Thoughts and Comments from Patients – 2014

Transplanted in 2013

- I remain cautiously optimistic concerning my daughter’s long term health. She has been doing so fantastic for the past 3 months – we are grateful for that. It is the long term that is worrisome. What may come, but right now she enjoys good health. Parent of Pediatric Autologous transplant patient 2013 who is now 2 years old

- For the first year from the transplant I feel very weak, fatigue, nausea & vomiting. But I don’t stop thinking that there will always be another day for me to feel GREAT. Thanks to my family, friends and relatives for their unconditional love, support and prayers for me. Autologous transplant 2013 – now 63 years old

- Basically, I am feeling pretty good. Appetite, energy, digestion...At day 180, I am catching up on how much my body was weakened/affected by drugs – especially prednisone and the chemo – but it is coming, bit by bit. Despite that, I struggle with depression and don’t know exactly why except that processing the whole experience makes me feel like I fell down the Alice in Wonderland rabbit hole. Allogeneic transplant 2013 – now 63 years old.

- Been noticing that I get angry more easily than I used to and not sure why. Autologous transplant 2013 – now 48 years old.

- The process of 6 months of chemotherapy, get to transplant eligibility, priming for apheresis, the apheresis itself, hip stem cell transplant itself and hip year since has been really beyond description and a life changing event. Since transplant I have been on maintenance chemotherapy. The process of recovery has seemed very slow. I am in an immune suppressed condition, heightened by chemo with 4 separate URI’s this year, each lasting more than a month. The tension between return to work and recovery has been a real challenge. Autologous transplant 2013 – now 66 years old.

- Never having been seriously ill a day in my life, the diagnosis of multiple myeloma at age 69 left me in shock and disbelief. Even more difficult than learning about the chemotherapy and radiation treatment I needed plus the stem cell transplant process. I am so grateful to the teams at SCCA who helped me get through the difficult times. They were encouraging and respectful truthfully answering all my questions, and I had lots of them. I am now enjoying my RV lifestyle once more and life is good again. Allogeneic transplant 2014 – now 71 years old.

- The transplant saved my life. I received (and continue to receive) wonderful treatment from the doctors, nurses and staff at SCCA and the U of Wash hospital. I feel optimistic about my future for the first time in a long time. Although my blood counts are still subpar, they inch forward. Autologous implant 2013 – now 70 years old.

- I will be returning to SCCA the last week in December and while it seems unusual to be looking forward to my one year post stem-cell transplant, I am, because even at holiday time – the staff at SCCA seems like a second family to my wife and I – The care was so individualized that we continue to be amazed at how we feel about the anniversary visit. Autologous transplant 2013 – now 67 years old.

- Would I do this again? With what I know now? I would be more scared because of knowing WHAT could really happen. But I would do it again in a heartbeat. Allogeneic transplant 2013 – now 60 years old.
Keeping active

- To celebrate 5,000 days post-transplant, I had a total hip replacement and hiked to the bottom of the Grand Canyon and back. Allogeneic transplant 2000 – now 68 years old

- I recently retired from my position as a plant manager at a company after 32 years. I am now traveling with my wife of 41 years. I can’t thank FHCRC enough! Allogeneic transplant 1988 – now 61 years old

- I work full time, work out three times a week – weights and 30 minutes on the elliptical machine. Am very active and look forward to travel, and dating again (partner passes away 1 ½ years ago). Was the transplant worth it? You bet! Most definitely adding 14 years to my life was worth the sacrifices. Allogeneic transplant 2000 – now 59 years old.

- Enjoying life at 74 years of age. Skiing 3-4 times a week. Aplastic Anemia 1997 – now 74 years old.

- I have been blessed with long-term health. I have travelled & walked all over the world. I have visited 150 countries since my BMT. Autologous transplant 1988 – now 61 years old.

- Thanks again. It’s been a great 30 years. Spent 2 weeks backpacking in Patagonia. Allogeneic transplant 1984 – now 51 years old.

- It is now 9 years since my transplant. I am 55. My skin is finely wrinkled, my hair is almost gone and my eyes get very dry, but otherwise, I am very much my old self. I am happy to spend a week on the Appalachian Trail lugging around a 55lb pack. I know just how lucky I am to still be alive, let alone to feel as good as I feel today. I bless Fred Hutchison for saving my life. And I thank God for giving me the quality of life I still enjoy. Allogeneic transplant 2005 – now 55 years old.

Coordinating medical care is a job in itself

- I am still having difficulty coordinating the various specialists that are involved in my complex medical care. It is overwhelming to stay (or try to stay) on top of things and, as excellent as my primary care physician is, I still feel that I am missing critical issues simply due to emotional, physical and mental fatigue. Allogeneic transplant 2001 – now 60 years old

- I think more help and education with financial resources is needed. My medications are all very expensive and FHCRC deals with this on a daily basis. There must be a wealth of information so patients don’t have to reinvent the wheel in dealing with medications. Allogeneic transplant 2008 – now 58 years old

- Who do you see when you have a medical issue you think is related to the transplant or GVHD? PCP or Oncologist? Allogeneic transplant 2010 – now 33 years old.

- I do not know if my experience is unusual. On one hand I have lived longer as a survivor, so many of my health issues are related to getting older. However I wish other areas of medicine outside of cancer treatments had a better understanding of how to treat those of us that have been so heavily treated. I hope this gives someone food for thought. Autologous transplant 1993 – now 71 years old.
Sometimes it is hard to find a GP doctor after a stem cell transplant. How is the best way to get a good one? Do you have a referral list in all the little towns? I am happy. Thank you for saving my life. Allogeneic transplant 2006 – now 67 years old.

Lingering effects after transplant

- I’m grateful for remission but still have problems with after-effects for 15 years. Kicked the cancer, but the cure is killing me! Radiation. Enjoy all comments, at least I’m not alone! Thanks. Autologous transplant 1999 – now 70 years old

- I have nightmares. Sometimes frequently, sometimes occasionally. Allogeneic transplant 2000 – now 24 years old

- I have never regretted having my SCT and will be forever grateful to the staff at UW and FHCRC. However, my teenage son (who was 6 when I was ill) continues to battle with PTSD and I fear that his life path has been negatively altered. Pending marital separation. We were all affected – some positive, some negative. Would this have happened if no illness/SCT - ??? Maybe.....Have experienced a "dampening" of emotions - ? Brain changes? Allogeneic transplant 2006 – now 50 years old

- I am in a better place this year than in the past. I have chronic GVHD which has stabilized. I no longer require anti-immune therapies. My body shows the damaging effects of GVHD. My skin and hair are thin, my joints are stiff and restricted, my balance is off and my eyes, oh my dry eyes, are an ever present reminder of how precious tears are and the hideous way GVHD attacks. I’ve stopped comparing myself to other survivors. It could be better, it could be worse. It is what it is. I remain hopeful that medical technology will continue to advance. Perhaps a breakthrough will heal my eyes. I know I am not alone in being hopeful. Allogeneic transplant 2006 – now 63 years old

- I would like to know what I can do, or who I could go to, to improve my libido. After treatment it’s gone. Is there a “Viagra” for women out there somewhere? This is my only complaint about the whole thing. Thank God I have an understanding husband, but I feel like this can’t go on forever. Autologous transplant 2006 – now 51 years old.

- Certainly happy to be alive but miss my former independent self. After the hip replacement in 2008, my life came to an indolent standstill… Hate myself because of the horrible weight gain and the inability to fix it! Allogeneic transplant 2007 – now 70 years old.

- Starting about 6 years ago I started having a little trouble walking. I started using a cane when walking in crowds. The disability has gotten worse. Jump to today. I can barely ambulate… Watching and fighting the deterioration of my legs has been a slow torture, death by a thousand cuts… I am thrilled that the BMT gave me 15+ good years during which I watched my daughter grow up. I would never give that up for anything. But now life is hard and I have a hard time convincing myself to get out of bed in the morning because the struggle starts when I get up (and, no, I’m not suicidal and yes, I do get out of bed every morning). Autologous transplant 1991 – now 57 years old.

- I never dreamed that the effects of transplant would be so lasting. However, I’ve learned to live one day at a time, doing what I can when I can. I grieve for what might have been while realizing that without transplant, there may not have been a time after. I’m especially thankful for doctors at The Hutch who continually research and explore answers to my chronic issues and are willing to try new approaches. I’m also so blessed to have had my local oncologist who has worked very closely with the doctors in
Seattle. I’m saddened that he is retiring this summer and a bit concerned that I won’t find a suitable doctor to take his place. Allogeneic transplant 2003 – now 57 years old.

**Feeling pretty good**

- I had my BMT for aplastic anemia 7 years ago from a non-related donor when I was 66 years old. Now I feel like I never had a BMT and live a normal life for a person my age. I never had severe graft vs. host and 18 months after the BMT what I did have was completely gone. Allogeneic transplant 2007 – now 73 years old

- I am reflecting upon the last 18 years since my transplant as I complete your survey. I think to myself how blessed I am, I am able to mark “no” to nearly all of the long term effects of my transplant. I am sitting in my kitchen, drinking a cup of coffee and watching my two beautiful (adopted) children watch cartoons and the lyrics of Louis Armstrong come to mind, “And I think to myself, what a wonderful world.” Thanks Hutch! Allogeneic transplant 1996 – now age 40

- I am amazed at how much of my life I have been able to return to after the intensity of transplant. The transplant process was extremely difficult, but I am now in complete remission and on the other side. I am fully independent, caring for my children, and back to work full-time. Many of my activities have changed, but the essential ones important to me have returned! Thank you, SCCA, for giving my life back to me! © Autologous transplant 2013 – now 50 years old

- I am 14 years out (last relapse Oct 2000) and feeling fine. Never thought pre-transplant that I would live to be eligible for Social Security and Medicare. Still working and feeling great!! Allogeneic transplant 1999 – now 64 years old.

- Life is GOOD – I could not run or do hard work. I have lived a GOOD life with going slower and being careful. Thanks for all your help. Allogeneic transplant 1982 – now 66 years old.

- Thanks! I’m in the best health of my life and will graduate from college next year. I never would have got here without your treatment. Thank you for everything! Autologous transplant 1997 – now 24 years old.

- Health is great, haven’t had any transplant related issues in 10 years. Currently attending my first year at medical school at Baylor College of Medicine. Allogeneic transplant 2003 – now 24 years old.

**Not what I expected**

- I’ve been lied to many times. One of the biggest lies was “Your life will go back to normal after your transplant”. I’m 11 years post-transplant, and I think I have more problems now than I did prior to my transplant. Definitely NOT anything like “normal” Allogeneic transplant 2003 – now 22 years old

- Thought after 6 months life would return to more normal. Was just informed otherwise. As long as I’m on Velcade, I’ll be immuno suppressed. Was surprised to learn that now at 6 months post-transplant. Autologous transplant 2013 – now 60 years old.

- If I had been fully warned about the reality of living with GVHD I never would have chosen bone marrow transplantation. If I had been warned about how horrifically neurotoxic Gleevec and Sprycel are, I never
would have taken them. Your treatments and drugs have left me permanently crippled, maimed, and disfigured and condemned to die alone in misery, pain, and humiliation that will never stop until I am dead. I feel I was lied to and I am extremely bitter and angry. Allogeneic transplant 2006 – now 33 years old.

- I realize how fortunate I am to be alive, and be doing as well as I am. But some days, I wish I hadn’t had the transplant. I feel like I lost so much that I can’t take back, or get back. My life was totally interrupted, diagnosed at 28, and I don’t know how to get back my faith in life. I’m so alone, and then isolate myself more so no one else has to deal with my issues. Allogeneic transplant 2007 – now 37 years old.

- At two years from allogeneic transplant, my life is still dramatically changed. Prednisone makes me fat and emotionally brittle. My skin is dry and fragile. I can’t do many things I feel I should be able to and I need help often. Given all that – I am a pretty happy guy! My granddaughter was born a week before my transplant. I got to go to her second birthday! I get to watch her grow up! I still do a lot of things, just slowly and much more carefully. All in all I am enjoying life. It’s just a different life than I expected, is all. Allogeneic transplant 2012 – now 55 years old.

- I was not prepared for the difficulty of coming home after transplant. The stress of everyday care and very slow recovery is difficult. Allogeneic transplant 2014 – now 60 years old

What I gained from transplant

- No one would describe a stem cell transplant as “fun”, but thanks to your warmth, kindness and expert care, there are many parts of the experience I continue to cherish 17 years later. I also cherish the gift of advancing old age. Unlike my friends, I view all my wrinkles, aches and pains as signs of victory. Thanks so much for what you did for me – you set a very high bar for all the medical professionals I encountered after you! Autologous transplant 1997 – now 66 years old

- My transplant has been a life altering event. I am a better person for having survived. I am stronger – emotionally, more in touch with my religious faith, closer to my family. I am able to finally live in the moment and enjoy the days I have. Do I have regrets – yes. During my recovery, my husband and caregiver of 40 years died as a result of a car accident. I regret that I worked so hard to recover only to be a widow alone and not able to enjoy the life I had with him. So now I’m 65, widowed, alone and facing a life without my life companion who fought so hard to get me well. So it is bittersweet living this life I was given back but I’m trying – one day at a time. It just shows there are no guarantees and we need to cherish the time we have been given. Allogeneic transplant 2009 – now 65 years old

- It has been a tough 8 years but I wouldn’t trade it for anything. I got to see my two great-grandbabies. I’m taking care of my mom who has Alzheimer’s. I may not be as strong as I was, physically, but emotionally, spiritually, I am stronger than I’ve ever been. Thank you for making this all possible. My oncologist even says I have surpassed all odds – with all the hurdles I’ve had to cross. Allogeneic transplant 2006 – now 69 years old

- Without all of the research and medications and treatments I would not be here. I was given a 15% chance of survival. I guess you could say I beat the odds and I only hope I can continue for a very long time. Allogeneic transplant 1991 – now 56 years old.
• Every day I feel fortunate to be alive, and the passage of each year post-transplant is a victory and a blessing. There were times before and during treatment when I did not expect to be alive in 2014. Allogeneic transplant 2006 – now 66 years old.

• Before the transplant I saw life as a gift. Since the transplant, I see each day as a gift and try, in some way, to add value to each of those gifts. And if and when those gifts run out, I hope to be thankful for the gifts received and not regretful for the gifts not received. And you, FHCRC, provided those gifts. Thank you! Autologous transplant 2002 – now 68 years old.

• Everyone with whom we interacted was very kind and helpful in every way. My treatment went extremely well, my life has returned to normal but with renewed purpose, and I look forward to many more years enjoying my family. Allogeneic transplant 2012 – now 53 years old.

• I clearly recall laying on the bed at the Urgent Care. The doctor and two others had just walked away after telling me my symptoms were consistent with leukemia. They would be making an appointment; they were calling themselves, with the best Oncologist in the city. I must go tomorrow. I was thankful I had done so many cool things for a young man of twenty-four, especially the travel. It was soothing. I recall that for you on the eve of the 30th anniversary of my BMT at FHCRC. Over the past thirty years I’ve been traveling about pretty darn well and the best is about to come. In just a few days, after eighteen months of planning, I will be overseas for five weeks. That day at the Urgent Care, not a soul, including me, would have believe it even remotely possible. Thank you for saving my life, it’s not being wasted. Allogeneic transplant 1984 – now 54 years old.

• Like some of the other commenters thank you for giving me a longer life, (23 years) at the time of transplant what I wanted most was to be able to raise our daughter & be a husband. All of that has worked out and I am in great health looking forward to many wonderful years yet to come. Even if I died today. Thank you from the bottom of my heart. Keep up the good work. Allogeneic transplant 1990 – now 57 years old.

• Life has been great! I just celebrated my 30th year of life post-transplant which means I’ve lived twice as long after the transplant compared to before. I sometimes wonder what my life would be like if I had never gotten ill. I’ll never be able to answer that, but I can say that pre-transplant- I was a young man not very happy in life and struggling in school. Post-transplant, I became a top student, got into Yale University and later became a dentist and a dental specialist in endodontics. The appreciation of life and health I gained from my experience has made all the difference. Allogeneic transplant 1984 – now 45 years old.

Chemo-brain

• My self-donated transplant was 1996. The lingering problem for me is memory. Not long-term memory – more like “When did I eat?” “Did I put the dog out?” “What day did you say it is?” Are there others like me? Autologous transplant 1997 – now 67 years old.

• I’m almost 3 years removed now. I’m working full time or more, supporting myself and staying healthy. My thoughts still get jumbled and I can’t always focus, but I think that’s just the way it’ll be. Some days I get too fatigued and have to sleep for 10+ hours, but overall I’m very stoked to be alive and healthy. Life is pretty good! Allogeneic transplant 2011 – now 31 years old.
Brain fog problems 4 years later. I assumed it happens very often. It depresses me to be so forgetful. I feel dumb – I was brilliant almost. Autologous transplant 2010 – now 62 years old.

Does your memory ever get better at this point after the chemo? Or are sticky notes the way to go? Autologous transplant 2005 – now 56 years old.

I have also been noticing that I am more forgetful than I have ever been and have misplaced and/or left valuable things in various different places I have difficulty recovering. Very meaningful things, that in some cases are irreplaceable. And this upsets me greatly. Often I feel I can’t think fast enough to communicate, for example, in order to carry on a conversation with others and people thusly become impatient and lose interest in what I am trying to say. I have also found that people seem to easily misunderstand me and, for example, don’t understand why I am “taking so long” at the checkout counter, because sometimes it takes effort on my part to “think” and be consciously aware about what it is that I am doing at the time. It is hard not to get discouraged. It is frustrating and aggravating for me and others at times. Syngeneic transplant 1978 – now 51 year old.

Feeling OK now but worried about the future

Seems as I am out longer from my stem cell bone marrow transplant I am getting secondary effects from my treatment. I would do it all over again but the long-term effects do worry me. I am 56 and already have very brittle bones, memory loss, and some physical limitations. What will I be at “60” or even “70”, God willing I live that long. Allogeneic transplant 1996 – now 56 years old.

Life is good thanks to SCCA. Somewhat worried about melanoma and recent finding that we are 2 to 3 times more likely to have stroke or heart attack. Allogeneic transplant 2007 – now 66 years old.

It just seems like this past year has seen more medical issues than ever before. Most concerning is the Atypical Ductal Hyperplasia. Going on the Tomoxifen was a decision I made after conferring with a medical oncologist who specializes in breast cancer and high risk prevention. The fact that I am high risk is frightening. My annual physical blood work in January showed a rise in TSH level. Will have that repeated in March. Allogeneic transplant 1984 – now 61 years old.

My daughter was 14 months old at the time of transplant. She’s now four and doing well! We recently had her three year post transplant work up and although the doctors are essentially no longer concerned that her JMML will return, we have now shifted focus to looking for transplant related issues. We are so, so grateful to be where we are but we are reminded that this “marathon” never really ends. Parent of Pediatric Allogeneic transplant 2011 – now 4 years old.

If I get cancer again, I won’t be able to pay for care. I expect to die of a heart attack in 10 years from my radiation (total body). I’m afraid to spend all our money because of medical costs, but want to enjoy the life I have left. Autologous transplant 2011 – now 59 years old.

I regard my health to be fairly good in general. However, there is the thought in my mind regarding risk of relapse. I don’t dwell on something beyond my control, but it might prove helpful if LTFU would be able to provide a basic list of things to do, medically to best detect any early signs of a relapse and provide a frequency of when/how often to do. Allogeneic transplant 2004 – now 48 years old.
I guess I am still unsure about what the future holds. Although my physician team talks about my GVHD ‘burning out’ it seems like a far-fetched idea and I am extremely concerned about continuing to pay for my health care for the rest of my life not to mention what additional health issues may come up. I am forever grateful for the transplant as it has offered me years of life, but I guess in hindsight I never thought it was going to be quite this hard. Allogeneic transplant 2010 – now 28 years old.

It has been a good recovery from my transplant in 2005 EXCEPT FOR lung GVHD/aka Bronchiolitis Obliterans which impacts my daily life and return to normalcy. Fortunately I have not had any major infections, but with a severely low FEV1, I live in constant fear of contracting some nasty bacterial/fungal/viral bug because I have nothing in reserve to see me through such problems. Allogeneic transplant 2005 – now 66 years old.

It’s hard to know, when aches or pains come, whether it’s the multiple myeloma relapsing, or just aging! I’ll be 67 in a month. There’s always the small elephant of possible relapse sitting on my shoulder. Autologous transplant 2012 – now 66 years old.

Filling out the questionnaire

Each year when this questionnaire arrives it catches me by surprise that another year has passed. That the majority of the time I forget about the breast cancer. Every once in a while when I’m involved with a dying patient, I’m a hospice nurse, it will hit me, “This could have been me!” As I get older and working with dying people I see so clearly that death is part of life and there are not guarantees as to when we die. Now I’m looking forward to a new phase of my life, retirement as an older person. I’m at a stage of my life that is full of change and I’ve been depressed, then spring arrived and this questionnaire and it reminded me of what I’ve managed so far in my life and a sense of excitement is stirring within me.....Great timing, thank you! Autologous transplant 1997 – now 66 years old.

Every time I complete these questionnaires I realize how truly blessed and fortune I am to have had such a successful transplant. Because of God’s blessings and Fred Hutch’s skill and care, I have seen my six children grow to adulthood, and the birth of my nine grandchildren. The joy of these experiences can never be captured in writing. My treatment and recovery from a fatal disease has also allowed me to bring hope, comfort and support to many in my large family of friends and relatives. I have discovered a peace in life that I never thought possible. Many heartfelt thanks to all at FHCRC! Allogeneic transplant 1990 – now 66 years old.

Please don’t add any more length to this survey. If it gets much longer I won’t want to participate any more. That said, I value the worth of these. Just be succinct! Autologous transplant 2000 – now 61 years old.

I am writing this for my husband. He gets irritated with the questions. I think it was an eye opener for him when I read all the comments and realized all the problems other people had when he was for the most part left unaffected and has very little if any problem due to his treatment. Since his treatment, he seems much more contact with life in general. After 4 years we are beginning to feel relief & the long time survivors’ accounts are very inspiring!!! He is not using sunscreen like he should; he also gets a hold of cigars on the golf course occasionally. I would like to see him eat healthier as well, but I remember he is living HIS life and he is wonderful to have around. I’m not going to nag him after what he has been through. Autologous transplant 2010 – now 55 years old.
Please continue to send these questionnaires out. Even if we skip a year, it is not because we don’t believe in the good this does for all, sometimes we just run out of time. Allogeneic transplant 2001 – now 14 years old.

Thank you for your follow up questionnaire every year. I had an eight year old in 1995 while having my stem cell transplant, now I have 5 grandsons, 2 live with me full time so I have a busy life. Don’t have any time to feel sorry for myself. Mind is happy, though body this year hasn’t been good to me. Will keep on getting up every morning praising God for everything I have. Allogeneic transplant 1995 – now 59 years old.

My only comment while filling out this questionnaire is that this year’s seemed to be a lot more depressing. This is my favorite section to read but I had to put it down & finish it the next day. My heart breaks for all these patients still suffering! But, “The Hutch” is the best & only choice for a BMT. Thank you! Allogeneic transplant 1996 – now 51 years old.

I apologize for the lateness. This gets to be a pain in the butt after 16 years. Allogeneic transplant 1998 – now 62 years old.

I believe this is the first questionnaire I have filled out in decades. I have accumulated all the other ones. My reasons/excuses: 1) jinx, if I fill them out, soon afterwards I would get a relapse, 2) Bad handwriting, hate just writing, don’t mind typing; 3) Procrastination? Allogeneic transplant 1986 – now 57 years old.

Glad to see the sexual issues questionnaire. I know my answers would have been completely different if I was answering it the 1st year out of transplant, especially the 1st year after diagnosis. I had sexual issues for some time, but it always seemed like low priority. Figuring out why I was vomiting seemed more important that figuring out why I couldn’t achieve orgasm. I’m not sure I felt the freedom and safety to bring that up anyway. I wish I had. I think it could have alleviated the extra strain that it brought into the picture. Thanks again & again for all the work you all do! There are little roles & big roles that all make a difference! Glad I can be part of your team! Allogeneic transplant 2005 – now 39 years old.

You’re very interested in any other comments I might have so I took the time to give them to you. About two minutes before I would have been done, my session was “timed out” and all of my comments were lost. This happened to me on the previous text question and I went back and re-wrote it. I don’t have the time or inclination to do it again. Maybe you should give a person a little more time before you time out their session and erase their thoughts. Allogeneic transplant 2010 – now 62 years old.

This was my five year transplant anniversary. It’s a pretty big deal to me. And for the first time in filling out this questionnaire I can tell you that I am glad to have had the BMT. I am also feeling better about my life and how I am feeling and doing. My health is stable right now. The exhaustion and fatigue are the major post-transplant issues I struggle with, along with the depression that has come with this new me. But even that is doing better. I am grateful to be alive! Allogeneic transplant 2009 – now 43 years old.

This is a privilege I appreciate each year – that I am still here and still participating in FHCRC good work by completing this questionnaire. I’d love it to be completely online, saving postage for you and making it easier for those of us who travel frequently and are not timely in response. Being able to fill it in online is fantastic, now if you could send it that way, too. Allogeneic transplant 1993 – now 65 years old.
Good for you, offering an online option. As someone who did data entry in my much younger years, you’ve saved someone LOTS of tedious work, well done. I hope many people choose this method, and it helps your information gathering. Autologous transplant 2010 – now 60 years old.

Old before my time

More questions on aging faster than your true age. I am 60 years old but experiencing a lot of the same age related health issues that a late 60’s/70’s man would have. Would like to know if other who are out 20+ years are experiencing the same thing. Allogeneic transplant 1992 – now 60 years old

As usual I complain about feeling dizzy, spacey, my memory is getting worse, my ability to find the right words. Accelerated aging mind, body, face, etc. Now I’m having dexterity problems in my fingers – trouble tying shoes, jewelry making. People think that I am 10-15 years older than I am. All of my friends are getting better with age, even one who had a transplant for non-Hodgkin’s and other cancers. But none of them had GVHD. My energy is so low. My balance is bad. Allogeneic transplant 1994 – now 59 years old.

Questions do not take into consideration problems and symptoms associated with aging. Allogeneic transplant 1993 – now 80 years old.

I feel that my loss of hair, loss of energy, loss of muscle mass, and loss of sexual potency, has taken a toll on my attractiveness as a person. I think this is causing a strain on my relationship with my wife. That in addition to: failing vision, worsening hearing, losing memory, and increasing level of depression. I feel I’m at the same level of health as those 20 years older. Allogeneic transplant 1999 – now 53 years old.

6 years ago and this was the first year I actually forgot my birthday. Life has moved on for me and now I deal with what other 47 year old men deal with such as weight control and getting sufficient exercise. I am extremely grateful though for having this time to watch my son grow as he was only 6 when I was diagnosed. I have every intention of seeing him become a man and having me there to teach, guide and mentor him. I also cannot even begin to say thanks for this gift of time to have an even better relationship with my wife. I sure hope to continue to participate in this questionnaire for many more years!

Autologous transplant 2008 – now 47 years old.

Things that make me feel better

I felt better after meeting the donor. Allogeneic transplant 2010 – now 74 years old

My wife and I just celebrated my 30th (B.M.T.) birthday! Biggest disappointment…never seeing my comments in this questionnaire! Ha ha! Allogeneic transplant 1984 - now 58 years old.

Last May I started working at SCCA on the infusion floor as a Patient Services Representative. I love getting to come to work each day that played such an important part of my life. Every patient I talk with is so inspiring and when I share my own experiences they are all very inspired themselves. I love being able to be proof to patients that there is a light at the end of the tunnel and to never give up hope! Also, I am getting MARRIED this March!! Lots of fun changes! Autologous transplant 2007 – now 29 years old.

Probably true for non-BMT patients, but exercise has a marked positive effect on feelings of well-being, stamina and overall vitality. Allogeneic transplant 1997 – now 67 years old.
• I don’t let self-pity get me down. I always try to think of the other people around me. I also make sure I stay busy and exercise. Eat healthy. It has been 40 years and my only problem is inheriting arthritis from the prednisone I was on before the transplant from my parents. Plus sinus problems from my donor. Allogeneic transplant 1974 – now 51 years old.

• After a decade of limping and pain, I had a bilateral hip replacement surgery during June-July 2013. I will urge patients who are currently suffering from avascular necrosis (AVN) to have this surgery. I could now wear high heels. Allogeneic transplant 1986 – now 51 years old.

• I’ve been investigating trying out diets through cancer lifeline classes and on line presentations sponsored by Harmony Hill on the benefits of anti-inflammation diet for cancer recovery and reducing risk for secondary cancers. Even if FHCRC & SCCA did not believe nutrition affects healing and overall health/fitness I would still expect more information, guidance & encouragement to eat better and feel better if only to provide some positive activity for survivors to engage in that makes them feel more in control and mindful of their health all around. Allogeneic transplant 2010 – now 16 years old.

• After my release in August of 2010 I went back to work full time at the railroad in October of 2010. It was very tough after losing all what I used to be after my cancer with AML. Going back to work helped me with my recovery and getting back to be where I was before. Allogeneic transplant 2010 – now 63 years old.

• Side effects from the BMT. Cataracts, heart attack and bone loss with a recent hip replacement. All tractable and I’m still here. I am so glad I got the hip done. Doctors kept telling me to wait... Technology will get better, last longer. It wasn’t until a younger doctor told me you’re young, you’re in good health... Why wait! Yeah why wait. It was so worth it! I feel I can do so much more now. Simple things – bending to tie my shoe, riding a bike, walking with no limp. Allogeneic transplant 1995 – now 51 years old.

• All is good. You guys rock. To all other survivors, do something to give. I make canes and walking sticks to give to our brothers in arms at the SCCA. Good for the heart & the soul. Autologous transplant 2012 – now 55 years old.

• I am thrilled to be celebrating my 25th BMT anniversary. Are my bouts of brain fog a result of chemo, ADHD, peri-menopause, aging or life with our two active and healthy sons, aged 4 and 9? I don’t know – but I do know that outdoor cardio exercise and weight-training help me mentally, emotionally and physically. Allogeneic transplant 1989 – now 47 years old.

• Dr. Shen’s bandage contact lens study has made a huge improvement in my dry eye problem. These contacts are over-the-counter and stay in for 30 days at a time, requiring antibiotic eye drops. I now administer drops in my eyes 4-10 times per day instead of 40. I hope this is being offered as a possible solution to all who suffer from dry eye as a result of GVHD. What a difference! Allogeneic transplant 2009 – now 48 years old.

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**Life marches on**

• In February 2014 I will celebrate my 30th anniversary of AML-BMT and January 2014 my husband and I celebrated our 30th wedding anniversary! I had severe GVH problems for 4 years after BMT due to the mismatch of 2 genes with my mom. Who ever thought I would live so long and can enjoy life so much as I
do now? I live a pretty normal life without any medications besides for osteoporosis. One and a half years ago we moved from Berlin, Germany to the exciting city of New York! My husband works for a German company here. I can’t believe that after 30 years, I’m living in the country that saved my life! Allogeneic transplant 1984 – now 55 years old.

- There was a time when I thought I’d think about blood draws and transplants and the SCCA every day of my life. And that was after my transplant and one-year anniversary. Today I am healed from cancer and don’t expect to fight leukemia again (but I won’t be surprised to come down with another kind of cancer before the end of my life). Time has faded the stark memories of losing my hair, considering death, counting neutrophils, and contending with GVHD. Sometimes I wonder, when I look into the milky-white cataracts of my 14-year old dog, if I’ll face dry skin or blurring vision, or another transplant side effect one day. But for the most part I’ve moved on, and I am thankful for FHCRC and the SCCA for helping me get here. Allogeneic transplant 2001 – now 41 years old.

- It took ten years but I finally quit thinking I am about to die. Allogeneic transplant 2004 – now 40 years old.

- I’ve been wondering who might be the oldest living AML leukemia patient (post-transplant of course). Allogeneic transplant 1979 – now 53 years old

**Things FHCRC/SCCA can improve**

- When I am seen at the SCCA/LTFU, I seen a different doctor every time. This is quite frustrating as there is never the same person to monitor my condition. You may all read the same documents, but there is a difference if you can visually “see” as person and evaluate their condition each time. Allogeneic transplant 2011 – now 52 years old.

- It is crucial that patients being discharge from SCCA have available recommendations for treatment specialists if the doctor they are returning to does not fit into this category. I would like to suggest that SCCA’s discharge follow-up include a phone call directly to patients to assure that this is happening and if not, be available to make specific suggestions and other recommendations for finding an appropriate medical provider. Allogeneic transplant 2014 – now 66 years old.

- I don’t have the financial resources to pay for all my co-pays and co-insurance parts of my medical bills anymore since I can’t work. The SCCA should be willing to FORGIVE that part of my medical bills. This causes tremendous stressfulness to me and my family. Allogeneic transplant 2012 – now 56 years old

- Upon completion of treatment at FHCRC, there could have been a clearer line of expectations as to if SCCA would still be involved; if so and at what level. Once we left we felt left to our own devices, not totally sure of the path for the future. I am still not sure of what is meant by long-term follow-up – is the questionnaire it? Allogeneic transplant 2012 – now 64 years old

- The questionnaire is glitchy – I last took immune-suppressants in early 2000 but the dropdown only went to 2009 and there wasn’t an option to skip the question. I noticed the “In the last week” or “In the last year...” preface statements also went away so wasn’t sure how to answer some of them. It might be good to have “comments” available on any question in case person isn’t sure of exactly what you want. Allogeneic transplant 1999 – now 56 years old.
Connecting survivors together

- Really I wish you would provide more resources so we can get information and feel connected to other people who understand us. For instance: I have a lot of physical problems due to GVHD of the vagina – and the doctors laugh from embarrassment. I’d like to network with others suffering the same problems. Allogeneic transplant 1998 – now 58 years old.

- Sleep related since like many others I have sleep issues that no one addresses. Would love to see a “message board” or group or listserv developed for long-term survivors so we can communicate and learn from each other. Aplastic Anemia transplant 1984 – now 59 years old.

Ideas for future research

- Enclosing a questionnaire for the caregiver regarding emotional/physical stress he or she may be experiencing. Allogeneic transplant 2003 – now 68 years old

- Does anyone who had a transplant develop PTSD? Allogeneic transplant 2000 – now 81 years old.

- Please ask about sleep/insomnia. I feel like I can’t ever stay asleep. It’s been a problem since my transplant. Thank you so much for giving me an extra seven years of life! I started grade school last fall (getting an MSW). I’m really happy to finally feel like I’m moving forward again. At the same time, it is very stressful. I don’t have much energy & I don’t feel very well physically a lot of the time. Allogeneic transplant 2007 – now 35 years old.

- Try to find a cure or a way to alleviate bronchiolitis obliterans. Even with my kyphosis (multiple spinal compression fractures). I was functionally well. The BOS has put me on oxygen 24/7, made me weak & much more dependent on others. My breath will become shortened & my heart will pound when I stand up & walk. I am an independent & positive person, but this dreadful disease has severely limited my life. Allogeneic transplant 2012 – now 62 years old.

- It might be helpful to have a section on work/employment and how the consequences of cancer and a stem cell transplant (or two) affect patients...also, how about a separate set of questions for caregivers to fill out? Caregivers are absolutely crucial. And since it’s required that each patient have a designated caregiver, it seems that they deserve more attention than they receive. Allogeneic transplant 2011, now 62 years old.

Many things I am thankful for

- 31+ years since my transplant. Life is good, thanks for the extra decades! Allogeneic transplant 1982 – now 46 years old.

- My transplant has given me 32 years of life I wouldn’t have had. In that time I’ve watched my 2 year old marry, have children and my 7 year old as well. What a gift it has been. Yes I have minor problems such as skin cancer and from going through menopause at age 28 and I worry that I am prone to other cancers but I am in excellent health and live a full quality life. These years have been a wonderful gift. Allogeneic transplant 1982 – now 60 years old.
• It is a miracle for me to have a little baby boy, after having all of my medical issues past and present. I had my bone marrow transplant in 1995, and my proudest and biggest achievement after fighting my severe aplastic anemia was the birth of my son. I don’t think anything would have happened without the technology Fred Hutch had to help me survive and live a wonderful life. Allogeneic transplant 1995 – now 35 years old.

• I feel full of life. Each day as I share smiles with my beautiful 3 year old daughter I am reminded just how precious life is. I celebrate each day as the gift that it truly is. Allogeneic transplant 1990 – now 49 years old.

• I am well, healthy, happy. My life is full and I am so blessed! I am now 41 years married to my wonderful husband. Four of our six children are married and we have eight beautiful grandchildren. I celebrate the miracle of my transplant all of the time. I consider everyone at FHCRC to be a huge part of my miracle and I am forever grateful for my amazing care and treatment. Everyone at the Hutch will always have my deepest gratitude for taking the best care possible of me and all their patients. Allogeneic transplant 2004 – now 58 years old.

• I am very grateful to all the people in the oncology field – it takes someone very special to do what you do. Allogeneic transplant 2005 – now 53 years old.

• Still have PTSD symptoms, but I know how many still suffer effects that never happened to me. I have been amazingly blessed, why am I so much better off than others? Allogeneic transplant 1997 – now 64 years old.

• This April was 21 years since my transplant (allogeneic). I am so thankful! I was not in remission when I had my transplant & my son was only 6 months old. Thank you for giving me the wonderful opportunity to be a mom & enjoy watching my son grow up these past 21 years! Allogeneic transplant 1993 – now 47 years old.

• I have no regrets; I’ve had 25 fantastic years – my next goal is to get into the record books for replacement parts. Allogeneic transplant 1989 – now 62 years old.

• Our daughter would not be here right now if not for a clinical trial for transplant without remission through Fred Hutch. She wasn’t even close to qualifying for the standard treatment transplant because of the amount of disease. I am phenomenally grateful for the brilliance and tenacity of the doctors at SCCA and Childrens and for an open door to try something unconventional. And again when she had trace amounts of disease at day +50 – they put her on a chemo rarely given to children, but it has worked so far – at her 1 year she is cancer free. We are so thankful for the countless hours her team has put into carefully consider her case and not give up on her. Allogeneic transplant 2013 – now 4 years old.

• Coming up on my 6 year mark it’s great to be alive! I am grateful for my care. I don’t worry about getting sick again. If it happens, I will deal with it. It has helped me deal with my recent broken arm. If I can get through a stem cell transplant, I can get through anything. Autologous transplant 2008 – now 60 years old.

• Thank you for 25 great years. Thank you for the wonderful Long-Term Follow-Up program. I cried when I opened the package from your facility and read “The Fred Hutchinson Cancer Research Center would like to take this opportunity to acknowledge the ’25 year anniversary’ of your treatment and to thank you for your continued participation in our Long-Term Follow-Up program.” You are simply the best. Allogeneic transplant 1989 – now 55 years old.