

# BCPRA EOL Champion Training



**Proactive and Successful Advance  
Care Planning in ESRD**



# Objectives

- Define Advance Care Planning
- Explore why Advance Care Planning conversations are important.
- Describe who Healthcare Professionals should initiate these conversations with
- Describe the components of effective Advance Care Planning
- Increase comfort with initiating and engaging in Advance Care Planning conversations



# Advance Care Planning

- A process that involves **understanding, reflection, discussion and communication...**
- Between a patient, the family/health care proxy, and staff (shared decision-making).....
- For the purpose of prospectively identifying a surrogate, clarifying preferences, and developing individualized plans for care near the end of life.
- May result in a written plan (advance directive)



**The focus is not merely death and the right to refuse treatment..... but rather about living well and defining “good care” for each patient near the end of life.**



# Goals of Care and ACP

Goals of care are inextricably linked with patient and family **understanding of illness** and expectations. In the context of facilitated ACP, it is clear that goals must reflect expectations that are in balance with **adequate knowledge**.

This includes **prognostic information**





**Annual unadjusted mortality rate ~22%**

**Withdrawal from dialysis ~ 20-25% of deaths**

**The majority lack capacity at the time the decision to withdraw dialysis is made.**

**Only 6-51% of HD patients have advance directives**

- **Address only limited treatment options**
- **Typically do not address withdrawal of dialysis**
- **Most do not choose DNR**

**Dialysis patients typically do not view themselves as terminally ill**

# Patient Preferences for ACP

- **The majority of seriously ill, hospitalized patients prefer that family make resuscitation decisions (ACP) as opposed to having ADs**
- **61% of dialysis patients with AD would prefer that their surrogates be given leeway to override previously expressed wishes**
- **~ 35% of patients would want their nephrologist to make medical decisions for them if they no longer had capacity**



# How EOL Decisions Are Made

- By family and health care providers
- Surrogates lack the knowledge of patients' preferences
  - Includes wishes for ongoing dialysis
  - Family consistently overestimates patients' desires to continue dialysis across hypothetical health conditions

Miura Y et al. AJKD 2006

	Current preferences for CPR	Wish for dialysis in a severely demented state	Wish for dialysis if they had terminal cancer
Family	50%	44%	47%
Physician	44%	47%	43%



# What do EOL Conversations Look Like?

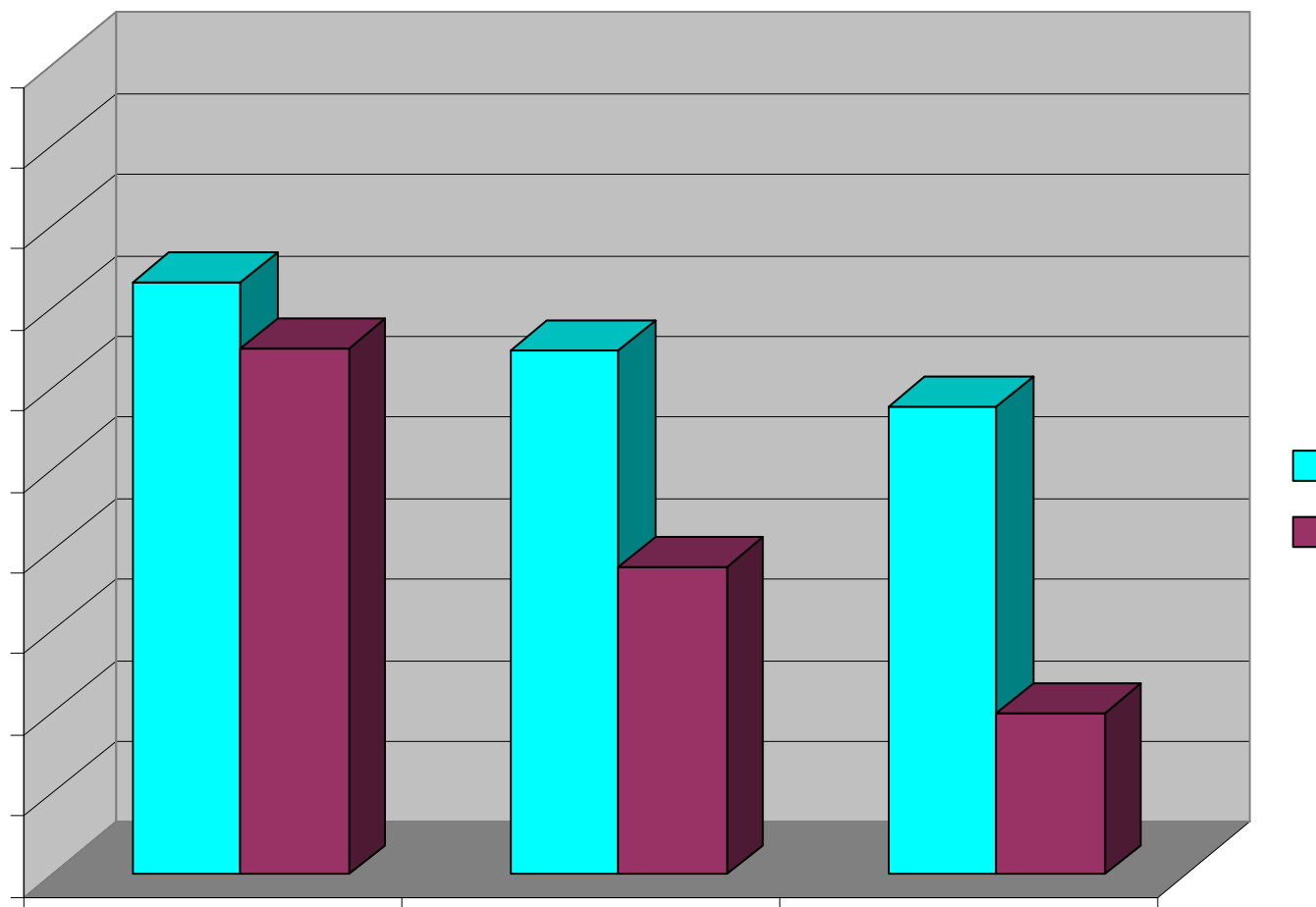
- **HCP do most of the talking**
  - “She didn’t listen and she spent more time in kind of a social chit-chat ... She wanted to find solutions for me and I didn’t want solutions, I just wanted to be able to find my own solutions....”
- **Focus on pejorative descriptions of LST**

## What is not discussed?

- **Prognosis**
- **Patients’ values , desired outcomes**
- **A set of positive treatment outcomes**
- **What treatments patients may want to forgo now v. treatment they would want to forgo if they become worse**
- **Spirituality (existential, religion)**
- **What dying may be like**



# Survival Rates for Cancer and ESRD Patients



Data from USRDS and NCI



## Moss AH, 1992

**N = 74**

**80%** died a mean of 4 days; in ICU

**Alive at discharge**  
**8%**

**Alive at 6 months**  
**3%**

## Pun PH, CJASN 2007

**N = 729**

**Alive at 24 h**  
**42.5%**

**Alive at 6 months**  
**11%**



## Davis TR et. al. KI 2008

```
graph TD; A[Outpatient dialysis facility  
N = 110 (2002-2005)] --> B[PEA or Asystole  
N = 38]; A --> C[VF or VT  
N = 72]; B --> D[Alive at 24 h  
37%]; B --> E[Alive at Discharge  
11%]; B --> F[Alive at 1 year  
5%]; C --> G[Alive at 24 h  
51%]; C --> H[Alive at discharge  
31%]; C --> I[Alive at 1 year  
19%];
```

**Outpatient dialysis facility**  
**N = 110 (2002-2005)**

**PEA or Asystole**  
**N = 38**

**Alive at 24 h**  
**37%**

**Alive at Discharge**  
**11%**

**Alive at 1 year**  
**5%**

**VF or VT**  
**N = 72**

**Alive at 24 h**  
**51%**

**Alive at discharge**  
**31%**

**Alive at 1 year**  
**19%**

## Lai, 1999

**Intradialytic**  
**N = 24 (over 3 years)**

**Alive at 24 h**  
**45%**

**Alive at 1 month**  
**8%**

**Alive at discharge**  
**0%**

# Patient Preferences for CPR n=584

Davison CJASN 2010

## **Patients with an advance directive (38%)**

- 37% were a “full code”
- 18% were unsure what their AD stated

## **Current preference for resuscitation (all patients)**

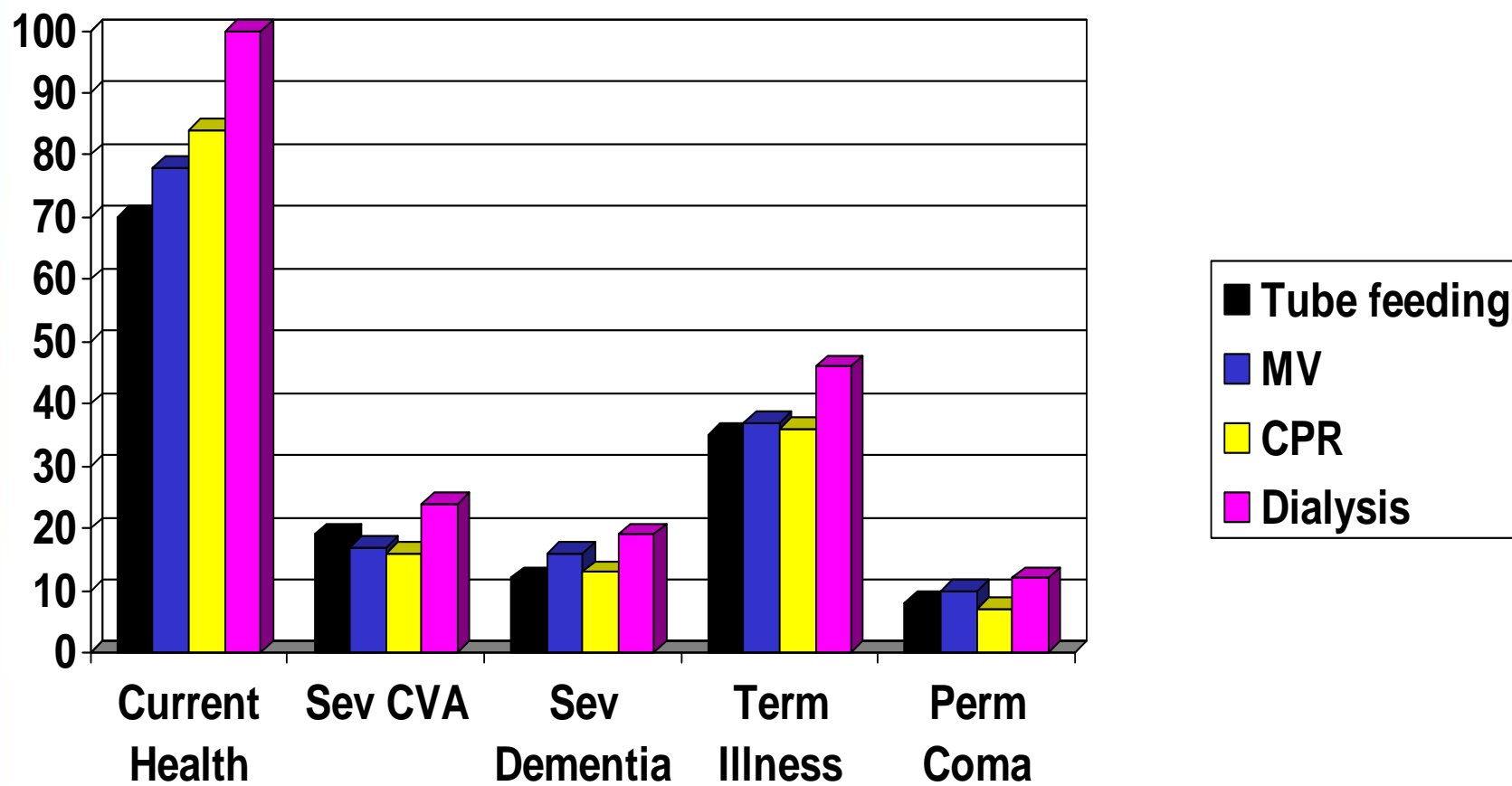
- 39% wanted full resuscitation
- 19% were unsure

## **Current preferences for EOL care**

- < 18% preferred a course of treatment focused on extending life at the expense of suffering, functional status and QOL



# Patients' Desires for Treatments in Various Health States (%)



Singer, et al. *J Am Soc Nephrol* 1995;6:1410-1417

# Physician Related Barriers to ACP

- **Time constraints – health care systems issues**
- **Lack of training and comfort with EOL decision-making**
  - 61% of nephrologists reported feeling not very well prepared to make EOL decisions

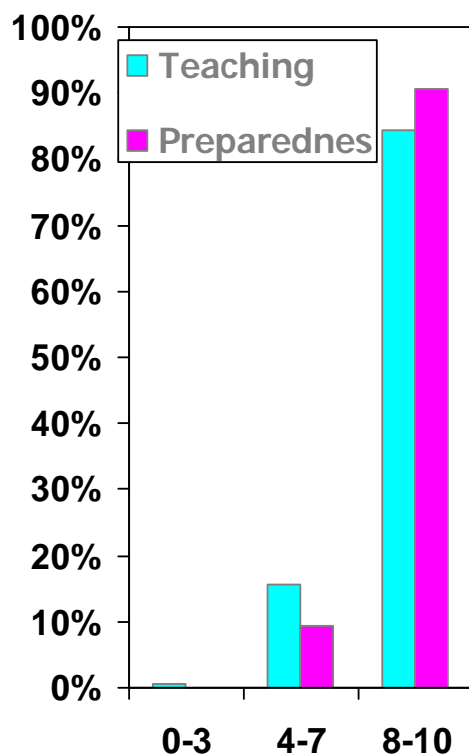
Davison CJASN 2006



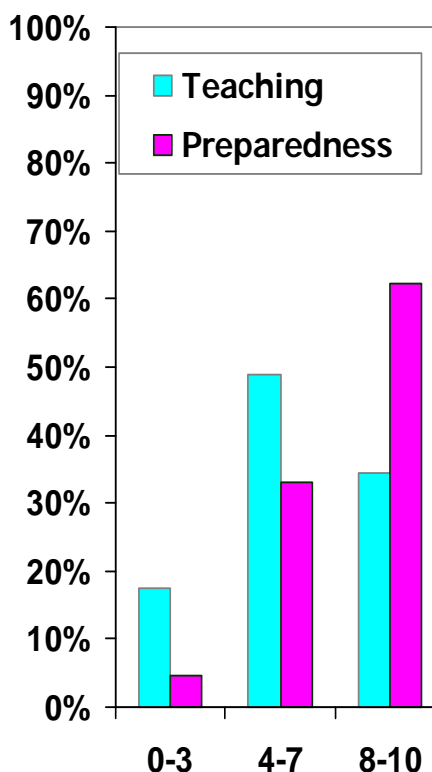
# EOL Training in Nephrology

AJKD2003;42:813-820

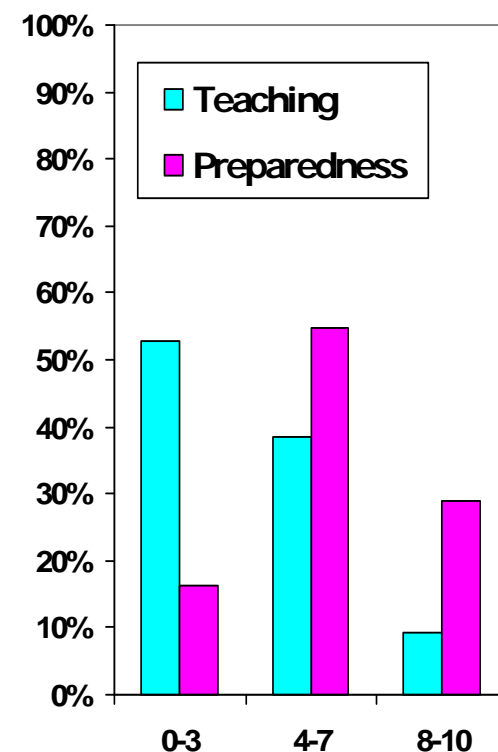
## Hemodialysis



## Distal RTA



## End-of-Life Care



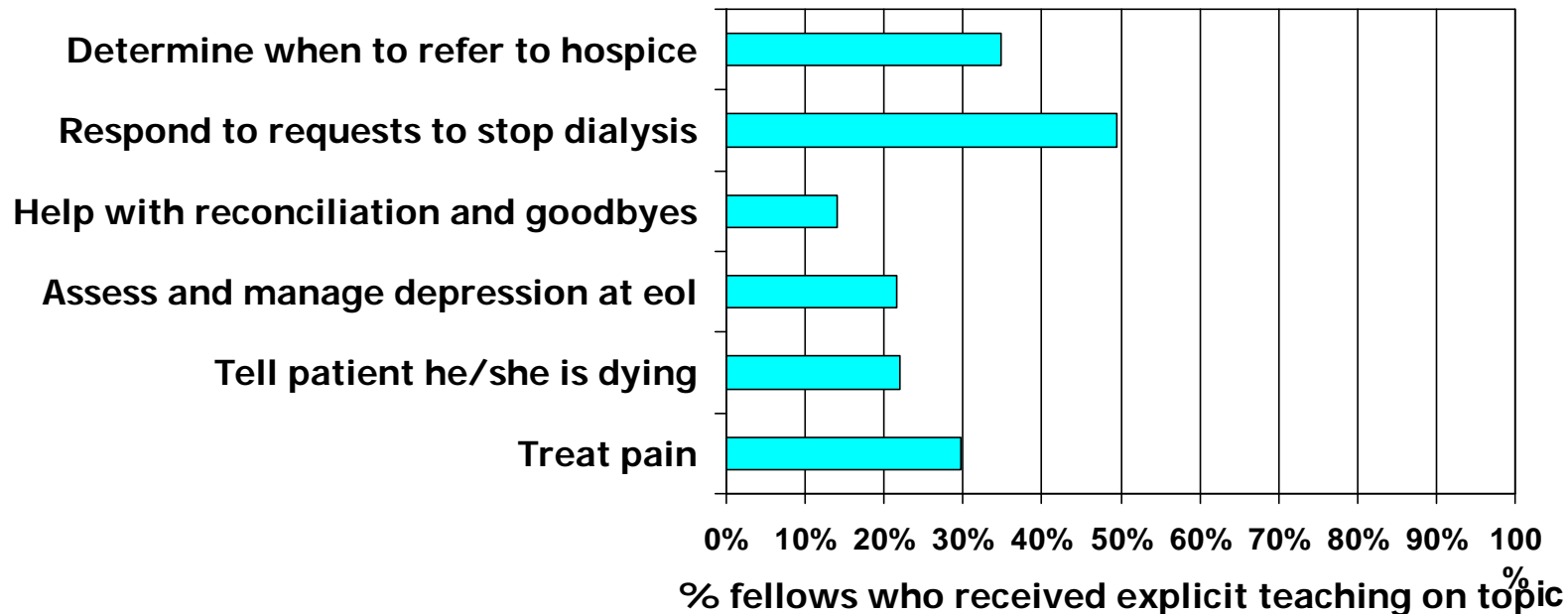
0 = no teaching or completely unprepared      10 = a lot of teaching or completely prepared



# EOL Training in Nephrology

AJKD2003;42:813-820

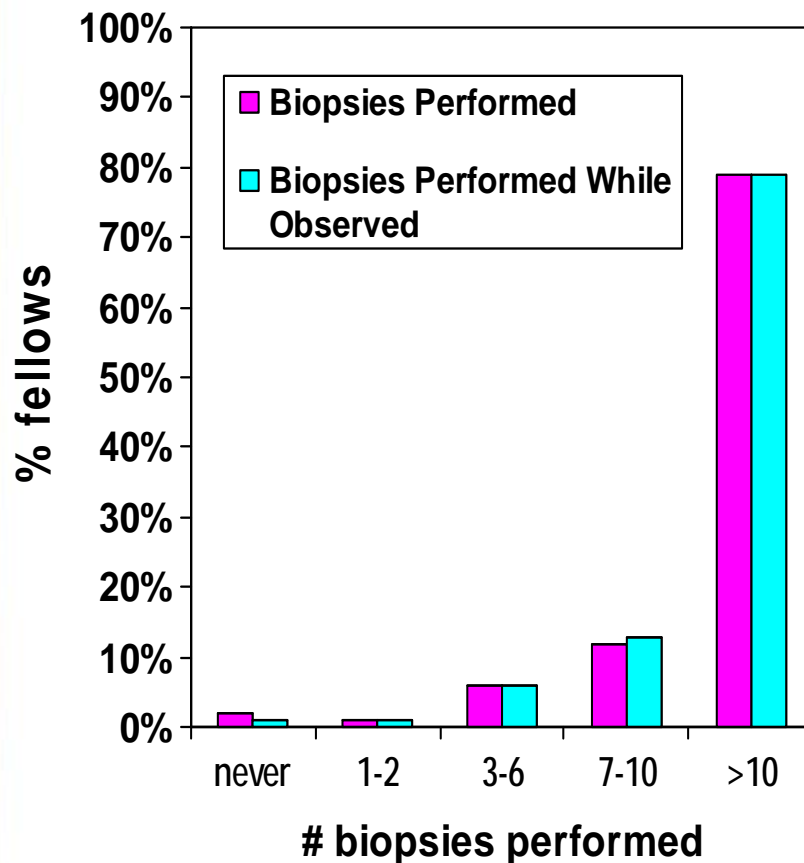
During your fellowship, were you explicitly taught to:



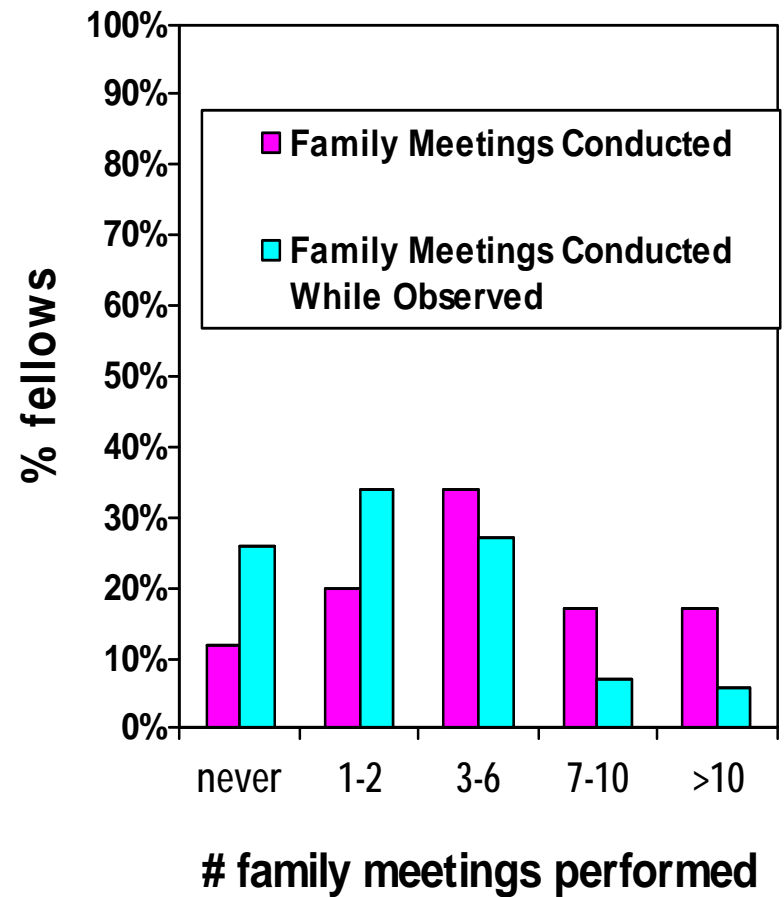
# EOL Training in Nephrology

AJKD2003;42:813-820

## Renal Biopsies Performed



## Family Meetings Conducted





*"There's no easy way I can tell you this, so I'm  
sending you to someone who can."*

# Physician Related Barriers to ACP

- Time constraints – health care systems issues
- Lack of training and comfort with EOL decision-making
  - 61% of nephrologists reported feeling not very well prepared to make EOL decisions  
Davison CJASN 2006
- **Belief that ACP is not needed**
- **Belief that patients and families do not want these discussions**
  - ~90% want detailed prognostic information, EOL discussions
  - ~ 65% patient comfortable with EOL discussions
  - < 10% patients have had EOL discussions with their renal team  
Davison CJASN 2010
- **Lack of familiarity with suitable alternatives to aggressive treatment**
- **Concern that discussing EOL issues will destroy hope**



# Talking About Prognosis & EOL Issues

Majority of patients are unaware of possible imminent death

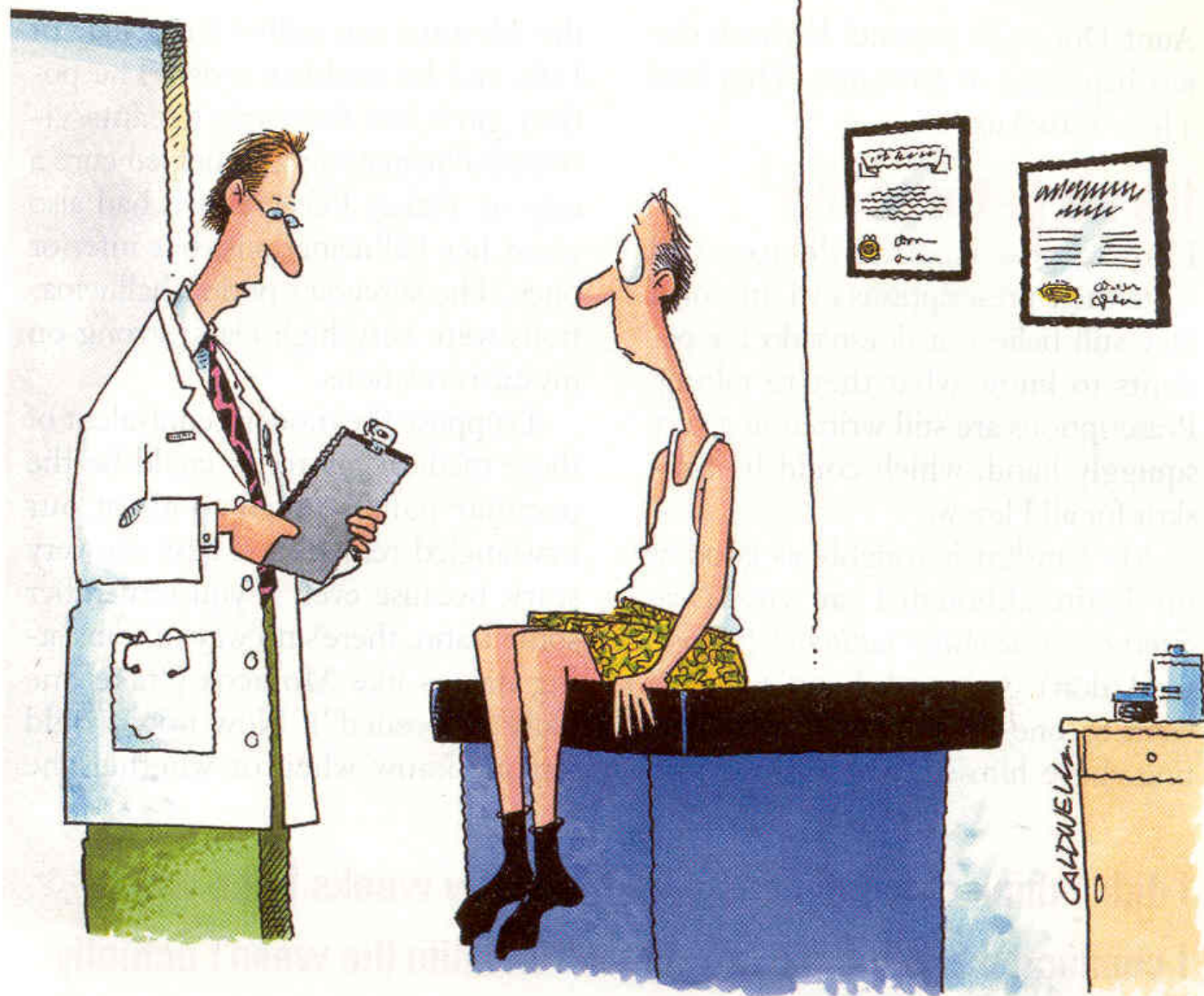
## Denial ?

Concern that discussing prognosis may destroy hope and is not appropriate while embarking on a “LST”



- **“I’m in bed at night and I just worry and I get up in the morning and I just worry. Even though I’m laughing, it’s only on the inside. Health care providers are reluctant to talk about end of life issues. I think they are afraid of how you are going to react. I don’t think they know what to say. No, I want to talk about it, but nobody will talk to me. At least that’s how I feel. Unless they think I’m not taking it in as much as I should because I’m laughing all the time. But, inside I am hurting like mad, but I can’t get that out.”**





*"Yikes! Okay, I'm going to pretend I didn't see that."*



# ACP Enhances Hope!

- **Information:** less fear
- **Patient empowerment**
  - By understanding their disease and the health care system, and being able to predict to some extent the outcomes of their illness, they perceived greater control over their lives and how they were going to live with their disease; and determine future goals.
- **Enhanced relationships**



## Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers

Latifat Apatira, BA; Elizabeth A. Boyd, PhD; Grace Malvar, BA; Leah R. Evans, MEd; John M. Luce, MD; Bernard Lo, MD; and Douglas B. White, MD, MAS

*Ann Intern Med.* 2008;149:861-868.

**Conclusion:** Most surrogates of critically ill patients do not view withholding prognostic information as an acceptable way to maintain hope, largely because timely discussions about prognosis help families begin to prepare emotionally, existentially, and practically for the possibility that a patient will die.



## **Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment**

Alexi A. Wright; Baohui Zhang; Alaka Ray; et al.

*JAMA*. 2008;300(14):1665-1673 (doi:10.1001/jama.300.14.1665)

**Conclusions** End-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient quality of life and worse bereavement adjustment.



# Patient-Related Barriers to ACP

- Lack of insight into health status and a false perception that ACP is not relevant for their care
- Expectation that physicians will initiate and guide ACP when the time is “right”
  - Patients typically do not feel they should have to ask for prognostic / EOL care information and are uncomfortable with exerting pressure on HCP to disclose this information.
- Inadequate knowledge about ACP/supportive care options
- Perception that even if completed, directives will not be followed (lack of control)
- View that ACP is unnecessary as family will know what to do.



# Stability of EOL Preferences

- Elderly often change preferences concerning LST
  - patients ‘downsize’ their perceptions of what is a reasonable QOL
- The manner in which treatment information is presented can influence the stability of preferences for EOL care.
- Cognitive status
- Patients with a living will are less likely to change their wishes (14% vs 41%)
  - 85% of patients  $\geq 65$  years, who had chosen to forego LST maintain that choice 2 years later
- 83% of ESRD patients request that physicians periodically check with them to determine if their CPR preferences have changed

Danis M, Ann Int Med, 1994



# Timing of ACP

- **Early** given illness trajectory, cognitive dysfunction
  - The majority of patients lack capacity when the decision to withdraw dialysis is made
  - **Prior to the initiation of RRT**
- Many dialysis patients have already considered EOL options and welcome the opportunity to engage in these discussions with their physician
  - 97% of patients starting dialysis want to be given prognostic information (without having to prompt their physician)  
Fine, PDI 2005
  - Primary care patients: most feel that EOL discussions should occur earlier in the illness trajectory when the patient is healthy and earlier in the patient-physician relationship than did primary care physicians  
Johnston Arch Int Med 1995



# Remaining Challenges:

Determining who Will Benefit from Conservative Management v. Dialysis



# Who to Involve in ACP?

- ESRD patients feel it is the physician's responsibility to initiate ACP
  - What is the role of social workers, RNs, other allied HCPs?
- Many (if not the majority) of these conversations will occur outside of the patient-physician relationship

	Have had EOL discussions	Preferences for future EOL conversations
With Family	<b>50%</b>	<b>91%</b>
With physician	<b>6%</b>	<b>36%</b> (50% with MD, 20% with RN)



# Interventions to Increase the Uptake and Effectiveness of ACP

- Providing dialysis patients with **written material** on ADs does not alter attitudes to ADs and only transiently improves perceived understanding of end-of-life care issues.

Holley AJKD 2003

- RCT of 203 dialysis patients found that **peer mentoring** increased completion of ADs, increased comfort discussing ADs, and improved subjective wellbeing and anxiety among the African American participants.

Perry AJKD 2005

- **Education: multi-component approaches “Respecting Choices”**
  - AD completion increased from 15% to 85%
  - median time between AD and death was 1.2 years.
  - Almost all ADs requested that treatment be forgone as death neared and treatment followed these instructions in 98% of cases

Bud Hammes & Linda Briggs



# Behavioural Change

## 1. Health Information Technology

- Identify at risk patients and provide automated reminders for ACP
  - ~ 8-fold increase in having an AD discussion with 45% of these discussions resulting in the completion of an AD.
- A multi-faceted automated intervention that prompted ACP discussions & sent out educational material on ADs to patients prior to their appointment.
  - More ACP discussions (64% v. 38%,  $p < 0.001$ ) and more documentation of these discussions (47% v. 24%,  $p < 0.001$ ).
- Share information across providers with a uniform instrument.
- Promote adherence to guide-line based care.



# Behavioural Change

## 2. Social Marketing

- “Respecting Choices”
- Training modules and educators are available to train ACP facilitators



# The Impact of ACP on EOL Care in Elderly Patients: RCT

BMJ. Detering et al. 2010

## Respecting Choices Program

- N = 309
- EOL wishes more likely to be known and followed (86% v. 30%,  $p < 0.001$ )
- For family members after patient death, less stress, anxiety and depression in the intervention group



# Impact of Disease-Specific ACP: RCT

Kirchhoff et al JAGS 2010 in press

## Respecting Choices Program

- N = 313 surrogate pairs (43% had ESRD)
- Surrogates demonstrated significantly better understanding of patient goals
- First step toward ensuring patient goals for care are known and honoured



# Behavioural Change

## 3. Legislative & Policy Change

- POLST (Physicians Orders for Life Sustaining Treatment)



## Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician, NP, or PA. These medical orders are based on the person's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section.

Last Name/ First/ Middle Initial

Address

City / State / Zip

Date of Birth (mm/dd/yyyy)

Last 4 SSN

Gender

M F

### A CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ Attempt Resuscitation/CPR ☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in B, C and D.

### B MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Patient prefers no transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). *Transfer to hospital if indicated. Avoid intensive care.*

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. *Transfer to hospital if indicated. Includes intensive care.*

Additional Orders: \_\_\_\_\_

### C ANTIBIOTICS

☐ No antibiotics. Use other measures to relieve symptoms.  
☐ Determine use or limitation of antibiotics when infection occurs.  
☐ Use antibiotics if medically indicated.

Additional Orders: \_\_\_\_\_

### D ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible.

☐ No artificial nutrition by tube.  
☐ Defined trial period of artificial nutrition by tube.  
☐ Long-term artificial nutrition by tube.

Additional Orders: \_\_\_\_\_

### E REASON FOR ORDERS AND SIGNATURES

My signature below indicates to the best of my knowledge that these orders are consistent with the person's current medical condition and preferences as indicated by discussion with:

☐ Patient ☐ Health Care Representative ☐ Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)  
☐ Parent of Minor ☐ Court-Appointed Guardian  
☐ Other \_\_\_\_\_

Print Primary Care Professional Name

Office Use Only

Print Signing Physician / NP / PA Name and Phone Number

( )

Physician / NP / PA Signature (mandatory)

Date

ORIGINAL TO ACCOMPANY PERSON IF TRANSFERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY



HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Information for Person Named on this Form Person's Name (print)

This voluntary form records your preferences for life-sustaining treatment in your **current** state of health. It can be reviewed and updated by your health care professional at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your surrogate.

Signature of Person or Surrogate

Signature	Name (print)	Relationship (write "self" if patient)
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Opt Out ☐ Check box if you **do not** want this form included in the electronic POLST registry.

Contact Information

Surrogate (optional)	Relationship	Phone Number	Address	
Health Care Professional Preparing Form (optional)	Preparer Title	Phone Number	Date Prepared	
PA's Supervising Physician		Phone Number		

Directions for Health Care Professionals

Completing POLST

- Should reflect current preferences of persons with advanced illness or frailty. Encourage completion of an Advance Directive.
- Verbal / phone orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- Use of original form is encouraged. Photocopies, faxes, and electronic registry forms are also legal and valid.
- A person with developmental disabilities or significant mental health condition requires additional consideration before completing the POLST form, refer to *Guidance for Health Care Professionals* at <http://www.ohsu.edu/polst/programs/docs/guidance.pdf>.

Sending to POLST Registry (Required unless "Opt Out" box is checked)

- For the POLST Registry, the following information on the other side of the form **must** be completed:
  - Person's full name
  - Date of birth
  - Section A
  - Physician / NP / PA Signature and date signed
- Send a copy of **both** sides of this POLST form to the POLST Registry.
  - FAX or eFAX: (503) 418-2161 Date \_\_\_\_/\_\_\_\_/\_\_\_\_
  - or
  - Mail: Oregon POLST Registry Date \_\_\_\_/\_\_\_\_/\_\_\_\_
  - Mail Code: CDW-EM
  - 3181 SW Sam Jackson Park Road
  - Portland, OR 97239

Reviewing POLST

- This POLST should be reviewed periodically and if:
- The person is transferred from one care setting or care level to another, or
  - There is a substantial change in the person's health status, or
  - The person's treatment preferences change.

Voiding POLST

- A person with capacity, or the valid surrogate of a person without capacity, can void the form and request alternative treatment.
- Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.
- Send a copy of the voided form to the POLST Registry as above (Required).
- If included in an electronic medical record, follow voiding procedures of facility/community.

PUT REGISTRY ID STICKER HERE:

For permission to use the copyrighted form contact the OHSU Center for Ethics in Health Care. Information on the POLST program is available online at [www.polst.org](http://www.polst.org) or at [polst@ohsu.edu](mailto:polst@ohsu.edu).

ORIGINAL TO ACCOMPANY PERSON IF TRANSFERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY



# Key Elements to Facilitate Effective ACP

Davison CJASN 2006, AJKD 2007

## Patient participation

1. Determine the patient's *ability* to be involved in ACP
2. Determine the patient's *interest* in participating in ACP
3. Determine the patient's *perception* of level of control and power
4. Determine the patient's *perception of potential benefits* of participation in ACP
5. Determine the patient's *resources* to participate in ACP
6. Identify *whom* the patient wishes to engage in ACP

## Decision-making and defining priorities for goals of care

1. Measure *understanding* of illness
2. Determine *how* patients expect to make decisions
3. Determine *expectations* regarding outcomes of end-of-life care
4. Determine patient *values* that drive end-of-life preferences



# Information-Giving within ACP

- **Prognosis**
  - Physicians admit to a lack of accurate survival statistics and often feel that patients do not understand, or misinterpret statistics.
  - Patients are sensitive to the inherent uncertainty in providing prognostic information but did not feel that this should hinder the provision of information.
- **Impact on daily life**
  - Patients look to HCP for assistance in making the needed connections between their lives and the vast array of information available to them. Helping patients see future possibilities consistent with their values is what maintains hope.



# Key Elements to Facilitate Effective ACP

## **Patient-physician relationship**

1. Use of lay language to promote understanding
2. Empathetic listening
3. Affirm patients' self-worth
4. Maintain trust, honesty, promise keeping, confidentiality, and caring

## **Documentation**

1. Easily identifiable
2. Travel with the patient across health care settings so it is available for all professional caregivers involved in the care of the patient.

## **Quality assurance**





## ADVANCE CARE PLANNING

### Welcome to ACP

#### Goals of Care Designations now in effect

#### Advance Care Planning (ACP) for Future Health Care Decisions

It is difficult to think about a time when we may not be able to communicate our wishes. If the time came, and someone had to tell your health care team what you would want them to do, would your family or close friends know what kind of care you would want? Do those close to you know what is important to you regarding health care?

How and where people die is changing dramatically due to the aging population and advances in health care. Two out of every three individuals will die with one or more serious chronic illnesses. Frailty due to conditions such as dementia, cardiovascular disease, renal disease and Parkinson's Disease will shape the last years of life for the majority of us. We may be sick enough to die but live for many years.



Have a voice in the care you receive if you become unable to speak for yourself.

- What would happen if you had a serious illness or injury and could not make your own decisions?
- How would your family, friends or healthcare team know your wishes?
- Who would speak for you?

Prepare now and start thinking about your wishes for future medical decisions today.



*What is the difference between an M2 and C1 designation?*

[Click Here](#)



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## ADVANCE CARE PLANNING

### ACP Tools

#### Tools

- ["My Voice" workbook - standard version](#) (FSD#103284)  
 PLEASE NOTE: When you complete the Personal Directive that is part of the "My Voice" workbook, it is recommended that you move these pages to the front of your "My Voice" workbook.
- ["My Voice" workbook - short version](#) (FSD#103285)  
 PLEASE NOTE: When you complete the Personal Directive that is part of the "My Voice" workbook, it is recommended that you move these pages to the front of your "My Voice" workbook.
- ["My Voice - Planning Ahead" Video](#) This 16 minute video introduces advance care planning including what it is and why it is so important. Members of the public and health care professionals discuss the benefits of advance care planning.
- [Understanding the Goals of Care Designations Brochure](#) (form #103516)  
 This brochure provides detailed information about the Goals of Care Designations.
- ["My Voice - Planning Ahead" Brochure](#)
- ["My Voice - Planning Ahead" Agent Card](#)
- ["My Voice - Planning Ahead" Wallet Card](#)

#### Tool Orders

[View Material Lists Here](#)

#### Sharing Our Resources

You are welcome to download, print and copy these resources for your own use. If you plan to use and/or distribute these resources beyond your own use or for your clients, please [contact us](#).

If you are unable to print these materials, we are able to send you a maximum of 10 copies of any brochure/resource item. Please contact our office at: 403-943-0249.

Indicate your name, full mailing address, phone number and the items and quantities (up to 10) that you would like to receive.

*Online Learning Modules for the Policy*

You must access WBT from an AHS computer

Adult and/or Pediatric Policy Module - WBT

Non-AHS Staff Policy Module

"My Voice - Planning Ahead" Module



## WHEN COMPLETED, THE "MY VOICE" WORKBOOK BECOMES A GUIDE FOR OTHERS TO USE IF YOU ARE NOT ABLE TO SPEAK FOR YOURSELF

This workbook will help you define and discuss:

- who you want to speak on your behalf
- the values and beliefs that guide you in making important decisions
- the types of treatment you would want considered
- the types of treatment you do not want considered
- your wishes for care at the end of life



“It is 3 p.m. A woman is rushed to hospital after being involved in a hiking accident. She is in a coma and has suffered severe trauma. It is unknown whether she will recover. Her husband is able to tell the medical team what his wife would want them to do, as they recently completed the “My Voice” workbook together. He is confident that he is making the right decision.”

## WHO SHOULD COMPLETE THE “MY VOICE” WORKBOOK?

- everyone – we never know when we may face an unexpected event or illness and will be unable to make our preferences known
- adults living with chronic disease
- seniors

(403) 943-0249

[www.calgaryhealthregion.ca/advancecareplanning](http://www.calgaryhealthregion.ca/advancecareplanning)

leaders in health - a partner in care



calgary health region  
leaders in health - a partner in care

## MY VOICE – PLANNING AHEAD



ADVANCE CARE PLANNING FOR  
FUTURE MEDICAL DECISIONS



calgary health region  
leaders in health - a partner in care

# Questions?



# **Cari Hoffmann, RSW**

## **Project Coordinator**

### **Fraser Health Authority**

## **Learning Objectives**

- Describe who Healthcare Professionals should initiate these conversations with.
- Describe the components of effective Advance Care Planning conversations.
- Increase comfort with initiating and engaging in Advance Care Planning conversations.



# Foundation of ACP Promotion

- Fraser Health ACP initiative based on the Respecting Choices® model:
  1. Curriculum for health care professionals
  2. Comprehensive public education (including web site, toll free number, My Voice Workbook©, etc.)
  3. Focus on the **conversation**, not the document
  4. System supports
- Focus on values, goals, and beliefs; engaging in *shared decision making* and planning for *incapacity* not just end-of-life care



# Our experience in the Renal Program Fraser Health Pre Pilot (2004)

## Nephrologists reported:

- Initiated ACP conversations with 10% - 20% of patients
- Only with seriously ill patients or those who expressed an interest

## Patients reported:

- 34% had ACP conversations



# Post Pilot for families and pts:

- Patients expressed *relief* and *gratitude* for being able to express and record their choices for future healthcare
- Family members expressed decreased conflict with the patient's decision
- 86% of patients discussed future healthcare wishes with family/friends following discussion with healthcare provider
- 71% completed My Voice workbook
- 100% of choices were honoured



# September 2008-September 2009

Two Clinical Resources Nurses hired to  
implement and imbed into practice:

Indicator	Baseline	Target	Actual (Sept 2009)
Proportion of Hospital deaths will decrease	95% hospital deaths	70% hospital deaths	64% hospital deaths
ACP notes present in 50% of pt charts	80	160	158
Completed DNRs and My Voice will be updated	0	100%	100%
ACP training workshop will be delivered to each site	0	80% of regular staff	130 staff attended
Education Sessions for Staff will be provided	0	3 sessions/year	MDs: 3 sessions Staff: 2 sessions



# Additional Results

- Formal link with Hospice Palliative Care
  - HPC service overview offered to renal staff at all sites
  - Admit patients to hospice
  - Provincial and acute CPR/DNR policy review



# Renal Program Today...

## six years later

- Part of routine care and assessment in Community Visits, Kidney Care Centres and Dialysis Units
- Development and delivery of one hour education sessions/video to further imbed into routine practice



# Throughout Fraser Health today

- Across many programs and with a variety of disciplines, there has been a significant shift with Advance Care Planning
- ACP Program in FH has front line support and we are challenged to meet demand for education and support



# Settings for ACP Conversations

- Primary Care: at point of screening, diagnosing
- Community clinics: pre-dialysis
- Dialysis: In-hospital or community
- Community visits: in patient homes
- Transplant discussions



# Who should HCP initiate these conversations with?

- **Ideally:**  
Healthy Capable Adults to create awareness and normalize ACP
- **More Imperative With:**  
Capable Adults with Chronic Diseases before they are acutely ill
- **Absolutely:**  
Capable Adults with Life Expectancy Less Than 12 Months



# Listening is a key clinical service

“The main problem with [clear] communication, is the illusion that it has taken place.” George Bernard Shaw

- We are always sending and receiving messages
- Learn how to listen



# Communication is a procedure – an intervention

- Good communication can be learned; Fraser Health curriculum focuses on skills-based exercises for health care professionals
- Mastering good communication requires practice and experience
  - Open ended questions
  - Listen to the stories
  - Explore the stories
  - Summarize (reflect back) the stories



# Exploration

**First:**

- Explore adult's goals, values, beliefs, concerns and priorities — these must be at the heart of the conversation/plans.

**Second:**

- Explore adult's treatment options/decisions/priorities:
  - Life-style changes,
  - Pharmacologic interventions,
  - Resuscitation,
  - Dialysis,
  - Transplant.



# Successful Conversations include:

1. Capable adult readiness to talk
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



# Opening the Advance Care Planning Conversation

- Let the adult (and substitute decision-maker) know that Advance Care Planning discussions are a routine part of good healthcare:

*“We can’t respect your choices if we don’t know about your values, goals and beliefs.”*



# Opening the conversation

- “Our first priority is providing the best care...it is difficult to predict when your health will change...it is important to talk about future healthcare choices that might need to be made...”
- Allow time for reflection.



# Opening the conversation

- “Have you heard of Advance Care Planning?”
- “One of my roles is to help our team understand how we can best respect you, and what you value and believe in.”
- “Talking about this before we get sick helps our family members know what decisions to make in time of stress or crisis.”
- “I’ve done it myself”



# General Comments

- “ACP involves thinking about what your healthcare choices would be if you were ever in a condition that would leave you unable to speak and make your own decisions.”
- “I have some materials, on our next visit we can talk about this.”



## Assess understanding of medical condition:

- Realistic information about the benefits/ burdens, risks/possible complications of treatments (dialysis, pharmacological interventions, transplant)
- Where possible, a description of how this person's disease is likely to progress and what treatments he/she might face in the future
- “Tell me about your diabetes/high blood pressure/kidney disease?”
- “What do you hope this treatment will achieve?”



# Explore living well/quality of life:

- “What do you expect in the future? What worries you most right now? What matters most to you?”
- “Do you value down-the-road benefits or do you have more immediate concerns about side effects/impact on daily life?”
- “What is the effect on your physical, psychological and social functioning?”



# Review Substitute Decision Maker roles and responsibilities

- “We would need to talk with a SDM if you were unable to speak with us. Who do you talk with about your health, concerns and beliefs?”
- “Could they honour your choices? Have you talked enough?”
- “It is important that they be included in these discussions”



# Explore Experiences:

- “Do you know anyone who has been on dialysis/had kidney disease/had a kidney transplant?”
- “Have you or anyone in your family/friends had any experiences in ICU?”
- “Have you heard of CPR? Known anyone who has gone through this experience?”



# 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



- Skills Based Practice Exercises



- Debrief Practice Exercises

What did you find or have you found  
to be one of the most powerful  
questions?



# Canadian Resources

- Educating Future Physicians in Palliative Care and End-of-Life Care. 2007. *Facilitating Advance Care Planning: An Interprofessional Educational Program – Curriculum Materials and Teacher's Guide*. [http://www.afmc.ca/efppec/docs/pdf\\_2008\\_advance\\_care\\_planning\\_curriculum\\_module\\_final.pdf](http://www.afmc.ca/efppec/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf)
- Cross-cultural considerations in promoting advance care planning in Canada. Andrea Con for Health Canada. 2007. [http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408\\_Con.pdf](http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf)
- The Glossary Report. Janet Dunbrack for Health Canada. 2006. [www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index_e.html)



# Canadian Resources

- ACP Project:  
[http://www.chpca.net/projects/advance\\_care\\_planning/advance\\_care\\_planning\\_index.html](http://www.chpca.net/projects/advance_care_planning/advance_care_planning_index.html)
- Environmental Scan:  
[http://www.chpca.net/projects/advance\\_care\\_planning/acp\\_environmental\\_scan\\_sept\\_9\\_09.pdf](http://www.chpca.net/projects/advance_care_planning/acp_environmental_scan_sept_9_09.pdf)

Contact: Louise Hanvey [lhhanvey@bruyere.org](mailto:lhhanvey@bruyere.org)



# Fraser Health Resources

- “My Voice” Workbook© in English, Chinese & Punjabi
- “Information Booklet for ACP” brochure in English, Chinese and Punjabi
- “Making Decisions About CPR” brochure in English, Chinese and Punjabi
- ACP Wallet Card
- Posters in 7 languages
- E-book “Planning in Advance for Your Future Healthcare Choices”
- Web site: [www.fraserhealth.ca](http://www.fraserhealth.ca)
- Toll free: 1-877-825-5034



# Fraser Health Resources

- Two 30 minute on-line ACP education modules; regular education sessions
- Greensleeves for patient medical files
- Advance Care Planning Record
- ACP Referral Card
- Educational DVDs in English, Punjabi & Chinese
- Green document holder for home use
- One hour Renal specific education dvd and curriculum



# Questions?

