

TIME TAKEN AS A CARING FAMILY

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Viewing caregiving from both a personal and professional angle has given the family in the following narrative a more holistic and realistic view of the role of family caregiver. "Dad," who lived caregiving on a daily basis, offers wisdom from experience for those facing the prospect of giving full-time (or part-time) care to loved ones. Their personal caregiving experience has helped the author as a social worker see that all kinds of interventions and choices need to be available to those who are caring for a loved one.



Take Time

*Take time to Hold Their Hand.
for their hands are what made
the things that give us comfort.*

*Take Time to Look in Their Eyes
for their eyes have seen our
world through the changing times.*

*Take Time to Help Them Walk
for their feet have traveled
a thousand miles.*

*Take Time to Listen to Them Speak
for we can learn from
their endless wisdom.*

*Take Time To Care
for someday we will all need
someone to take time with us.*

By Vicki Walleck (One of the students wrote this poem after working in the Caregiver Unit at the Topeka VA Hospital.)

I realized I needed to write this with my father when I saw the Reflections call for the special issue entitled "No Map for the Journey: Professionals Reflect on their Experience with End-of-Life Caregiving." Several months after seeing the call I received a letter from my dad talking about the future not in years but "as the seasons come and go" and I realized that if I were ever to write with my father about

our experience as family caregivers, it was now.

Twenty years ago, we became a "family with Parkinson's Disease," as my father puts it. My mother, diagnosed at the early age of 58 with Parkinson's, was now ten years into her diagnosis and no longer able to function on her own. At the same time, I made a career change and after 15 years of practicing social work, mostly with children and families but also with people with renal failure, I moved from California with my two grade-school-aged children to Kansas where I entered the Ph.D. program at the University of Kansas. At the time of my acceptance interview, they asked if I would like to start up a Caregiver Support Unit in the Topeka VA Hospital. Not knowing what the term "caregiver" meant, but being the true social worker that I am, I said "sure" and thus helped to develop the first caregiver unit in any of the VA hospitals across the country. In so doing, I learned what the term "caregiver" involved and have since devoted my academic scholarship to helping better the plight of caregiving for family members. My parents remained in California and the following letters were sent to me by my dad as I embarked on writing a national manual of caregiving for the VA. Our family, especially my father, became more enmeshed in the daily caregiving of a loved one, my mother.

Now almost twenty years later and ten years after my mom's death in 1997, Dad agreed to write this article with me, or alongside me as it appears to be falling into place. The

following are excerpts from letters written to me by my dad in November 1988 and April 2007. To differentiate between our two voices within the dated entries, my thoughts are written in italics.

November 10, 1988

Dear Sue,

Surprise! Your Dad will write a letter, once-in-a-while, when given a chance.

I always loved getting letters from my dad because it was not a frequent occurrence; Mom was the one who usually wrote, and as is usual with the diagnosis of Parkinson's, writing became progressively harder for Mom. Dad occasionally would write to catch me up on the daily happenings in their lives. I savored these infrequent letters from Dad.

I'm at the public library, enjoying a day of respite. We have a lady staying with your Mom from 8 A.M to 5 P.M today, and I'm on my own. I played 14 holes of golf this morning (decided that was enough for a first time out.) Then I went to Nancy's and finished a wiring job I've been working at off and on for several weeks. I've put in a shop light over the workbench and put in outlets for my bench saw and other power tools. I had lunch at a fancy Mexican restaurant and am now at the library.

As a family we talked about ways that Dad could have some time by himself and he had hired someone to come each week to allow him a "day off."

I just finished re-reading your paper which I received a couple of weeks ago: *Exchanging Caregiver Well-Being: A New Role for Social Work*. I've also studied through an *Aid to Empowering: A Caregiver Well-Being Scale*. I find both very interesting, although some of the latter escapes me, largely due to the research methodology vocabulary and the statistical terminology.

My dad is a retired academic and so as I began to learn more about caregiving I shared my writing with him both for editing comments, which I valued, but also so he might glean some of the information that I was learning from other family caregivers and researchers. The first of his comments focuses on the fact that most caregivers that I dealt with were female, as is the case today. Dad's comments made me realize how he personalized what I was writing, wanting me to be sure to look at the male side of providing care. My hopes were raised in reading his letter because I realized he might be obtaining some suggestions to better care for himself in the materials that I was sending him.

The following are some comments that occur to me:

1. If a choice must be made as to use of "she" or "he" in referring to the caregiver then yours is an appropriate choice as it focuses attention on the major segment of the caregiving population. (I'm not sure such a choice must be made however. Also, selecting terms to use generically on the basis of majority application can add a negative burden to the minority—whatever that minority may be.)

2. Such focusing of the social workers' and researchers' attention on one segment of the caregiving population can turn that attention away from some possibly different questions related to the male minority of caregivers.

Words of wisdom from a male caregiver's point of view who wanted to make sure he was heard. At the time few male caregivers were being heard from and the same is true twenty years later; it is recommended that caregivers be studied by gender (Pinquart & Sorensen, 2003). Researchers have noted, as Dad tried to point out to me, that over-sampling of one particular type of caregiver may influence the development of interventions and thus we are not able to best serve many of those providing care (Berg-Weger & Tebb, 2003-2004).

3. Your paper refers to “loss of control” by the caregiver, as regards his/her environment, as a major source of frustration. I can attest that this is of tremendous significance. How to increase the measure of control, or to expand it to new, meaningful areas, is something greatly sought by all of us.

4. When approached from the patient side, this loss of control has long been recognized. Now what of the areas of conflict that arise over need for control by both patient and caregiver in their interrelationship? How may these be resolved, or risen above? Ideally, the caregiver gains greater control of the sort needed in the very act or process of enhancing the patient’s control. Some of this should be possible; but the stuff of conflict on control questions is daily there.

Numbers 3 and 4 are areas we often would talk about when together or on the phone, especially when there were conflicts between his loss and Mom’s, such as in the area of Dad’s need to have friends, continue active traveling, and be involved in his community. Mom was unable to comprehend how she affected his ability to do the things he enjoyed. I believe these discussions helped me to better understand the caregiver’s and the care receiver’s points of view as I worked with and supervised students who provided support to caregiving families. It greatly influenced my ability to offer respite opportunities and to help others develop interventions with respite provided. My research influenced by these comments looked at and continues to look at how caregivers manage both the loss of and gain of control as their caring continues over time. For me it is the sense of or lack of well-being that is key to how well a caregiving family manages (Berg-Weger, Rubio, & Tebb, 2000; Tebb, S. 1995).

Well that’s enough of that, possibly more than I’m in position to knowledgeably give. But I want you to know that I think your approach is excellent. I haven’t seen anyone undertaking it from this approach, and it is greatly needed. (It’s also one more way to get

social work moving toward constructive models.)

In his career as an academic administrator he had helped start an MSW program at a college and was very much in favor of social work programs building their theoretical base in what he calls the “constructive model” which is what I term the strengths model. His use of “constructive” meant helping people see that they had the ability to make positive changes within themselves. (This is one of the first times I have realized that my strengths-based social work model was grounded in my upbringing.)

My effort in all this is simply a way of trying to share with you my deep respect for what you are doing. If anything I’ve written sounds critical, believe me, it is not! Suggestions and questions are my way of expressing support.

That last sentence has other applications. I’ve never been able to get your mom to understand that about me. Now, when I voice a question it is often interpreted as criticizing her or arguing with her. I guess that underneath it has always been that way. Present circumstances seem to exacerbate it, however. Thus, I must choose my words with greater care, lest I upset her. And emotional upsets now have severe physical consequences—consequences that then affect my ability to work with her and to “run smoothly.” It is potentially a neat control tool also, which she is adept at using, all the while being totally unaware of that fact. That’s probably one of the toughest things I have to deal with.

As I reflect on this now, this is an important insight into my parents’ marriage and also into how I relate to my husband. Active discord has always been the way dad has interacted with all his children and grandchildren. It is not a conversational mode easy for many who have not grown up in it, as my mother and my husband.

We are doing reasonably "OK." Mom has fairly extreme "on-off" periods related to her medication. During the "on" she can do most things for herself, and even forgets to expect the "off" times. During the "off" she is greatly handicapped, forgets what her next medication can do for her, and is convinced this is the worst she has ever felt and she will never feel better than this again.

I often wonder what it must have been like for my mom to go through these on-off times each and every day and not to remember that she would soon have a better time as soon as the medication kicked in. Looking at care receivers and learning from them is one of the influences my mother has had on my scholarship path. Often people working with the sick person have no idea what she was like when healthy, and I have encouraged, both in my teaching and in my writing, those involved with caregiving families to get to know the care receivers as they are today and also as they were before they needed care. These perspectives help in selecting interventions that might help (Berg-Weger & Tebb, 1998).

I don't want to burden you with any of this. It's just that I've never written some of it before, and it keeps coming out, once I have started to write.

She is on a three-day no protein diet just now. The effort is to see to what degree, if any, protein interferes with her absorption of her Parkinson's medication. She completes that program tomorrow morning. "No protein" is leaving her with increased weakness and shakiness. I'll be glad when we're through it. If it shows us anything, then the trick will be to withhold protein through the day and give her the minimum required at the end of the day. (Another problem for the chief cook, me).

Daddy hated to cook and Mom was a great cook. He could put together a breakfast if he had to and open a can of soup when needed, but beyond that he depended on Mom. Now he is the one who has to plan her meals and fix most of their

meals. He did work with a dietician and my sister and I gave him meals ideas, but this has never been an interest of his. But he did it and now is not a bad cook, but still does not enjoy cooking for himself.

We appreciated the copy of the booklet on Parkinson's that you made and sent us. I'm writing for more of them to share with other Parkinsonians here at Rosewood.

Rosewood is a retirement community my parents bought into in 1987 with the thought that my mother would need nursing home care and she could receive it there and Dad could live in an apartment on the grounds. Mom ended up living in the nursing care unit for eight-and-a-half years. (My dad remarried after Mom died and moved to another community in California that had a sister facility. He was able to transfer to the sister facility and his new wife bought in at a lower rate since he was already a member. He continues to live in an apartment at this facility.) This housing plan worked well for Mom and Dad.

Thanks for your regular letters. They are a really bright spot in the week for both of us. I know how hard it is to write and how overburdened you are—thus the letters are appreciated many times over.

My first year in college, the President's wife told me I should pick a day each week and write my family because I owed that to them for all that they had given me. To this day Sunday is the day I make contact with family, less now in writing but if I do write it is on Sunday. At the time my father wrote me I was still writing each week on Sunday to my parents; it had been twenty-five years since I was a freshman in college.

Well, I must wrap this up and head for home. My break day is about to come to an end. I'm delighted it gave me a chance to write at length. Love to all, and I love you.

Dad

November 17, 1988

Dear Sue,

Came across this item in an American Baptist newsletter for pastors. Course materials look expensive, but I think might be useful for learning what other caregivers are doing. I feel sure this would not be a bible-thumper's conservative approach, but a constructive one.

Dad had found material on caregiving and was sending it to me but also wanted to make sure that it would be helpful or if I thought it was helpful and grounded in what I was seeing in other caregivers. I realized upon reading this that dad was looking for help in whatever medium he could find it to help him deal with the daily life of giving care.

Mom has been doing about the same. Sure wish we could get some sort of "normal" schedule established—then we'd know how to plan our day and I'd be able to get at least something done.

Oh, well—so it goes.

"Normal" soon began to mean not knowing and not able to have a regular schedule. He had to learn that his day could not be planned and often he felt as if he had accomplished nothing during the day. This was very hard for my father because he usually had control of what happened each day before Mom became ill. It reminds me of mothers of young children who try to say what they did during the day but can think of nothing but that they cared for the child, which is a huge accomplishment but one that is not recognized or appreciated; nor is caring for an older adult. I think now as Dad reflects back on the time he cared for Mom he finds that he eventually became more comfortable with not living a regular schedule and now is probably better able to deal with the irregularities of his daily schedule today due to being over 90 years of age.

Love, Dad

November 30, 1988

Dear Sue,

Here is the copy of the manual you sent me. It is an excellent piece of work, professional and humanly sensitive. I congratulate you on it!

As supervisor of the Caregiver Support Unit at the Topeka VA Hospital, one of my tasks was to write a manual for family caregivers to be distributed to all VA hospitals. As I researched to prepare myself to write the manual I began to have a better sense of what my parents were experiencing and would send material to my dad to read. When I had a draft of the manual I sent it to him and this letter is what I received following his read of the manual.

I've taken the liberty to proofread it and to make editing suggestions. Since you said this is a first draft I hope some of this might be helpful. If I haven't caught what you want (in some of the changes I suggest) or if some of what I have done is too trivial, then just "consider the source" and ignore it.

My relationship with my father has always been one of "interested discussion." He and Mother provided us as we grew up with opportunities to question, discuss, and debate within the family. As I read this now I realize that Dad's approach to me has always been one of good positive criticism and he has asked the same of me. As an academic I have sought always to be open to constructive input from those with whom I work and live and I now better understand where that constructive criticism is grounded.

For a part of this, you had some difficulty with gender references. I tried to phrase around some of those. Others need to stand as "her/his" or "his/her" as you have them (where primary reference is to the general caregiving situation. Where attention turns more specifically to the caregivers with whom you work, you have gone entirely to the feminine gender, which is fully appropriate.

This is in view of the fact that the highly preponderant numbers of veterans (thus of care-receivers) are male and thus caregivers are female. Perhaps a note to that effect at an appropriate place (such as bottom of page 32) would be helpful.

Dad's attention to gender has encouraged me to look at the male view in caregiving. Much of the research is with females, but Dad's experience and his urging made me more aware of the plights of both male and female caregivers.

We're about as usual. Your mom is having a bit more difficulty week by week. I find it almost impossible to know when to respond to her requests for help and when to insist that she try to do it for herself. I think I encourage more dependency by giving help, and I don't want to do that. Her insistence often wins over however. We had a confrontation on that the other night, and she informed me I just didn't know what it is like to have Parkinson's. I told her she has never experienced what it was like to care for a Parkinsonian either so I guessed she would just have to deal with the way I do it—I think it was a “thought stopper” for her for a little while at least.

I remember reading this nineteen years ago and thinking—yea for both of them to have a “normal” argument, how healthy. My parents, before Mom was sick, had good healthy disagreements and could talk it out and compromise, but I had not seen that in their relationship for some time; and here it was, a brief glimpse of what they had had.

Getting her to bed now is almost like getting a four year old to bed. The lights have to be just so, her hips and shoulders must be aligned in the right position (varying from time to time), she needs a drink, a Kleenex, her bed socks, etc. Then every 30 minutes she must have help getting to the bathroom. It is getting a bit thick. I'm coping OK for now. Prayer helps a lot; having a sitter once a week makes a difference (I very soon shoot for twice a week); etc. There is friendly support

here (though few direct and immediate help) and we're making it. For how long I don't know, but I feel it can be dealt with as each new level of need occurs. Out of paper; hope you can read my scrawl.

Love ya!
Dad

This last paragraph helped me with the caregivers we were working with at the VA hospital. It provides coping ideas and that is what most of our work with the caregivers was, helping them find good coping mechanisms for themselves.

I asked Dad to reflect on these letters he wrote almost twenty years ago and to think about what he learned that might help caregiving families today. The following is the letter I recently received.

May, 2007

Dear Sue,

Ever since you sent copies of those three letters of mine you had hung onto from November, 1988, and asked me to write my perspective looking back on the caregiving situation I was in at the time, I have been at a loss to know what to say. I have a severe case of writer's block (and not only associated with this “assignment”). The days are passing swiftly and the month of May (when I planned to do the writing) is already more than half over. So here I am at the keyboard looking for a way to make a start. I have decided simply to begin writing (in the form of this “letter” to you) with the hope that the effort will begin to uncover some of what I have filed away in my consciousness as being “in the past,” and have given little or no attention for several years.

The 1988 letters do trigger a line of thought, so I'll try to develop that for a bit. I remember well the circumstances of discovering that your mom had Parkinson's. In the late spring of 1976, I noticed a change in her walking. She was developing a shuffle and also a tendency to take small, mincing

steps while on her tippy-toes. When she gave thought to her walking she strode along in her normal way, but when her attention was elsewhere she lapsed more and more into this new and strange way of movement. We went shortly thereafter to Canada for the summer and stopped by Miniwanca on the way. Dr. Robert Shank of Washington University Medical School was serving as Camp Miniwanca physician at the time, so I took this opportunity to discuss with him my puzzlement and concern regarding your mother's walking. He suggested we would do well to have her seen by a neurologist after our return from Canada in the fall. He did us the favor of arranging an appointment with a leading neurologist in the Chicago area.

A battery of tests and two thorough consultations with the neurologist produced a tentative diagnosis of Parkinson's disease. We, as a family, were set upon a journey we had not contemplated and of which we had little knowledge. Through succeeding years we came to realize that your mom's disease was not hers alone—it was ours as a family as well. Year by year there were adjustments necessary to enable her to keep functioning and to keep strong family bonds supporting her.

The need for physical support was obvious for the most part, and family rallied around and increasingly provided that support. Changes were made in the home; changes of major proportions were also made at the summer home in Canada; and ongoing changes were made in transportation, shopping, meal planning and preparation, and countless other areas of family life.

Need for support in the realms of mind and spirit provided the greatest challenge, for these are subtle in their origins, difficult to sense and to define, but tragically devastating if not well and adequately served. As with most long journeys, we began in full strength, and found the going relatively easy. In its early years, little seemed altered, little special effort was required. As the years proceeded, bit by bit your mom experienced losses in body and

spirit resulting in behavioral changes, and increasingly defining differing roles—that of the one requiring care and of those giving care. The letters you have unearthed reflect a time (roughly mid-way in the twenty year Parkinson's journey) when those roles were clearly in play, but had not yet been fully accepted by your mom. This was the time of multiple falls, broken shoulder, broken femur and continuing denial. For the caregiver(s) the time brought frustration and fatigue.

Also we as a family were gaining a better understanding of what relationship changes were occurring with Mom and those of us giving the care, especially Dad, and how Mom had become so dependent on others for care and this was not in her nature.

A few years earlier your sisters had invited me to their apartment (in Downer's Grove) for dinner, discussed their observations of what was taking place with their mom, and then focused their concern on me. The issue was the condition of my health of body, mind and spirit as I continued as primary caregiver in this ever-changing scene. Their concern was, "We don't want you to die of her disease." That brought me to what, on reflection, I see as a significant turning point in the way I would fulfill my role. No longer could I permit my activities and interests to be controlled and determined solely by the progress of your mom's disease.

Nor could we as a family. That summer, for the first time since my parents bought the land in Canada, Mom did not go to Canada. Dad used the care facility to care for her that summer and hired people to look in on her when he was in Canada. The summer before, her final summer in Canada, was not a rest for anyone. Dad was exhausted so he did nothing while there but read and relax, and my sister and I who were there with our three active grade school and middle school children did nothing but cook, clean, and do laundry, which was no small chore because mother was soiling herself most days and the

laundromat was half an hour drive away. The children could not understand why their mothers were so tired and not willing to play. My sister and I told Dad something had to change because the summer was not good for any of us. That next year things did change; Mom fell and broke her hip. She only saw her beloved Canadian cabin in photos after that.

Three main concerns became intertwined in my caregiving efforts. Ideally, none of the three should be in competition with the other two—each should be pursued with full regard to the others, in ways supportive each to all. And those three concerns?

1. Attend directly and fully to those things which must be done and which only you can do. If time and energy permit do whatever else can be comfortably done, otherwise seek additional help.

2. Share together with her, at whatever level she can function, the ongoing relationship of two people on a life path together. Memories, family stories, family activities, celebratory moments, special events, sometimes even frank discussion of the disease process and what together we are able to do about it—these and other ways of sharing create the context within which meaning for everyday living can be preserved and extended.

3. For yourself, look through, beside and beyond the confines of her illness. Define and seek activities and relationships that are nurturing to your own sense of self. The “Servant Self” must also be the “Growing Self,” else burnout will cancel all hopes, all joys and all meaning for both parties to the journey.

In retrospect, your mom’s time of multiple falls and fractures and the caregivers’ time of frustration and fatigue mentioned above provided the threat and the challenge which confirmed the necessity for me to actually weave those three strands into the fabric of my living. However vaguely they were recognized in my mind before, now they became a lifeline for me.

Two months or so after you received those letters from me your mom sustained another fall, resulting in a broken hip. During her hospital stay she began having strange hallucinations. That, of course, is not unusual for many folk confined in a strange bed following an accident, and here it seemed to pass very soon. It proved, however, to be the beginning of observable dementia, for it recurred, at first occasionally, then with increasing frequency in the months that followed.

Reflecting now on the course of my mother’s illness I realize that as a family the discussion of death is one that we do not shy away from. We did not with Mother’s; we discussed what she wanted in regard to end-of-life care and we have not with Dad’s. Each of us has talked about what we want at our own funeral and what if any life-support measures we might want. This has been especially poignant because my daughter was diagnosed with ovarian cancer at 25 years of age and we again had this conversation, painful for me, but necessary, thanks to what my mother helped us realize is an important part of living.

Her fall and hip fracture marked a significant turn in the journey both for your mom and for the rest of us as her caregivers. She was released from the hospital to the health center at the retirement facility where we lived. For a number of months there was a question as to how soon she would recuperate sufficiently to return to our apartment. Her physician, the Director of Nursing and family members monitored this issue carefully, and finally came to consensus that the answer to the time question was “Never.” That, of course, changed the caregiver role to one of “attending to,” and no longer “caring for.” That is another chapter in the story, another passage in the journey, which would merit its own account.

But as many of us know, the “attending to” is also very stressful and many caregivers of people in nursing homes fall ill themselves. Maybe it is because they are

finally able to "let down," and in doing this their immune system is affected and they fall victim to many illnesses. Dad was diagnosed with colon cancer about a year and a half after Mom began her residency in the nursing care unit. Studies demonstrate that caregivers have a lower immune response and thus they are at risk for cancer (Kiecolt-Glaser, Dura, & Speicher, 1991. Vitaliano, Zhang, & Scanian, 2003).

I conclude these musings with statements of some learnings that came to me in or from efforts to perform the caring role. I think all are important, even though some came to me too late to really help to any great extent. But here they are as they occur to me now:

1. Although it is the patient who bears the chronic problem, the entire family suffers the problem and is inescapably its victim also.

2. The caregiver could truly "die of the patient's disease," if he/she permits burnout to occur.

3. Don't take negatives personally when expressed by the patient.

4. Your loved one is a fractured person. You may not be hearing from the person with whom you once shared life and love.

5. Live your life anyway, even when you must serve her in crucial ways. Take regular and special breaks.

6. Find and/or create events/settings where she is included in group experience. Help her continue to belong.

7. Do not lay expectations on her that she cannot fulfill, even if she has carried that item all her life before she became very ill.

8. Teach yourself the art of silent grief—dispose of grief, day by day as losses occur.

9. Project your own life not only "with," but also "aside from" and "beyond" the stresses of everyday caring.

10. Seek all the help you can get as caregiver. Call on every resource you can unearth. Even then it will never seem enough. Few primary caregivers are as fortunate as I in having in the family both a social worker and a nurse as helpers, consultants, and supporters. (Still, there were times when even

more insight and assistance could have been helpful.)

Of course every list should contain ten items. OK, there are probably several more learnings that hit me at the time or on the spot, but these are what come to me now. Thanks for pressing me to do this, even against my apparent reluctance. It has been a good exercise for me. It has helped me remember and understand why I am touched by the pains and problems of many of my peers, especially here at San Joaquin Gardens.

Love,

Dad

Dad has continued to stay in a retirement community and, as he notes, because of what we shared as a caregiving family, we are able to help many approach and confront family issues around death and dying. I know that my siblings, our children, and I have grown from this caregiving experience. We have had numerous and long talks about how this experience has touched our family and four of the gifts we received as a caregiving family are:

1. *The experience has helped our family understand and be touched by the pains and problems of other caregivers and hopefully will prepare us for when it is our time to care or receive it.*

2. *Because of what we learned as a caregiving family, Dad especially is able to help many of the residents in his community to live "with," "aside from," and "beyond" the everyday care they are giving their loved ones. We, as Mom and Dad's children and grandchildren, are all able to work with and be around older people. All three of the grandchildren have a strong compassion and respect for older people.*

3. *My siblings, our children, and I have grown from the caregiving experience. We are more aware of the possible changes that occur in families and how families need to continue to work, grow, and support each*

other through the difficult times of needing care.

4. We also are very aware that we will more than likely be caregivers in our lifetime and hope we can be as gracious as it as our Dad/Grandpa was. (Dad became more sensitive and appreciative of the everyday little things that my mother did for him each and every day that he did not notice while she was well. He began to think about how people in similar situations might be helped and what was helpful and what hindered caregiver's well-being.)

In writing this article with my father I realized that I also have grown into the caregiving role over the past twenty years. As I noted earlier I had not heard the term "caregiver" until I started at the VA hospital in Topeka. While there I set up a caregiver unit in the hospital and wrote the VA's first national caregiver manual. Upon leaving the VA, I continued to direct my scholarship in the area of caregiver well-being and with colleagues have written over 30 articles and two books on the subject. My teaching is enhanced by our family's experience because I can speak about caregiving both from the heart and as an academic and, I hope, am better able to encourage new social workers to develop caregiving interventions that will help caregivers gain control and better well-being. I think more than anything this experience has helped me to see that caregivers and their families need options, all kinds of options for end-of-life care and that they need to be allowed to make the decisions that best suit their situation no matter whether it is understood by others or not.

I find that the following quote by Olympia Dukakis (May 2007) describes what we as a family came to learn, believe, and support in our twenty years of caregiving:

"Whether the illness is cancer or Alzheimer's, there can be no hard-and-fast rules about life after diagnosis—except that you need to be honest and flexible. It's an inherently personal process, and I doubt that care giving decisions are ever easy.

But made conscientiously...those decisions should be respected." (p.35)

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