



Nevada Department of Veterans Services

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INTRODUCTION:

Delighted to be presenting to the Nevada VA Community

Born in Ely

Story about Rotary Club of Reno

Different venue

Mike's and my story:

Husband diagnosis in 2002, died in 2011, (9 ½ years)

My fears: Mike would run away or get lost, he would harm me,

someday he would not know me, Mike's anger, could I do this?

Mike's fear: "I don't want to leave you and our home." (Page 15)

NONE OF OUR FEARS CAME TRUE

What can I say that is most meaningful for you?

THREE KEY POINTS:

1. STAY HEALTHY

If you don't take care of you, then everything falls apart.

The person you are caring for also needs to stay as healthy as possible.

2. STAY SAFE

Has new meaning today with corona virus.

It includes body mechanics, transfers (sit to stand), walking and falls—gate belt, and in our case anger management.

3. STAYING IN LOVE

If this is not your partner in life or a beloved family member, then this might be thought of as "appreciate" the one you provide care for.

When your relationship is on track, then you can go about your day with ease.

Now let's discuss the three main points in detail.

1. STAY HEALTHY:

It is easy to let everything else come before your health.

KEY CONCEPT: If you do not take care of yourself, then you cannot provide care of those you care about.

Chapter: *The Best Medicine of All* (Page 206)

Norman Cousins introduced laughter therapy in 1979

Growing body of research supports laughter can improve the quality of life.

Relaxes the body, boosts the immune system, triggers endorphins.

Perk-up when family and friends came to visit.

Insights: (Page 213)

1. Some cancer treatment centers have introduced daily "laughter sessions" for their patients."
2. New York Times featured a group called "Nurses for Laughter" at Oregon Health Science University. The nurses wear buttons that say: "Warning: Humor May Be Hazardous to Your illness."

Chapter: *Keep the music Playing* (Page 206)

Chapter: *Why I Finally Hired a Professional Caregiver* (Page 232)

It was not easy for Mike or Me to get on board with the idea.

"Mike, I need you to help me. This is something you can do for me."

Sabina, listened when things were difficult.

Offered moral support.

Gave me praise and encouragement when I needed it most.

Taught me how to do things safely and efficiently.

Alerted me to what we might expect next.

Honored Mike's presence and included him as fully as possible in our conversations. Instead of talking *about* Mike, either in person or behind his back, we made a constant effort to talk openly *with him* and *to him*.

Chapter: *Why I Finally Hired a Professional Caregiver* continued (Page 235)

CRITICISM: pointing out something negative in your partner or blaming them for a problem by naming personal flaws.

REMEDY: COMPLAIN WITHOUT BLAME

DEFENSIVENESS: Is used to protect against feeling blamed or attacked.

REMEDY: ACCEPT SOME PERSONAL RESPONSIBILITY.

CONTEMPT: Roll your eyes or put him/her down.

REMEDY: APPRECIATION

STONEWALLING: when the listener withdraws.

REMEDY: TAKE A BREAK

(To learn more about these concepts read: *The Seven Principles for Making Marriage Work* by John M Gottman, PH.D.)

Insights: (Page 235)

Having a professional caregiver can be compared to couples having a birth doula. What sets the doula apart from what other loved ones can provide is that she/he had done this before and knows what lies ahead.

2. STAY SAFE:

Has new meaning with a pandemic:

masks, social distancing, handwashing and more.

Includes: body mechanics, transfers (sit to stand), walking/ falls, gate belt

And in our case anger.

KEY CONCEPT: In order to continue to provide care at home, you have to be sure it is safe for you and those you care for.

Chapter: *When Words Begin to Fail* (Page 125)

This can be a time of frustration for you and the one you provide care for. Mike was always able to communicate with me.

Insights: (Page 137)

1. Listened when he wanted to talk about the difficulty.
2. Told him often what a good job he was doing communicating.
3. Later, I became his voice and told others what he liked and did not like. I even verbalized his feeling when I thought I knew them.
4. Learned to remain patient, pausing often to give him time to process words or information.
5. Focused on what Mike said and valued what he said.
6. Stayed calm, and encouraged a break when we needed it.
7. Refrained from using the word "DON'T." I helped Mike by communicating what to do rather than what not to do.
8. Used simple sentences, such as "lift your foot."
9. Included him in conversations I had with others.
10. Talked with him about his day, my day, and our day.
11. Remember your loved one may not have the words to tell you something, but he or she knows more than you might think.
12. Never give up, just keep communicating any way you can.

Chapter: *Understanding Alzheimer's Anger* (Page 97)

Stories (Page 101 and 102)

Insights: (Page 106)

1. An opportunity for closeness.
2. Mike's emotions were much like a young child's when they cannot make you understand what they are trying to tell you. I had to always remember how difficult it was for Mike not being able to get me to understand him.
3. The caregiver can make a difference in the number and intensity of unwanted emotions.
4. There were times when Mike's anger made it seem as if Mike was no longer Mike, but that was not true. Throughout the entire 10-year illness, Mike was always Mike, I just had to find ways to tap into who he was and not lose him in those brief angry moments when he seemed to no longer be with me.

3. MOST IMPORTANT STAYING IN LOVE:

Keeping your relationship on track with your partner when you are also the caregiver is not easy and Corona Virus makes it even more challenging.

KEY CONCEPT: If your relationship is on track, then you can manage your day with ease including the difficult times.

Chapter: *Arguments will happen* (Page 82)

Travel story and Mike driving Don't fear the arguments, they are an opportunity to enter their world.

Take a break

Soften Start

Listen and hear their perspective (challenging with limited speech)

Discuss calmly and compromised

Yield to win

Neither person get it all their own way

Chapter: *Can a Spouse be a Caregiver and still be a Spouse?* (Page 181)

Friends said I could not do both!

I had to do two things: take care of me and

Taking Care of our Relationship: (page 183)

1. Daily stress reducing conversation:

At the end of the day, had a chat

2. Even at the very end, I was still talking to Mike---he was still Mike.

3. Departures and Reunions (Hugs and Kisses Page 215)

Rituals enhance relationships

4. Praise him for what he did right.

5. We took time to reminisce about our lifelong love story.

6. We continued to create love stories.

7. I was patient with Mike and careful not to criticize him.

8. I listened to Mike and showed I sincerely valued what he said

CLOSING:

Research dollars are pouring in.

New medication, soon blood test for early diagnosis, medication early can slow the process

Studies: Life style makes a difference.

DIET--- Mediterranean (Fish, nuts, fruit, grains, vegetables 8-12 per day)

EXERCISE---What is good for the heart is good for the brain.

SOCIAL---What you are doing right now.

SLEEP---Mike's brain needed sleep (route).

Summary:

- Remember to laugh
- It's ok to ask for help
- Anger is an opportunity for understanding: give yourself breaks
- Rituals of departures and reunions

Chapter: *We are All in this Fight Together* (294)

Please don't fall into the trap of talking to others without acknowledging the person with Alzheimer's (or with other challenges). Continue to smile and make eye contact with them, even though it may not seem they are tracking the conversation. The truth is, a person with Alzheimer's (or a physical or a mental disorder) usually knows and feel much more than people give them credit for. Your kind and compassionate acknowledgement of their presence in your conversation can mean the world to them.

As Mother Teresa reminds us, "We shall never know all the good a simple smile and a caring work can do."

End of Life: STORY: Friends 50th Anniversary

Celebration of Mike's and my 45th anniversary on May 21

Mike died June 6 at home, just as he wished, and still in love with me. Some will ask how was this possible?

IT WAS ONLY POSSIBLE BECAUSE OF A CIRCLE OF FAMILY, FRIENDS, AND CARING PROFESSIONAL CAREGIVERS-----THANK YOU FOR BEING THERE!