# “Can we talk?”

- Tips for having difficult conversations, borrowing from the work of Vitaltalk.

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"THE SINGLE BIGGEST PROBLEM IN COMMUNICATION IS THE ILLUSION THAT IT HAS TAKEN PLACE."
GEORGE BERNARD SHAW
Lifehack Quotes

This presentation borrows liberally from the ideas of:

- Dr James Tulsky
- Dr Robert Arnold
- Dr Anthony Back

All oncologists whose passion is to help doctors communicate with patients more effectively.

Their work is presented in Vital Talk, formerly known as Oncotalk.

Dr. Back
University of Washington

Dr. Arnold
University of Pittsburgh

Dr. Tulsky
Dana Farber

- Aspires to teach clinicians to be the clinicians they wish to be…
- Navigate tough conversations with ease
- Develop greater self-efficacy
- Find more meaning in your work
- Join a supportive learning community
- Provide care that aligns with your patients' values
- Connect with a larger mission of culture change

All patients should have and benefit this type of communication. Ask for it…expect it…

VITAL talk

Scenario

Recognizing and Articulating Empathy

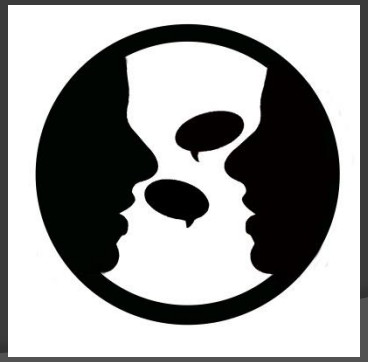
# NURSE

Mary has been on maintenance chemotherapy for about a year. Her fatigue has increased to the point where she doesn’t want to leave the house or be with her friends and grandchildren. She plans to discuss the option of a treatment holiday with her oncologist.

- **N**aming –
  - Name the emotion that you are expressing, “I am frustrated by my lack of energy.” “I am sad because I don’t feel like spending time with my friends, I feel like I am missing out.”
- **U**nderstanding –
  - Ask if the doctor understands or appreciates how you feel. “Have you had this happen before with a patient? What did you do then?”
- **R**especting –
  - State the obvious – “I understand that you are trying to help me, and give me the very best chance at living as long as I can”.
  - State your appreciation for the doctor’s experience and care for you. “We’ve been through a lot together, maybe we need to talk about other things to try, this is just not working for me right now.”

- Supporting –
  - Express your support of what the doctor feels is in your best interest, but make it clear that you want to talk about your values and desires as well. These are equally important. “I appreciate what you are trying to do, and understand your viewpoint, but I am valuing more time with my family right now.”

- Exploring –
  - Asking for more clarification if you don’t understand something. Keep asking until you understand what is being said to you. There are no “dumb” questions. “When you said that a treatment holiday would not be in my best interest, what did you mean by that? Will the cancer cause more symptoms? What would these be?” Tell me about both sides.”



# Skills to Use:

- “Tell me more” – ask for clarification, don’t assume.
- “Ask-tell-ask” – what does the scan show, I feel pain in my back, does the scan show that the cancer is back in my bones?
- “I wish statements” – allows you to align yourself with your doctor’s best self. I wish you had other treatments to offer, but that doesn’t seem to be the case.

Scenerio
Talking about serious news….

# GUIDE

Mary has been stable for 6 months. She is on hormonal therapy. Lately she has begun to notice pain in her hips, especially when she gets up in the morning. She has had a CT scan, and has an appointment with her oncologist to talk about the results.

- **Get Ready** – Information you want to know, people there with you, place (as best you can).
  - Privacy
  - Opening statement like… “Can we take some time to discuss the results of my CT scan” Set the tone.
  - Make sure supportive people are in the room with you, have someone take notes.
- Understand what is known -
  - Have you had a chance to look at my recent scan?
  - Have you discussed it with other doctors who are taking care of me?
- Inform with a sentence –
  - Your doctor should express clearly what the scan said in a “headline”. He may need to give more information, but it should be shortened. He should avoid medical jargon if possible.
  - When he stops, this is your chance to ask questions, express emotions if you want, seek clarification.

- Dignify emotions -
  - Your doctor should pause here and give you a chance to catch up. If she doesn't, ask for a pause.
  - Take a breath. Express what you are feeling.
  - Allow others in the room to express their emotions.
  - Take the time you need to catch up to the news being expressed.
  - Understand that your doctor has emotions too, especially if you have been together for a long time. This may be equally hard for him. Acknowledge this.

- Equip yourself for the next step –
  - Your doctor should ask you, "what can I do to help?" If he doesn't tell him what would be helpful at this moment.
  - She should tell you about the next steps. If she doesn't, simply say, "what do we do now?"
  - You can ask…"do you need more time to discuss my case with others, or do some research…
  - Your doctor should not use "catch phrases" like "everything will be fine… ask her for details.

Scenario
Defusing Conflicts…

Mary recently moved to a new area, and has transferred her care to a new oncologist. She just doesn't seem to have made a connection with her. She is reluctant to bring up concerns, feels nervous about going to appointments.

- **N**otice, Acknowledge the conflict –
  - Talk about the “elephant” in the room. If you need help, bring some support with you.

- **F**ind a non-judgmental starting point –
  - “Could we talk about how it’s going so far?”

- **B**e listened to, listen –
  - Be concise in your concerns, expect to be listened to, try not to accuse. Remember that doctors are people to.

- **I**dentify what the conflict is about if you can –
  - ‘My oncologist from before always told me about the results of the scans on the phone. He knew that I would want to hear, sooner rather than later. Is there a way that you can do that as well?”

- **B**rainstorm options –
  - “Could call me when you have the scan results ready, and we can go over them on the phone. Could I see your NP alternating with you, because they have more time to talk.”

- **L**ook for options that recognize the interest of all involved –
  - Could we consider doing scans at 6 month intervals, try to avoid the unexpected scan, that way… I can be more prepared.
  - I understand that you like to follow that tumor marker, but if we could measure it less often, I would feel more comfortable.

- **R**emember that some conflicts cannot be resolved. It’s no one’s fault.
  - If both you and your doctor have been open and honest with each other, and the conflict remains… it may be time to talk about changing providers. Sometimes it is a bad match. Sometimes you need to agree to disagree.

Scenario
Family Conference Tips

Mary's breast cancer has progressed, and she is now on her 4th type of chemotherapy. She is exhausted. Her husband is exhausted. She and her family request a meeting with the treatment team to talk about discontinuing treatment and moving to hospice care.

- Introduce everyone in the room, clarify their roles, make sure everyone is comfortable.
- Explain what is happening, what is the agenda, what would be a constructive outcome of the meeting?
- Make sure each person is heard, don't call people out, but ask each person if they have something to say.
- Don't allow the doctor to prescribe the outcome, make sure the patient's (YOU) voice is heard.
- Plan next steps together. Make sure that you check in about the plan. When should we know about this? When can we plan to start?
- If you feel comfortable, reflect on the outcome of the meeting as a "wrap-up". "I feel like I know what I will do next." "I will call you tomorrow, once we've had a chance to reflect."

# Scenario Prognosis

What Vitaltalk teaches doctors about conveying prognosis. The **ADAPT** tool.

“I’d like to talk with you about what the future holds…”

- **A**sk what the patient knows –
  - What have other doctor's told you about the future?
  - How have you been thinking about the future?

- **D**iscover what information about the future would be helpful to the patient.
  - Do you like your information in numbers or statistics?
  - Some people like to talk about living to a particular date. Is this what you would like to know?

- **A**nticipate ambivalence –
  - Talking about the future can be scary.
  - What are the pros and cons of discussing this right now?
  - If the patient is clinically deteriorating, "would talking about this right now affect the decisions you need to make?"

- Provide information in the form the patient wants
  - Statistics – Worst case scenario is 25%, and the best case is 75%.
  - If I had 100 people with a similar situation – 25 would have died with cancer, and 75 would still be alive.
  - Without statistics – “From my knowledge of your situation, and how your cancer has been responding/changing, I think there is a good/slim/poor chance that you will be able to be around for that event.”

- Track/Expect Emotion –
  - “I can see this is not what you were hoping for…”
  - “I wish I had better news.”
  - “I can only imagine how this information feels to you. I appreciate that you want to know what to expect.”

  - Realize that your doctor is human too, and may feel equally emotional in giving you this news. Acknowledge his emotions and empathy. Say thank you.

# The Conversation Project

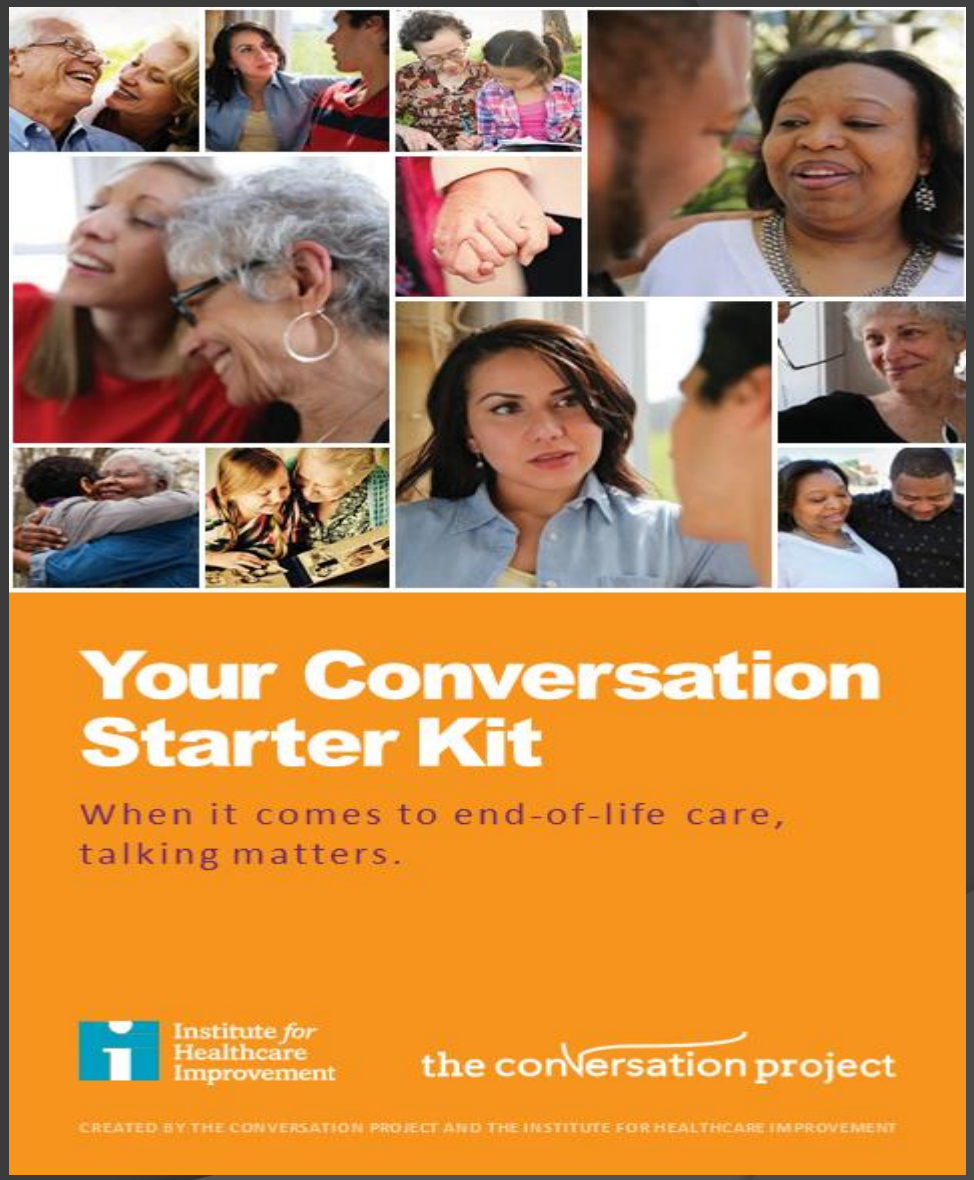
The Conversation Project is a public engagement initiative with a goal that is both simple and transformative: **to have every person's wishes for end-of-life care expressed and respected.**

Too many people die in a manner they would not choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.
It's time to transform our culture so we shift from not talking about dying to talking about it. It's time to communicate about the kind of care we want and don't want for ourselves.

We believe that the place for this to begin is at the kitchen table—not in the intensive care unit—with the people we love, before it's too late.

Together we can make these difficult conversations easier. We can make sure that our own wishes, and those of our loved ones, are both expressed and respected. The Conversation Project offers tools, guidance, and resources to begin talking with loved ones about your and their wishes.

http://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf



# **Step 1** Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**

? **What do you need to think about or do before you feel ready to have the conversation?**

? **Do you have any particular concerns that you want to be sure to talk about?** (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

**REMEMBER:**

- You don't need to have the conversation just yet. It's okay to just start thinking about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- You might consider having a practice conversation with a friend.
- Having the conversation may reveal that you and your loved ones disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.
- Having the conversation isn't just a one-time thing. It's the first in a series of conversations over time.

## How to start

### Here are some ways you could break the ice:

"I need your help with something."

"Remember how someone in the family died—was it a 'good' death or a 'hard' death? How will yours be different?"

"I was thinking about what happened to _____, and it made me realize..."

"Even though I'm okay right now, I'm worried that _____, and I want to be prepared."

"I need to think about the future. Will you help me?"

"I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

### What to talk about:

- ☐ When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- ☐ Do you have any particular concerns about your health? About the last phase of your life?
- ☐ What affairs do you need to get in order, or talk to your loved ones about? *(Personal finances, property, relationships)*
- ☐ Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? *(This person is your health care proxy.)*
- ☐ Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?

- [ ] Where do you want (or not want) to receive care? *(Home, nursing facility, hospital)*
- [ ] Are there kinds of treatment you would want (or not want)? *(Resuscitation if your heart stops, breathing machine, feeding tube)*
- [ ] When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

***This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you'd like them to suggest more questions to talk about.***

**REMEMBER:**

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances change.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

**Now, just go for it!** Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

# Can we talk?

Discussion, questions, concerns?
Thank you!