Association for Palliative Medicine

StChristopher's
More than just a hospice

"It's okay to Talk about dying"

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Objectives

- Review fundamental components of effective communication with patients and their families
- Explore boundary issues when addressing difficult scenarios
- Discuss potential barriers to effective communication
- Consider an approaches/framework to challenging communication issues

Communicate

"to transmit information, thought, or feeling so that it is satisfactorily received or understood"

Merriam-Webster Online Dictionary

...AND THAT IS WHY WE LIFT ON THREE...
COMMUNICATION

General Principles

Bad News

- Any news that drastically and negatively alters the patient's view of his or her future .

- As health care professionals the majority of us, at some time will have to break bad news to a patient , relative or carer. The psychological sequel of breaking bad news in an abrupt or insensitive way can be devastating and long lasting

- Remember in reality the news is bad

Silence Is Not Golden

"Ask me no questions, and I'll tell you no lies"

attributed to Irish playwright Oliver Goldsmith (1728-1774)

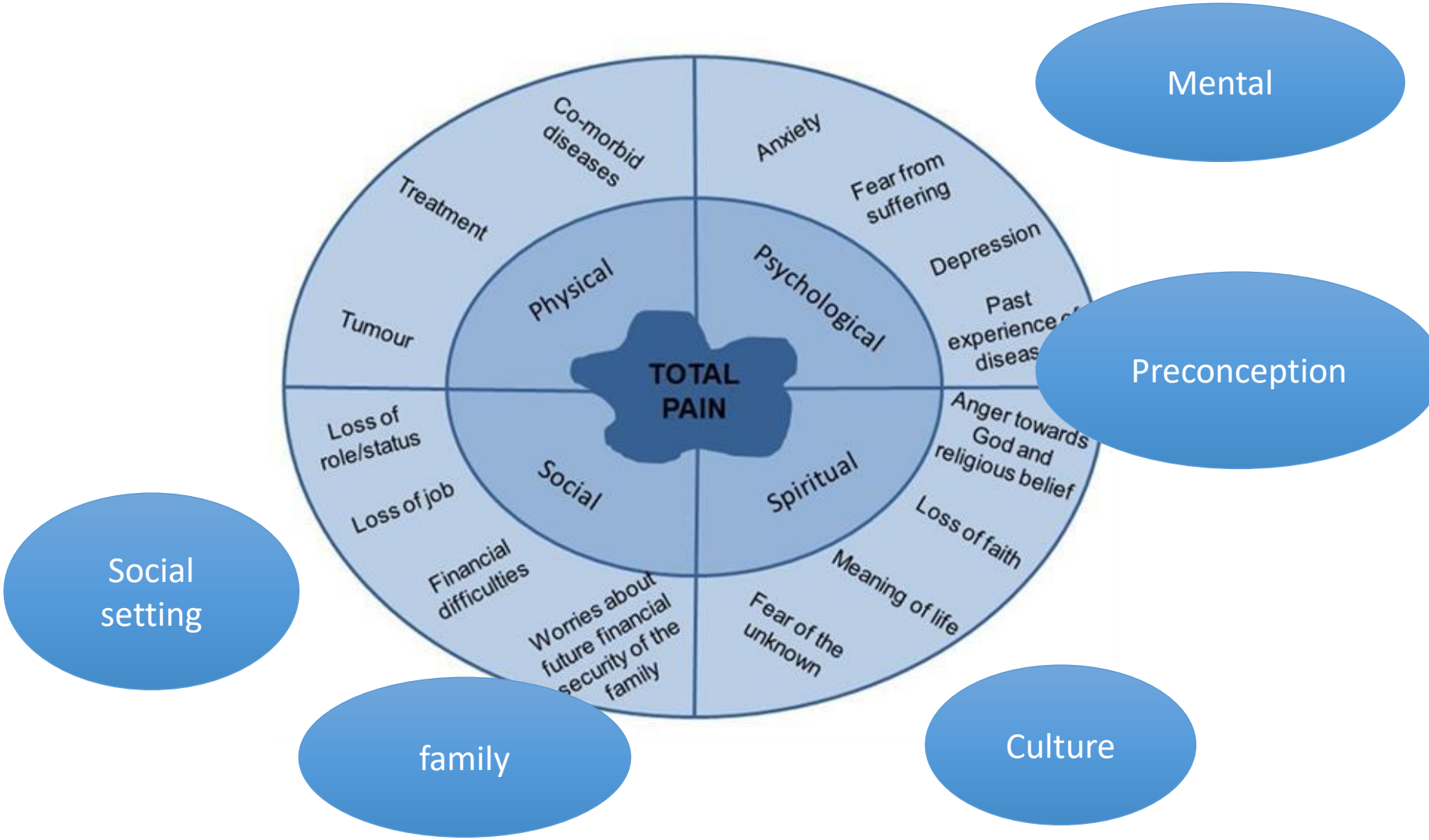
- Don't assume that the absence of question reflects an absence of concerns
- Upon becoming aware of a life-limiting Dx, it would be very unusual not to wonder:
  - "How long do I have?"
  - "How will I die"
- Waiting for such questions to be posed may result in missed opportunities to address concerns; consider exploring preemptively

The evidence

Professionals need to be prepared for such discussions.

- Different studies have shown that healthcare professionals could feel ill-equipped to deal with issues related to death and dying.
- Kuuppelomäki showed that the professionals' views of death and dying could mean that at times they are more afraid of death than the patients and their families.
- Several studies have produced examples that show that what the patients and their loved ones really want to have is information about the prognosis, the treatment of the disease and how to manage pain.
- They also want to be supported to sustain hope and maintain some degree of ambiguity about the future.

No man is an Island



Barriers to Effective communication

- Physical (environmental)
- Psychological (Personal)
- Social
- Spiritual

Physical

- No space
- No privacy
- Poor Environment
- Disability
- illness

Psychological

- Lack of Confidence
- Shyness
- Personal Trauma
- Discomfort
- Attitudes
- Preconceptions

?Social

- Time barriers
- Administration
- Staffing
- Semantics

Spiritual /Cultural

- Language
- Culture
- Beliefs

When Families Wish To Filter Or Block Information

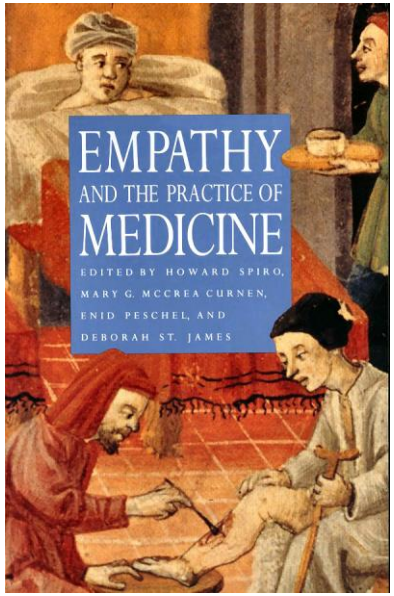
- Don't simply respond with "It's their right to know" and dive in.
- Rarely an emergent need to share information
- Explore reasons / concerns – the "micro-culture" of the family
- Perhaps negotiate an "in their time, in their manner" resolution
- Ultimately, may need to check with patient:

"Some people want to know everything they can about their illness, such as results, prognosis, what to expect. Others don't want to know very much at all, perhaps having their family more involved. How involved would you like to be regarding information and decisions about your illness?"

Connecting

- A foundational component of effective communication is to connect / engage with that person… i.e. try to understand what their experience might be
  - If you were in their position, how might you react or behave?
  - What might you be hoping for? Concerned about?

- This does not mean you try to take on that person's suffering as your own, or actually experience what they are going through, or pretend that you could even if you wanted to


EMPATHY
AND THE PRACTICE OF
MEDICINE
EDITED BY HOWARD SPIRO,
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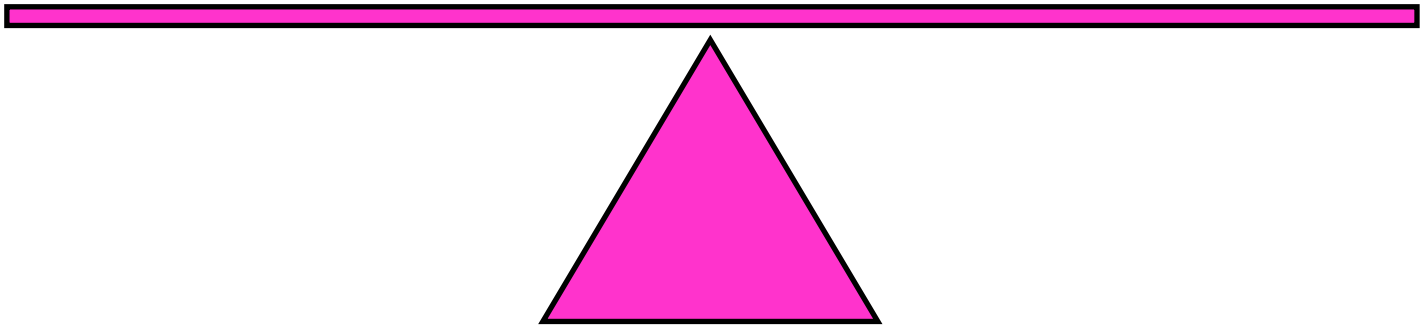
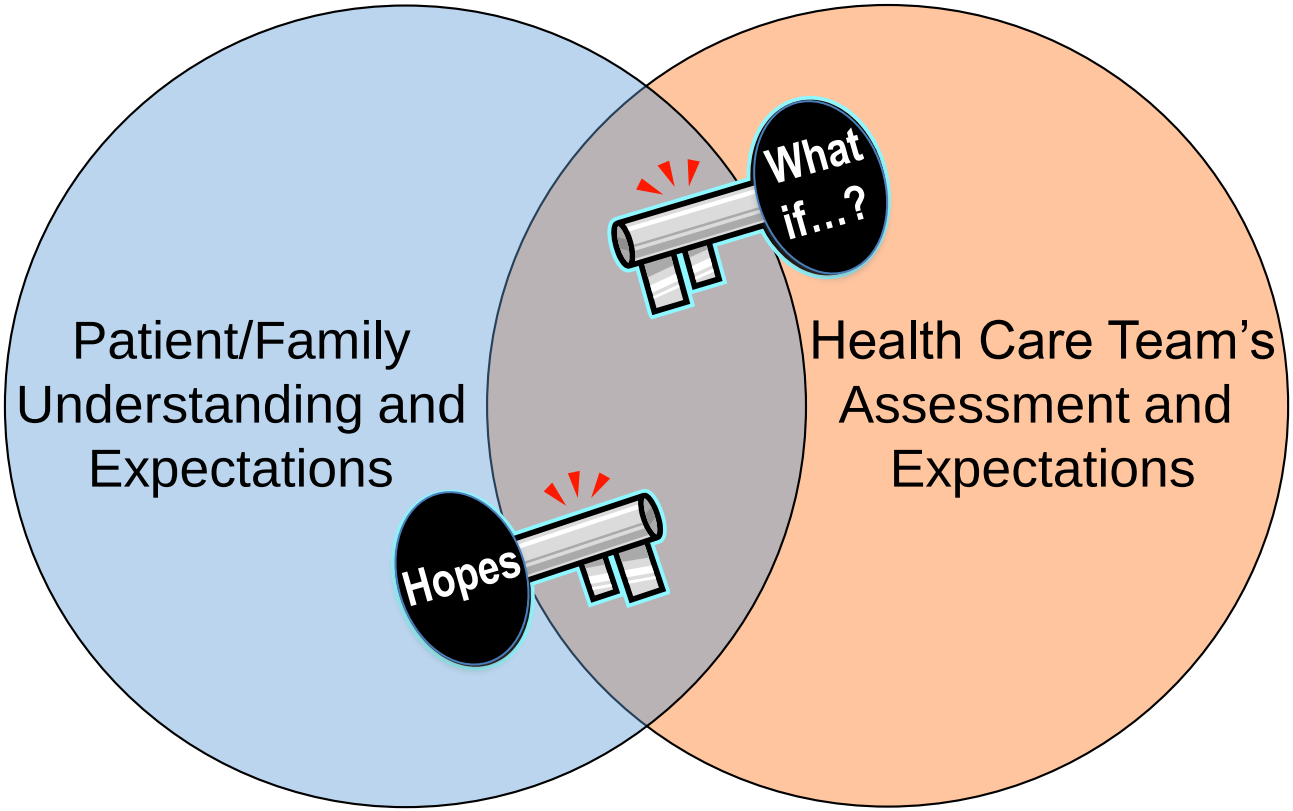
APATHY




Patient/Family Understanding and Expectations
Health Care Team's Assessment and Expectations
What if…?
Hopes

Active Listening ?

- Hearing
  - Receiving Auditory/ Sensory Input
  - Purely a receptive activity
  - Physiological

- Listening

  processing auditory /Sensory Input

  Meaning making activity

  cognitive

Barriers to listening

- Multitasking
- Perception
- Planning ahead
- Selective listening (focus on content and ignoring non verbal communication /complete message)
- Communicating in a stereotypical way

Listening well

- Listening well involves both the content of the information and the feeling being conveyed
  - Summarising
  - Paraphrasing
  - Empathetic response (reflecting feeling statements that verbally convey your understanding of the essence of the emotional meaning of another persons communication. Non verbal communication that show care and attention to the individual

So the practicalities

YOU NEED A SCHEME

- You might be thrown off-balance by a very direct and difficult question
  - How long have I got?
  - Am I dying?
  - Why can’t you just give me something to end everything right now?!
- Helps to have a framework to help you pause, regroup, rebalance… perhaps even guide the patient to answer the question

Responding To Difficult Questions

1. **Acknowledge/Validate and Normalize**

   "That's a very good question, and one that we should talk about. Many people in these circumstances wonder about that…"

2. **Is there a reason this has come up?**

   "I'm wondering if something has come up that prompted you to ask this?"

3. **Gently explore their thoughts/understanding**
   - *"Sometimes when people ask questions such as this, they have an idea in their mind about what the answer might be. Is that the case for you?"*
   - *"It would help me to have a feel for what your understanding is of your condition, and what you might expect"*

4. **Respond, if possible and appropriate**
   - If you feel unable to provide a satisfactory reply, then be honest about that and indicate how you will help them explore that

11 TIPS

1)Preparation

- Know all the relevant facts
- Who should be present ? Doctors, nurse, relative, carer. Let them choose
- Set time aside
- Privacy and set the scene

- who am I and why am I here ??

2) What does the patient know

- It would help for me to know what you understand about your illness
- What did the previous doctors/team tell you about your illness
- What sense have you made of your illness so far
- When did you first have symptoms and what did you think it might be due to .

- ASK BEFORE TELLING

3)Is more information wanted?

- STOP

- I have your results, would you like me to discuss them with you ?
- If this is serious are you the kind of person that would like to know everything?
- Would you like me to go on? (intervals)

- Do you want me to answer that ?

- GIVE THEM CONTROL

4) Give them a warning shot

- I am afraid it looks more serious then we had hoped
- I am afraid it is not good news……..would you like me to go on

- Stop

5) allow them to decline

- It must be difficult for you to talk about this today
- Contact details , provide a way in .

6) Explain (if requested)

- A short narrative
- Clear
- Unambiguous
- Reiterate
- Check
- Premature reassurance doesn’t reassure
- Silence
- Honesty

Be Clear

Make sure you're both talking about the same thing

There's a tendency to use euphemisms and vague terms in dealing with difficult matters… this can lead to confusion

UP

Being Clear

- How long do you think I have?
- Am I going to get better?

7) Elicit and listen to concerns

- These may be very different to our own
- I know this is bad news but is there anything particularly distressing you or on your mind

8) Encourage ventilation of feeling

- Relief
- Anger
- Upset

- Do not assume you will know the reaction

- How does this news make you feel ?
- I can see that this news has left you ..

9)Summary and plan

- Don’t forget this

- Your main concerns at the moment seem to be
- Have I left anything out ?
- Is there anything/something else?
- Do you have any questions right now?

10) Offer availability and support

- A clear appointment of opportunity (MDT)
- Remember they may recall limited information (but recall the way it was given) and need the chance to discuss or question .
- (it takes time to adjust to bad news)
- Support
  - We will work on this together
  - Key worker

11) Communicate with the team

- Everyone needs to know
- copy letter

- Picking up the pieces …for all

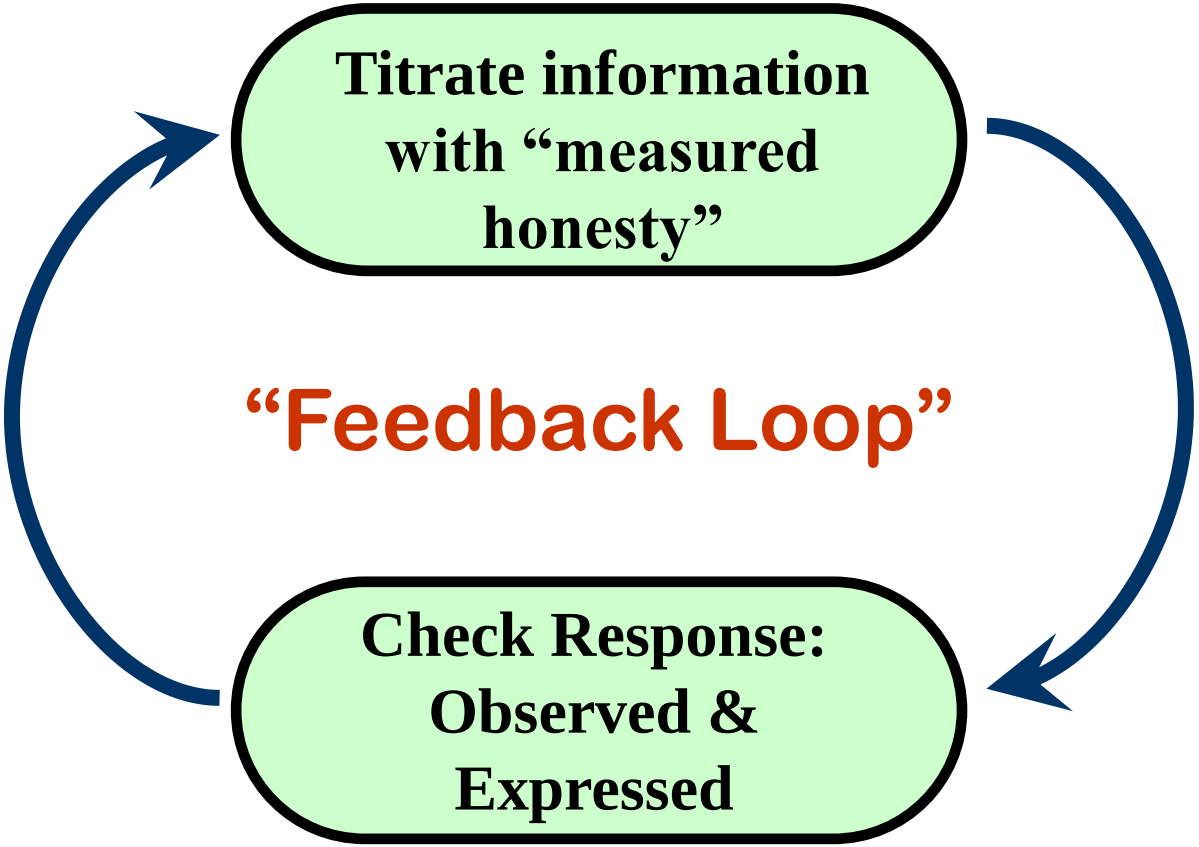
Preemptive Discussions

"You might be wondering…"

Or

"At some point soon you will likely wonder about…"

- Food / fluid intake
- Meds or illness to blame for being weaker / tired / sleepy /dying?



The response of the patient determines the nature & pace of the sharing of information

Summarizing, Debriefing

- Clarifications, further questions
- Are other supports wanted/needed (SW, Pastoral Care)
- Do they want help in discussing with relatives/friends?
- Next Steps

Specific Situations

DISCUSSING PROGNOSIS

"How long have I got?"

1. Confirm what is being asked
2. Acknowledge / validate / normalize
3. Explore "frame of reference" (the "Who"… understanding of illness, what they are aware of being told.
4. Check if there's a reason that this is has come up at this time
5. Tell them that it would be helpful to you in answering the question if they could describe how the last month or so has been for them
6. How would they answer that question themselves?
7. Answer the question

TALKING ABOUT DYING

"Many people think about what they might experience as things change, and they become closer to dying.

Have you thought about this regarding yourself?

Do you want me to talk about what changes are likely to happen?"

First, let's talk about what you should *not* expect.

You should *not* expect:

- pain that can't be controlled.
- breathing troubles that can't be controlled.
- "going crazy" or "losing your mind"

If any of those problems come up, I will make sure that you're comfortable and calm, even if it means that with the medications that we use you'll be sleeping most of the time, or possibly all of the time.

Do you understand that?
Is that approach OK with you?

You’ll find that your energy will be less, as you’ve likely noticed in the last while.

You’ll want to spend more of the day resting, and there will be a point where you’ll be resting (sleeping) most or all of the day.

Gradually your body systems will shut down, and at the end your heart will stop while you are sleeping.

No dramatic crisis of pain, breathing, agitation, or confusion will occur -

we won't let that happen.

Approach To Decision Making

An Approach to Decision-Making in Palliative Care

- It helps to have a fundamental approach to guide decisions in palliative/end-of-life care
- A similar approach is used for virtually all clinical decisions

Interventions You Will Recommend Or Do If Asked

Interventions You Will Not Agree To… "Cross The Line"

- How well do you know your "inner line?"
- Are you aware that it's there, or will it surprise you and everyone else during discussion of care options?
- What is its basis… personal feelings, religious beliefs, medical opinion?
- How informed is it? Literature, knowledge of resource availability, practice guidelines and policy statements…
- Do you need an "inner line consultant"?
- Can you articulate it, explain it, perhaps debate it, in a manner that is accessible to patients and families?

Decision Points

- Decisions are “forks in the road”… as health care providers we help inform the decision
- Explore goals and expectations of care, and whether these might be possibly achieved
- Present possible options, and discuss how things might unfold if specific options are taken

Pitfalls

- Futility - the “F” word
- The Illusion of Choice
- The Unbearable Choice

Palliative Care… The "What If…?" Tour Guides

Can Help Inform The Choice Of Not Intervening

- What would things look like?
- Time frame?
- Where care might take place
- What should the patient/family expect (perhaps demand?) regarding care?
- How might the palliative care team help patient, family, health care team?

The Illusion of Choice

- Patients / families sometimes asked to make terribly difficult decisions about non-options
  - i.e. there will be the same outcome regardless of which option is chosen.

CPR
Chemo
No CPR
No Chemo

CPR
Chemo
No CPR
No Chemo

The Unbearable Choice

- Usually in substituted judgment scenarios
- “Misplaced” burden of decision
- E.g.:
  - Person imminently dying from pneumonia complicating CA lung; unresponsive
  - Family may be presented with option of trying to treat… which they are told will prolong suffering… or letting nature take its course, in which case he will soon die

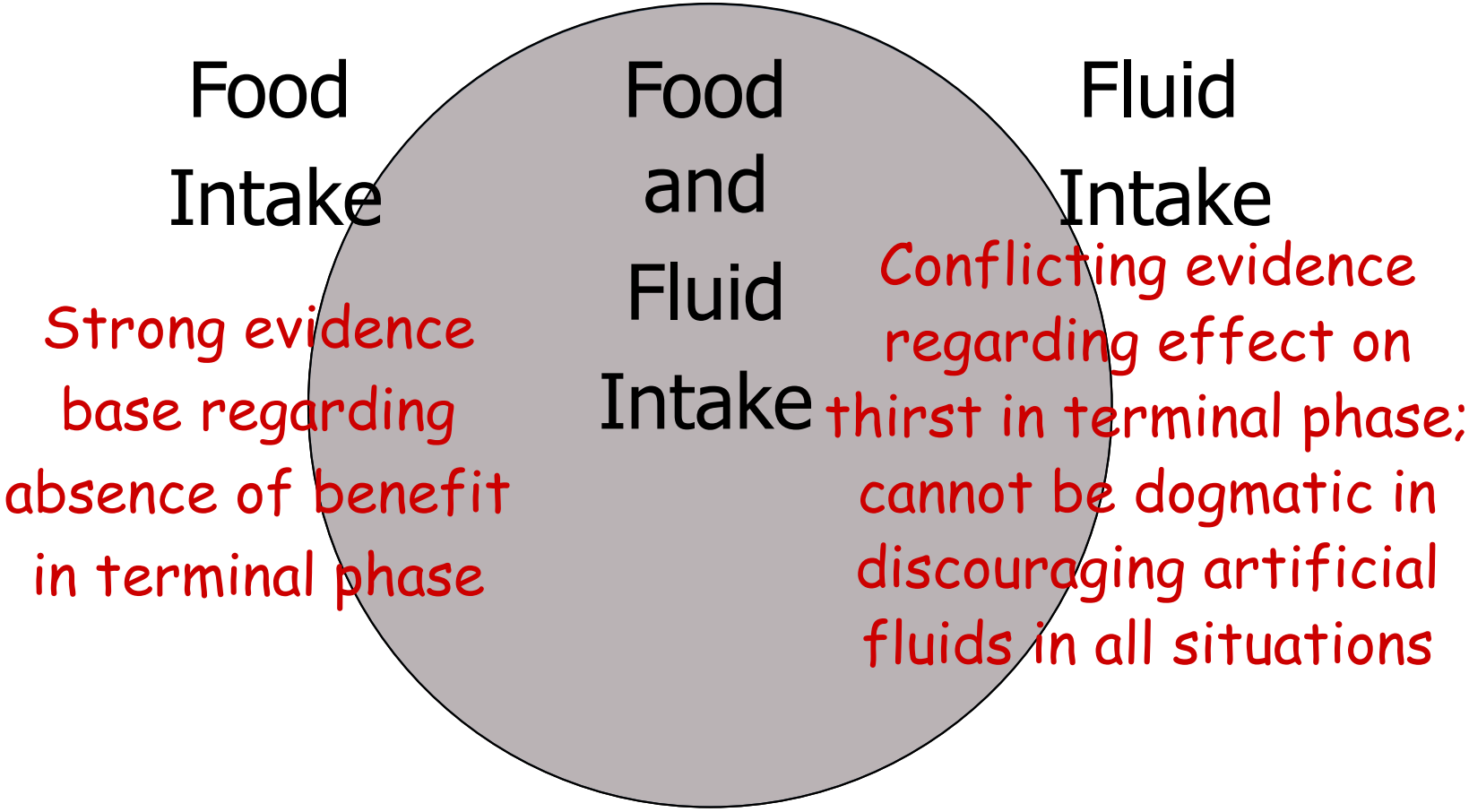
PHRASING REQUEST: SUBSTITUTED JUDGMENT

"If he could come to the bedside as healthy as he was a year ago, and look at the situation for himself now, what would he tell us to do?"

Or

"If you had in your pocket a note from him telling you that to do under these circumstances, what would it say?"

Consider Concerns About Food And Fluids Separately



A Proposed Approach….

Intervention Considered or Proposed

Discuss hoped-for goals - whose goals they are, and if they are achievable

Can the goals possibly be achieved?

Yes, or at least perhaps

Go ahead, or…

Consider a trial, with:

- predefined goals reassessed at a specified time
- plan for care if the goals are not met

Impossible

- **Discuss; explain the intervention will not be offered or attempted.**
- **If needed, provide a process for conflict resolution :**
  - **Mediated discussion**
  - **2nd medical opinion**
  - **Ethics consultation**
  - **Transfer of care to a setting/providers willing to pursue the intervention**