

*****Please give this to your caregivers*****

Thoughts and Comments from Caregivers – 2015

(compiled from the Caregiver survey)

Five to Fifteen years (2000-2010)

- *Early on in my wife's journey, I had tried to bring up some issues verbally about the caregiver's role in the patient's recovery, but the staff did not have time to absorb the comments. SCCA has an outstanding LTFU department, but back then they did not have the resources to consider implementing any caregiver suggestions. So kudos to you for finally going down this path. Caregiver of Allogeneic transplant 2002 – now 65 years old.*
- *Being a caregiver was one of the most challenging and rewarding roles I've played in my life. It truly brought my husband and me closer and we share something special from what we faced in our later 20's to early 30's. Gave our life great perspective and deeper meaning. Bittersweet and full of gratitude. Caregiver of Allogeneic transplant 2005 – now 40 years old.*
- *I actually found caregiving for my wife rather rewarding. She has had an excellent outcome and I feel that I share in the success. Caregiver of allogeneic transplant 2006– now 65 years old.*
- *When I heard you were doing a caregiver survey, I thought, "Finally – someone cares." Unfortunately, this survey does not bear that out – I didn't get ill from my husband's cancer – it's not contagious. What I got was an altered world view. You saved his life – thank you, but mine took a huge dent. I'm frequently sad + angry & can't seem to get past it – it's not your fault, but cancer SUCKS. And being a caregiver is HARD. No one tells you how to do it or help, so you're always wrong – no matter how educated or well intentioned...Caregivers could use more than the intro, "Don't go bonkers," talk. Caregiver of Allogeneic transplant 2006 – now 48 years old.*
- *At times I feel like the first wife of Stephen Hawkins as my husband is a nationally renowned research scientist in his field. Like Ms. Hawkins, who was also a PhD, I feel invisible most of the time. When my husband passes, there will be a great deal of notice. When I pass, only my closest family + friends will do so – will understand. If I pass before him, most will worry about him – in spite of my having literally saved his life time and time again. Caregiver of Autologous transplant 2006 – now 72 years old.*
- *I'm very lonely now and have trouble making new friends at my age. I still worry about my daughter's long term health. I get confused a lot and I'm often preoccupied with the memories of what we have endured. I am less happy in spirit, but my daughter is healed. Caregiver of Allogeneic transplant 2007 – now 38 years old.*
- *The caregiver makes or can make a huge difference in the outcomes for the patient. Listen to the caregiver more and give more encouragement to them. They are mostly ignored. Offer them emotional support also. The patient is often too sick to know what is happening. The caregiver is*

not. Besides fear they are usually sleep deprived and overwhelmed. Caregiver of Autologous transplant 2009 – now 70 years old.

- *I learned I was stronger than I ever though emotionally. I learned medical procedures I never knew I was capable of handling and did just fine. Caregiver of Autologous transplant 2010 – now 54 years old.*

Why are you doing this?

- *The reason I am writing this is because, 25 years ago, the questionnaire might have seemed more appropriate. We have dealt with these issues on our own over the last 25 years and you just now resurface these feelings? Caregiver of Allogeneic transplant 1990 – now 46 years old.*
- *When your wife is ill and needs care it is the duty of the spouse to stand with her no matter the issues. What does it benefit to have caregivers fill out the survey, I would love to know the what's and why's and where it helps in the treatment of other patients. Caregiver of Allogeneic transplant 1990 – now 70 years old.*
- *Instead of asking so much about me ask how I feel my spouse is recovering. She is the one that went through he**. Caregiver of Autologous transplant 2014 – now 30 years old.*

Patients can help their caregivers by helping themselves

- *The biggest frustration for myself and our family is his not having taken care of himself by quitting smoking after his transplant. Were it not for marijuana, he would still be smoking. Caregiver of Allogeneic transplant 1993 – now 62 years old*
- *Post-transplant was harder for us. They structure of the day wobbled. Not being a nag, I found it necessary to repeatedly correct his memory of doc's instructions and limitations. As he improved he pushed and went against all safety and most hygiene rules. It wore me down. Caregiver of Autologous transplant 2015 – now 74 years old.*
- *The frustrating part of caregiving is when the patient doesn't follow doctor's orders and I have to chase around to clean up the mess over and over again. Caregiver of Allogeneic transplant 2015 – now 71 years old.*
- *As time passes and immediate worries of infection and the chances the cancer returning lessen, it becomes harder and harder for me to tolerate behaviors that are not healthy on his part. Nutrition is one, exercise is another, adequate sleep is a third and water is fourth. My husband sees a counselor on a regular basis and is working on self-responsibility. But the road is hard. He thinks that if you have been snatched from the brink of death many times by modern medical wonders and a supportive family, it is not necessary that you take responsibility for yourself. A juvenile, expensive and exhaustive attitude. But my big questions are: When does caregiving stop?; And what are the consequences of that stopping?; Who will have to bear the brunt of the return of the cancer or other diseases?; I took my role of caregiver very seriously, but what happens now?; Perhaps caregiving has turned into enabling? Caregiver of Allogeneic transplant 2011 – now 70 years old.*

- *I have to not be so frustrated that he doesn't seem to be more careful in taking care of himself now. With all of the efforts people have taken to help him to be healthy! Caregiver of Allogeneic transplant 2013 – now 70 years old.*

Worries

- *My failing health (cancer x 2) makes me worry that I will not be able to care for my spouse when she most needs me or, worse, that I will rely on her to be my caregiver. Caregiver of Allogeneic transplant 2008 – now 69 years old.*
- *I find it difficult to make plans – both short and long term. Feels like always waiting for the next crisis. Caregiver of Allogeneic transplant 2014– now 61 years old.*
- *Unfortunately, I as the caregiver, am suffering from PTSD. My first anxiety attack happened July 2011 and I have not fully recovered since. It has been quite a ride for me – my therapist said that after my son got stable and healthy again, I then “crashed.” Caregiver of Allogeneic transplant – now 26 years old.*

Caregivers need to be cared for too

- *I'm having some challenges getting used to doing more of the things my husband was usually responsible for. Also miss having my husband as my caregiver when needed. The other thing – and this was huge during the transplant experience – is that I still feel that as a caregiver I'm largely ignored by the health care team – I'm never asked how I'm doing or even how I feel my husband is doing – When will providers get that caregivers stress/health is directly related to the patient's health and well-being???? Caregiver of Autologous transplant 2011 – now 72 years old.*
- *Being a caregiver is emotionally draining. There are so many days that you have to be a mental therapist, nurse, constant cleaner, cook. And no downtime for you. You also have to be very organized and be full aware of every medication the patient takes. There are times when you want to say “I'm done!” but you have to keep going. Caregiver of Allogeneic transplant 2015 – now 58 years old.*
- *Caregivers need “respite.” If family members could give that to a caregiver it would help so much. My husband (patient) is actually healing faster than I am. As the caregiver I feel a lot of PTSD. It all comes after transplant and you're finally home trying to get back to normal. During that time of transplant I didn't want to leave my husband at any time but we had “No” family that could help or wanted to so if there is just the small thing it helps beyond words. SCCA needs more workshops or “something” to suggest (to caregivers) how to handle the “stress.” Caregiver of Allogeneic transplant 2013 – now 56 years old.*
- *Personally, I have a difficult time sharing feelings. We did meet with the social worker in the beginning before transplant and knew she was available for consultation. However, for me, a personal caregiver check-in, during the 100 days would have been helpful. Maybe once or twice to be sure the caregiver is receiving enough support. Caregiver of Allogeneic transplant 2015 – now 72 years old.*

- *The one concern I continue to have is there seemed to be no follow up counseling for caregivers during the 100 days or after return home. If there was, I was too concerned for my daughter to realize availability. After one year of her treatment I was alone in processing the events. The realization of her illness and course of treatment hit me all at once. She was better – able to return to her normal life (a result that I will forever be grateful for) and I felt left behind and alone with the horrifying reality of what has passed. I was unable to justify my feelings because, “I can’t complain...my children are healthy,” and, “How can I complain or seek help for my minor concerns.” Caregiver of Allogeneic transplant 2004 – now 30 years old.*

Taking care of myself

- *My wife’s cancer had made me more aware of the importance of maintaining my health to care for her. In the last 4 weeks, after a blood test showing high cholesterol and prescribed a statin I have been dieting and lost 24lbs. I feel much better than a month ago. Physically and mentally, I am better prepared to help as needed. Caregiver of Autologous transplant 2013 – now 71 years old.*
- *Being a caregiver is an extremely challenging task emotionally. More people have said to “take time for yourself,” but I found that to be more challenging than I expected. One year later I now understand how important that really is. It is hard to be your best and supportive when you are mentally exhausted. If I could give any advice to a new person in a similar role, I would say take any time you can if its 10 minutes, 5 minutes, or an hour...Time to quiet your mind and breathe. Caregiver of Allogeneic transplant 2015 – now 29 years old.*
- *During the past 6 weeks I have gone camping and fishing for three days every other week alone. As a result, I am feeling better and my grey hair has gotten light brown. Some alone time can be good for one’s physical and mental health. I will be doing this more. Caregiver of Autologous transplant 2012 – now 71 years old.*
- *Would be helpful to have more support groups. Caregiver needs a big support system. Isolation for caregivers is very difficult. Giving up activities was very difficult. Caregiver of Allogeneic transplant 2015 – now 69 years old.*
- *Having some relief for caregivers to get away for a little while would be helpful during the transplant process. Like a “baby sitting” service. Caregiver of Allogeneic transplant 2014 – now 61 years old.*
- *The past additional 12 years of dealing with his anger and depression have been the most draining. While I am forever thankful that he survived to see his children grow up, his emotional state has taken a heavy toll on all of us over the years. Perhaps, if he had been willing to seek professional support life would have been easier for the family – including him. That aside, it is critical to move away from the role of caregiver when that is finally possible and to return to personal goals and pursuits though some of those may need to be modified. I believe our children grew up and became successful partly because they saw that it is important to pursue interests, personal health, and career. There is life again after caregiving! Caregiver of Allogeneic transplant 1997 – now 67 years old.*

Never being able to let go of the caregiver role

- *I do know that I do not have the same energy level or enjoyment in life as I did before. I've lost interest in one of my main hobbies and like to stay away from people more since his illness and treatment. I miss our life together as it used to be. I feel I've lost the intimate part of my life and now it's just caring for a patient and maintaining a household. Caregiver of Allogeneic transplant 2012 – now 61 years old.*
- *I found as the time has passed since the transplant that it has taken me effort and energy to “let go” of the hovering done during transplant and follow up. It has taken effort to focus on myself and my health. It has taken therapy to gain strength to “stay in my lane” and let it be!! Caregiver of Allogeneic transplant 2011 – now 71 years old.*
- *When I think back at the time after diagnosis when he was so sick and getting infection after infection before the transplant, I almost think I get post-traumatic stress anxiety. Memories can trigger a dread of fear and tears that I did not feel at the original time it occurred. A fear like the life can be pulled out from under me and I could be back to that terrible time again. Caregiver of Allogeneic transplant 2008 – now 19 years old.*
- *I told my family that I was moving out of the role of “Caregiver” with a capital C to a lower case “caregiver” role. Caregiver of Allogeneic transplant 2015 – now 63 years old.*

The rest of our lives

- *At the time of the transplant I remember us watching a couple who were walking – they were probably in their 90's and thinking how wonderful it would be to be together at that age, all pain and infirmity aside. The joy of growing old together. So far – so good. We try to take good care of ourselves and each other. Caregiver of Allogeneic transplant 2009 – now 66 years old.*
- *The hardest part of recovery is the passing of others with cancer. The post-traumatic stress of letting down your guard. “Not knowing” has to be okay. Planning futures together gives pleasure but also evokes fear. Caregiver of Allogeneic transplant 2014 – now 64 years old.*
- *Being my husband's caregiver was the most difficult and most rewarding job I have ever had! I was lucky to be so healthy and clear thinking as the job required both. I also had incredible love and support from family and friends. (Our oldest/best friends gave us their mother-in-law's apartment to live in during the six months we were up in Seattle!) I journal my thoughts, emotions, and the events of our experience. (I would recommend this to all caregivers.) Finally...my husband and I have never been closer and more in love. We take nothing for granted. Life is so precious! Caregiver of Allogeneic transplant 2014 – now 66 years old.*
- *I felt the first 3 years following the transplant our lives were in limbo. We just waited as all the bad stuff (GVHD, pneumonia) passed. I continued to work full time during his transplant + recovery process. We have the belief, “This too, shall pass.” We just needed to wait until he recovered. Now, I am 5 months from retiring. Life is great! We have a fantastic retirement plan. We look forward to many, many, many wonderful years together. Thank you SCCA for being there for us. Caregiver of Allogeneic transplant 2007 – now 70 years old.*

Complaints

- *SCCA + LTFU have not been helpful. Phone calls went unanswered. Questions deferred. Staff + practitioners appeared too busy and indifferent. Messages went on unanswered. Very disappointed. Expected more.* Caregiver of Allogeneic transplant 2015 – now 54 years old.
- *Far too often he would only hear the “doom and gloom” message and then I would be accused of being a “polly-anna” as I attempted to encourage him. At the time of transplant he was 46 years old, fairly active, a dad of 4 young girls. He has every reason to be positive and needed his doctor to tell him to not dwell on the negative. That was left to me – which led to conflict.* Caregiver of Allogeneic transplant 2012 – now 50 years old.
- *During the last 3 years I had confronted many difficult, urgent crisis situations. I had called LTFU line. I could never figure out whom to ask for, to talk to, and to get immediate help or feedback. Many times I just had to figure out myself what to do during the crisis.* Caregiver of Autologous transplant 2012 – now 62 years old.
- *The spouse caregivers are already stressed out over the condition of their loved one. Going through the treatment process is very, very, stressful and time consuming. There is a great deal of confusion as you are fed information via firehose. It is a horrible experience and I will never be the same.* Caregiver of Autologous transplant 2014 – now 58 years old.

Kudos

- *I discovered a pill reminder app for my iPhone that was a great aid in helping remember all the medication. It also had reference for side effects and drug interactions that was helpful. Other patients may find it helpful as well. It is called “Pill Reminder” by Drugs.com.* Caregiver of Allogeneic transplant 2014 – now 64 years old.
- *I appreciate the fact that you continue to do these follow-ups to track aspects of cancer treatment and all it entails.* Caregiver of Allogeneic transplant 2008 – now 43 years old.
- *The SCCA should be commended for the caregiver classes they provide. All of the classes were beneficial to me and my husband. They truly helped me to do a better job of ensuring my husband received the best care I could provide.* Caregiver of Autologous transplant 2015 – now 73 years old.
- *We both were very impressed and thankful for the care my wife received while we were in Seattle at the SCCA. We feel that, although someone might be diagnosed with a disease that is, or may be life- threatening. A positive, thankful, and caring staff can be a real booster and uplift one’s spirit which makes a difference in outcomes!* Caregiver of Allogeneic transplant 2015 – now 54 years old.
- *It was 31 years this year since my son had a BMT transplant and though his birthday is in April, I celebrate his October 11th transplant date even more in my heart. Such a beautiful gift! Thank you always.* Caregiver of Allogeneic transplant 1984 – now 55 years old.