Serious Illness Conversation Guide: Initiating the conversation

如何展開晚期照顧的話題:「嚴重疾病對話指南」

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Advance planning when facing serious illness: the earlier the better!

面對嚴重晚期病患時
預設醫療計劃及指示愈早愈好

Science, Art and Compassion in Communication at End of Life

- All quality medical care rely on communication!

Quality communication:

-*Better early than late!*

-*Better late than never!*

-*Never without a heart!*

- 早溝通, 好過遲溝通
- 遲溝通, 好過唔溝通
- 有心,用心,由心地溝通

The benefits of Advance Care Planning is evidence-based!
First RCT on Advance Care Planning

BMJ

RESEARCH

The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

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Cite this as: *BMJ* 2010;340:c1345
doi:10.1136/bmj.c1345

ABSTRACT

Objective To investigate the impact of advance care planning on end of life care in elderly patients.
Design Prospective randomised controlled trial.
Setting Single centre study in a university hospital in Melbourne, Australia.
Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.
Interventions Participants were randomised to receive usual care or usual care plus facilitated advance care planning. Advance care planning aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes.
Main outcome measures The primary outcome was whether a patient's end of life wishes were known and respected. Other outcomes included patient and family satisfaction with hospital stay and levels of stress, anxiety, and depression in relatives of patients who died.
Results 154 of the 309 patients were randomised to advance care planning, 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%; P<0.001). In the intervention group, family members of patients who died had significantly less stress (intervention 5, control 15; P<0.001), anxiety (intervention 0, control 3; P=0.02), and depression (intervention 0, control 5; P=0.002) than those of the control patients. Patient and family satisfaction was higher in the intervention group.
Conclusions Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.
Trial registration Australian New Zealand clinical trials registry ACTRN12608000539336.

INTRODUCTION

Since the 1990s there has been an increasing awareness of the inadequacy of end of life care and of the poor knowledge of patients' wishes about their medical treatment at a time when they lose the capacity to make decisions,[1-3] resulting in patients being cared for in a way they would not have chosen.[2] This has continued to the present day.[4] Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions."[5] The process of advance care planning informs and empowers patients to have a say about their current and future treatment. Advance care planning and the importance of improving end of life care are both supported by legislation in Australia,[6] the United Kingdom,[7] and the United States,[8,9] and are endorsed by professional bodies, including the Australian,[10] British,[7] and American[11] medical associations.

Elements of advance care planning include clarifying a patient's understanding of their illness and treatment options; understanding their values, beliefs, and goals of care; and identifying their wishes. If required a substitute decision maker (surrogate) is nominated.[12 13] The potential barriers to advance care planning include the availability of trained staff with the time, competence, and confidence to discuss advance care planning with patients; organisational commitment and policy to support advance care planning; and ensuring that doctors understand and support advance care planning.[14-16] Carrying out effective advance care planning in elderly patients is challenging, especially when they are acutely unwell and have a short length of stay in hospital before discharge.

Much of the focus on advance care planning has been on improving the completion rate of advance directives.[16 17] Such improvement does not necessarily improve medical care[1 16 18] or end of life care.[1 19] Models of advance care planning such as the Respecting Choices programme have shown that a coordinated, systematic, patient centred approach to advance care planning by trained non-medical facilitators can improve outcomes for patients.[13 20-22] Evidence also shows that advance care planning and end of life discussions reduce stress, anxiety, and depression in surviving relatives.[23-26]

Abstract

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Conclusions **Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.**

Communication in Serious Illness: An Innovative Approach to Clinical Care and Quality Improvement

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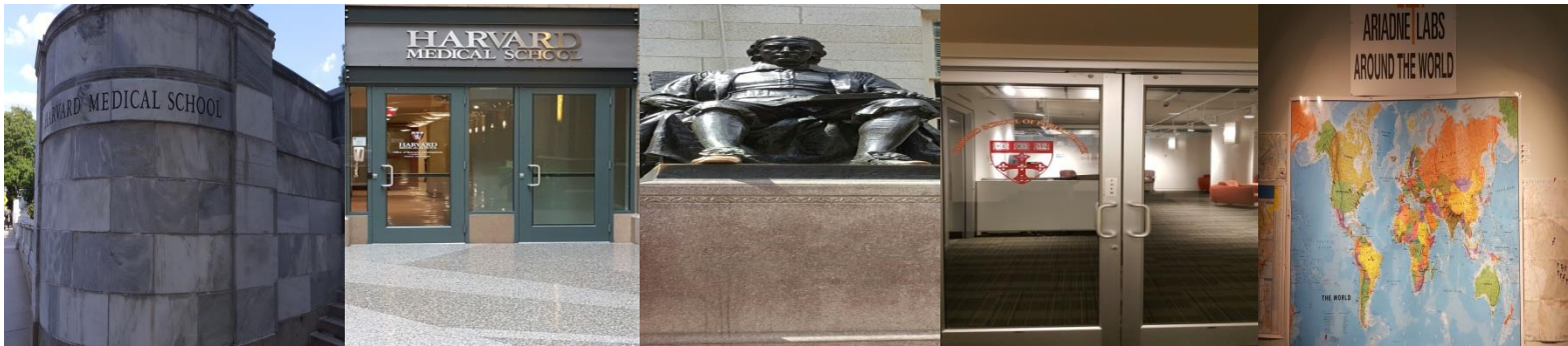
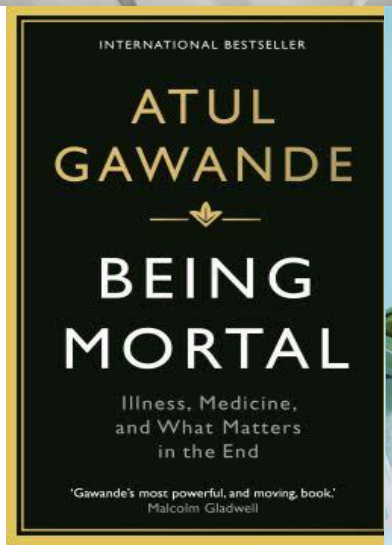
Dana-Farber Cancer Institute

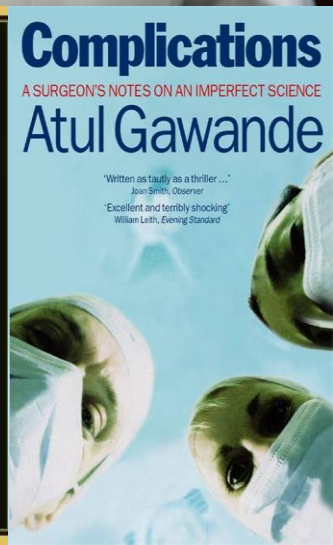
DANA-FARBER CANCER INSTITUTE



Dr. Atul Gawande's 5 questions!

- What is your understanding of where you are and of your illness
- Your fears or worries for the future
- Your goals and priorities
- What outcomes are unacceptable to you? What are you willing to sacrifice and not?
- What would a good day look like





Serious Illness Conversation in Advance Care Planning: what it isn't

It is not about:

- Rationing treatment options
- Imposing one-off decisions
- Un-informed planning of treatment
- Painting a pessimistic future
- Giving up

- 絕非限制局限治療方案
- 絕非強迫一次性决定
- 絕非計劃不知情的治療
- 絕非繪劃悲觀未來
- 絕非放棄!!!

Serious Illness Conversation in Advance Care Planning: what it is

It is about:

- Understanding patients preferences
- 了解病人意願
- Anticipating future plans
- 準備预期計劃
- Facilitating family discussions
- 促進家人商議
- Respecting patients decisions and autonomy
- 尊重病者自主决定
- Maximising comfort and dignity at end of life
- 盡力提升舒適及尊嚴

Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention.

Bernacki R, Hutchings M, Vick J, et al. BMJ Open. 2015;5(10):e009032. doi:10.1136/bmjopen-2015-009032.

Open Access Protocol

BMJ Open

Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention

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To cite: Bernacki R, Hutchings M, Vick J, *et al*. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 2015;**5**:e009032. doi:10.1136/bmjopen-2015-009032

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2015-009032).

Received 9 June 2015
Revised 3 September 2015
Accepted 14 September 2015

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ABSTRACT

Introduction: Ensuring that patients receive care that is consistent with their goals and values is a critical component of high-quality care. This article describes the protocol for a cluster randomised controlled trial of a multicomponent, structured communication intervention.

Methods and analysis: Patients with advanced, incurable cancer and life expectancy of <12 months will participate together with their surrogate. Clinicians are enrolled and randomised either to usual care or the intervention. The Serious Illness Care Program is a multicomponent, structured communication intervention designed to identify patients, train clinicians to use a structured guide for advanced care planning discussion with patients, 'trigger' clinicians to have conversations, prepare patients and families for the conversation, and document outcomes of the discussion in a structured format in the electronic medical record. Clinician satisfaction with the intervention, confidence and attitudes will be assessed before and after the intervention. Self-report data will be collected from patients and surrogates approximately every 2 months up to 2 years or until the patient's death; patient medical records will be examined at the close of the study. Analyses will examine the impact of the intervention on the patient receipt of goal-concordant care, and peacefulness at the end of life. Secondary outcomes include patient anxiety, depression, quality of life, therapeutic alliance, quality of communication, and quality of dying and death. Key process measures include frequency, timing and quality of documented conversations.

Ethics and dissemination: This study was approved by the Dana-Farber Cancer Institute Institutional Review Board. Results will be reported in peer-reviewed publications and conference presentations.

Trial registration number: Protocol identifier NCT01786811; Pre-results.

INTRODUCTION

Ensuring that patients receive care that is consistent with their goals and values is a critical component of high-quality care.[1] Early conversations about advance care planning (ACP) with seriously ill patients have been associated with better outcomes for patients and families.[2–4] However, multiple deficits in the timing and content of these discussions have been described. Discussions occur too late, when patients are in crisis or unable to make decisions for themselves, or clinicians who know the patient are not available.[5–7] Even though most patients want to know about their prognosis, such information is often not shared,[8 9] leading to poorly informed decisions. Furthermore, contrary to expert recommendations,[1] physicians tend to focus these critical conversations on choices about procedures (eg, resuscitation or feeding tube insertion) rather than on the goals, values and wishes that form the basis of an informed patient's decisions. Clinicians are underprepared and undertrained to conduct high-quality end-of-life conversations,[10] and tend to avoid them.[11] Several studies of physicians in the UK,[12] the USA,[13] and in an international palliative care training programme[14 15] demonstrate that communication skills instruction programmes are effective,[16] with participants showing sustained improvement in patient-centered communication skills, including significant improvement in responses to patients' emotional cues.[12] Interactive, case-based learning sessions with communication skills practice are the most effective;[17] however, most often, these training programmes have been intensive, multiday off-site retreats which are not always feasible for busy clinicians in practice.

One proposed solution to deficits in ACP and end-of-life discussions is for palliative care clinicians, who are trained to conduct such conversations, to see all seriously ill

- Cluster randomised controlled trial of a multi-component, structured communication intervention.
- Aim is to identify patients, train clinicians to use a **structured guide** for advance care planning discussion with patients, **"trigger" clinicians to have conversations**, prepare patients and families for the conversation, and document outcomes of discussion in a structured format in the electronic medical record

Serious Illness Communication - Executive Summary

面對嚴重病患時: 怎樣溝通 – 撮要

Principles in Serious Illness Communication: Harvard approach

- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- You will not harm your patient by talking about end of life issues
- Patient wants the truth about prognosis
- Anxiety is normal to be expected for both patients and clinicians during these discussions
- Titrate conversations based on patient's responses(esp anxiety)
- Giving patients an opportunity to express fears and worries is therapeutic

Hong Kong Chinese version of Serious Illness Conversation Guide

- 現在希望和你談一談病情及未來進展，可以嗎？
  1. 請問你此刻了解你病情狀況有幾多呢？
  2. 關於你將來病情，你希望我告訴你幾多呢？
  3. 病情:“我擔心時日無多”
     " 有幾多得幾多？”
  4. 若你健康轉差，那幾項人生目標對你是最重要？
  5. 關於你將來健康，你最担心及恐懼的是甚麼？
  6. 當你考慮到將來的病況，有甚麼最能給到你力量？
  7. 有那方面的能力你覺得是最重要，如果沒有了你不可以想像繼續活下去？
  8. 若你病得更重，你願意接受幾多來換取更長壽命？
  9. 你家人知道你所着重的及所願望的有幾多？
  10. 似乎這_____ 對你來說十分重要？
  11. 顧及到你的目標及首要考慮，及了解到你此刻的病況，我建議 _____
  12. 我們會一齊去面對.

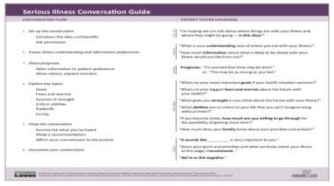
Two way communication:
如何促進與醫生的溝通？

Serious Illness Conversation Guide

Overview of materials

Two tools are available to you, the clinician, to help you have successful conversa
with your patients about serious illness care goals. Use these tools and the langu
within them at least 30 times so you become comfortable with the language anc
flow. Then, you can feel free to ad-lib.

For clinicians



Conversation Guide

The backbone of this project, the Conversation G
will help you have successful conversations with
your patients. It consists of steps to elicit import
information from patients about their goals and
values: setting up the conversation, assessing th
patient's illness understanding and information
preferences, sharing prognosis, exploring key to
and closing and documenting the conversation.

Reference Guide for Clinicians [this document]

This reference guide is available to guide you through all aspec
of serious illness communication. It provides detailed informat
about how to introduce the serious illness conversation, what
language to use, and tips for dealing with common patient
scenarios.

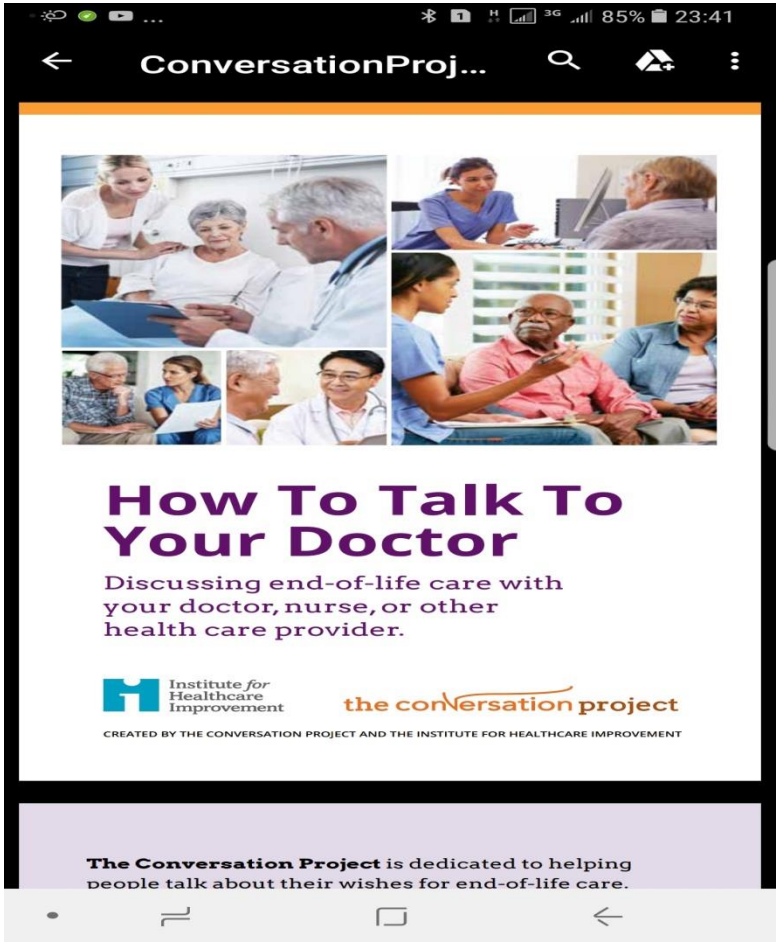
For patients and families

Pre-Visit Letter

This letter is designed to prepare patients for a serious illness
conversation with their clinician. It includes topics for patients
to think about in advance, reinforces the importance of the
conversation, encourages them to engage family members, an
reassures patients that talking about the future will help them
more control over their care.

Family Communication Guide

Designed for the patient's use with their family, this guide will
your patient talk with their family and friends about the same
you bring up with them in your conversations. Like the clinician
materials, it provides language for the patient to relay informa
to their family and to continue the conversation by exploring t
concerns. We encourage you to remind your patients that this
resource is available to them.



Other resources:

- https://www.nhsinform.scot
- https://americanhospice.org
- www.virtualhospcie.ca
- https://theconversationproject.org
- https://getpalliativecare.org

了解自己:
增強與醫生溝通

- 作出充份準備
- 掌握自己狀況
- 列出担心的問題
- 訂出最重要的事項
- 携帶病歷，藥物，及有關資訊
- 安排家人及好友一起陪診
- 分享自己所最珍惜
- 表達內心感受

Difficult Scenarios

- I don’t want to talk about it
- I am going to beat this
- Patient is not ready to make a decision
- Patient intensely tearful
- Patient expresses anger
- Patient is reluctant to stop disease modifying treatment

My 5 “E”s in general approach to patients with serious illnesses and at end of life

- Empathy
- Encourage
- Educate
- Empower
- Extend support

Practices in Serious Illness Communication: Harvard approach

- DO:

Give a direct, honest prognosis when desired by patient

Present prognostic information as a range

Allow silence

Acknowledge and explore emotions

Focus on the patient's quality of life, fears and concerns

Make a recommendation(*"Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend…"*)

Document conversation

Principles in Discussing Serious Illness and Advance Care Planning

- Establish trust with patients
- Attending to patients and relatives affect
- Communicating with hope

Communication in Serious Illnesses

If properly done, communication is proven to be therapeutic!