

PReP 8.2 - Palliative Care

Lesson 3 - Struggling at Home

Judy:

Friends telling me what to do... Doctors telling me what to do... It's the last thing I need.

I'm so tired of fighting this thing. I just want to be with them. Talk. Listen to music. I want to tell them things - things I never said.

Amy:

Do you think you can tell this to Nancy and Pat?

Judy:

Pat, maybe. Nancy - I don't know. I'm afraid I'll hurt her. I know how much she cares. I'm just afraid I'll say the wrong thing.

Amy:

Would you like me to be there and bring the subject up? I'm sure you'll be able to speak your mind once the conversation gets started.

Judy:

Would you?

I think I'd feel better if you were here.

Host:

"Be brave enough to start a conversation that matters." Dau Voire

Amy:

Judy, the day program at the hospice has meditation, yoga, music therapy - other things you might like.

Judy:

No, Amy. I want to move into hospice permanently. I'm so tired

Nancy:

But you said you'd NEVER want to move to hospice.

Aren't we doing enough? What's wrong? Why? We said that we would care for you no matter what.

Judy:

I know, but things are changing. I've changed my mind. I can't do it.

Amy:

Nancy, Judy knows you're here for her. I think she's just worried that if something tough happens it would be too hard on both of you. She's really grateful for everything you and Pat have done for her.

Judy:

I want to be somewhere safe where there's a nurse at the end of a call bell.

Nancy:

Maybe you're just feeling bad today. Maybe tomorrow you'll change your mind.

Pat:

Can you hear what she's trying to tell us Nancy?

Nancy:

Yeah, I hear what she's saying! She's saying she doesn't want our help. Judy - I love you. I don't want you to go.

Amy:

She wants you here with her. What if we give her a chance to share her thoughts? I know how hard this is on all of you. Judy, what are you thinking?

Judy:

You guys are the best. You've done so much for me. You - you organized my papers; you organized my meds so I don't forget. You've kept my place shiny and clean... Taken me on magical outings. You've done so much, and I love you for it. And I wouldn't have missed any of this for the world.

But things are changing. I'm so tired. The apartment doesn't matter to me anymore. I just want to be somewhere simple and safe.

Pat: If it's what you want, we'll make it happen.

Host:

It's OK to change our minds. The key is to remain as 'fluid' as possible to the needs of the patient. Sometimes the patient will reverse their initial plans and confuse those supporting them. Accepting a patient's varied choices without judgment provides a sense of unconditional support for them. This does not mean that the palliative team and family members should never make suggestions, but they must be presented tactfully – explained clearly and should, whenever possible, be flexible enough to incorporate the patient's wishes. The trajectory of the palliative process twists and turns as certain things matter more and others diminish in importance as the patient nears death.

Judy:

And you're both so busy, all the time - helping me. So don't get to be with you.

I get lonely. It would just be nice to talk things through. I get scared.

Nancy:

I'm so sorry Judy. I didn't know you were feeling this way.

Pat:

How do we go about doing this?

Amy:

We can start the process today. Why don't I explain a little bit more about hospice, so that you know a little bit more, and maybe we can understand why Judy has made this decision.

Host:

As Rose Kennedy said, "Life isn't a matter of milestones, but a matter of shared moments."

Some patients and families begin the emotional journey as soon as they hear that the diagnosis is terminal. They fear death is imminent - their focus is on dying. Others approach the news with a steely determination that they will beat the prognosis- thus their focus is on living.

Each person reacts differently to a terminal prognosis, and emotions fluctuate, from denial, anxiety, fear and grief, back to denial. The patient's emotions are rarely, if ever, in sync with the emotions of their family and

friends at any given time. This disconnect between loved ones can lead to stress; a sense of not being loved and supported by those they trust; loneliness; and a reluctance to share their fears. Of course, these negative emotions have a huge impact on the wellbeing of the patient, adding to their sense of panic or anxiety.