Thoughts and Comments from Patients – 2017

Travels

- Feel wonderful – this is late since I was on a 7,500 mi. motorhome trip this summer doing all the driving. Would never have expected to feel this well at 76 years! Autologous transplant 2008 – now 76 years old.

- Thirty-two years and still doing well! I would have never dared to think I would have made it this far. I loved travel before my BMT and I’ve kept it up afterwards. I checked off my fifth continent this year with plans for the sixth in the next 18 months if possible. Thanks for what I call my “bonus round” of life. I’ve not wasted the opportunity. Allogeneic transplant 1984 – now 56 years old.

- I apologize for the delay in completing this survey. We just returned from a two-month trip to New Zealand, a trip I dreamed about even prior to my transplant. I’ve had nineteen years of experiences I wouldn’t have had with you. Can’t say thanks enough. Allogeneic transplant 1998 – now 67 years old.

Cognitive dysfunction

- You ask a lot about emotional status, but not mental functioning. I feel my processing is slow, memory (short term) is terrible and word-finding impaired. This also affects what I can do in a day and whether I can return to work. Allogeneic transplant 2015 – now 64 years old.

- My productivity is limited not by my physical health, but by my cognitive health. It seems to take me significantly longer than my peers to process information, make decisions, and conduct my daily life. Allogeneic transplant 1989 – now 49 years old.

- My memory seems to be getting very bad, short & long term. Very frustrating. Does anyone else have the same problems? Allogeneic transplant 2011 – now 51 years old.

- I do struggle with memory – also pausing in conversation sometimes because “I can’t think of the word…” Allogeneic transplant 2009 – now 59 years old.

- I continue to struggle with lack of energy and apathy and continue to try different things. I also continue to struggle with poor memory, attention, retention and word finding. In general, my health is good and for that I am thankful. If only I could find motivation and enthusiasm. Allogeneic transplant 1996 – now 50 years old.

- I am quite concerned about cognitive changes in the last year. Tests so far indicate symptoms are NOT consistent with Alzheimer’s or aging-related dementia. Further tests are planned. Allogeneic transplant 2004 – now 58 years old.

- It is great to have the energy to do things but it is hard to go back to work. The changes one experiences after the transplant are subtle. Multi tasking is almost impossible and processing information takes longer. Perhaps, this is just a result of being away from work but even on a personal and emotional note, it is very overwhelming when you return to socializing. Or perhaps, I am so excited to have the energy to do things that I am pushing myself too hard. I guess I am still trying to find the right pace and balance. I am so grateful to have this opportunity to learn to live and work again. Thank you. Allogeneic transplant 2015 – now 36 years old.

- My memory gets worse all the time. I can’t remember why I go into a room. I’m a customer service rep & the caller will tell me their name, what they want etc. and in just a few moments I can’t remember what I was told to do. It’s starting to affect my work. Allogeneic transplant 1998 – now 54 years old.

[LTFU comment: The next survey module starting in mid-2018 will ask about problems with thinking, memory etc. Please fill it out whether or not you are having problems. It helps us to hear from everyone, including those who do not feel they have any problems.]
Financial toxicity

- I hope work is continuing somewhere to understand the financial impact of transplant and post-transplant care on patient families. It is considerable even for patients with good insurance. Allogeneic transplant 1997 – now 69 years old.

- I am still paying medical bills from 2013 that would have been covered by my insurance had the tests been performed by the SCCA. Unfortunately, because I was in Alaska, I was told by SCCA that I needed to have the bone marrow scan done here (though we were returning to Seattle for other reasons and could easily have had the tests done there) … Because the procedure was done outside of the Alliance, my insurance did not cover it, and I am still paying for the MRI. Autologous transplant 2013 – now 60 years old.

Things to celebrate

- Ta-da! I’ve reached my balance year! I’ve lived 24 years pre and 24 years post BMT. I am alive and feel great. Next year, when I tip the scale, I’m throwing a big party. Autologous transplant 1992 – now 48 years old.

- I found while completing this questionnaire that I’m actually doing quite well! Autologous transplant 2015 – now 73 years old.

- I am 37 years post transplant and just recently retired from 32 years with the same company. Thank you Fred Hutch for that opportunity. Allogeneic transplant 1980 – now 65 years old.

- I used to dread birthdays ending in zero before transplant. Next month I gleefully celebrate my 70th. So glad SCCA gave me the opportunity to still be here. Allogeneic transplant 2005 – now 70 years old.

- 1st grandchild! Life is good. Allogeneic transplant 2000 – now 58 years old.

- Thank you for the care I received at SCCA + The Hutch. Can’t believe it’s been 33 years. Next year is the half way point in my life before + after the BMT. I think the first 5 years were the most difficult dealing with GVHD and other health issues but when I look back I feel it was all worth it. Allogeneic transplant 1984 – now 67 years old.

- I was first diagnosed at age 63 with MM and was surprised at how well I was doing at age 65. The thoughts came to me that I might make it to age 70. I was doing well at age 70 so I made it my goal to make it to age 75. Now my goal is to make it to age 80. And…I’m halfway there! Autologous transplant 2004 – now 77 years old.

- I have a lung problem from radiation that limits me to a degree. However, I am very active (given my age). Every other day I either row 4 mi or ride a bike about 15 mi. And I have a cool car (Slingshot). I know, that’s not relevant, but, you know, it’s cool and you said I could tell you anything. Autologous transplant 2008 – now 69 years old.

- I was transplanted in 1989. There is something spiritual about outliving what would have been your expectancy in another era. This sensation has allowed me to devote more time to charity and my community, to explore the world, enjoy beauty, and just grow into myself in ways I did not before the transplant. From the perspective of 29 years out, my BMT was a ‘gift’ I would not wish for anyone to receive this way, but it does set you free to be happier and more content if you want to be. If you are just coming through yours, welcome to the club. Allogeneic transplant 1989 – now 66 years old.

- I am very thankful for the care I received and always happy to participate in the follow ups. I was a baby when I had my transplant, and the next time I receive this survey will be the 25th anniversary of my transplant. Allogeneic transplant 1993 – now 24 years old.

- I didn’t expect to live this long but I am sure glad I have. Allogeneic transplant 2004 – now 43 years old.
**Losses to mourn**

- I am 7 years out from my second transplant for my second relapse of leukemia; I am now 27 years old and dealing with emotional and mental health more than anything else. As a teenager getting cancer treatment, I always felt weird and out of place. At Children's I would feel too old and at the SCCA or UWMC I would feel too young. I also never felt like there were resources for people my age. There are the teen rooms but that didn't really help with the loneliness. Who do I talk to about how much this sucks and can actually relate with me? After returning to school, it's been hard for me to relate to people my age because I have a long and complicated medical history. Allogeneic transplant 2010 – now 27 years old.

- My husband passed away very suddenly and without any prior warning... My husband was only 51. As a result of this, I am still dealing with a great deal of grief and shock, and have decided not to go back to work for a while. I suspect that I qualify as 'depressed,' but have chosen not to ask for antidepressants at this time. I don't know where my path leads from here. Because this is the 40th anniversary of my transplant, my husband and I were planning to visit The Hutch to say 'Thank-you' to everyone and to visit the families of patients there, to show them that there can be long life after a transplant. However, now that my husband is gone, I've decided against the trip. Still, I want to convey my deepest thanks to everyone at The Hutch for all of their research and medical care that have given me another 40 years of life. Allogeneic transplant 1977 – now 52 years old.

- I am tired you guys. Tomorrow is my 13th re-birthday. I feel like my health peaked about four years back. The last two years have been draining, physically and emotionally. I know I should be thankful that I am able to be mobile and not as bad off as others. My chronic GVH remains relatively stable. Luckily, not severe enough that requires hospitalizations, but enough to keep my spirits down and myself home bound a lot. Last month I lost my canine companion, Rocky. He was a part of my life since I returned from Seattle 13 years ago. That was so devastating and made the last 2 months feel like hell. I have remained single and the likelihood of finding a partner decreases every year. What the hell kind of dating profile do we make?! You guys should start a dating service for survivors! Allogeneic transplant 2004 – now 43 years old.

**Children**

- What is the best thing that had happened since your transplant? Birth of my daughter March 2015!! Allogeneic transplant 2009 – now 30 years old.

- I didn’t think I could have conceived a child naturally from my radiation treatment, but me and my wife were pleasantly surprised this year and have a healthy baby girl. Allogeneic transplant 2002 – now 32 years old.

- Thanks for giving me a wonderful 24 years since my transplant. My son was only 6 months old & I’ve been able to see him graduate college! Allogeneic transplant 1993 – now 51 years old.

- I am doing well and despite the odds and am a mother of a healthy one year old boy. My younger sister was an egg donor and I was able to carry! Allogeneic transplant 2004 – now 31 years old.

- I have been very fortunate to live a fairly healthy life since my transplant over 15 years ago. We are sending our last son off to college who was 3 when I got sick and I was just hoping to see 1 more year of his life when I was diagnosed. Thanks to Fred Hutch, University of Washington Medical Center and Seattle Cancer Care Alliance! Allogeneic transplant 2002 – now 54 years old.

- I am blessed to have had my second baby (donor egg) in November of this year. I was fortunate enough to be able to carry the baby myself. A bit sleep deprived but otherwise I am happy and healthy and strong. So thankful for my treatment at Fred Hutch and evermore thankful for my donor willing to give a stranger her marrow. Allogeneic transplant 2001 – now 40 years old.
Post-traumatic growth [or “silver linings”]

- Twenty years. Twenty amazing years!!! MY bone marrow transplant was most certainly a physical transformation – mutant marrow out, life giving marrow in. But there was also an even more important emotional and spiritual transformation. The transplant helped me recognize the fight of life for what it truly is. All of my life priorities changed. Family, friends, and helping others moved to the top of my short priority list. I began living out of my abundance – instead of my fear. Beating cancer gave me a new confidence that I could get through anything. Allogeneic transplant 1996 – now 62 years old.

- Thank you for 23 years post-transplant which has been a period of re-evaluation for me. Family & friends are more valuable than things. I am grateful for every day and often remember details of my Hutch experience that make me smile (and, yes some make me grimace) but overall I feel quite blessed by the whole experience – life is full and good. Allogeneic transplant 1993 – now 68 years old.

- My life is going awesome right now. Going through what I went through changed my life in a good way. Made me look at life differently. Learned to not worry about the small things in life. Allogeneic transplant 1974 – now 46 years old.

- These surveys always trigger a flashback to 1988. I believe it is good to look in the rear view mirror periodically to appreciate the current and future joys of life. Such as grandchildren, travel, golf, friends & family. I wake up every morning with the thought of what wonderful, enjoyable things [I] can do today. Allogeneic transplant 1988 – now 64 years old.

- My cancer had a 70% change of returning, but so far, so good! I have the “returning cancer” fear that I live with daily. Then there is the damage of all the body radiation to my internal organs that might push me into an early heart attack. I miss not having the memory, energy, stamina, and sex-drive I once had. The pre-cancer activities I enjoyed are now very limited. It is like I am a computer that has been “wiped” and all the programs have to be reinstalled. I have re-evaluated everything in my life. I look at my checkbook and my calendar and I know what is now important to me. Autologous transplant 2011 – now 62 years old.

- After 33 years post transplant, I don’t even feel that my illness was a negative event in my life as it gave me a new appreciation for my life. As a result, I feel I have taken much better care of myself and tried to make the most of my life than I would have otherwise. I sometimes wonder where I would be in life if I hadn’t gone through what I did. Whatever the case, I feel healthy, happy and living near the potential of my abilities. Allogeneic transplant 1984 – now 48 years old.

- I find I have much more empathy for people today than I did ten years ago, and am much more able to respond calmly to external stuff. Perhaps a silver lining, or perhaps I’m just in my mid-50s and it’s time I did this anyway. Not everything is about the Lymphoma. Autologous transplant 2007 – now 55 years old.

Post-traumatic distress

- I am 25 years out of BMT and I still can’t hear the word “cancer” – as it related to me – without crying! It’s almost like an extremely mild form of PTSD. I am totally logical and have it together, but tell me I have “skin cancer” and I am a mess! Allogeneic transplant 1991 – now 33 years old.

- There needs to be more information available about post transplant PTSD, my sister was transplanted 5 years before me and she has suffered with it. You should include evaluations at your 1 year check ups. I think that it needs to be studied further. Allogeneic transplant 2015 – now 34 years old.

[LTFU comment: Thanks all who filled out the PTSD module during the second half of last year – we are analyzing the data now and will share results with you]
Paying it forward

- I appreciate these 27 years I have enjoyed and see any limitations I’ve had [as] a result of my transplant a tradeoff and a worthy one. I recall the expert and compassionate care I received – even had my “Hickman line” port inserted by its originator, Dr. Hickman. I have tried to pay it back and forward by fundraising activities in support of the Leukemia-Lymphoma Society and volunteering in the community with a young writers program in 8th grade and support for your local symphony. Allogeneic transplant 1990 – now 77 years old.

- Since the stem-cell transplant in December 2002, and my being cured, my life has been enriched in many ways. It was become “pay-back time” for me by fundraising via the Leukemia/Lymphoma society. I have done nine Team in Training marathons which have raised over $40,000 for needed research and improved my health and stamina at the same time. I did no marathons before beating cancer. Autologous transplant 2002 – now 71 years old.

- We remain very thankful & grateful for the excellent care received at the Hutch. February-May, 1990. Every day remains a gift. We are very aware how blessed we are 27 years post-transplant. He retired right before 67th birthday & keeps busy as a volunteer several days a week. We really believe in “Paying it forward.” Allogeneic transplant 1990 – now 69 years old.

- Thank you – I can’t say it enough. I may not be the old grey stud I used to be, but I am still alive. I can still be of some use as I give to several charities and I’m still able to do so. I very much enjoy my life and my family. I take joy in doing what I can and remembering what I used to do. Allogeneic transplant 2004 – now 75 years old.

- I live a wonderful life that I could not have imagined 9 years ago. Thank you for saving my life. After only about 3 years out from transplant, I was living a completely normal life. I only hope that I can return the favor with contributions of my own to the improvement of global living standards. Allogeneic transplant 2008 – now 21 years old.

- I’d just love to be helpful in any way that I can to your study. Coming up on my 15 year anniversary next week, and thinking about how very fortunate I am to be able to check so many 'nos' on this survey, I feel very grateful. Thank you. Allogeneic transplant 2002 – now 43 years old.

- We applaud your cutting-edge research and the teamwork of your staff. Your combined knowledge and expertise brought us from a very dismal place – to renewed health, hope, and a new appreciation for the pains and joys of life. My wife (my caregiver) and I have now volunteered at our local cancer center for the past 12 years. We thank you for that opportunity. Allogeneic transplant 2006 – now 75 years old.

Teachers

- One unexpected side effect of my transplant is an ability to hold a student's attention. I have been teaching high school biology for several years. I always start off my genetics unit with this statement 'I am a mutant,' and of course they are expecting me to shoot lasers out of my eyes. I then explain my Philadelphia chromosome. What really blows them away is the fact that my white blood cells contain DNA from someone else! Allogeneic transplant 1996 – now 43 years old.

- Good job Hutch! I will give you an “A+” from an old retired teacher. I will celebrate my 20th birthday next year!! Allogeneic transplant 1998 – now 69 years old.
**Health challenges**

- I am suffering from very painful spinal compression fractures... I use a walker or a wheel chair to get around. It makes life miserable. Autologous transplant 1998 – now 68 years old.

- My cancer and subsequent treatment has stolen from me the person I was prior. My blood counts still remain low; I am still very fatigued most of the time. I am unable to work as a result. Many things I use to have interest in, I have no interest in doing at all. Autologous transplant 2013 – now 55 years old.

- Sorry for the delay in getting this done.... Was busy recovering from lung transplant. Allogeneic transplant 1988 – now 62 years old.

- I'm exhausted and weak all the time. I have severe pain 24/7 muscles and bones. Autologous transplant 1995 – now 55 years old.

- After 13 years of survival I go to bed every night thinking when I close my eyes and fall asleep. I would be perfectly happy never to wake up. I'm not depressed, but I'm tired of getting up every day and enduring the pain and fatigue that the BMT has provided me. I am a health care provider and have taken care of several post BMT patients who were on Hospice. I had conversations with them and I find many who feel the way I do. Am I grateful I survived? Would I do it again? Allogeneic transplant 2003 – now 60 years old.

- My transplant was just over a year ago and I'm concerned that I still get tired enough to require a daily nap of ~30 minutes and I have yet to return to work. Allogeneic transplant 2015 – now 49 years old.

- At 3 years post-myeloablative transplant I am once again having to accept that GVHD (and being post-transplant in general at the age of 48) is a chronic condition and that I will continue to go through cycles of flares and cycles of “improvement.” I had a few months last fall of minimal symptoms + increased mobility, strength, and activity level. At the time I fell into the trap of considering this “progress” and was then very disappointed when it all went away with a flare of GVHD and associated medications. I am now learning again to be in the present, appreciate what I can do, and have patience and gentleness for myself. Allogeneic transplant 2014 – now 49 years old.

- The vision loss that was a result of transplant has pretty much ruined my life. I have no independence and functioning is not easy. Allogeneic transplant 2014 – now 61 years old.

- I am listed for double lung transplant. I have held this off since the year 2000. I stopped working in 2007 due to this most severe disability. GVHD has taken its toll on me but the lung condition is the worst. Allogeneic transplant 1998 – now 60 years old.

- I had a stroke on 12/31/15 and I have not been the same since. It has been very hard trying to recover + regain function. I had left-sided paralysis. I still can’t seem to walk normally and I tend to drop things when trying to carry them in my left hand. I have tended to feel a bit depressed (low) since the stroke. Syngeneic transplant 1978 – now 54 years old.

- I am very busy with starting dialysis at home and do not have time to complete this whole questionnaire. But I am still suffering from some GVH in my lungs and skin... I have many complications because of my transplant and they take up my time. Allogeneic transplant 2012 – now 31 years old.

- I would like to start working again, but feel overwhelmed easily and I'm not sure how to approach a potential employer about my health history. This alone brings on more anxiety. Feeling like I'm not living my life as fully as I can is distressing. Autologous transplant 2014 – now 45 years old.
Good health

- I am now 61 years old and still going strong, 29 years after my transplant. Yesterday I completed a strenuous 10 mile hike in the LA Mountains. I kept up with my niece and her children. I am so grateful to have all these years with my husband and family. Allogeneic transplant 1987 – now 61 years old.

- Well, I’m still skiing the black diamonds, working on my classic cars and motorcycles, hiking, watching our granddaughter evolve into a magnificent young woman and enjoying every minute to the fullest. I owe these last wonderful 19 years to my lovely spouse, a great “caretaker.” A perfect donor and fantastic staff and facilities at the Hutch. A toast to all of you. Now if I can squeeze out at least another 19 years life will truly by good. Allogeneic transplant 1997 – now 75 years old.

- As I read through other folk’s comments, my heart goes out to those who are suffering, especially long term. Like another writer, I feel a bit guilty about how well things have gone for me. Other than mild GVHD in my mouth and eyes, I feel great. If I didn’t have permanent neuropathy in my feet and ankles to remind me, it seems as if I was never sick. Allogeneic transplant 2012 – now 61 years old.

- I am just approaching my first year birthday and I feel so grateful and lucky to be alive. After a year of failed treatments for acute aplastic anemia, I have a bone marrow transplant. I am now walking up to eight miles a day, beginning to jog again and have just now started cross country skiing again! Allogeneic transplant 2015 – now 64 years old.

- Although each day of my life, I have pain in some part of my body, I am so grateful to be alive 34 years post BMT. I realize that many survivors have poor quality of life as a result of GVH, but I am thankful that my mild GVH disappeared within 2 years post BMT. I do not have to live on anti-rejection meds along with their horrible side effects. Thanks to Fred Hutch, I have lived to see my son become a USAF Major, my beautiful granddaughter grow and have celebrated my 60th birthday. Life is good! Allogeneic transplant 1982 – now 60 years old.

- It’s been another fantastic year living my life as fully as possible! I remarried, added more exercise to my weekly regimen, increased my activities at work and even found time for more travel. I couldn’t be more grateful for these experiences, especially for the ability to be part of a loving family. Watching my nieces and nephews grow into incredible adolescents and teens as well as spend time with my mom and sister means more to me than anything. Thank you Fred Hutch for 23 years of post-transplant living! Allogeneic transplant 1993 – now 43 years old.

- 9 years post-transplant (second transplant) thanks to SCCA and Fred Hutch’s research, the haplo transplant has blessed me with 9 years (so far) of amazingly good health. I am now 62 and active with our 6 children and 8 grandchildren. Could I be in better health? Sure, if I would do more cardio and weight training, but I am healthier than many of my peer age group. Allogeneic transplant 2008 – now 62 years old.
Thank you to the clinical staff and researchers

- Has been an amazing life. Donnell Thomas’ persistent pursuit of BMT success and the example of expansive, rigorous clinical investigation I saw at the Hutch and that continues today has been an inspiration. You should all be so proud of the great work you do and the impact it has had on your patients and their lives and contributions to society. Allogeneic transplant 1985 – now 61 years old.

- I just wish there was a way to thank the people behind the scenes – like the researchers. I’d so like to shake their hand and tell them that their hard, difficult work saved my life!! Two years ago at this time I was at SCCA. Today I feel good! I forget I even have cancer many days now. The other day my 24 yr. old daughter (who was my caregiver) asked me to walk more slowly when I was with her! Allogeneic transplant 2014 – now 65 years old.

- Exactly 1 year to the day since stem cell transplant and I feel great. Still working on getting muscle tone back. I did not realize how sick I was until I started getting better. Big thanks and much love for my Aqua team at SCCA. World class treatment. You guys rocked. Same goes for UWMC. Autologous transplant 2016 – now 55 years old.

- Just happy to be here. I love my life! I am thankful to you and my donor every day. Thank you! P.S. Look forward to this survey every year... (Know it’s another year I made it). Allogeneic transplant 2001 – now 59 years old.

- Each day, I drive past SCCA on my way to work and each day, I am thankful for you! 14 years of my new life; I suppose that makes me a teenager – a teen with graying hair. Thank you again. Autologous transplant 2003 – now 58 years old.

- Thanking all for 25+ years of survival. Amazed when I think of all the decisions and procedures that had to be done wisely and skillfully in order to arrive at this point in life. Remarkable! Still have the fondest memories of Fred Hutch staff involved in my care. Allogeneic transplant 1992 – now 70 years old.

- Thank you Hutch for giving me another 20 years of a healthy life. I will never forget nurses, doctors, and staff I met there. I am so much a better person in every way. Love every minute of my life. Allogeneic transplant 1998 – now 73 years old.

- Last week my husband and I were in Seattle prior to taking a cruise to Alaska. We had the opportunity to visit the UW Medical Center (stood outside my room on the 8th floor), the SCCA & the Hutch, including the Mundie Courtyard where I found my slate. We also celebrated my 16th ‘birthday’ at Elliott’s. Thanks and praise to God, the Great Physician, all the doctors, nurses, staff at UW, the Hutch & SCCA, my donor, my family and friends. What an incredible journey this has been! Life is good!!! Allogeneic transplant 2001 – now 66 years old.

- Although this survey will indicate that I am tired, worn out, and a little depressed at times, this is not an indicator that I am disappointed with my care or my care choices. I had a relapse in 2014, but was able to get it under control with lots of radiation and nearly 2 years of chemo. This added to some depression, as well as additional weakness and fatigue. Thank you SO much for helping keep me alive! My family thanks you on most days! =) Allogeneic transplant 2011 – now 54 years old.

- I am so grateful to have the opportunity to be alive and well today. I was blessed to see two of my nurses at the last reunion. Such caring and giving individuals are common at FHCRC and my admiration for them continues year after year. My treatment team was excellent as well as my family support team. From my brother (donor) to my husband, mother and daughters, each one gave up parts of their lives to see me recover. Allogeneic transplant 1991 – now 68 years old.

- I live a good life thanks to the efforts of so many at The Hutch. I am grateful beyond words. I’m 56 years old now and a few years ago I got a tattoo at my son’s urging. It says simply ‘Grateful’ and has my bone marrow birthday: 4-4-90. Thank you. Allogeneic transplant 1990 – now 56 years old.
Another commenter from this year brought a tear to my eye by recollecting a special nurse who held his hand and comforted him during a hard time. Amen! I so do also remember that, from several nurses over the years who fit that description. Some were at Fred Hutch and they deserve to know that the incredible difference they make is never forgotten. Allogeneic transplant 2004 – now 64 years old.

It has been 10 years since I received my stem cell transplant. When I wake each morning, I try to remember to put a smile on my face to remind myself to be thankful for waking each day and to make each day special. I am thankful for the gift of life that I received from my donor through the Hutch. Now, 10 years later, my wife and I are looking forward to welcoming our first grandchild in a few months. I wouldn’t have this in my life without my transplant. Thank you. Allogeneic transplant 2007 – now 58 years old.

15 years ago I received excellent, professional, and caring services from Fred Hutch, the University of Washington Medical Center, and Seattle Cancer Care Alliance. It was absolutely the worst of times and the best of times. The staff that helped me were so very kind. It takes a special type of person to be optimistic, gentle, professional, attentive, responsive to my needs, and give free smiles whenever it is needed. As sick as I was, I still have fond memories of the kindness bestowed upon me. Autologous transplant 2002 – now 66 years old.

I loved my doctors and nurses who took care of me while I was there. They were very professional and caring. They showed me a great deal of concern for my health. From the initial nurse all throughout my stay in the apartments (shuttle driver too!) If I hear someone looking for a hospital, I always referred and commented that Seattle Cancer Care is the best place to go. Thank you Seattle Cancer Care for everything you have done for me! Aloha! (I can honestly say that I hated Seattle’s weather when I was there—but the care you’ve shown me helped me overcome it!) Allogeneic transplant 2011 – now 56 years old.

I just celebrated my 9th anniversary of my transplant with my kids, now young adults. I am looking forward to a graduation next May. We raised our glasses “to the wonderful people, scientists and staff at the Hutch who gave up their lives to make this possible”. I feel fortunate to be able to contribute to their lives and otherwise albeit at a reduced capacity due to fatigue. But that wine glass we raised was certainly half FULL!!! Thank you! Autologous transplant 2008 – now 60 years old.

My FHCRC nurse set me straight, back in 1986, she wrote on my board, in my LAF room, that I can’t be X% alive and X% dead, I had to choose which one I wanted. In other words, keeping a positive outlook can make a tremendous difference. Thank you, Karin! And Thank you all at FHCRC! Allogeneic transplant 1986 – now 51 years old.

The community of fellow patients

I have adjusted my diet (eating less) and behavior (exercising more) in order to feel healthier. It is working. I spend very little time thinking about my cancer from 18 years ago. Thanks, as always, to the huge community of care-givers, researchers, and fellow travelers for this blessing of life as usual. Autologous transplant 1999 – now 60 years old.

I feel that the Fred Hutch might be somewhat remiss in [not] drawing on the experience from someone such as myself who underwent a brutal transplant but somehow made it to the other side in one piece. On the contrary, all I ever receive from the Fred Hutch are this annual questionnaire, bills for stem cell storage and requests for annual giving. The Fred Hutch never appears to have any interest in personal follow up with patients such as myself who might be considered success stories for the organization. I think that I could offer a measure of hope to people about to embark on the transplant process. Allogeneic transplant 2007 – now 56 years old.

I’d like to see some interaction between former clients & some newbee clients. I believe there’s a lot to be gained from hearing from successful survivors. Myself, I was given a 20% chance of survival. I took the 20% as a challenge. Having positive vibes around me during my treatment was essential. I didn’t see any
response from survivors till I was done. It would be helpful to have seen their stories at the start. Allogeneic transplant 2016 – now 66 years old.

- Even 17 years out I suffer from it. Met a neighbor last year who just had his 3 year post transplant anniversary. I never wanted anything to do with support groups, but I feel like having someone who could relate to me has really helped. Allogeneic transplant 1999 – now 38 years old.

- Being part of this annual survey and reading the comments of others makes me feel positively connected to a network of those who have suffered, succeeded, lost, grieved, and celebrated--the whole spectrum of human experience within a very specific (and hard to understand if you haven't been there) range of medical experiences. Being part of this larger network brings a sense of meaning and peace into my life. It's a good reminder to both remember and to let go and live! Autologous transplant 2005 – now 49 years old.

- I am in better health than a lot of people I know with chronic health conditions. I was blessed to meet my bone marrow donor, so very grateful for her gift of life! It is reassuring to read comments from long term survivors! Thank you survivors, as those comments permit us young ones to remain optimistic! Allogeneic transplant 2015 – now 66 years old.

- I met someone the other day, completely randomly, who is about to go through the whole auto-transplant, with a story that had many parallels to my own. She was nearly in tears as we ended our short conversation - she was so excited to see someone who had been through what she's about to experience, and to hear that although it sucks, it's do-able. She can come out on the other side and look and feel as good as I do! Autologous transplant 2010 – now 45 years old.