

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Advance Care Planning is *not a:*

- Task
- Code status (MOST) conversation
- Single conversation about treatment options
- Document or form without conversations with Substitute Decision Maker or Health Care Professional
- Refusal of medical treatment
- Power of Attorney (in BC for legal and finances only)
- Plan only for individuals who are dying

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Does Advance Care Planning take away hope?

When the conversation is timely and appropriate it can "positively enhance rather than diminish hope."

Davison & Simpson, 2006

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Why is Advance Care Planning *needed*?

- Prepares for living well and dying well
- Honours wishes
- Decreases not knowing what decision to make in a crisis
- Promotes person/family-centered care
- Decreases moral distress, for families and Health Care Provider
- Promotes a peaceful end of life experience for all
- Reduces burdensome interventions

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1. Thinking about the clients and families in your clinic, how might you prioritize those in need of Advance Care Planning?
2. What factors are contributing to your decision?

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When do we engage in Advance Care Planning?

Initiate *Routine* discussions at Initial Consult following disclosure of Dementia Dx

- ✓ Determine if there are any documents or previous conversations
- ✓ Ensure interdisciplinary involvement
- ✓ Explore understanding of diagnosis & prognosis
- ✓ Involve physician

Re visit conversations as needed

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Successful conversations include:

1. Client and their family
2. Healthcare Professional prepared to:
   - Initiate conversations and follow up
   - Explore and clarify statements
   - Elicit beliefs, values, goals and quality of life
   - Assess understanding of medical condition
   - Understand cultural considerations

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Who can do Advance Care Planning?

- EVERYONE – should recognize cues and know who to refer to
- Following this education, engage clients and/or their Substitute Decision Maker in conversations
- Each discipline has a role to play in the process
  - Who are your Key Clinicians in your clinic?
  - When would it be appropriate to refer to a key clinician?

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Recognizing Verbal Cues

1. What cues have you heard from clients and families?
2. How did you respond?
3. What would you document on the Advance Care Planning Record?

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Core Elements of Advance Care Planning

1. S.P.E.A.K to adult about Advance Care Planning
2. Learn about & understand the client & what is important to them. Involve substitute decision makers
3. Clarify understanding & provide medical information about disease progression, prognosis, & treatment options
4. Ensure interdisciplinary involvement and utilize available resources/options for care
5. Define goals of care, document and create plan (including potential complications)

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Approaches to Advance Care Planning

1. S.P.E.A.K to client & family about Advance Care Planning

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2. Learn & understand what is important to the client. Involve substitute decision makers.

" What fears or concerns does you have?"

"What do you look forward to everyday?"

"What do you think you would be prepared to endure to live as long as possible?" "What are the trade offs?"

3. Clarify understanding. Provide information about disease progression, prognosis, & treatment options.

"Tell me what your understanding is of living with this disease?" …the possible complications?" …the risks and benefits of possible medical interventions?"

"Have you noticed any changes? What do the changes mean to you?"

"What are your family's expectations if you went to the hospital?"

4. Ensure interdisciplinary involvement and utilize available resources appropriately

How do we support all disciplines to be involved as their role requires?

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5. Define goals of care, document and create plan (including potential complications).

Discuss specifics of plan to ensure understanding of possible complications and how to manage them. (i.e. ↓ swallowing, ↑ infections not responding to treatment)

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Video Clip

View an example of an ACP Conversation….George's scenario, Harjinder's scenario,

1. What do you think the HCP did well?
2. What examples of open ended questions did you hear the HCP use?
3. What would you do differently?

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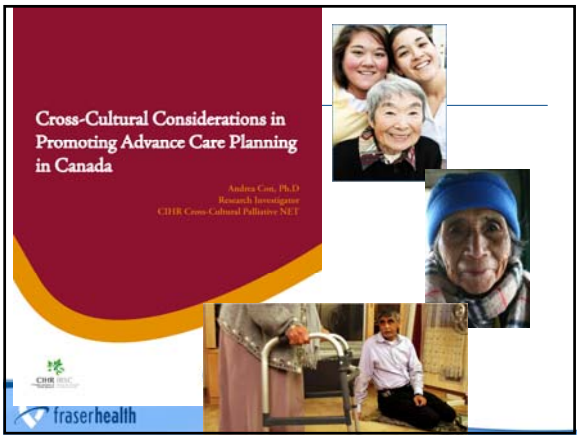

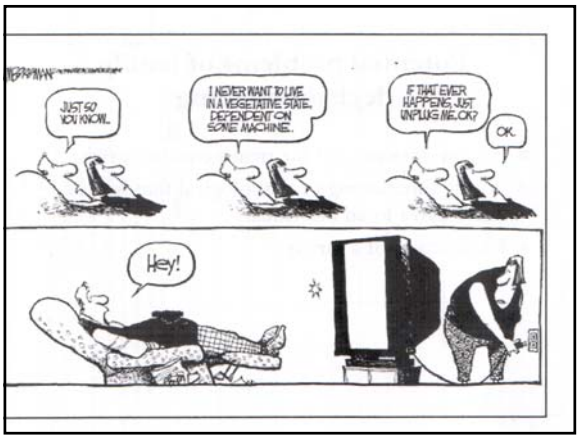

Fraser Health Resources

- IntrAnet
  http://fhpulse/clinical_programs/end_of_life/Pages/AdvanceCarePlanning.aspx
- http://fhpulse/initiatives/scope_of_treatment/Pages/Default.aspx
- IntErnet
  http://www.fraserhealth.ca/your_care/advance-care-planning/
- 1-877-TALK-034 (1-877-825-5034)
- advancecareplanning@fraserhealth.ca
- Cari Borenko Hoffmann 604 587 4408
  cari.hoffmann@fraserhealth.ca

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- **On-line modules**
  https://ccrs.vch.ca/Secure/StartOnlineCourse.aspx?cid=2222
  https://ccrs.vch.ca/Catalog.aspx?cid=3099
- **Education sessions**
  https://ccrs.vch.ca/Catalog.aspx?cid=2383

***MOST education for physicians:**
michelle.veer@fraserhealth.ca

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www.advancecareplanning.ca

Speak Up

Start the conversation about end-of-life care

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International Society of Advance Care Planning and End of Life Care

International Society of
Advance Care Planning & End of Life Care
www.acpelsociety.com

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Two: Legal Aspects

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Let's start with the Greensleeve

Every chart should have a Greensleeve

- Kept at the very front of every chart – acute, residential and clinics (or under Risk/Legal in EMR)

What goes in the Greensleeve?

1. MOST
2. Provincial `No CPR` form
3. Advance Care Planning Record
4. Advance Care Plans. **This may include:**
   a. Advance Directive
   b. Representation Agreement
   c. List of Temporary Substitute Decision Makers

What goes in the Greensleeve?

1. MOST


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

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What goes in the Greensleeve?

2. Provincial No CPR Form


NO CARDIOPULMONARY RESUSCITATION

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What goes in the Greensleeve?

3. Advance Care Planning Record


ADVANCE CARE PLANNING (ACP) RECORD

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Other Documents in the Greensleeve

My Voice Guide
A Ministry of Health booklet that explains Advance Care Planning and contains an Advance Care Plan for residents to complete. It includes legal forms for Representation Agreements and Advance Directive

Representation Agreement
A 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 Standard Rep Agreement
2. Section 9 Enhanced Rep Agreement

For more information about Representation Agreements ask, your Social Worker

Staff must ask for a copy of the Advance Care Planning documents, understand them, Photocopy, and place it in the Greensleeve.
Adult keeps the originals

Other Documents in the Greensleeve

Advance Directive
is 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 health care conditions and treatments noted in the advance directive.

Staff must ask for a copy of the Advance Care Planning documents, understand them and place in the Greensleeve.

NOTE: Enduring Power of Attorney or Power of Attorney

- A document in which a capable adult authorizes another person (called their attorney) to make decisions in relation to the adult's financial or legal affairs, business and property. The attorney does not make health care treatment decisions

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Healthcare Consent Hierarchy BC

1. Capable Adult (19 yrs)
2. Committee of Person (*Patient's Property Act*)
3. Representative (*Representation Agreement Act*)
4. Advance Directive *NEW*
5. *Temporary Substitute Decision Maker *(Health Care (Consent) and Care Facility (Admission) Act)*
   a. Spouse (common law, same gender)
   b. Adult children (equally ranked)
   c. Parent (equally ranked)
   d. Brother or sister (equally ranked)
   e. Grandparent (equally ranked) *NEW*
   f. Grandchild (equally ranked) *NEW*
   g. Anyone else related by birth or adoption
   h. Close friend *NEW*
   i. A Person immediately related by marriage *NEW*
   j. Another person appointed by Public Guardian & Trustee

*No conflict and contact within 12 months

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Public Guardian & Trustee (PGT)

Public Guardian and Trustee of British Columbia
Rights, Choices and Security for All British Columbians

- Why are they involved?
- Are there any restrictions we need to know about?

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Role of the Substitute Decision Maker(s)

1. Consult with the client to the greatest extent possible
2. Comply with any instructions or wishes, values, beliefs the client expressed while capable
3. If no instructions or wishes, then decisions are based on best interests
4. Decisions are not based on Substitute Decision Maker's personal values, beliefs or wishes.

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Three: ACP approach for people with dementia

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Why is Advance Care Planning particularly important with people living with Dementia?

From the UBC Geriatric Medicine Presentation June 4, 2013
by Dr Anson Li

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Outline

1) Define Advance Care Planning in relation to Dementia Care

2) How/When to deliver Advance Care Planning for the Dementia Client

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Why should we care?

People with dementia consistently receive suboptimal care at the end of life.

E.g. Referral to hospice setting
E.g. Referral to palliative services

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Why should we care?

Table 2. Management of patients with (n = 35) and without (n = 65) dementia prior to death

	No. of patients (%) receiving intervention		
	Dementia (n = 35)	No dementia (n = 65)	P-value
Arterial blood gases	28 (80)	38 (58)	0.024
Nasogastric tube	14 (40)	15 (23)	0.062
Central line	1 (3)	13 (20)	0.014
Ventilation	2 (6)	6 (9)	0.422
Urinary catheter	37 (77)	27 (57)	0.035
Neuroleptics prescribed	5 (14)	5 (8)	0.238
Imminente death diagnosed	13 (37)	33 (51)	0.137
Resuscitation status discussed	33 (94)	56 (86)	0.185
Discuss limiting procedures – professionals	21 (60)	42 (65)	0.404
Discuss limiting procedures – family	21 (60)	35 (53)	0.353
Referral to palliative care	3 (9)	16 (25)	0.042
Spiritual needs assessed	0 (0)	3 (5)	0.270
Palliative medications prescribed	10 (28)	33 (51)	0.026

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What does ACP mean to you?

Is it just Code Status?

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ACP – BCMA Guide

G78720 - *Specialist ACP Discussion*

Advance Care Planning is when a capable adult thinks about and discusses their beliefs, values, and wishes for future health care, in the event the adult becomes incapable of making such decisions in the future.

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Broad Definition

A multi-stage process whereby a patient and their carers achieve a shared understanding of their goals and preferences for future care has been introduced.

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ACP in Geriatric Medicine

Frail elderly patient with multiple comorbidities.

Patients with cognitive impairment.

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Barriers

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Barriers: Limited Evidence

There is limited evidence for ACP in people with cognitive impairment/dementia.

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Barriers: Limited Evidence

Some studies have found increases in DNR but no changes in terms of living wills, POAs.

While some have seen increases in the intervention group in pain assessment but no overall change in pain medications given.

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Barriers: Limited Evidence

One study found lower hospitalization rates and hospital costs.

Another found similar results in reduction of healthcare resource, annual rate of hospital admission, and use of hospital day beds, and number of calls to ambulance service.

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ACP – G78720

Challenges exist

Requirements:

- Develop plan to address chronic medical illness or comorbidities that will cause deteriorating quality of life or end-stage disease state
- Advanced Care Plan & instructions on how to fill out Advanced Directives

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ACP – G78720

Requirements Cont'd

- Care Plan shared with patient, patient's GP
- Not paid for physicians on salary, sessional, or service contract arrangements

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Other Barriers

Caregivers often anticipate adverse reaction/distress to pursuing ACP with the person with dementia.

Caregiver attitudes often influence likelihood people with dementia being exposed to aggressive treatments.

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Other Barriers

Lack of information on disease and its prognosis left family carers unprepared to make effective decisions about end-of-life care for their relative with dementia.

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Delivering ACP

ACP discussions with trained professional over period of time are most successful.

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Other tips on delivery

An MMSE of 18-20 seems to be threshold score required to make an ACP.

Hence, engagement of meaningful ACP would have to be done early for people with dementia.

BMJ 1999; 318:493

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A Video on ACP (*Arch Int Med* 2007; 167:828)

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Delivery of a video

Prior to watching video: 21% wanted life prolongation, 18% wanted something in between, 11% uncertain.

Post video, 89% wanted comfort-oriented approach and no one wanted life-prolonging treatment. 3% unsure about preference.

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Approach to ACP

In patients with capacity, assist patients in identifying or appointing a primary decision maker (Rep9) for future decisions.

Educate surrogate decision maker that dementia is a terminal illness.

Have surrogate understand they are there to represent patient values and preferences.

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Approach to ACP

- Establish goals of care: comfort, life-prolongation, preserving autonomy, maintaining quality of life, reduce burden on family
- Translate goals into practice to address: prevention of suffering, promoting dignity, facilitating caring

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What about Nutrition?

Dysphagia is expected consequence of end-stage dementia. Other common behaviours are food refusing, clamping mouth shut, and holding food without swallowing.

No suffering with hunger.

NG feeding does not prolong life, relieve suffering, or reduces aspiration.

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SSC Scenario

- Ms K referred to SSC for cognitive issues
- Younger lady from Ontario who moved to BC to live with her brother
- Disoriented, poor STM, paranoid
- Several co-morbidities and currently confused about meds she needs to take

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Ms K cont…

- Plan was to come out to BC and then find a place for herself to live.
- This plan now on hold when brother noticed Ms K's functional and cognitive decline
- Ms K's only living children are back in Ontario or in US

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Ms K scenario

What are your next steps?
Who on the team needs to be involved?

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In Summary

- Engage in ACP early, when the patient is still capable.
- Multiple visits with patient and caregiver are required to address goals of care.
- Education regarding dementia and end-stage dementia is key.
- Surrogate's role is to represent patient's values and preferences, not their own.

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A few more thoughts about Dementia

Dementia is a progressive terminal illness for which there is no cure.

Studies found that dementia is not viewed as a terminal illness
(Sampson,2006; Mitchell, 2004; Morrison & Siu, 2002).

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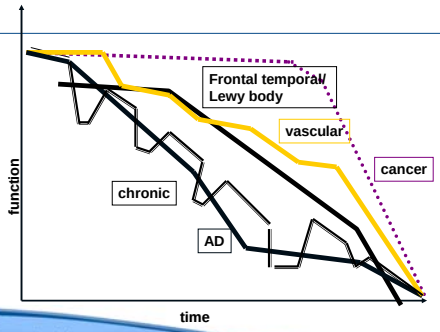
The Perception of the "Sudden Change"

When reserves are depleted, change seems sudden & unforeseen. Yet, changes *were* happening.

diminishing reserves

Co-morbid trajectories



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- "Most chronically ill older [sic] people have ambiguous medical prognoses…they could be living on thin ice for some years or die in a week" (Lynn & Adamson , 2003)

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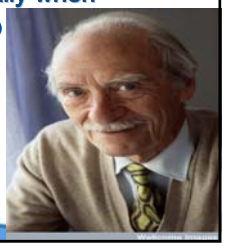
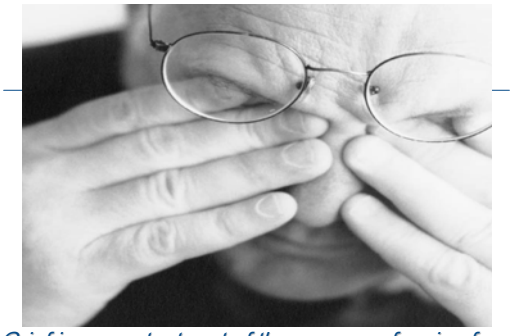
Some caregivers have described dementia as the longest goodbye (Bourgeois 2002)

What families told us

- "I am going to three funerals; first when she was diagnosed, second when she went into the home and finally when she dies". (Residential Care focus group)





Grief is a constant part of the process of caring for a loved one with Alzheimer disease. (Liken & Collins, 1993)

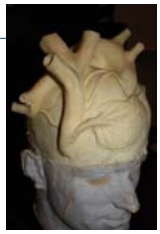
Psychosocial care for family

Helping family maintain a positive relationship with the person with dementia contributes to overall well-being for everyone.

Psychosocial care for family : team approach

Families learn on two levels: emotional and intellectual

- Families might listen through their hearts or their heads.
- Our facts, values & beliefs might be different from families.
- Often useful to start by agreeing on the facts



Practice

Video: Monologues

Four: SSC Team Roles and Responsilibities

With whom should we be initiating ACP conversations?

After hearing the information presented this morning has your perspective on who you would engage in ACP with changed?

Ideally, I would start with….

More imperative, I would start with…

Absolutely, I would start with…

With whom should we be initiating ACP conversations?

Ideally with:

- Healthy capable adults, to create awareness, normalize ACP and being with culture change

More imperative with:

- Capable adults with chronic disease before they become ill with complications

i.e. patients with known family conflict, patients with known cognitive decline (i.e. MCI, early Dementia diagnosis)

With whom should we be initiating ACP conversations?

Absolutely with:

- Capable adults with life expectancy of less than 6 to 12 months*

i.e. Age of +75yrs, experienced a sentinel event, frequent hospitalizations, decline in physical/cognitive functional status, additional disease diagnosis,

**Surprise Question:*

As the HCP, would you be surprised if this patient died in the next 6 to 12 months?

Video Clip

Learning From Experienced ACP Facilitators from the DVD titled:
Starting the Conversation, working ACP into Everyday Health Care

Roles & Responsibilities

Does the adult have:		HCP role	Question(s) to ask adult or SDM	What next?	
S	Substitute Decision Maker (SDM)		Who is your SDM? Do you have a Representation Agreement?		Document SDM on ACP Record and Kardex Enter into Meditech Refer to SW if identification of SDM is complex and/or requires completion of documents Obtain copy of SDM documentation for Greensleeve

Engage in building team capacity and identifying approaches for sustainability.

Making ACP Sustainable

1. Senior and Clinical Leadership Engagement
2. Staff involvement and training to sustain process
3. Staff behaviour towards sustaining the process
4. Infrastructure for sustainability
5. Credibility of Evidence
6. Benefits beyond helping patients
7. Fit with the organization's strategic aims and culture
8. Adaptability of improved process
9. Effectiveness of the system to monitor progress

Source: NHS, Institute for Innovation and Improvement

Group Activity

1. Partner up with colleagues within your site and/or broader clinical setting
2. Identify 5 strategies for making ACP sustainable in your area
3. Which 2 barriers previously identified commonly occur in your work setting and how might you and your colleagues address them?

Suggestions for Sustainability within your clinical setting

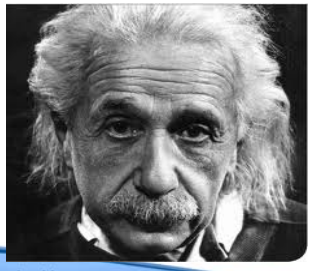
Developing a plan:

- to review all existing charts for completeness of ACP documents
- for how the team can maintain ACP annual reviews
- for sending all existing ACP documents to health Records for uploading into Meditech (beyond order entry of MOST and SDM by UC)
- Identifying team member roles in the assessment of patient ACP readiness with all new patients
- Identifying team member roles in the revisiting of ACP content annually and with patient's whose health is deteriorating
- Identifying a long term strategy for addressing both staff and patient's ACP educational needs

We challenge & support you to…

- Engage in the Advance Care Planning process yourself
- Begin implementing Advance Care Planning into your daily practices with patients and families
- Set small achievable goals

Insanity is doing the same thing over and over again, but expecting different results.



Albert Einstein

Evaluation

Further Reading

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