

FINAL EXIT NETWORK

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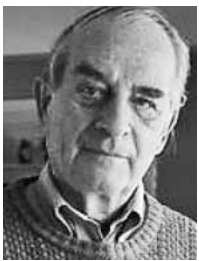
VOL 7 NO 5

SPECIAL EDITION NO 2 • 2010

SUPPORTING THE HUMAN RIGHT TO A DEATH WITH DIGNITY

HAVING THAT DIFFICULT TALK WITH YOUR ADULT CHILDREN

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Discussing death with children can be traumatic, and many people postpone it forever. Yet death comes, inescapably, leaving both parents and kids to deal with it eventually. Early dialogues are essential, revealing our conceptions, fears and worries, and theirs too. Talk is not a panacea,

but its absence can create tragic misunderstandings and difficulties for everyone. What we say, when and how, depend on our relationship with them, their ages, communication skills, degree of maturity and experiences, and our own.

Rosalie Guttman and I do a monthly radio show on Chicago Access TV. A common topic with parents is death and options concerning it, as well as the difficulty their offspring have in breaking the ice. Those expressed needs inspired this article. We urge you to remember that there is no one-size-fits-all formula.

THE HOMEWORK:

Prerequisite to any discussion is self-awareness by the parents concerning which medical procedures you will accept and which you will not. What is your personal threshold concerning suffering? These particular decisions you make, not your children. You bring your conclusions to the conversation, documented in writing in your Advance Directives, (ADs) which include, at the least, options for end-of-life care, desires about nursing homes, Hospice, ventilation, pain relief, hastened death, your criteria for quality of life, etc. With you thus prepared, the conversation can begin.

THE PRESENTATION:

Possible Icebreakers: Mail the ADs and say, "Look these over and digest them.Consider these decisions a given. We'll talk." Or, mail an article on hastened death to the children and spouses with a note: "This is required reading! Not optional. Then we'll discuss it." Or, have literature handy as a catalyst for communication. Or, if your kids already know your involvement with FEN, ask if they understand how deep and personal your interest is, and what decisions you have made concerning your own demise. Or, watch a movie together, like The Sea Inside, The Barbarian Invasions, Wit, or Bill Moyers' 4-DVD series, On Our Own terms.

NO-NO'S:

Do not ask their opinion nor their advice. Your decisions are not subject to discussion. This is your life, Parent, and your choice how to end it. Asking "Is this a good idea?" may bring you an answer you don't want to hear, or a brush-off like "Oh, you'll live forever, Mom," or, "Let's not talk about it." (You are interested in their feelings: fear, sadness, etc., but none with strings attached.) Do not wait till you're sick to broach the subject. Don't whine. Don't talk about being a burden or costing too much money. (Such statements invite obligatory reassurance by your children.)

SUGGESTED DO'S:

Advise loved ones in advance which quality-of-life issues are crucial to you. Discuss "good deaths" and "bad deaths," using as examples people they knew. Express your wishes as a manifestation of your love

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for them. Later in the dialogue, explain the method you expect to use when the time comes. Declaring your wishes to your children and eliciting their promise to respect them are crucial.

SUGGESTIONS FOR ADULT CHILDREN WHO INITIATE THE DIALOGUE:

Ideally, the children have prepared their own ADs and share them with the parents, ostensibly as an opener in getting their own needs agreed to. Then they reverse them: "We also want to honor your wishes exactly, as you get older, and we need to know exactly what they are, so that we are prepared. For example, what quality of life will you accept? Do you want to eke out every last moment, or do you have limits? (Parents appreciate being asked these questions; they know they will have control over the details of their dying.) Hospice may be mentioned by either party as a means of support in the final stages of life.

After a stated, unqualified commitment to the parents' well-being as Mom and Dad define it, the children might suggest that there are options for ending one's life quickly and painlessly if the parent so wishes. That information becomes even more crucial when a parent is already very ill.

THE ROLE OF DR. DOE:

Don't count on him (or her). A recent New York Times article, carefully and responsibly researched, stated that doctors rarely raise the subject of dying, especially older doctors and specialists. Most of the doctors said they would rather wait until they had exhausted all possible (!) treatments. New York State just passed a new law mandating that doctors speak to patients about options at the end of life. (Mandate, schmandate. Don't hold your breath!) No other state has such a law. So the likelihood is that maybe your doctor will bring it up only when you're too sick to exercise any options previously available to you.

Yet without such a dialogue, most of us will die the way we most dread: tethered to machines and surrounded by strangers in a hospital, terrified. Therefore, we have to assert ourselves with our doctors and insist on what we do or don't want. Passivity, timidity, and blind faith in our doctors' decisions will ill serve us under these circumstances. We- and our families- need to be tigers! Remember: Be clear and specific with everyone with whom you discuss the process of your dying. Insist that your desires be respected even by those who disagree with them. Talk about your religious and spiritual beliefs as they impact (or don't impact) the dialogue.

This is a time for all involved to open the closets and let the truth out, sharing the hidden concerns, speaking the unspoken.

REALITY TIME HAS COME.

Your sharing too, dear readers, is welcome to us.
Jerry Dincin, Ph.D.

Our thanks to several wise people whose contributions helped us: Dick MacDonald, Lester Hunt, Rosalie Guttman, Ruth von Fuchs, Wendell Stephenson, Fran Schindler, Sidney Wanzer ("To Die Well") and Jane Brody ("Guide to the Great Beyond").

