

The Liddy Shriver Sarcoma Initiative

The Liddy Shriver Sarcoma Initiative — helping those dealing with sarcoma.

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End of Life Care

End of Life Care: Some Resources to Consider

Within a few hours after we had received the pathologist's report stating that our daughter, Liddy, had Ewing's/PNET soft tissue sarcoma, she and I were doing some initial research on the disease on the Internet. I found a dozen or so papers for us to read. I remember only too well that Liddy and I were quietly reading one of the papers together when we encountered the frightening statistic that 85% of the adults who are diagnosed with this disease die within 2-years of their diagnosis. We looked at one another and although no words were spoken, we knew from the very beginning that it was going to be a tough battle to beat these odds. Yet, she faced this disease with courage even when the many disappointing rounds of chemotherapy mounted up, even when the results of the various clinical trial she tried results were disappointing, and even when the disease metastasized to her lungs and then to her brain and then to her abdominal region. She maintained her poise, her humor, and her zest for life. She used her passion for biking and the bike tours she went on as a source of personal strength and, in doing so, inspired others.

It was not until Liddy's oncologist told us after her craniotomy that we "Should think in terms of months and not years", that I attempted to locate some websites and books that help those dealing with dying and death. Hope for a cure was always getting in my way to undertake such a search. But, given only months were left, I began searching with a very heavy heart. I hoped to locate a book or any other material for our immediate family—for Bev and me, for Liddy's three brothers and their wives, and for Liddy and her husband, Tom—to read. I thought this would put us on some "common ground" to help all of us understand what she and we would be going through in the months ahead. I looked at over a dozen or more books before finding one that I recommended that we read. It was "Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying" by Maggie Callanan and Patricia Kelley. It is difficult not to be moved by the many stories these two dedicated hospice nurses recount from their many experiences with tending to the terminally ill. I found the book both comforting and useful in many ways and I believe that each of us benefited from reading it.

When it came down to the last six weeks of Liddy's life, Tom, Bev and I were given a very special gift because she was in hospice care in our home. It was the gift of being with her during this time—to care for her, comfort her, stroke her, read to her, talk with her and at times "be her voice", to help her with her beading and other projects, play the music that calmed her and made her less anxious, give her ice chips for her dry mouth and her dry lips, kiss her, and to tell her how much she was loved and admired. So many people are not given the gift of being with their loved ones as they take their last steps on their final journey. We were blessed in this way. And, as Liddy slipped away, we sensed that she knew we were there, trying to help her along her journey.

Realizing that the path we chose might not be the path for everyone to follow, I will merely list a few of the resources that I encountered concerning end of life care that I found helpful. I think a more exhaustive list would get in the way. I encourage those of you who are to the point in dealing with this disease that you need to review them to do so, no matter how hard this process may be. Your entire family will benefit from locating something that is in tune with your needs.

Peace,

Bruce and Bev Shriver

Books

[Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying](#), by Maggie Callanan and Patricia Kelley, Avon Press, ISBN: 0553378767

[The Grace in Dying, how we are transformed spiritually as we die](#), by Kathleen Dowling Singh, Harper, ISBN 0-06-251565-9

[How to Provide Fearless, Compassionate Care for the Dying](#), by Margaret Coberly, Ph.D., R.N., Shambhala Publications, ISBN: 1570628505

[Dying Well: The Prospect For Growth At The End Of Life](#), by Ira Byock, M.D., Riverhead Books, ISBN: 1573220515

[Graceful Passages: A companion for living and dying](#), by Gary Remal Malkin and Michael Stillwater, Companion Arts, ISBN: 157731428X (This is a gift book and audio CD combination)

[The Needs of the Dying](#), by David Kessler, R.N., Quill, ISBN: 0060958219

Websites

The Northwest Sarcoma Foundation's webpage on "[Death/Dying/Grief](#)" contains links to many useful

resources.

The [National Hospice and Palliative Care Organization](#) (NHPCO) website contains much useful information on their Hospice and Palliative Care webpage.

The [International Association for Hospice & Palliative Care](#) website has a large amount of information about hospice & palliative care services.

An article, [A Dying Person's Guide to Dying](#), appears on the [American College of Physicians](#) website.

There are "Planning for the [End Of Life](#)" and [Pain](#) modules on the [CancerSupportiveCare](#) website.

You might want to read "[The Death of an Adult Child](#)" before visiting [The Compassionate Friends](#) website (see the entry below).

An article, [Funerals and Memorials: a Part of Recovery](#), appears on the [American Psychiatric Association's](#) website.

An article, [How to Deal with Grief](#), appears on the [National Mental Health Information Center's](#) website.

The [Caregiver.com](#) website has some useful articles. Their free weekly Caregiver's Newsletter also has a useful article or two. You can also subscribe to their paid subscription magazine, Today's Caregiver.

Additional Readings and Websites

Pain and Possibility: Writing Your Way Through Personal Crisis, by [Gabriele Rico](#), St. Martin's Press, ISBN 0-87477-642-2

[GrievingChild.org](#) provides peer support groups for children and teens from 3 to 18 years of age who have experienced the death of a parent, primary caretaker, brother, sister or teen friend. The National Center for Grieving Children & Families also provides support and training locally, nationally and internationally to individuals and organizations seeking to assist children and teens and grief.

The mission of [The Compassionate Friends](#) is to assist families dealing with grief following the death of a child of any age and to provide information to help others be supportive. It is a national nonprofit, self-help support organization that offers friendship, understanding, and hope to bereaved parents, grandparents and siblings.

There is an interesting article *Grief Tips* by Jim Miller on the [Willowgreen](#) website.

There is an interesting article [Loss of an Adult Sibling](#) by P. G. White on [The Sibling Connection](#) website.

Quotations

"*There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief... and unspeakable love.*" — Washington Irving

"*There is no death. the stars go down to rise upon some other shore. And bright in Heaven's jeweled crown, they shine for ever more.*" — Andrew Marvell

"*Grief is a price we pay for having loved.*" — Sister Marilyn Carpenter

"*The only thing you take with you when you're gone is what you leave behind.*" — John Allston

[Quotes to Inspire](#): On Death and Dying

Feedback

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