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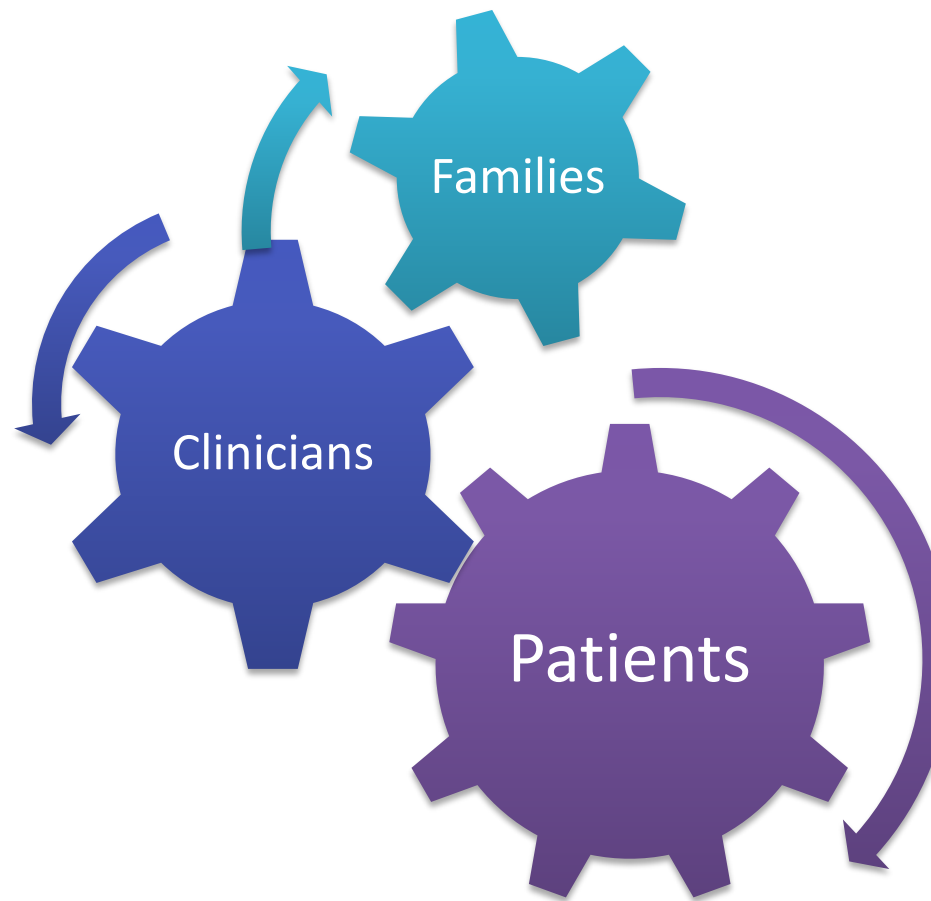
# When and How to Start End-of-Life Conversation: Perspectives from Doctors, Patients and Relatives

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# End-of-life Conversation

- Advance Care Planning
- Tripartite
- Should be in a broader scope
  - Not limited to decisions on DNACPR and life-sustaining treatments



# Families

- Uncertainty in disease severity
- Ignorance about palliative and end-of-life care



Chan HYL, Lee DTF, Woo J, Huso Y. The development of palliative and end-of-life care in Hong Kong. Public Policy Research Funding Scheme (2016 – 17).



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# Uncertainty about disease severity

Family members had not been told of the disease trajectories and prognosis explicitly, and so sometimes it is hard for them to accept the health changes.

*“All the things changed so quickly...The doctor had told that the surgery was very successful just 2 weeks before her readmission...The doctors should not just present all the hard facts to us...What does 20% survival rate means? We would not know which is the best option...Until today, I am still unsure if I have provided the best care to my mum.”* (a young lady whose mother died of gynecological cancer)

*“The doctors have not explained her condition in detail, but I think it is not going well.”* (a son whose mother had congestive heart failure)



# Ignorance about palliative & EoL care

Public awareness about palliative and end-of-life care seems poor.

*A young lady reverted the DNACPR decision for her husband who had lung cancer in the last minute because she thought that the decision was made in a rush. Although the resuscitation procedures were not able to rescue his life, she thought that **at least she had done something for him.***

*“Probably **because there are nothing they can do**, they referred him [the patient] to palliative care.” (an elderly lady whose husband had lung cancer)*

*“I have never heard of that [palliative care] before. Previously **I thought it was just a place for people waiting for death**, but my perception changed totally after my mum was transferred to there. It is like the difference between hell and heaven...” (a middle-aged lady whose mother died of breast cancer)*



# Clinicians

- Determining the timing of transition
- Assessing the readiness of patients and family members



Chan HYL, Lee DTF, Woo J, Huso Y. The development of palliative and end-of-life care in Hong Kong. Public Policy Research Funding Scheme (2016 – 17).

Chan HYL, Chan SSH, Ng WM, Tsang SM, Mak K, Tsang MC. Challenges in end-of-life care decision making for patients in long-term care setting: Perspectives of health professionals. 2016.

# Determining the timing of transition

- Some clinicians concerned if it is premature to introduce the conversation because:
  - some patients have lived with the condition for a long period of time
  - some patients' conditions are stabilized or improved after the treatment
  - new therapies are available
  - the health care team cannot reach a consensus
  - ...etc.

*“It is hard to answer the Surprise Question.” (a medical doctor)*

# Assessing the readiness of patients and family members

The clinicians were hesitant to introduce the conversation.

*“It depends on their emotional status and whether they can accept the reality. It takes some time for observation, or else the patients and families may feel that they were being cursed or given up.”*

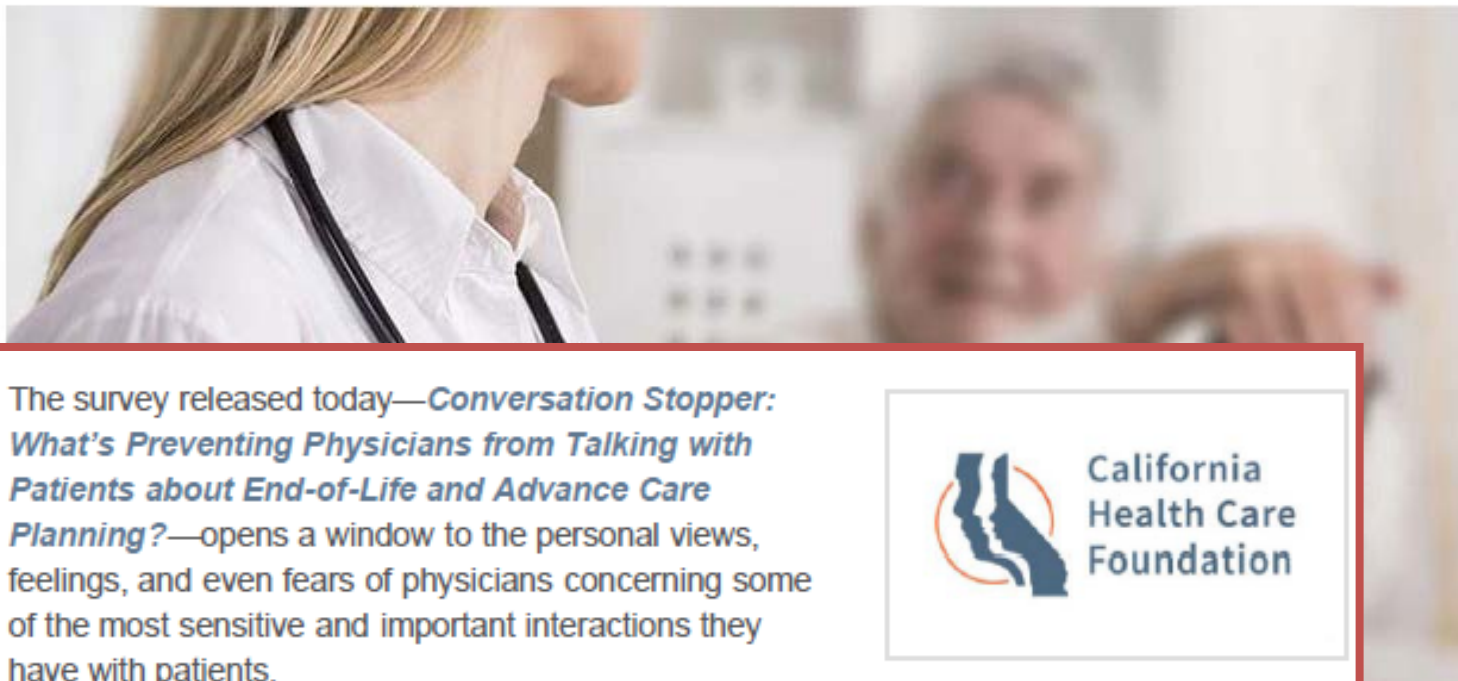




# Most Doctors Unsure How To Discuss End-of-Life Care, Survey Says

| Kaiser Health News

By **Barbara Feder Ostrov** | April 14, 2016



The survey released today—*Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?*—opens a window to the personal views, feelings, and even fears of physicians concerning some of the most sensitive and important interactions they have with patients.



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For example, **nearly half (46 percent)** report that they frequently or sometimes feel unsure of what to say. And **less than one-third (29 percent)** report having had any formal training specifically on talking with patients and their families about end-of-life care.



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# “Conversation Stopper” Physician Survey (2016)

736 primary care physicians/internists and specialists: oncologists, pulmonologists, and cardiologists in 50 states



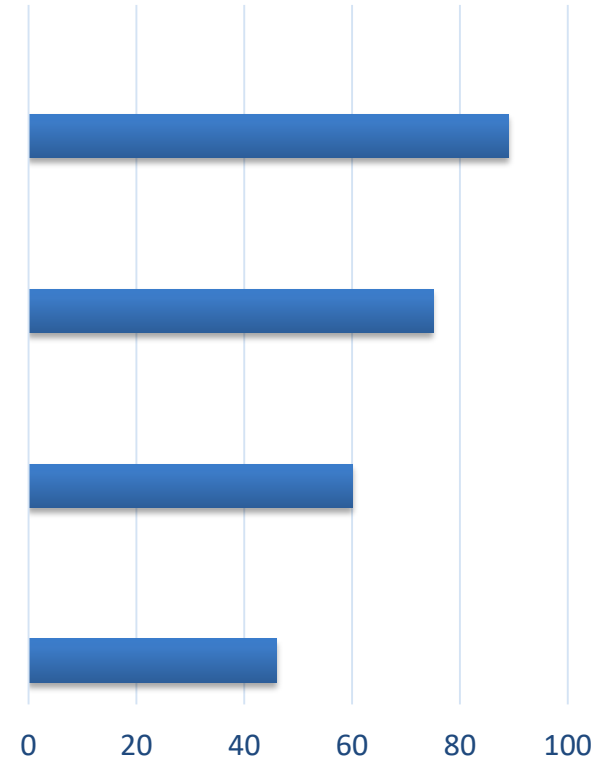
## Poll results

Found the conversation highly important

Physician's responsibilities

Unsure about the timing

Unsure of what to say



# Patients

- Concerned about burdensome death
- Felt relieved with advance care planning



Chan HYL, Ng JSC, Chan KS, Chan LN, Ko PS, Leung DYP, et al. Effects of an advance care planning programme among Chinese patients with advanced disease: A randomized controlled trial. Palliative Medicine 2016, DOI: 10.1177/0269216316646056

# Concerned about burdensome death

The patients acknowledged that their health conditions were irresponsive to the treatments and getting worse. Their concerns have shifted to the quality of death.

*“I don’t afraid of anything, the only thing I worry is that I would be in **great distress** in my last days.” (67-year-old man)*

*“Since the condition is so serious, all these [life sustaining treatments] are just to lengthen the time. **What’s the purpose?** I don’t want to **be a drag on my family.**” (78-year-old lady)*



# Concerned about burdensome death



Some patients have initiated the conversations with their doctors actively, but...

*“I have told the doctor that I wanted to sign an advance directive for myself, but he said it is **too early** for me to think about this.” (an elderly singleton)*



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# Felt relieved with advance care planning

Some patients have forethoughts about end-of-life issues and so they appreciated the opportunities to share their views with their significant others.

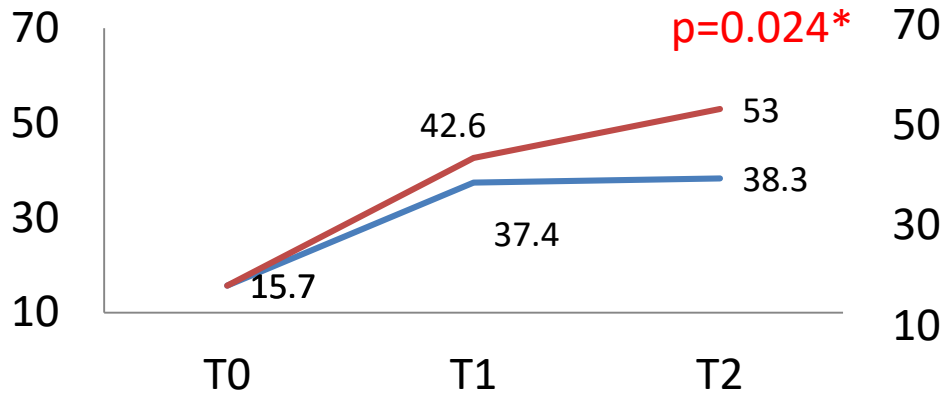
*“I have thought about these [end-of-life care], but my children always asked me to be optimistic. It is really good to have a chance for me to make clear about my wishes. They have been **suppressed in my heart for a long time.**” (89-year-old lady)*

*“This [ACP] let me experience a **peace of mind.** Birth, ageing, illness and death are just part of life.” (72-year-old man)*

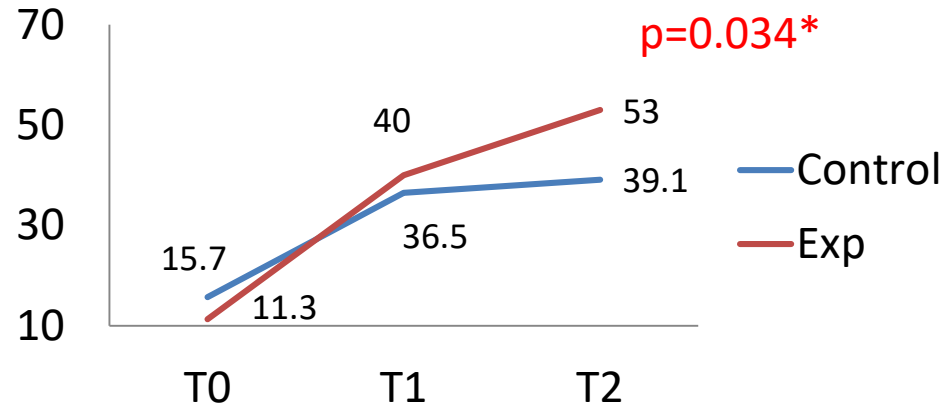


# Dyadic agreement on EOL care preferences

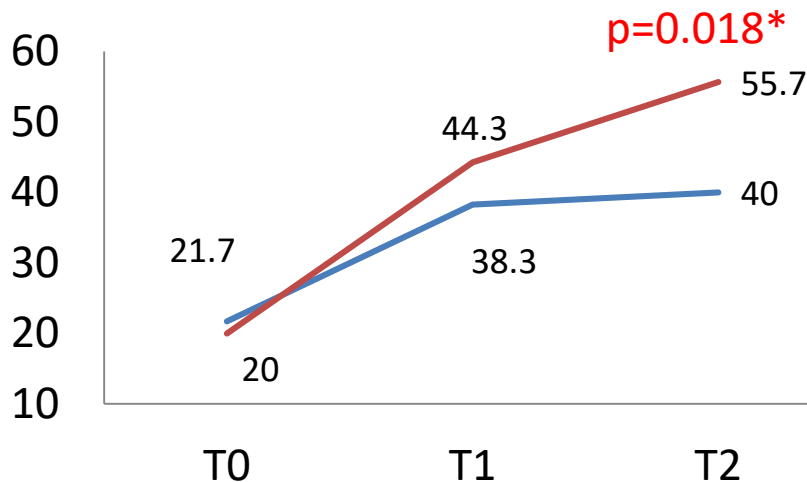
## DNACPR



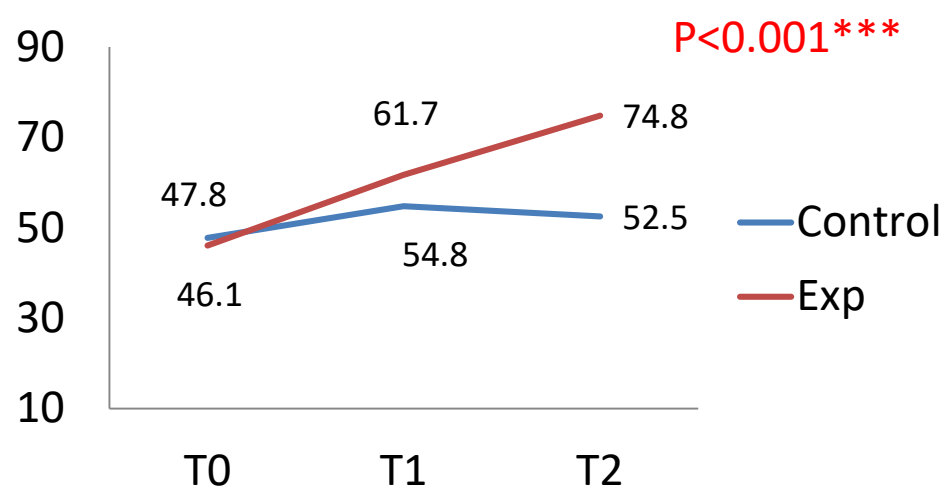
## Not for tube feeding



## Not for intubation



## Goal of care



*“Anticipation of the precise timing of death is less important than anticipating the fact of death itself... It is the acknowledgement of the latter that allows families to **make choices & plan their lives**”*  
(Fraser et al., 2010)



Fraser J, Harris N, Berringer AJ, Prescott H, Finlay F. Advanced care planning in children with life-limiting conditions – the Wishes Document. Arch Dis Child 2010;95:79-82.







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# How to start the end of life conversations?

# Serious Illness Conversation Guide

## CONVERSATION FLOW

### 1. Set up the conversation

- Introduce the idea and benefits
- Ask permission

### 2. Assess illness understanding and information preferences

### 3. Share prognosis

- Tailor information to patient preference
- Allow silence, explore emotion

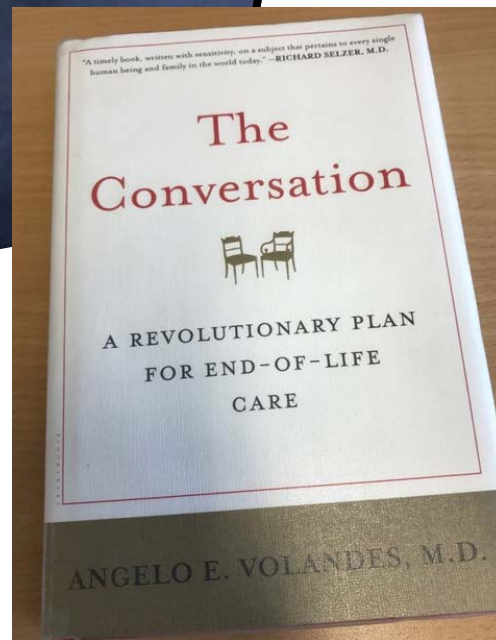
### 4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

### 5. Close the conversation

- Summarize what you've heard
- Make a recommendation
- Affirm your commitment to the patient

### 6. Document your conversation



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**THE BIG CONVERSATION**

**Dying Matters Awareness Week**  
9th-15th May 2016

**#YODO** you only die once

**Dying Matters**

Talking about dying won't make it happen!

[www.dyingmatters.org](http://www.dyingmatters.org)

[www.facebook.com/DyingMatters](https://www.facebook.com/DyingMatters)

[twitter.com/DyingMatters](https://twitter.com/DyingMatters)

**Advance**

Initiating palliative care and advance care planning: training and resources for General Practice Nurses

**CPA CPD**  
ACCREDITED

FUNDED BY THE AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH

**Living Matters**  
advance care planning

**HAVE YOU HAD THE CONVERSATION?**

Help get it out in the open. When it comes to end of life, I want mine to be...

Share how you want to live the end of your life.

**the conversation project**

**Speak Up**

Start the conversation about end-of-life care

**Ask me about advance care planning**

**Speak Up · Parlons-en**

Start the conversation about end-of-life care | Dialogue sur les décisions de fin de vie

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

**Posez-moi des questions sur la planification préalable des soins**

**VITALtalk**

# Bad examples...

*“We would not ask the patients directly about how they think about death, you would be challenged. I would ask the family members to **discuss the issues among themselves** and let us know their decision.”* (Focus group interview with clinicians)

*“I can **see from their faces**, they are very **annoyed with our silly questions**. Please tolerate with us even though these questions seem silly to you, we really do not know what we should do at that moment.”* (a family carer)

*“In my memory, I have only met the doctor once. You could never find them during the visiting hours. The doctor informed us about the DNACPR decision **through phone** only. At that moment, I was shocked and not knowing what to do.”* (a family carer)



# Conclusions

*Clinicians' attitudes, competence in communication skills and the approaches used to introduce the end-of-life conversations are highly influential*

- ACP as an **ongoing process** and introduce **early**  
→ avoid equating options = giving up
- Important to explore the **needs** and **expectations** of patients and family members towards the goal of end-of-life care  
→ affect their experiences, decisions, relationships with health professionals



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# Thank you!

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