

## **Palliative Care: Communication and the Patient Experience**

### **Effective Listening and Support**

Rachel:

I can't do anything that I used to do; and I just sit here and I'm just waiting - waiting and listening to what's going on with my body. It's different; I can't get up; I can't, you know - nothing's working - but my brain is working. My brain is working overtime.

Sharon:

You're just engulfed in grief. Rachel, you're engulfed in grief. Mourning the loss of your life.

Rachel:

I don't -

Sharon:

The losses to come.

Rachel:

That's right. Yeah. To come.

Sharon:

It's painful. So painful.

Rachel:

I can't - I can't - I hate my life but I can't - I don't want to let go either. You know, how do people do it. How do people do it. How do they - how do they just say "I'm dying, and I love"

Sharon:

And is that how you do most things? You just accept them - this is how it is? I don't think that's you, Rachel. You rage and you fight.

Rachel:

I don't want to go.

Sharon:

No.

Rachel:  
I'm not ready to go.

Sharon:  
No.

Rachel:  
I'm not.

Sharon:  
No.

Rachel:  
It's not fair.

Sharon:  
It's not fair.

Rachel:  
It's just -  
I don't - I don't even - I don't know how to be alone with my thoughts.

Sharon:  
This is your challenge, right now, Rachel. This is - this is your challenge right now. How do you reinvent yourself right now. How do you pull forth who you really are. Who you've always been. Yes, you're in the midst of all this grief.

Rachel:  
I don't know who I am.

Sharon:  
Oh, I think you do, though.  
You still have that strength. You have the strength to rail against what's happening to you. You have the strength to express your grief.

Rachel:  
I don't feel like I do.  
I feel so weak.  
I'm sorry.

Sharon:  
You don't need to apologize. This is a battle you're having with yourself.

Rachel:

It's a battle I'm having with myself - that's right.

Sharon:

A battle you're having with yourself, yeah. But only you can determine the outcome. Only you can determine how you're going to manage this journey.

Rachel:

How. How do you do it?

Sharon:

No; how do YOU do it? How does Rachel do it?

Rachel:

How do I do it?

Sharon:

How does Rachel do it?

Your way is not going to be like anyone else's. It's going to be your way. Just as you've had - you've expressed your way in so many other aspects of your life.

You're the teacher now, Rachel. You're going to teach the rest of us how it's done.

Rachel:

Oh boy.

Sharon:

You're going to find that courage. You have that courage. You're just going to bring it forward; you're just going to re-frame it.

Rachel:

Really?

Host:

After watching this, would you say that Sharon was warm, empathic, and truthful? What did you observe? How do you imagine the patient felt during their conversation? It is not always what you say but how you say it that impacts how information is received by a patient. Studies show the effectiveness of communication is split. Words are 7% effective. Tone is 38% effective. Body language is 55% effective. Paying attention to small things

can demonstrate warmth: "Is the sun in your eyes? Shall I draw the blind?" To a patient in palliative care, experiencing warmth from others is extremely important.

In palliative care we often deal with difficult situations. It is easy to hide behind a uniform or our role. We forget sometimes that it is alright to say "I don't know". It is not a sign of failure, but a truthful response. As long as it is accompanied by an attempt to find out, or address the patient's needs, not knowing is human. Being genuine builds trust. You do not have to be demonstrative in order to show warmth. Warmth is shown by being attentive to a patient's needs, respecting their values, showing your concern for their wellbeing.

*Voiceover:*

*"I hate the word 'terminal'. It makes me feel like I'm waiting to take a bus on the final journey. I wish they'd use the word 'dying' instead of terminal or incurable. It's as if dying is a dirty word."*

*Host:*

To improve end of life care, death and dying needs to be brought out from the shadow of superstition and fear, and discussed in the light of support and understanding. Good communication should be at the heart of all patient-centred care. "Communicate well and you will always be remembered... communicate poorly and you will never be forgotten."