

A Journal of Life, Love and Dying

by Valerie A. Stein

The Best of It: A Journal of Life, Love and Dying

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Valerie A. Stein 2009

Sometimes a work needs no introduction, but some twenty-five years after the death of my mother this piece of writing has come to fruition, and it seems fitting that I explain its origins. Built around my own journal entries, poetry and song lyrics from the time surrounding my mother's diagnosis and subsequent death of terminal illness, it could be the story of any number of children who face the death of a loved one. The differences lie in our own response to this ride we all must take at some time in our lives. I wrote this piece for my own health; to process what it was that we had gone through, to participate in mourning in a real and positive way, and to set down those things we learned which might help others on a similar path. There were books which helped me greatly in the months and years surrounding my mother's process of dying and her death, but none were written in quite this way; for me the poetry and songs and observations of daily living were part and parcel of our acceptance of how to go forward. It is important that I share this insight with others, however small it may be. The smallest things are sometimes the ones from which we learn the most.

This work is dedicated to all my loving friends (who know their names), for letting me cry and helping me laugh; to my father, who knows me better than he may realize; and to my mother, whose laughter I still feel now and then.

VAS 1984

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PRELUDE

On July 30, 1983, at 6:30 in the morning, Elizabeth Merrill's tired body finally gave up its fight with illness and subsided into peace. Our father said, after our mother had stopped breathing, after the life had gone from her body, that had she been on a monitor, a pulse would have been discernible for some minutes. The minutes had no meaning then. The life was gone. Time was suspended and nothing was important but that the struggle had ceased. That life was changed now, in a moment, in an hour or a day, would enter into our senses slowly. As a breeze creeps into spring, we would soon feel an absence touching our awarenesses. Now there was simply a pause. We looked upon our mother, our wife, our tired companion, straightened her on the bed and tucked the covers under her chin. Time had little meaning, but it seemed that the day was beginning.

I first faced my mother's mortality when, in my thirteenth summer, she had a heart attack. It seemed more possible after that that I might lose her before I was ready, and this possibility became part of the way I looked at things. Now I am more than thankful to have been allowed that insight—the ability to look loss in the face. It has been a growing process all my life, and especially over the last three years, to watch and be a part of the conscious effort of working at dying.

I am my mother's youngest daughter. To her I offer this writing. Perhaps she'll give it a name as I share her journey, her building of a true Self from hard looking. She did it well, our Betsy, and she taught me much in the doing. Thanks, Mom.

Valerie A. Merrill November, 1984

WE BEGIN

It is best to begin at the beginning. Why don't I run away or shove Mom into a dusty closet and lock the door? The whole thing could be remembered as painful, from the heart attack on a camping trip in Maine in the summer of '73. Ever afterward I wondered often how soon I would lose my mother. I didn't run away then. I looked it in the face—and it hurt—but it was a true feeling. A real one. And looking it in the face took it out of the realm of the unknown.

We begin. I remember that she told me her condition had been diagnosed as terminal when I called home one day in the spring of 1981. The background doesn't matter much anymore, but the phone conversation stays with me even now. It was then that she also put into words the idea of looking at what one wants to do and doing it. Because of her I did it. Because of her I had the vision to know when it was time to look in different directions for my own life. We began, and I sent my energy into dealing with the acceptance of all that was to come. I broke off a nearly-dead engagement, went home and washed dishes. I got a driver's license because it was finally truly necessary. I watched Mom sleep 18 hours a day.

We talked, when she wasn't sleeping. We told each other things we had needed to know for years. Things each of us had done which hurt the other. Things we wished we'd get to do. Things we hoped and feared. Mostly, though, she slept. I learned the pathology of cardiomyopathy and watched the symptoms progress.

4/11/81

So it is beginning in earnest—when I came home four days ago, Ted was still planning to go to San Francisco to see Grandma & Granddaddy. Now he's not going to go. Betsy is just getting worse—even in the last couple of days—feeling worse, eating alarmingly less, sleeping moreSpring, 1981 Mother of mine your body Spirals, spitting, Jerking downward— Will it crash, tumbled, broken,

> Ceasing and jarring in the dust Or waft you gently as a feather To simply touch down ?



The things she expressed regret at missing are worth remembering, at least for me. One day as she was looking at the hill through the front door, we suddenly felt tears and she said that she suddenly knew, really, that she'd never see their house built. Another time she matter-offactly stated that she regretted that she'd not see Haley's Comet on its return. Once she told me that she hoped when she died and Dad married again, his wife would like to bake bread.

Our mother was a woman of ideas. More than large philosophies, however, she embraced the more immediate raw materials. She was the planner; the doer rather than the seeker after ideals. As a weaver, a baker of bread, she made things from other things. She spent less time discussing politics or society than discussing personal relationships. She spent less time cleaning up after an idea than getting it started or making something of it. That seems to be the way in which she went about dying as well. She took what there was and made something of it; this time, though, the conclusion of her project was there, waiting for her. Do I stray? Have we begun? I think of what she made from what there was; this book is, in a way, just that; what my mother made from what there was.

I am remembering what there was when I was in high school; for her, for me, for us. For her there wasn't much, as my memory has it. Through seventeen-year-old eyes, she certainly didn't have much; I saw her as a fat smoker over fifty whose children didn't really need her anymore, and who wasn't doing much else with her life. I hated almost everything about being seventeen and though I loved Mom because she was my mother, I didn't find much to like about her. Apparently neither did she.

We spent much of our time trying to talk things out and being mutually hindered by mutually uncontrollable tears. I encountered a journal entry from my seventeenth year, and indeed we were both very unhappy. We went about loving much more relaxedly when I was younger, taking trips and planning projects together often in my pre-adolescent years. I ended high school with the beginnings of an ulcer, however; though Mom did not cause it by any means, my lack of communication with her in those days added fuel to the fire. I believe it was then that we had to start to make something together with what there was, beginning the path toward openness between two women who truly loved one another.

We began. It is hard to define a true beginning; since life itself is a series of beginnings for all of us I will not worry that I've found more than one starting point for what there was. WE GO ON WITH IT

10/21/81

I ran headlong into a poignantly, painfully beautiful moment today; clarity of sky, of breeze, of thought—and all of it so short—going by so quickly.

Betsy grows worse—a very uncomfortable woman—I ache for her. The spiral spins downward not a pretty sight.

But life goes on. Our mother is dying & we still have to clean lamb hides and can pears. Laundry still gets dirty—so do dishes and floors and toilets...

This was the time of patience. There were so many priorities to keep in mind and so many new feelings to look at and to deal with that we had little time for just sitting and breathing, it seems. My memory of that time is mostly one of doing dishes—endlessly, repeatedly, ever and ever amen. We dirtied them tempting Mom's palate. We dirtied them catching a bite to give us energy for the next task.

The waiting was sometimes overwhelming. As we cleaned and canned and cooked we wondered what came next. There were many medicational adjustments made over a long period of time; there were times we simply knew that the end had come. It hadn't. I was horrified to find that I wanted it to come. I wanted Mom's pain and fear to be over. I wanted the waiting and the discussion of new developments and all the vain hoping to be finished. I wanted Mom to get better or to be done with it. We waited and the waiting was gray. And yet, there were moments of sterling clarity, almost painful in their beauty. Looking back I can see now what the waiting and the pain did for us; heightened awareness will be with us always.

10/22/81 Locust leaves these days fall like rain

> Greens are fading to quiet brown

I shiver at night with the stars

Breathing crisp dreams of Coming days

Pulling gusts deep into waiting lungs. Time was gray, dotted with flashes of color. Mom spent most of her time in bed or on the couch, watching the world go by, watching influence over her environment slip through her fingers. Her priorities were not always what we saw as foremost in importance; she had nothing else, though. I remember the feeling of juggling all the various tasks to include what she wanted and needed while trying to get by with the rest of the work around the place. We got frustrated at times with what seemed to be her lack of vision for more far-reaching problems—while trying to understand, too, that *she* must have been incredibly frustrated with her growing lack of control.

Our mother was always most comfortable when in command of a situation. She dealt more easily with a schedule of events of her own choosing than with that of someone else. Suddenly, unable to influence the world around her physically as she might have wished, confined to verbal involvement, vicarious experience, she became frustrated with us. We didn't cook rice as she did; I tore lettuce instead of cutting it; I scraped the carrots for soup instead of peeling them; I sometimes left the skins on when I boiled potatoes. These seem now to be incredibly unimportant things—but at that time she could not comfortably mix together the ingredients of a batch of bread. What *was* there to make from what she had?

Fall, 1981

There is pain in too-hot water; Cleansing, crisp pain The day is grey and gaunt.

A red-tail shrieks, echoing the sound caught in my throat Like a bone, swallowed sideways.

It is cold behind my eyes; fingers numb in brown endless dishwater, shriveled.

Somewhere a dry leaf scrapes against the wind.

Much of the time spent with my hands in dishwater was also spent in praying for patience; for tenderness when I felt much less than tender; for strength to finish one more task. Tempers were ragged. I know that I got more practice in keeping my mouth shut over nasty remarks in those times I spent at home than I ever had or ever will again. I have never been a great one for nasty remarks in general, but the capability has always been there and I think my control of it grew over all those scraped carrots and pots of rice cooked the wrong way.

I remember vividly one chilly afternoon when the drudgery in the kitchen was nearly done but we were picking at each other for this and that. I couldn't seem to say anything in a reasonable tone of voice and the very fact of that simply frustrated me so much that I suddenly heaved a soapy sponge at the kitchen cupboard and ran out to commune with the sheep for awhile so that I wouldn't say anything mean or petty to anyone else. When I came in a short while later I was fine and all the nastiness was gone; my poor family, though, were still wondering what they had done to make me explode in such a manner.

Communication of small frustrations was more difficult for me than talking about the greater emotional issues. Did they seem less important? Possibly it was simply that there was so much of the little unpleasant daily stuff to deal with and the frustration with it was bigger because we were in the middle of so many big emotions without being able to stop and look at them.

Of course we did look at them and we dealt with them. There were, as I've said, moments of clarity. There were poignant moments of beauty, of poetry dropped into the scheme of things. I seem to keep returning to those moments of awareness; of clarity; of beauty. These moments became more and more important to all of us as time went on. If we could find small bright spots in every day they helped us to look for more. They held the fabric of our daily lives together.



5/26/81

One yellow wild rose, blooming — under soaring shouting sun it's almost shy — Gives me a little lonely feeling down where those things begin...

5/29/81

...Shutting the chickens in at the first of a ... blustery wind and rain storm, I suddenly saw a big <u>bunch</u> of blossoms on the yellow-rose. It's like the Big Wind blew them bloomed.

Looking at the world in this manner has always been important to me. I call it the wonder of the everyday, and in hard times such as we were experiencing, my appreciation became greater than ever. The feeling of this importance of everyday occurrence is epitomized for me by a sentence from <u>A Tree Grows in Brooklyn</u>, by Betty Smith: "To look at everything always as though you were seeing it either for the first time or the last time; Thus is your time on earth filled with glory."

There truly was glory in moments when Betsy would smile and ask us to step closer; we had brought the freshness of outdoors in with us on our coats, in our hair. There was glory in coming in from an early snow, laughing, hands bright red with cold, to give her the first pressing of cider from a tin cup.

Only the symptoms of Mom's condition could be treated. She took an astonishing amount of medication. Each chemical level was affected by all the others; adjustments were a constant problem. Of all her prescriptions, though, one stayed constant throughout the illness, and gave all of us much support and pleasure.

Somewhere near the beginning of the whole business Mom and Dad were doing quite a bit of research about the condition of cardiomyopathy and they stumbled onto something entirely unrelated: research indicates that humans need a minimum number of hugs a day for survival.

The Merrill prescription, actually taken from a couple of sources and embellished as the moments dictated, was this: four hugs a day were required as a minimum for survival; twelve were needed for maintenance and twenty-four would contribute to personal growth. The cry, "Maintenance!" became a watchword in our house. This prescription helped immensely to cure blues or a bad case of snappiness, to relieve fears and to spread warmth in general.

I do not believe that we would have made nearly the progress we did in communication if it hadn't been for that prescription. That pattern carried to the very end, too, when Mom was comatose. Touching was really the only sharing possible then. Communication was at gut level she could hardly formulate words to tell us what she needed, let alone communicate what was going on in her head. Holding, stroking, touching, kept us all connected.

In addition to constant adjustments in medications (except our hug therapy, of course), the adjustment to each day's change was very difficult. Some days Mom looked just great — so good that people would comment that she must be cured, or getting over the illness. Two days later she might not be able to come to the table to eat. It seems, looking back now, as if we became a cocoon of changes. We looked at death, at illness, at ourselves, deeply. We looked at them differently than we had ever been required to before.

It became habit to redesign activities normally left to a single person so that Mom could participate in the everyday. We made "gang" salads, "gang" meals, but in particular we developed the fine art of gang bread baking. It must be clear by now that the baking of the bread was a very important ritual for Mom. It

was a craft and an art to her just as weaving was, and becoming unable to do it all herself was one of her greatest frustrations. She then discovered that she could start the bread as batter and things would progress accordingly, with various family members called in from the garden to contribute assorted skills. Mom would painstakingly assemble the ingredients. After one of us beat the batter, Mom would take charge of it and could sometimes knead a little flour in when the first rising was done. We would take turns kneading the dough, depending on our own physical or time limitations, and Mom would shape the loaves. In this way we all accomplished our own work and were able to share a meaningful task with Mom as well. Gang bread. We became accustomed to adjusting.

We became quite familiar with things which might have seemed more than strange to anyone who was not in the cocoon. It is still, when I think of it in passing moments, a shock to me to realize that it was once commonplace for me to fall asleep thinking of the Heimlich maneuver; of how to set up the oxygen tank; of how to remove Mom from the house in case of fire. This is the stuff of the cocoon. We become so accustomed to the everyday occurrences that we do not really see them.

In this time we became accustomed to things which, to others, were not only out of the ordinary—in some cases they seemed startling, in others very uncomfortable to contemplate. Surely many of the things I remember about Mom's illness were ugly. At the time, we saw them differently—they were never beautiful things, the physical manifestations of the illness. But they were a backdrop to the mundane, everyday things which still filled our lives and which we did not notice as acutely before Mom became ill. Even now I remember the roses and the color of the mountains at falling evening, feel the raw crisp cold of new cider on my tongue. Looking back, I can watch the animals grow and change. Against a gray background of confusion, change, pain, these things became the beauty and reality of all we held as people who cared about living and feeling fully. We shared these things with one another and made something from what there was.



CHANGE

We are ever-changing beings. In the process which our family underwent, the one to whom greatest change came, of course, was our mother herself. Throughout her illness there was, for her, constant change; weekly blood tests monitored medicational adjustments, necessitating constant re-ordering of expectations about what her body seemed to be doing. There were those times when she would sleep eighteen hours a day and I would despair of her lost appetite. It seemed that she could not possibly survive those times. Perversely, sometimes on the very heels of these periods of physical ebbing, she would occasionally experience times when her body gave her respite for a time and her spirit would assert itself anew. It was almost painful to see her smiling and striding along into her days because I had become afraid of hoping.

Why should I fear hope? With hope came the confusion of changing our expectations once again, another painful time of re-ordering, reexplaining to ourselves and others what was happening. So many folks who saw Betsy at these times expressed extreme joy at her recovery. I could only receive these felicitations silently. I had a picture of the future which didn't fit these hopeful wishes of continued good health. Thinking of that attitude now, I wonder at how defeatist it must seem to others, how lacking in faith and the practice of positive thinking. We were so very tired, physically and emotionally, from going on and on with it that, yes, I found myself wanting it all to be over with. I wanted my mother to be able to be well all the way, or I wanted the changing and the waiting over and done with.

In the cocoon, hope is relative. We had a general hope for long periods of health and wellbeing for Mom, and for the shortest possible periods of pain and discomfort. But one must understand what it is like every day to see a body which is working against itself physically, chemically; it cannot simply reverse a process in which the imbalances within are breaking down the parts of the whole, constantly, daily, hourly. Would hope, and faith, given in full measure, have reversed those physical manifestations? There are some who believe that enough positive energy or earnest enough prayer in a given direction could theoretically achieve a reversal of disease. If we had directed all our energies in this way, we might possibly have gotten positive results in some measure. The fact is that we all die at some point in time; to deny this is to deny our reality as well as our mortality; in some ways, it might even be messing with God.

We had hope. We had faith. We hoped that we would muddle through today and tomorrow and tomorrow. We hoped that we might do it gracefully, and that we might give our mother all the love and support she so richly deserved. We hoped for wellness in her spirit. We could no longer bring ourselves to hope for the healing of her body; the mercy I prayed for was not that of a life returned to us. 11/13/81

I was so – <u>snappy</u> – today. As I was clinking through the dishes I told sister Kath wishfully that maybe if I could be nice for a whole day, God would come down and kiss me on the nose. She smiled and asked if that's ever happened to me & nodded understanding when I said yes, but not very often.

Acceptance of our situation was how we dealt with things, and while this was difficult for those who did not join us in the day-to-day, it was what we started from, and what we found to work on in a positive way.

We went on, and on. There were many times when my spirit cried out for it all to stop changing so drastically one way or the other.

11/16/81

...And Betsy worsens. The same over again, distressing dark days. Betsy says she thinks this just another hint—her body reminding her what's to come—feels we'll muddle through it & see better times only for an even worse one next time around.

11/19/81

Last night Betsy suffered a sorry bout of depression—& pain, & sorrowing. Said she is scared—her liver is an unknown quantity in this, and it HURTS her. She said, dry sound of sobs in her throat, it's the beginning of the end, & she's not ready to face the pain. Pain. Too many things she wants to do, yet. She said, why don't they knock her out with painkillers like a cancer patient so she won't be in pain? She's afraid... she feels a coward.

She said all these things, & it hurt to hear them and to have no answers—but she needed to say them. We all needed to hear them.

So many complexities—everything all mixed in—fear, death, loneliness, bitterness, impatience humility, faith, profound and moving joy—despair? No. Not despair. Overwhelming sadness, a feeling of helplessness, but not despair. Despair is for another time. Despair is when there is no hope. Around the time of all these changes, Mom gave a sermon entitled, "To Die is to Live." She was weak and nauseated and not feeling brave at all; yet she preached it at two of our parish churches before becoming too ill to make it to the third. We did not know, at this time, that she had nearly two more years to live. These are her own words on the subject of her death.

"Has it <u>ever</u> occurred to us to realize that we should all be teaching ourselves to be widows and widowers, to be talking to our children about the death of people they love, to talk to each other as husbands and wives about what death means to us—the death of each other? Of <u>course</u> there will be grief. Those of us who are dying will grieve for the things we haven't done, for not being here for important occasions, for ourselves, for missing out on some years that others will have in which to live. Those of us not dying, will grieve because someone we have loved will be <u>gone</u>, not here, not available for the hugs and comforting and physical contact so necessary to people, because relationships of love leave us vulnerable to this kind of grieving. But would any of us give up the relationships to avoid the grief? Not I!"

12/17/81

So much to do, but it all seems possible now. There is good in today.

My mother enjoys a bit of respite. The sun is shining! Christmas and family are coming soon. We felt very tired, for the most part; there was really no other way for us to feel. Yet, even through this incredibly draining physical and emotional upheaval, a spiritual evolution was taking place. This was where the bright moments in gray days saved us; this was where our heightened awareness truly came to be a gift, a blessing. We were so *very* tired — but we found ways to let the beauties energize us, a moment at a time. Possibly the seeking of these ways became, in a sense, our mission. 12/27/81 Tired. Fighting a cold, I'm sure.

> Morning will look fine; Sun on snow, sleeping hills frosted Gently white & blue—

Day will look better; Celebration of life, what's to come running Around my brain.

Big tasks won't look so big Once begun, little by little Moving it all forward—

EXPECTATIONS

One of the most difficult aspects of this experience, for me, was dealing with the expectations which came from outside our cocoon of changes. Our own expectations were constantly being re-ordered. This was part of the everyday, and something we all adjusted to; even when Mom herself chortled that, "even yet!" she might beat Death, we all knew that it was simply her way of looking positively at her situation. For those outside this situation, however, things looked somehow different.

I remember, in one of the bad times, early on, traveling to our brother's house for Thanksgiving. Many of the people we would be visiting with had not seen Mom since some of the more distressing aspects of the illness had manifested themselves. We at home had developed a certain way of dealing with these distresses, but I knew that the incredible change in appearance would be a horrible shock to them. I felt, in considering this idea, that I had not the energy to begin with others at their beginning. I wanted to be able to help them get to where we were, but I was in the middle and simply could not start over again. This was very frustrating, partly because, at the time, I could not express myself at all well.

11/23/81

Nausea. Poor Betsy—how can one feel brave or able to deal with anything while retching over the bowl?

Day after tomorrow we leave to go to McMinnville —oxygen tank, IV equipment, bed and all—because as Dad said, best to go while we can—

In the face of Betsy's illness and the surprise of how bad it really is to folks who haven't watched it happen, I dread seeing...other people. The shock will cause pity. I don't think pity is in order. I think it stinks. Having dealt with this all to a point, and having struggled with acceptance, when another person views the situation and wants to share the burden, <u>their</u> acceptance is all to go through again, and I can't. I can't begin at the beginning. I can't. I'm tired. 12/5/81

A friend and I were talking about dying — he kept saying and saying I have trial before me, as if to warn me. We are <u>in</u> the trial and the worst is yet to come, and I know it in myself better than anyone can know for me. Instead of being so mean and frustrated I could just point these things out to him...at this point in my life I have no strength left to respond to so much emotion—



This, too, was the stuff of the cocoon; it was a protective measure, I'm sure. I may have seemed utterly defeated to others, or maybe I just seemed to be without feeling at all. In any case, I think we were all just where we could be, though to this day it frustrates me that all those Mom loved could not be on the journey with us. It showed those of us who were present the true nature of loving in a unique way.

The most difficult aspect of this, even as I look back at our changes from the perspective of passing time, is that the journey we made is, by virtue of its intimacy and uniqueness, so difficult to fully describe. It was a time which concentrated and centered on our mother for anyone who was home at all; yet, as I read various writings concentrated in and about the time of her death, her changes leaked out of the cocoon and into the greater world in some wonderful ways. This is a comfort to me, so many years later.

When I realized that I was the only one of us who kept a regular journal of this experience, though all of us are prolific writers, I felt a sense of loss for the timely perspectives that might have helped all of us in other ways later. I am thankful I recorded all of our ups and downs. There are triumphs in the human spirit to be seen from a family pulling together to help a loved one live their dying with grace. There are moments I would rather not have seen in my short life. And yet, there were moments which more than made up for the pain we all endured, though I might not even have seen them until these many years later.

The physical changes of Mom's illness, and what occurred as her body gave out, are not easy to look at. The details would prove for some to be too stark; too ugly. But it wasn't only her body which changed for her. Her essential view of herself changed; her relationships with others changed. It isn't that she became another person. If anything, it was as if she became more essentially herself as time passed and as she had to let go more and more of normalcy in her life.

Earlier I spoke of my mother's feelings about herself as seen through my seventeen-year-old eyes. Though her illness may have heightened the feelings of inadequacy which I felt she possessed, it seems to me as if all those feelings were in some way concentrated in her illness on the physical aspect, leaving her essential spirit, Betsy herself, free to get on with the dying. This by no means indicates that she wanted to die. But in knowing and accepting that death was inevitable, she was somehow made able to move beyond inadequacies to something of a peace and pride in herself.

We all like to think that when the chips are down, we would be noble and wise. In Mom's case, we saw it happen, in a way. It is really as if the more important took over. I don't say all this for the sake of making her death sound noble and somehow melodramatically important. It was important for her, and for us. The effort of it hurt us all, but it was real and it was meaningful. We observed this process of change along with all the others. It was something our mother made from what she had.

DEATH

After more than two years of illness, our mother finally came to be at rest. I had gone back to school in the last year of her life, mostly because of some advice she had given; a gift, as it were, to do more and experience more than she herself had been able to in sixty short years. She wanted me to be sure that if there was something in my life I wanted or needed to try to do, I ought to try. It was important to her sense of peace, I think, to know that a woman she had raised could go on with it for her.

It was hard, though, to be gone from the cocoon; though it held pain aplenty, it also held a shelter, a freedom to talk about what was real to us at that time. I still shudder when I remember being at a pizza dinner with colleagues from school. The pizza and beer were being consumed with the usual banter as side dish, and someone said something about the comet to come. Without thinking what the result would be, I commented that yes, it was one thing Mom regretted that she wouldn't see. In the same bantering spirit, someone asked what she was planning on doing,

and made a joking conjecture of some sort. I have to say that I have never stopped a conversation as effectively as the moment I replied, "She's planning on being dead." The feeling of unreality which accompanies these moments still haunts me, and the unspoken demand for normalcy from those not surrounded by death still hurts deeply too; I felt it in the horrible times of waiting from afar, and even more strongly in the months following her death.

5/7/83

Two nights ago Mom went into the CCU in Bend —she's one sick lady—angina the last few weeks and then a pain in the chest that wouldn't go away with the nitro—it's pericarditis—a virus—nothing they can do but wait it out—and in her case what does <u>that</u> mean? She sounded truly scared when I talked to her Thursday. Such a dose of mortality—<u>I'm</u> scared she'll die while I'm far away—it makes no difference, because I am there in spirit, but I'm scared anyway.

5/15/83

I'm still thrown by Mom's sickness—she's feverish & sweaty, & <u>yucky</u> these days—don't know what's coming—

I have walls in me—I want it to be all right to try & push down those walls—in me—so unfamiliar and so very strong.

5/20/83

I am alternately calm and tearful—what am I to say? Am sitting here in the CCU in Bend, Oregon. Such a complex series of emotions—

What to say? She came so close to dying that her eyes rolled back & such terrifying stuff. Sister Kath, who has been home all this time with them, said it's the closest she's seen Dad come to crying yet. Blowin' in the wind. One day at a time. That's all it is, but I want to be coherent about it all. How?

Mortality's such a strange thing—at moments we're laughing and close & at times the tears hang so close to the surfaceThere are times when I'm o.k. & then the times I think of going back—that's when I get scared—I'm very needy now and afraid to push that need on my friends.

My friends, the ones who knew and were open to what we were going through, were constants. It was very difficult for me to believe that it really was okay to need them as much as I did. They were on the fringes of the cocoon, and the walls I had put up at this time did not allow me to open up much outside. I was—we were so afraid of the actual moment of departure, and afraid of being taken by surprise.

5/22/83

... I guess keeping from caring is really the wrong way to go-Dad and I were saying this weekend how when you love, death or loss hurts—but that it's worth it—truly is.

Mom and I decided that <u>now</u> is what's important. So complex—the whole thing.

5/24/83

I guess one thing that's hard to accept is that when my mother gets unhooked from the monitor to sit in the sun for awhile it's supposed to be a triumph that's <u>hard</u>.

5/25/83

... But Dad said today, "now more than ever" Mom needs to be in the CCU. Fever, sub-safe BP, infection, possibly from the catheter, so it's out now—but needed... As we were saying, little improvements are pretty big ones when they're looked at from a limited reserve.

<u>Hang on</u>.

Dad said, "I love you". He doesn't, normally, say it that way. They picked the right moment to take her out-of-doors, Dad says—just before and just after & since she's been pretty damn bad—especially last night. Now I feel anger at not having been there for their anniversary party—but I already know that it's okay. I told myself as I left the CCU. We are close in spirit, no matter what happens—<u>no regrets</u>. Simply keep in mind the joy in living, all that we have known, all we have learned from each other. Mother of mine, we are inseparable always mother-daughter souls swinging sparking peaceful or sleeping each moment is green with growing, grey-weathered & calm with age. I love you.

5/28/83

The amazing thing is that I can still laugh. Of course I remember dealing with that when Mom had her heart attack—is that really less than 10 years? Chicken hearts at Cape Neddick. And last night it was chickens with parachutes? It's not necessary for my sanity to describe the situation.

It is more than likely very near the end. How many times have I said that before? But this <u>is</u>.

What do I feel? Sorrow, yes. Pain at all the pain she's had to know. Exhaustion at waiting for her pain to be over—

6/18/83

It isn't pretty around here. Whatever—Betsy is still with us—for a little longer at least—It's not knowing <u>when</u> that's hard to deal with—and no one can say, & I'm lonely and that's all there is to it.

6/21/83

I keep thinking of <u>Last Letter to the Pebble People</u> and wishing that I could do <u>this</u> part of the working at dying any sort of justice at all—how to keep a journal of what's happening or what feelings are going through us? It's hard because all I feel now is exhaustion—I'm running on reserve which feels as if it's <u>got</u> to run out soon... I'm so tired.

6/23/83

Suddenly today it hit me—something always does—that Betsy may not see me married. It washed over me—what she'll miss—how she'd want to be there—it was—and is—sorrow.

But I accepted it somehow—she may not see me graduate from college, either, but she knows I will.

I don't know—the closeness of Liz and Norbert's wedding becomes more poignant with every passing moment and somehow it makes one think of what one's own will be like when it happens—which leads to other thoughts, and pure unadulterated sorrow today. I'm not sure why I feel so sad and so unwilling to show it...

7/8/83

Betsy's back in the hospital after a bout of atrial flutter. Back to the proverbial drawing board? Not really—we're still here.

7/11/83

I seek peace in the imposed patience of threading the loom—but, not finding the patience, the peace escapes me as well... I am tight inside, gray haze before my eyes, tears hanging in my throat—my back & breasts & chin are made of plywood. A true sense of loss, suddenly. When the waiting is truly over and Betsy has died, today or tomorrow or a year from now, there will be an emptiness I cannot imagine—it will be an essence from our past which will fade as we go on & change.

7/22/83

Been praying, crying, wondering—Oh, what it is to be human! I'm so confused and lonely and full of pain, but I wouldn't trade it for anything because it's living. 7/22/83

Full moon like a beacon, bidding me to follow — Full moon like a beacon, bidding me to stay. Full moon like a beacon bidding me to stay tonight Stay tonight and dance in the full moon light. Tears in every day coming close in every way But joy in our living & our song Seems so hard to see the living with clarity But facing the end with singing makes it strong.



7/22/83

Got a letter from Kath today. Mom wants a Christmas tree. Doesn't expect to last long. She's getting tired. Too tired. Oh, mommy-girl—

7/26/83

Going home tomorrow—talked to Dad last night and things are simply going on down... So. What to say? She's got her tree, lights and all. Doesn't get out of bed anymore. Probably has pneumonia again, too, & hardly any way to fight it. God keep her. Hold her. Where is your comfort?

7/28/83

So. Here I am & here it truly is — not getting out of bed anymore is putting it lightly.

"I don't know what's going on. It seems to be a think. It's at the core. Just a minute—something's about to give but it's—not." 7/28/83 (later the same day)

I am writing because I need/will need to express the depth of it & when I get back this haze which covers and carries all before it will have made it too far away.

It is all here right now—time has no meaning and no telling. We go by the ups & downs of pain and other readjustments.

Body chemistries are all connected. That is why we function relatively effortlessly. But here it is (they are) shutting down. Shadowed photos of the past flit in & out—with every breath snatches of impressions we can't see come to the surface, and it is sometimes hard for us to find out what context any words fit into.

Words. Effort. "Oh, my dear. Oh." Angles and corners of pain. "I'm all wrong. It's not. Oh, my dear. Oh."

And yet with the smell & look & feel of death around, it's not ugly. Just searingly painful & poignant & real & at moments, something to smile at, when it is as if we are all bound. Like one great nerve sheath or muscle fiber. Like a single egg, encased. Like a bud. Or one tear, working very hard but very gently at being shed.

We are on the way to comatose: to slowing down; to phasing out. May it go gently from here.

The hardest thing is communication. She is elsewhere & it is difficult to make sure of what she is trying to tell us as opposed to what she is trying to say.

At times this evening I saw her hands. The hands of a weaver. Of an artisan. She is still Betsy.

7/29/83

I certainly got here just in time for the next series of events. Dad & I were just talking about comatose condition—& how the person phasing out is still present. Though the conversations are not the same, there is still conversation sometimes. "What a strange and wonderful experience," he said.

Betsy's no longer taking any medication except what she asks for (& oxygen, which she doesn't really think of, probably). The balances are screwed up and since the endpoint is the same it just doesn't make sense to try & keep a meaningless schedule. We could get a blood test (only from the femoral artery, though), & give pill parts & make her swallow the damn things, some of which work against each other now that her kidneys are pretty much shot—she can hardly use a straw, let alone take the glass to her mouth to swallow a handful of pills. Let us fill her time with as much comfort and love as we can give.

7/30/83

Thursday when I got home and said hello to Betsy she said, "I opened my eyes & the sun was shining & I saw a sparkling face—my face and then I looked and there was my Valerie."

It's done now.

On July 30, 1983, when the youngest of her five children was 23 years old, Elizabeth Good Merrill died. Surrounding her with love were her husband and two daughters. She was at home, in her own bed, as she had wanted to be, and she passed without the pain of which she had been so afraid. As she began slipping away, our father came crying to us in helplessness and loneliness at watching the passing and not being able to do anything. We touched her, and one another, again the egg, encased; as one being we held the moment quietly until it passed.

As we were, in the cocoon, holding to that moment, the presence of transcendent peace was palpably there. We were indeed embraced that day, as we had been able to embrace our mother, wife, sister, beautiful being, to ease her path.

She made the best—her very own Self—with what there was, and shared its power with us in the making.

AFTERWARD

Last year marked a time when my mother's death was half my life ago. Time dulls the intensity of the pain of this type of loss, yet surely that loss molded the young woman I was then into a completely different adult than I would otherwise have been. It is true that the pain never does go away, but it changes dramatically after a time. Living honestly through this experience whenever it shows its face, and acknowledging its presence, allows it to evolve. It has become part of my very own Self, creating the best from what I've got. What you have read is the gift I received in the living of it.

Valerie A. Stein November, 2007

Acknowledgements

A Tree Grows in Brooklyn, by Betty Smith

Last Letter to the Pebble People: "Aldie Soars", by Virginia H. Hine

<u>Letters from Motherless Daughters: Words of</u> <u>Courage, Grief and Healing</u>, by Hope Edelman

<u>Motherless Daughters: The Legacy of Loss</u>, by Hope Edelman

Author Biography

Valerie A. Stein

Born the youngest of five siblings in Oregon's John Day Valley, the author grew up amid sage brush and rocky crags. Long married to her college sweetheart, with one daughter now in college, Stein has spent more than half her life teaching a range of students a variety of topics, from weaving and felt-making to library skills. She lives with her husband in Edmonds, Washington.

We had hope. We had faith. We hoped that we would muddle through today and tomorrow and tomorrow. We hoped that we might do it gracefully, and that we might give our mother all the love and support she so richly deserved. We hoped for wellness in her spirit. We could no longer bring ourselves to hope for the healing of her body; the mercy I prayed for was not that of a life returned to us.

