

Talking with Loved Ones about Neuropathy Hands Feet & Heart – Austin West Group Meeting

"Talk Neuropathy" Interview with Rev. Mother Dolores Hart, O.S.B.

Q. What can we do to make our family and friends aware of how we suffer with peripheral neuropathy? They think we make the symptoms up or exaggerate. And the most cutting remark, "You look so good, you must be feeling better," hurts so much.

Mother Dolores: Forget trying to make your family and your friends aware of how you suffer; it's a lost cause because they are suffering something too. Suffering is a personal problem; as soon as we get that spiritual reality into our head, suffering becomes our own way through to redemption; redemption is our process to find our spirituality; this is how we are working it out our own way, nobody else is going to understand it. If we have some real need to get through something, we can ask for help, but don't ask for pity or sensitivity because they won't understand our path. We have to get over the need for somebody else to pick up our cross; Jesus didn't ask anyone else to pick up his cross; Simon did it because he wanted to. I don't mean to say this in a glib way, I say this as a fellow sufferer: I've been there, I've done it...don't do it, it just doesn't work.

Taken from <http://www.neuropathy.org/site/News2?id=8061>

Tips for the talk

Before talking, know what you need to say

Know how much you want to share

Find a good resource to recommend

Know your sensitive spots

Tell others what you need from them

Have a practice partner

Handle unhelpful responses

Avoid self reliance when help is needed

Relational Needs

Acceptance – receiving another person willingly and unconditionally; being willing to love another in spite of offenses

Looks like: *someone likes you even though you are not perfect; the welcome mat is always out; you are loved even if you blow it badly.*

Sounds like: *I love you even if you don't change! I'm glad I know you even when you mess up.*

Affection – expressing care and closeness through non-sexual physical touch and verbalized love

Looks like: *hugs, kisses, pats on the back*

Sounds like: *I love you.*

Appreciation – expressing thanks or praise; recognizing someone's accomplishments or efforts

Looks like: *certificates, notes, rewards for effort as well as accomplishment*

Sounds like: *You did a great job! Thank you for your thoughtfulness. I appreciate your diligence. I know you are working on that.*

Approval – building up or affirming another; affirming positive character qualities (liking or loving someone for who he/she is)

Looks like: *Pictures/videos are taken of you at events. You are "bragged on" to others.*

Sounds like: *I'm proud of you! You are a gift from God to us. I am glad I get to know you. I love you for you.*

Attention – conveying appropriate interest, concern, and care; taking thought of another and entering his/her world

Looks like: *Attending your event. Doing what you like to do. Individual, undivided listening. Cooking your favorite meal. Time just with you.*

Sounds like: *Tell me about your day. How did your day go? How about if we hang out together now? What do you want to do?*

Comfort – responding to a hurting person with appropriate words, feelings, and touch; feeling and expressing sadness for another's pain

Looks like: *Putting an arm around you when you're sad. Sitting quietly and just "being there." Crying with you.*

Sounds like: *I'm sad for you. I'm so sorry that you are going through this. I know it really hurts when...*

Encouragement – urging another to persist and persevere toward a goal

Looks like: *A phone call on your "big day." A note expressing belief in you, that you can do it.*

Sounds like: *I know you can do it. Don't give up, keep at it. I believe in you!*

Respect – to value and regard highly; treating someone with importance

Looks like: *Asking you before taking something that belongs to you. Returning what was borrowed from you. Listening without interrupting. Checking with you before making plans that affect you. Appropriate tone of voice. Confessing wrong to you.*

Sounds like: *I'd like to hear your ideas. What do you prefer? I was wrong...will you forgive me?*

Security – confident of harmony in relationships; free from fear of harm

Looks like: *Not threatening to leave you. Not harming you in any way. Setting appropriate limits and reasonably enforcing them. Providing for needs. Not losing temper at you. Being dependable*

Sounds like: *I'm here for you. We're going to work this out. I'm going to keep my promise to you.*

Support – coming alongside and gently help carry a load

Looks like: *Helping you with a big task. Teaching you how. Doing hard things together.*

Sounds like: *I'll be glad to help you. Just let me know. Do you need some help?*