

Excerpts from
LOVE SONG AT THE END OF THE DAY
A Journey into Alzheimer's

by

Muriel Weyl

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TO THE CARETAKER

Eleanor Roosevelt was right. She said:

“We do not have to become heroes overnight. Just one step at a time, meeting each thing that comes up, seeing it not as dreadful as it appears, discovering that we have the strength to stare it down.”

NOT TO WORRY

"There is a simple solution as to why you and I forget," he says. Alzheimer's disease is contagious. Dr. Alzheimer lived in Breslau where I went to school as a child. Since he and I lived in the same place, I caught it from him. And, later, since it is a sexually transmitted disease, you caught it from me."

IS IT – OR WAS IT – A DREAM?

WHAT IS FOREVER?

Third grade, fourth grade, fifth grade, they all blend together into one winter memory with friend Herberta playing Buck Rogers and me as Wilma, his faithful female companion, or as Dr. Heuer, the scientist who could predict the future or reflect on the past. We were the Buck Rogers team. We could invent a 25th century adventure with imaginary earphones that clued us in to other languages on other planets, we could deal with the Martians who came to capture us, we were confident and unafraid as we wandered in the open space across the street from where we lived. It was a city block long and a city block wide, its unattended, uneven land providing small hills for sledding, large trees to hide behind, craggy land to climb over and our favorite spots where we could collapse after our active play and wait for the darkness to slowly cover us.

We didn't think about our heavy, wet snow suits. We felt warm and safe in the glistening snow as the stars slowly appeared. That's when we would make up stories, tales about how we could be like Robin Hood saving the world and how we would be saved from evil by brave princes. Herberta would sing to me, her alto voice awakening our very young romantic imaginings gleaned from stories like Rapunzel who let down her golden hair so that her prince could climb up to rescue her.

As the twilight came, she would sing "Red Sails in the Sunset" and we would dream of entering other worlds. We would half close our eyes as her mellow voice surrounded us with "When the deep purple falls over sleepy garden walls". . . and "In the

mist of a memory, you wander back to me.”

The deep purple became the night and we would finally remember we were children. We would hurry home, worrying that we would be scolded for returning so late, but promising each other a repeat performance the next day. In those days we never thought about the future. We knew we would live forever.

So, in our real world, what is forever? In our eightieth years, has forever been long enough to see the world without our childish eyes, without the personal comfort of an intimate love song at the end of the day? Has forever been long enough to have seen Herberta’s Bob lose his sense of reality before he died and to know that my own Peter has Alzheimer’s? Is forever ever long enough when there are still songs to be sung and stories to be told?

THE ADMONITION

On our wedding day his mother gave me a wooden darning egg and many yarns of many colors. She told me that she was giving me her son in perfect condition and if ever I returned him, she expected him back in the same condition. Privately, I laughed. I threw away the darning egg. I never darned a sock. On a wedding day no bride thinks she will return her groom. But I didn't forget the admonition that if I returned him, he should be in the same condition as he was when I got him, young eager, healthy, unafraid. It's 58 years later. There is no one left to return him to. And, even if there were, he is certainly not in the same condition.

WILL THE PILLS MAKE MAGIC?

He knows that he knows what he knows and he knows that he knows what he doesn't know. For instance, every morning he knows that he has already taken his pills and every night he knows that the pills have already been consumed. But I know better! So it takes cajoling, persuasion, argument and insistence to get them down the hatch.

You would think it would be easy. Put the pills in compartmentalized boxes. Leave the squares for yesterday's pills empty so that it is obvious which pills must be taken today. Always fill the pill boxes on the same day of the week so that there is no question that one day has been repeated or overlooked. Be sure not to interchange the boxes so that the day pills and the night pills are always in the same box.

To insure that the pills are taken correctly, you repeat every day that you have to be in charge, that you will remember the pills and administer them. Easier said than done! You don't always remember to give them to him and he always remembers that they were taken when they weren't. Never mind his pills, you have to remember your own, which are in other boxes and should be taken at other times. There is the pill an hour before breakfast, the pills with breakfast and then the various times at night when the others should be taken.

There are the twice a day prescription pills obtained from the pharmacy, the pills that have to be ordered from Germany, the pills for the medical trial, the pills that are nonprescription and the pills that are there but are set aside unless there is special cause,

like headache or dizziness or leg pain or stomach upset. And then, when you really forget the pills, he blames you because you are supposed to remember.

Never mind. It's all done in a few minutes in the course of the day and the rest of the day is filled with the excitement of life. But first there is the list that has to be accomplished, the household, the laundry, the grocery, the cleaning and shopping needs and he has helped by compiling a list which is attached to a magnet on the refrigerator. It contains the items I bought yesterday or last week, the laundry soap and the butter as well as the items that really need attention. It requests tonic water which we already have an oversupply of in the garage, the special black bread he used to have in his childhood in Germany and the extra sharp gouda which can only be bought in New York.

Not to worry. It will all be taken care of in between carrying out the other plans, plans for friendly lunches and dinners or a little tea in between with a friend here or there, plans to help the various organizations on my list, like in the arts or politics, plans to take care of friends who are ill and need help, plans to visit museums and galleries locally or further afield, plans in the city, plans to visit the children, plans to go out east, plans to plan trips and plans for time to write these stories.

Now in order to accomplish all these things we must leave home and that requires taking the time to leave the notes, leaving the notes at the last minute when time is of the essence because someone is waiting somewhere for some event. He will be happy if he knows what, where and how I am doing all these things.

Don't forget the cell phone, Muriel. Not that he will ever call me. But I must call to check, to remind, to change the time of my return and to keep the calm.

After all, where we live, where we never have any time, where we make time for

everything, and where we have no time to contemplate anything, I want time for that too.

Peter, on the other hand, has no problem with time. He knows that he doesn't know the time. He knows that he thinks it is June when it is August. He knows that when he is in the doctor's office and there are no windows that he has even forgotten what season it is. He might still have the perspiration on his body from the searing heat of an August day and when queried, he will be puzzled and respond that it could be April. Spring, summer, fall, if he can't see the outside, he doesn't recollect what the weather was. Winter, when it is very cold, that might make an impression. But he is sure that he can figure it out. He knows that he only has to consult his watch to tell him what time it is, what day it is, what month it is.

Of course he is always traveling with me, from the east coast to the west coast, and from the east coast across the Atlantic. Then there are all the places and times in between. When he resets his watch, he forgets to set it back. But often he doesn't set it and so he is constantly trying to figure out what the time difference is. When we were in Texas this past summer, it was one hour earlier, in Albuquerque it is two hours different, and on the west coast, three hours behind New York. We were in all those places in July and in August, when we were in Prince Edward Island, it was one hour ahead. His watch never had the right time and when he came home he was constantly busy trying to reset it, the technology of which is impossible.

Lucky we weren't in England as well this summer. When we visit daughter Ruth, who lives in London, it is five hours ahead. Ruth tells us to call her when we need the right time because she lives on the first hill south of London and from the study upstairs she can look through her telescope and read the time on Big Ben.

Peter may not be able to remember the time but he always has the time, time to read the books, more than fifty of which are stacked in piles beside him, time to help me with whatever I need, time in which he doesn't worry about having time. He cannot understand why I rush around, why I worry about time, why my time is in deficit when his time is his bounty.

It strikes the world that this is a burden for me, but what they don't know is that he's worth it. His weaknesses are only the tip of life's iceberg. Just think, he travels with me, he watches over me, he waits for me and he waits on me, he helps me and he educates me. He cuts out the articles which he knows will interest me, he underlines the paragraphs I must read in his beloved books and, best of all, he comforts me. At night, as he asks for the fifth time what my plan is tomorrow, his gentle hands warm me into a sound sleep, assuring me that in my 80th year, I will wake up in the morning.

HOW DELICATE IS THE BALANCE?

From the stage of the Irish Repertory Theatre, when she was asked after her husband's death what she missed most about him, she responded, "It was all in the fight, Maggie. The fight kept us going." We can't remember who the actress was or what the name of the play was. But the statement hit home. It became an adage, a maxim, a motto and a joke during our marriage of fifty-eight years.

When Aunt Gretel came to visit for the first time and baby Stephen was demanding milk from my breast and toddler Ruth was exploring the household, and people with babies were coming and going, and Peter was experimenting with making mobiles, and the house was a mess and I yelled for help, she went back to the family in England and she told them we'd never make it.

Aunt Gretel was right about so many things. Like she insisted that Uncle Paul leave Germany with her in 1933 so that he could practice medicine freely and because of that move, Peter and his sister and his parents were saved from the Nazi peril five years later. But, for once, about us, she was wrong. It may have taken more than 50 years to prove it. But about us, about Peter and me, she was definitely wrong.

When, for years after our marriage, and even now, when he would refuse to join me in activities or events I had planned or to keep invitations we had, when he only wanted to stay home to read and study, I would say, "Go, go find another woman, get a younger woman who will take orders and do what you want when you want it." and he

would answer, “You’re right. But I’m not going to find a younger woman; I’m going to find an older woman. That’ll fix you.”

When there was an argument about fixing the washing machine or the vacuum cleaner one more time when I would lose my patience watching him trying to fix it and wanted to throw it out, he would remind me that the only reason we were the perfect couple was because I made the problems and he fixed them.

But when my parents followed us around the country, moving two or three thousand miles three times, there was never any problem with that. And when my mother came to live with us for the last fourteen years of her life, he welcomed her and there was never an argument about her presence. When I wondered aloud why, at forty, with two teen aged children, I now had an infant and an elderly mother, Peter would remind me how we needed them both because they needed each other.

When Linda and Charlie would amusedly call us Mr. and Mrs. Bickerson when they came from the city for dinner on Friday nights and we were cooking and preparing dinner together, he would remind me later that bickering was like “scientific” argument. It might be the only way to reach the perfect solution.

But when I would voice a regret over some decision that he had made, he would always say, “ I only made one bad decision in my life. When I saw how your mother treated your father, I knew that the apple didn’t fall far from the tree, so I asked you to marry me. How did I know you would turn out to be assertive like your father and not angelic like your mother?”

Well, then there was the other side of the coin when friends and visitors came and praised us and told us we were models for them. They liked the banter. They saw the

argument as humor. They didn't take it seriously. What is bickering and indifference to some seemed like humorous banter and a healthy independence to others. So how do I to know what is style and what is content?

Just the other night, Sharon said, "I understand now. You don't take each other seriously. Here he is with Alzheimer's and you treat him like he has a common cold. And there he is following you around with his book bag on his shoulder, waiting for the moment when the curtain doesn't go up or when there is an intermission at a concert or when he can pull out his trusty book and read in a quiet place while you shop. He has what he needs and you have what you want.

These days, after all those years, as we travel around and appear to be the loving elderly couple, people are always asking us how long we have stayed together and, when we tell them we are in our 58th year,, they want to know how we have done it.

In Santa Monica it was the young man behind the counter of the pharmacy. "What is your secret," he asked as we paid the bill?. In the Berkshires it was the middle aged woman at the dance concert who told me about her recent divorce as she asked how we could stand it. Coming back from Scotland to London, it was the man on the train making paper flowers out of paper napkins. He gave me one of those flowers and asked how long we had been married. When I told him, he was apparently so impressed that he invited us to his company's Christmas party. We came to Richmond on the appointed day and found that we were honored guests given sequined cowboy hats and American flags. They all wanted to know the secret of our long marriage and Peter told them the story of how when the Arab had wanted to buy me for a thousand camels on the deserts of Israel, he had told them that one wife was trouble enough.

When they ask us these questions, we look at each other in wonder. We are such extreme personalities. Why, how in the world did we last together for so long? We could have had other opportunities. Maybe! What is the secret of this game of sometimes moving three steps forward and only two steps backward? Is it ignorance, is it argument, is it having a sense of humor or is it a nonchalant attitude toward each other?

After all, there were many things we never argued about. The big things were never a problem. For instance, the children! We lived in an age when he didn't participate much. He was always there, but I was responsible for bringing up the children. I made the decisions about their activities and their needs. No problem. And then, the other big item, money. How should it be spent? For so many years he made the money and I spent it. And then I made the money and I spent it. No problem.

Well, at this stage of the disease, it is true that I haven't had to really change my lifestyle. Answer the questions, leave the notes, remember the medications, forget the losses and carry on.

One of the hundred items on the questionnaire for the new medical trial asks me to rate from one to five how good I feel about being a caretaker and having him as a patient. Does that mean "enjoy?" What kind of a question is that? Did he enjoy taking complete care of me for seven months fifteen years ago when I was in dizzy despair two days out of three, when I couldn't get out of bed on those days, when I couldn't stand noise or move my eyes without nausea, when I thought it would never end, but when I insisted he take me to London to visit the children and he had to cope with me, dizzy, in noisy airports and on long airplane trips?

Life is a toss up. Heads or tails, rich or poor, sick or well, let the dice roll. Unlike

the last line of the opera *Pagliacci*, when he says the comedy is finished, we have to say
“La comedia e no angora finite,” This comedy is not yet finished.

DESTINY

Years ago when we moved from Texas to Oregon, young son Stephen had no patience with sightseeing. Why should we walk on the White Sands of New Mexico? Why should we have to view the Grand Canyon from all corners? Why should we explore a cave in Oregon?

"Be patient," we said. "Enjoy your life."

"You don't understand," he said. "I'm in a hurry to get to my destiny,"

He was wrong, of course. He meant that he was in a hurry to reach his destination. He was too young to understand about getting to one's destiny. Well, we weren't in a hurry to get to our destiny then and we certainly aren't in a hurry now.