

The image features two solid black silhouettes of human heads in profile, facing each other. The silhouettes are positioned on the left and right sides of the frame, with their mouths slightly open as if in conversation. The background is plain white. Centered between the two silhouettes is the text 'COMMUNICATION ISSUES IN PALLIATIVE CARE' in a bold, blue, sans-serif font. The text is arranged in four lines: 'COMMUNICATION' and 'ISSUES' on the top line, 'IN' on the second line, and 'PALLIATIVE CARE' on the bottom line.

**COMMUNICATION
ISSUES**

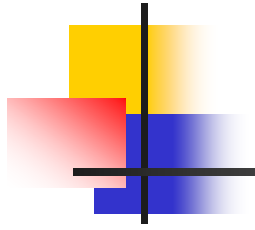
IN

PALLIATIVE CARE





*Location,
Location,
Location!*



Palliative Care:

Communication,

Communication,

Communication!



Key Features of Communication in Palliative Care

- Appropriate setting
- Permission
- Be clear about topic and messages
- Acknowledge / Validate / Normalize
- Explore current understanding of illness
- Anticipate concerns – Preemptive
- Skillful titration of information
- Listen and watch for cues
- “Check points” – do they understand?
- The Aftermath – follow-up, letting others know, where to go from here



“Set the Stage”

- In person
- Sitting down
- Minimize distractions
- Family / friend possibly present



Seek Permission

- “Many people experiencing such circumstances wonder about / are concerned about ...*[fill in blank]*.
Would you like to talk about that?”
- “Are you comfortable discussing these issues?”



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?"



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



Being Clear

When you think people are asking about prognosis...

- "How long do you think I have?"
- "What kind of time frame am I looking at?"

... they might well be asking about discharge

"Do you mean how long do you have stay in hospital, or are you wondering about how long you might have to live"?



Being Clear *ctd*

“Am I going to get better?”

- Seems like a straightforward question, but...
- Might be referring to specific symptoms, or to overall illness (“big picture”)



Acknowledge / Validate / Normalize

- This is a biggie!
- People can spend an entire lifetime without hearing others talk about dying... their worries, fears
- End up feeling as if they are cowards for their concern – alone in being worried about dying



Explore “Frame of Reference”

What is the context / frame of reference into which this information is being received ?

- Understanding of illness
- Expectations / hopes / goals
- Concerns / worries / fears
- Cultural / Spiritual factors that may influence individual's approach to illness / dying / communication
 - ❖ “Micro” (family) vs. “Macro” cultures



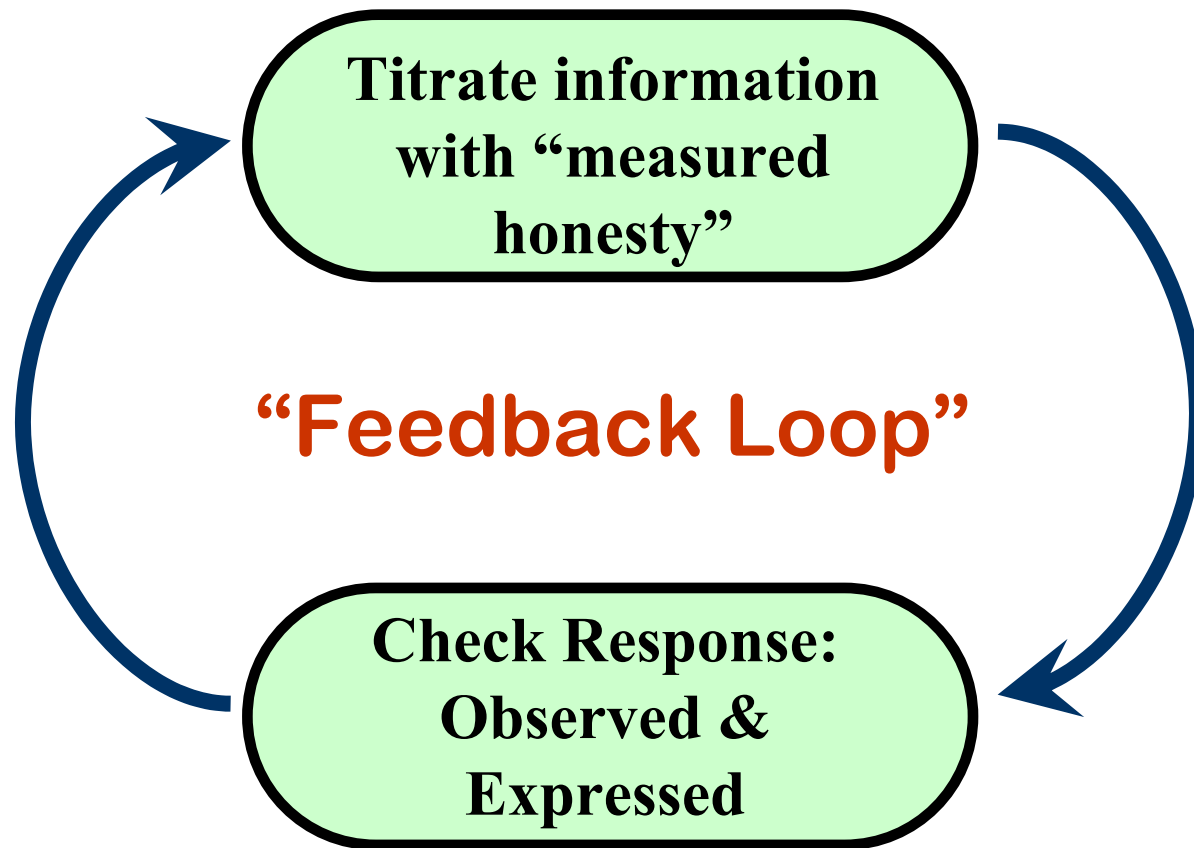
Preemptive Discussions With Family

"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?



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



Debriefing

- Clarifications, further questions
- Are other supports wanted/needed (SW, Pastoral Care)
- Do they want help in discussing with relatives/friends?
- Plans for follow-up
- Do they want you to call someone to pick them up?



DISCUSSING PROGNOSIS

“How long have I got?”

1. Confirm what is being asked
2. Acknowledge / validate / normalize
3. Explore “frame of reference” ... 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



Prognostic Awareness in the Terminally Ill

*Chochinov HM, Tataryn DJ, Wilson KG, Ennis M, Lander S.
Prognostic awareness and the terminally ill.
Psychosomatics 2000;41:500-04.*

- N = 200 mean age = 71.0 yrs
- Degree of prognostic awareness: None: 9.5% Partial: 17% Complete: 73.5%
- clinical depression associated with prognostic denial; 3X higher incidence of depression in those who did not acknowledge their prognosis
- no signif. association between prognostic awareness & survival time
- lack of association between prognostic awareness & hopelessness
- men more likely to have limited prognostic awareness
- ? intense family contact associated with less prognostic awareness



UNREALISTIC EXPECTATIONS

- E.g.:**
- "I'm going to beat this thing"
 - "I'm so much looking forward to..."

- Acknowledge / validate:

"That's something really nice to hope for."

- Consider a "warning shot"

"I'm concerned that things are changing with your strength because of your illness, and this may not be possible."

- "Hope for the best, plan for the worst"

"Why don't we set some short-term goals to aim for as well, and see how things go?"



**“Why Can’t You Just Give Me Something
Just Get This Over With Right Now?”**

UNHELPFUL RESPONSE:

“I can’t do that - it’s against the law”

While accurate, this shuts down further dialogue, such as exploration of the reason for these sentiments



A MORE HELPFUL APPROACH

- **pause**
- **sit down**
- **touch**

“It must be so difficult for you to have things reach the point that you’d rather not be alive. Why do you feel this way?”



Explore concerns that have led to the desire for death.

- loss of control over life in general
- being a burden
- anticipation of:
 - ❖ *severe pain*
 - ❖ *choking to death*
 - ❖ *losing mental faculties*
 - ❖ *loss of dignity*
 - ❖ *loss of meaning / purpose*



ADDRESSING DESIRE FOR EARLY DEATH

❖ *Give control back to patient*

- information, knowledge about illness - expected changes
- education about medications, opioid use
- Health Care Directives

❖ *Involve support networks*

- spiritual support: Church, Pastoral Care
- emotional support: Counseling, support groups
- cultural support

❖ *Is there a treatable depression?*

❖ *Is there a significant risk of suicide?*



Close Calls

- After a resolved pain / dyspnea crisis
- People experiencing such bad symptoms often believe that they are dying
- While they may be glad that you've made them feel better...

... if that wasn't dying... and it was the worst experience that I could possibly imagine... what will dying be like?



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.



OBTAINING SUBSTITUTED JUDGMENT

- Avoid making families feel as though they are making a choice, when the illness has dictated that no choice exists
- Ideally, phrase the discussion in terms of their thoughts on what the patient would want
- Avoid presenting the “letting die” vs. “prolonging suffering” choice to families.



C'mon, C'mon - it's one or the other



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?”

Just One More Day...



Extending the final days in terminal illness:
Prolonging life or prolonging the dying phase?

Consider the rationale of trying to prolong life by
adding time to the period of dying



“You wouldn't let a dog suffer this way”

- Try to help them see whose suffering they are describing... often it's their own, not the patient's
- That family's suffering is still very relevant... but should be addressed in ways other than contemplating speeding up the death of their loved one



PERCEIVED SUDDEN CHANGE

- “He was fine a week ago...he’s changed so fast!”
- “She was fine until I brought her in...”

- ❖ did things *really* change suddenly?
- ❖ changes *had* begun, necessitating admission
(If things were going so well, why come in?)
- ❖ diminishing reserves → accelerated decline



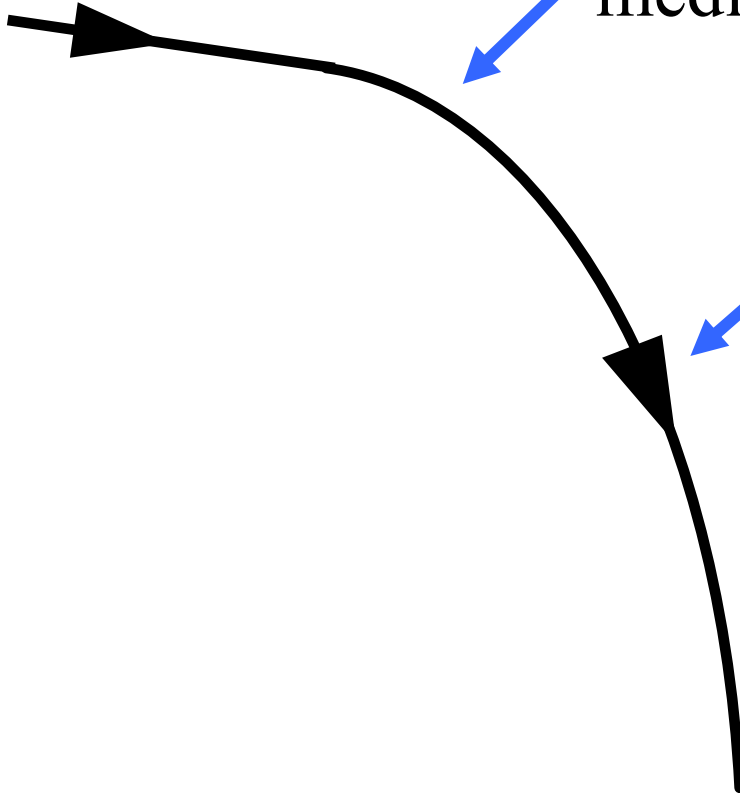
Which Came First.... The Med Changes or the Decline?

Steady decline

Accelerated deterioration begins,
medications changed

Rapid decline due to
illness progression with
diminished reserves.

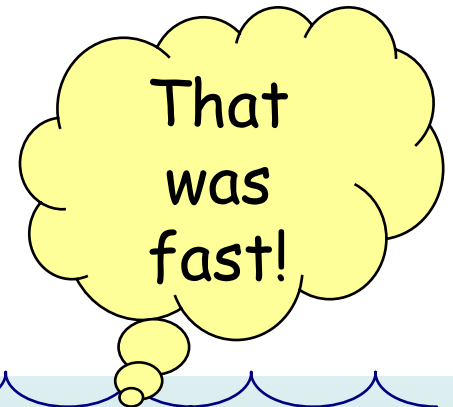
Medications questioned
or blamed



The Perception of the "Sudden Change"

When reserves are depleted, the change seems sudden and unforeseen.

However, the changes *had* been happening.



Melting ice = diminishing reserves

Day 1

Day 2

Day 3

Final



Can They Hear Us?

- Hearing is a well-supported sense
- Hearing vs. Awareness of Presence
- If the working premise is that they can hear, then bedside communication should reflect that
- Encourage ongoing communication with unresponsive patient
- Some visitors may wish for private time

“What about an IV
a feeding tube
a transfusion
antibiotics?”
surgery
physiotherapy
resuscitation
etc..

This Is Not The Correct Response!



Approaching Decisions

Treatment Considered:
Are Goals Achievable?

Possible

Review:

- hopes and goals of treatment
- expected course with and without
- potential burdens and benefits

Impossible

Discuss, but do not present as an option only to be withdrawn as such when asked for...

Rather, explain why this will not be pursued / attempted

Eg: "You might be wondering why we can't just..."

Benefits

Positive Effects

Burdens

Side Effects

