

LIFE AS A NEN PATIENT CAREGIVER

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WORLD NEN LIVES 2020

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FEAR AND HOPE



Included with kind permission of the Carcinoid Cancer Foundation,
50th Anniversary Videos
www.CARCINOID.org

OUR LIFE TOGETHER

- I first met Mack in the Fall of 1964.
- My husband, Mack, was diagnosed with carcinoid cancer in 2000. (I call it carcinoid because at the time of his diagnosis that was what it was known as.) I know that in the video you just watched that he said he was diagnosed in 1997. I did not realize until months after the video was made how much his mind was already affected.
- I was Mack's caregiver for 18 years
- I want you to know that you will have good days and bad days. But through faith, family, and friends you can get through anything!

- July 2000:
 - Episode of severe vomiting and abdominal pain.
 - ER visit
 - While waiting to see the doctor Mack stopped vomiting and the pain was gone. The treating physician told us they could find nothing wrong.
- October 2000
 - Vomiting and having severe abdominal pain.
 - Intestinal blockage
 - Surgery: removal of appendix (we later learned there were a cluster of lesions surrounding this area) and 15 inches of his small intestines. He spent 2 weeks in the hospital. Recovery was extremely difficult! We did see the pathology report prior to leaving the hospital. It mentioned **carcinoid**, but the word had no meaning for us. Cancer was not even on our radar.
 - **Liver Specialist: How long have you had cancer?**
 - Surgeries, blood tests, CT scans, Octreotide scans, MRIs, Sandostatin injections

OUR LIFE TOGETHER

- 2007 – Dr. Michael Choti – Johns Hopkins, Maryland
- *During this time, I felt it was my job as caregiver to support any decision Mack made pertaining to his disease. I had basically been quiet during the visits to Emory, Florida, and Louisiana, but when I met Dr. Choti I felt we had found the doctor for Mack.*
- 2008 – Abdominal Lesions removal
- RFA on liver lesions
- 2004 – Beginning of MACAG – Metropolitan Area Carcinoid Awareness Group – Atlanta Georgia
- Mack became Leader in 2009
- Telephone and in person counseling of patients and families throughout USA
- *“HOPE IS A GOOD THING” – Mack*
- Michael became a co-leader

- When Mack was diagnosed it was understood that we *were a team no matter what was needed.*
- One of the things needed was the person behind the leaders of the support group. So, while Mack and Michael did the talking and research, *I became their “wing-woman”.* I responded to emails requesting permission to join the group, approved them for membership, typed all the newsletters that Mack wrote and posted them to the MACAG website. I updated the website when needed, sent notices for the meetings, and made certain lunch was available for each meeting.
- Spent *hours on the phone talking with new patients,* because they always seemed to call when Mack was on the golf course. I made certain that the group ran smoothly so that Mack and Michael were available to give each member the knowledge needed to deal with their disease.
- 2008 – 2016:
 - doctor visits, testing, scans, sandostatin injections, and his work with the support group, our church, family, friends, and our dog.

OUR LIFE TOGETHER

- 2016 - 2017
 - Four Partial Bowel Blockages
- 2017 – December 2018
 - Numerous hospitalizations due to difficulty with the healing of the incision (fistula), pain, and the inability to eat or gain weight. We tried power drinks, milk shakes, high protein drinks, TPN. But none of these worked.
 - Mack continued to work with the support group alone since Michael had moved to Israel in 2017.

- Last six 6 months of Mack's life
 - Mack had periods when he was short tempered with everyone, including me.
 - We had been married 50 years and suddenly he told me he did not trust me
 - He often had difficulty remembering names, appointments, or what he told someone on the phone. He told me he did not trust me.
 - He could not remember our address or what day of the week it was.
 - Many days he was mad at the world. He was often very unkind to me, our friends, and to his beloved Petey.

OUR LIFE TOGETHER

- Last six 6 months of Mack's life
 - PRRT – Mack preferred to go through it alone while I took care of our dog Petey who was ill
 - *It was difficult for me to not go with him, but I felt as his caregiver I needed to do as he wished.*
- *Last two weeks of Mack's life*
- He was no longer able to walk or take care of himself. Mack once again changed back to his old self. He especially wanted his friends to visit.
- Mack finally lost his battle with Neuroendocrine cancer and went to be with his Lord and Savior

- Last six 6 months of Mack's life
- In March of 2018, Mack was honored by the Carcinoid Foundation for the outstanding work and contributions he made to the understanding of this disease. Plus, it was in appreciation for his tireless efforts helping others who were searching for answers. He was asked to make a video for the 50th anniversary of the Foundation. In the video Mack states that he was first diagnosed in 1997 (he was diagnosed in 2000). *I did not realize until later how much his mind was already affected.*

OUR LIFE TOGETHER

- What you can do for your Patient
- The caregiver does not go through the testing, surgeries, treatments, etcetera, that encompasses the life of the patient! But *you do all you can to make their life a little easier*. Whether it's keeping track of their doctor appointments, making certain their prescriptions are picked up from the pharmacy, getting them what they want to eat, helping them to shower, helping them get dressed, driving them to where they need to go, waiting with them at doctor appointments, listening to them, staying with them at the hospital, or just being with them. Your life revolves around the patient and their needs.

- You *shed many tears* because you know there is not anything you can do to take away the uncertainties, the pain, the suffering that the patient goes through.
- As a caregiver, *you need to have (although at times it will be difficult) compassion, kindness, gentleness, and patience*.
- What they need is for you to be there with them, for them, to hold their hand, or to offer them words of encouragement.
- Most importantly, let them know how much you love them!

IMPACT ON THE CAREGIVER AND FAMILY

- Initially life did not change much for me. Mack was an easy and independent patient
- After his third surgery, my life totally changed! It was as though I was always “on call”.
- Mack being an extrovert It became difficult to get out of the house due to nausea, diarrhea and such.
- Life became tenses
- Mack had very little appetite.
- I Learned TPN, became “nutritionist”, became “nurse”, became his “secretary”, provided pain medication per schedule. Mack was no longer able to follow a schedule

- Cleaned him when he was no longer able to take care of his body
- I should have asked for in-home assistance earlier – I could no longer take care of his needs by myself and I am a healthy person!
- I started losing patience with Mack – he constantly wanted to know where I was.
- Did not know what to answer him what to say when he wanted to end things since he no longer had the quality of life he enjoyed
- There were days when I wished I were not burdened with a sick husband. There were many days I wished that my life would just get back to normal or what I thought it should be like.

IMPACT ON THE CAREGIVER AND FAMILY

- It was good to be able to take our dog Petey for a walk. I needed it.
- You need a Petey in your life, a friend who can simply listen without giving solutions.
- We were and are surrounded by very close friends. I always had someone who could be with Mack when I needed to be out of the house.
- I encourage you to advise your caregivers to reach out to those who are more than willing to help.... whether assisting with meals, visitations, or anything else they can do. They are the ones who provide the encouragement needed, who help you laugh, lift your spirits, and pray for you.

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- As a caregiver, you need to have (although at times it will be difficult) compassion, kindness, gentleness, and patience.
- What they need is for you to be there with them, for them, to hold their hand, or to offer them words of encouragement. Most importantly, let them know how much you love them!

IMPACT ON THE CAREGIVER AND FAMILY

REMEMBER
TO TAKE CARE
OF YOURSELF