Thoughts and Comments from Patients—2013

People 20 or more years after transplant

- Mostly wanted to thank all the people at Fred Hutchinson for the life-saving, life-improving work you do. It has been a long time since my transplant – 27 years!!!, but, I’ll never forget my days in the Swedish hospital where I was literally reborn. Allogeneic transplant 1985 – now 49 years old

- Health is great! Just happy to be here another year and be able to take part in this survey. Highly doubtful 27 years ago. Allogeneic transplant 1985 – now 68 years old

- At 37 yrs. post-transplant, I’ve lived nearly twice as long as a survivor as pre-transplant. I often think how lucky I was that FHCRC was doing research when I was diagnosed. Identical Twin Allogeneic transplant – now 56 years old

- Today is my 22nd anniversary. As I tucked my 2 (year-old) daughter into bed, I thought to myself – had my treatment not worked out – I wouldn’t be looking into those beautiful eyes. A smile came over my face. Life is wonderful! Allogeneic transplant 1990 – now 48 years old

- I was a little unsure how to answer some questions due to the length of time, 33 yrs. (yeah!) post-transplant. It’s getting harder to determine whether some issues are age or transplant-related. I guess that’s not a bad problem to have. Allogeneic transplant – now 52 years old

- Simply, thank God and FHCRC for the last 23 years of my life. I have lived to see all 6 of my children grow to adulthood and to now enjoy my 7 grandkids in my retirement. How blessed I was that as the second oldest of 8 kids in my family, my baby brother (#8) was my match for the transplant – thank God my parents had 8 kids! Allogeneic transplant 1991 – now 62 years old

- Am doing quite well…am 62 yrs. old – was 41 when I had BMT. Thanks for the 21 extra yrs.! Allogeneic transplant 1991 – now 62 years old

- Very grateful for 21 (so far) years that I know I wouldn’t have had. It seems like just yesterday at times and then sometimes feels like another lifetime. But, then, I guess it was really another lifetime. Thank you! Allogeneic transplant 1992 – now 55 years old

- This year I celebrate 30 years post-transplant. My family and my church really made me feel special. It is at times like this I would shed a tear if I could (inside BMT- patient joke, but, not a joke). I am a better person because of the transplant. I love God, my family, and practically everyone I have ever met. I love being alive. I love talking to people about my transplant experience. Of course, any patient five years out and less will not agree with my statements. Believe me, it will get better, and better, and better. Allogeneic transplant 1983 – now 53 years old

- I admit I don’t often think about my marrow transplant any more, maybe because I was so lucky to not have any long-standing side-effects, but, filling-out this questionnaire and then reading the patients’ comments brings it all back home. And now here I am, 32 extra years into this miracle called life, with all its challenges, joys, and difficulties. I’m now trying to get used to the physical effects of aging, which is a bit ironic. Life hasn’t always been easy, but, it has been full and rich. My son was 6 months old when I was diagnosed, I thought he would grow up without a father, but, I now have the joy of seeing my granddaughter
growing up. For that and so much else, thank you, Dr. Thomas, and thanks to “the Hutch.” Allogeneic transplant 1981 – now 59 years old

- Twenty-nine years ago I flew into Seattle for the first time, thinking how beautiful the Pacific Northwest was and wondering if I would survive what was to come. My son, who was 5 at the time, was my reason for living. I was determined to be one of your success stories. Many nights I cried in my “bubble” room, scared that I wasn’t strong enough to handle what was to come. I had a nurse...that would spend time in my room holding my hand through the plastic and comforting me. I prayed I would live long enough to see my son graduate from high school and college. I have been privileged to see him grow into a man that I am so proud to know and call my son! Thank you for a lifetime of memories I would never have had without you! Thank you for continuing to follow-up on us! Allogeneic transplant 1984 – now 63 years old

- Marching forward toward the light. Allogeneic transplant 1984 – now 55 years old

- Life is good. Tomorrow I celebrate my 20th year since my BMT. Autologous transplant 1993 – now 73 years old

- 27 years! Thank you! Reading through others’ comments, I heard a lot of people struggling with their challenges. It made me think about my life. Yes, I have repercussions due to my transplant, but, it’s my “normal” now and I’ve learned to make the best of it. “It is what it is.” And, I’m thankful I have what I have! Actually, I’m very, very thankful! Thank you, Hutch! Allogeneic transplant 1986 – now 47 years old

- 20 years! Got to watch my son grow to be a man, marry and give me a beautiful daughter-in-law and 2 beautiful grandsons. 20 more years with my wife and family. Thank you. It was worth it. 3 left hips, 1 right, 1 shoulder, cataracts, no problem. Still on this side of the grass. Riding my motorcycle, doing roller coasters and loving the time that FHCRC & God have given me. Allogeneic transplant 1993 – now 55 years old

- After 23 yrs., doing very well! Hate to admit, but, pretty much have “forgotten” about transplant, unless prompted by something. Thank you!!! Allogeneic transplant 1990 – now 57 years old

- Thank you for your continued effort in not only attempting to cure cancer, but, in helping reduce and manage the long-term effects of the current and post-transplant methods. Pediatric Allogeneic transplant 1985 – now 31 years old

- Life has been great since transplant, though filled with ups and downs, the ups being higher than the downs lower. Having contracted HIV & Hep C from infected blood in 1980 is quite the downer, but, it’s a whole lot better than not getting the chance/opportunity to live all of these wonderful years and enjoy my friends and family. They told me (the FHCRC doctors) that 10 years would be my life expectancy...I’m glad they were wrong. I know that in 1980 the technology was a far cry from todays’, but, it worked well enough to keep me going for 30+ years. Too bad they didn’t have all the answers to todays’ problems back then, but, that’s why they call it research. I do realize that I am one of a handful of people that has had such a long post-transplant life and I am very thankful to have it, so livin’ the dream!!! Allogeneic transplant 1980 – now 51 years old

**Recovery taking a long time**

- When I came home after my transplant 3 years ago, I expected that by now I would be pretty much back to “normal.” That is not the case and at times I seem to be backsliding. I have improved physically, but, emotionally seems to be more of a problem. Both seem to be a bit of a roller coaster ride – not knowing how
much energy I will have or what kind of a mood I will be in on a particular day. Allogeneic transplant – now 66 years old

- This year, I celebrated 15 yrs. since transplant. It has been a struggle, but, one I’m thankful for having. Along with the difficulties, I’ve had 15 additional years to enjoy my wife, daughter, extended family and friends. What a gift. Allogeneic transplant 1998 – now 60 years old

- Sometimes it sucks to be me...but, I’m alive, happy and grateful. Allogeneic transplant 2011 – now 33 years old

- 9+ years post 2nd transplant and still struggling to define who I am. I am doing much better physically than emotionally. I am making progress, but, it is slow. Allogeneic transplant 2004 – now 68 years old

**Enjoying more time**

- After I was first diagnosed with CLL in 1977, I was afraid that I might not live to see my grandchildren, but, I now have four. Every time I am with them I think about how lucky I am. Allogeneic transplant 2006 – now 65 years old

- Feel blessed to have lived 7 years. 7 Christmases, 7 birthdays, 7 daughter birthdays, 3 grandson’s birthdays, and remarried my divorced husband. Life is good. It was 30 years ago that we divorced. Allogeneic transplant 2006 – now 66 years old

- I continue to be amazed that I am still alive today, 14 years later. When my treatment started in 1999, my youngest daughter was 3 and my oldest was 6. I am blessed to have been here to raise them – so they didn’t have to grow up without a mother. Today my youngest graduated from high school and my oldest is in her last year of college. I cannot thank you all enough – your work has made the impossible happen! Allogeneic transplant 1999 – now 56 years old

- My transplant was the most difficult thing I have ever gone through, but, it was worth it because I have “today” with my family. I am so thankful to have more time to raise my precious girls! Life is an amazing gift! Allogeneic transplant 2012 – now 43 years old

**Was it worth it?**

- I’m writing this on behalf of my husband as he is in the hospital for GVHD and has been there for 5 months. GVHD has affected his gut and (he) has not been able to eat or absorb nutrients. Skin was also affected. Numerous other problems arose due to his treatment – blood clots, PICC line infections, bladder infections, extreme weight loss, muscle weakness, nausea and the list goes on. As he is one year into transplant, he is having a difficult time determining if this was a good decision due to poor quality of life. Allogeneic transplant 2012 – now 69 years old

- When I developed my bronchiolitis obliterans & it has gotten progressively worse requiring oxygen 24/7. I have become depressed for the first time & feel a bit overwhelmed. There are times I wonder if it was worth it. Allogeneic transplant 2001 – now 69 years old
It is strange to have fully recovered 13 years on and still see the effects daily. At work, many students comment and joke about my height, some maliciously, but, the majority only because they don’t believe I’m an adult. The risk of GVHD prevented me from doing National Service, which makes it harder for me to get a job with the government. Yes, my life was saved, but, I’m always left wondering what could have been if not for the cancer. I realize that I seem very melancholic and that it is how I usually feel when talking about my leukemia. Every relationship I’ve had ended when I told my partner about my leukemia. My parents are on the road to divorce because of things that happened during my treatment. So, I’m alive, but, all of those “joys of life” don’t seem to be there. And I’m 23. My friends from college are getting married, advancing their careers, while I feel like a spectator rather than a participant in the Game of Life. The good, fun times have happened in spite of the leukemia, but, to this day, I feel the negative effects - And probably will for the rest of my life. The total body irradiation has left me at 5’2” and without any sperm. Even if I do find a lasting relationship, I can’t have kids of my own unless I adopt. Pediatric allogeneic transplant 2000 – now 23 years old

I have been in remission from my (ALL) and bone marrow transplant. The radiation I received, along with the chemo, has affected my growth, my learning abilities, my physical strength, my loss of hair, my eyesight, my stamina, my lung capacity, my short-term memory, my sexual activity, my social life (I had one transfusion in 85/86 and that’s how I got Hep C), being able to drink alcohol beverages, and my marriage. I’m unable to have children. I have regular marital therapy sessions, physical therapy sessions, regular doctor visits, I have had hundreds (literally) of blood draws – (and plenty of scar tissue associated with them). My medical history has extremely affected my financial life. I have never been able to financially pay for my medical bills since my transplant. My family and I have spent at least $125,000 on medical bills over the last 27 years without support. I have never been financially independent. Pediatric Allogeneic transplant 1986 – now 28 years old

Overall, I’m disappointed in the treatment. A lot of time and effort was spent and all I got was 9-1/2 months. I expected more. Autologous transplant 2012 – now 60 years old

Brain fog – cannot remember – agitated with people most of the time. Even less patience than ever had before. Personality seems to be different. Mood swings and no tolerance. Fatigue and life in general seem to get him down most of the time. Allogeneic transplant 2004 – now 66 years old

The stem cell transplant process, with all the chemotherapy leading up to it, has been an enormous ordeal. While the MDs and SCCA staff have been enormously supportive throughout, it is really impossible to have anticipated the toll this has taken on me and my wife. Happy enough to be alive, but, the price has been very high. Autologous transplant – now 65 years old

Tips for coping

I am coping better with memory and attention issues. Ironically, my smart phone has apps to help with lists, calendar, reminders, etc. to help me remember and organize the details of my life. Pediatric Allogeneic transplant 1999 – now 27 years old

When Dr. Petersdorf told us to freeze embryos before the transplant, I thought he was crazy. I believed that was a waste of time, especially during the first year of recovery where I was so fatigued. Getting through the first year was the most challenging part of the transplant process. I learned a lot about not doing too much too soon, taking naps, and being patient. It was hard watching other moms volunteer at school & be busy with kids while the best I could do was get my daughter to and from school… My husband and I had to work through a change in roles and many times I wasn’t sure if the transplant was worth it. The biggest thing that
helped was a change in my attitude & changed thinking. I finally let go all the things that I couldn’t do & stopped comparing myself to all the healthy, busy moms I knew. When I embraced the fact I was alive, I needed lots of rest & gave myself permission to recover, things got better including my energy. When my two year anniversary came, I couldn’t believe how great I felt. My life will never be the same since the transplant. Sure, I’ve lost some things (physical strength, catch a lot of colds – I used to), but, my life is so much richer, deeper & meaningful that I’m happy I went through this very difficult experience. I’m actually expecting twin girls this July 2013 and really can’t believe how far I’ve come. Allogeneic transplant 2010 – now 32 years old

- When I returned home to my oncologist, I didn’t know his knowledge did not go beyond diagnosis, as a result, I came down with the worst GVHD anyone could have at age 74. Please, anyone reading this should be very careful about checking these facts before returning to your previous doctor. Learn from my mistake. Allogeneic transplant 2013 – now 74 years old

- This is a sad time for me because instead of just rolling with the punches, I am coming to terms with all the hurts, disappointments, and anger with regard to all my life events, including the transplant. I would encourage all patients to talk about how they feel, negative or positive, regarding their life after transplant. Until recently, I couldn’t talk about the negative. It is hard trying to bury all those negative emotions. I so appreciate hearing the negative comments because it helped me realize that I have the same hurts and disappointments and that it is OK to voice those out loud. I also thank Fred Hutch for printing “the worst of times” and providing a balance of good and bad experiences. Maybe now that I can freely release my tears and fears, I can truly heal. Allogeneic transplant 1977 – now 56 years old

- At first I stressed over my disease returning, now I live life to the fullest and spend as much time doing the things I like to do most – camping, traveling, gardening, spending time with family. If you keep busy, you don’t have a lot of time to dwell on the ‘what ifs’. P.S. Thank you for the gift of life. Autologous transplant 2007 – now 51 years old

- I am thankful every day to be in this state of health that I am. Every day I do some form of exercise, whether at the gym with machines & weights, long walks, working in my garden, yoga, biking… I think this, in addition to being mindful of what foods I eat & choose for my family, is what is bringing me closer to good health. Also, we all have a choice for being positive or negative towards our life. We can’t change our past, but, we sure can change our outlook towards today & the future. I choose to be positive & happy! Pediatric Allogeneic transplant 1981 – now 48 years old

**Side-effects of steroids**

- You might want to tell the women who will be taking the medications that make you gain weight and swell-up like a balloon, a little heads-up. I was not at all ready for the 40 lbs. of weight that I put on during the process. I know it’s a little vain, but, after losing your hair too, it kind of takes you off-guard. Allogeneic transplant 2012 – now 37 years old

- I was prescribed 100 mg of prednisone per day to fight severe skin graft vs. host (disease). I had no idea how harmful high doses of prednisone could be & now have severe osteoarthritis & multiple spinal compression fractures which has resulted in kyphosis. I wish that tests were done on my spine, before the prednisone was administered, to show that I would be at-risk – perhaps another method could have been used. I was in excruciating pain for months before being given a dilaudid pca, which I am continuing to use since May 2012. Allogeneic transplant 2012 – now 61 years old
• When my prednisone is increased, it affects my moods a lot! I find myself on the edge of depression and snapping at my family a lot more often. I pay close attention so I am not getting upset about a lot of little things. I think we should be warned ahead that that may happen. I feel very fortunate to be alive today and able to be with my family. I am thankful for all the research and people willing to be a part of it so that others may benefit from it. Allogeneic transplant 2009 – now 45 years old

• Chronic sclerotic Graft vs. Host Disease dramatically interferes with daily activity. Long-term negative impacts of prednisone cannot be overstated. People need to be encouraged (prescribed) daily exercise regimen before steroid-induced muscle wasting. Extremely difficult to recover after decline. Allogeneic transplant 2004 – now 67 years old

Are new symptoms due to transplant or getting older?

• It has been over 10 years since my transplant and I am closing in on 74 years of age. My problem is that everything that happens to me (bad), I question if it has to do with the transplant, the excessive medications, or just a natural thing with aging – like losing sight in left eye, heart attack, chickenpox, then shingles, losing my hearing, etc., etc… Allogeneic transplant – now 73 years old

• After 15 years, it is difficult to determine if any physical problems are BMT-related or just a natural result of the aging process. I guess as long as I continue to receive these forms, that is a good thing. Allogeneic transplant 1998 – now 61 years old

• I feel like I am aging 10 years ahead of my 62 yrs. - double chin, wrinkles, then, skin age spots. I need help walking more often. Fall a lot. Pretty bad ones, like broke my nose! Worry about getting around & climbing stairs, etc. I still want to travel – going to London in summer. Trying to swim more and lose weight. Try is the operative word. Can’t believe I’m 62. Feel like I only have 10 years before I can’t travel. Cramming it in now! Allogeneic transplant 1998 – now 62 years old

The new normal

• Life is now the “new normal.” I have come to accept that the way my body now looks, feels & functions is “my new normal.” Am I happy with it, no. Am I pleased to be alive, yes, very much. Would I want something different, yes, but being alive trumps all else. My retirement dreams have changed and I am happy to be able to do what I can, but, wish it were different. I battle chronic fatigue and moderate to severe muscle & joint pain. Allogeneic transplant 2009 – now 64 years old

• Since my transplant, my attitude about life has changed. I am more patient with people. I enjoy life’s little pleasures more. I am so empathetic & patient with people. I smile more. I laugh more. Although I am completely disabled to being able to work or perform most of the activities I so much enjoyed before cancer, it really doesn’t seem to matter anymore. I am worried that my condition will get worse. Autologous transplant 2012 – now 58 years old

• I may no longer be the energizer bunny, but, life is good and I still ice skate at 66. Plan on competing at adult nationals – April 2014 in Hyannis MA. Memory is challenging, but, with good notes, I am still productive. Autologous transplant 2011 – now 66 years old
• I am a physician with greater appreciation of caregiver’s role, stress of waiting for test results, respect of patient’s choice of sharing information & very grateful to be able to share my experience with first year medical students. Allogeneic transplant 2002 – now 66 years old

• Reading about fellow myeloma patients’ experiences has given me perspective that I didn’t have before. I’m glad that I can still work, though it is a struggle. Every day is a blessing. A day above ground is a good day. Autologous transplant 2010 – now 60 years old

• Fatigue seems to have cut my activity in about half – which now seems to be my “new normal.” Pain from bone damage, secondary to multiple myeloma, is my major problem. Otherwise, after reading the questionnaire and other people’s remarks, I consider myself fortunate not to have a multitude of other problems. Allogeneic transplant 2009 – now 67 years old

• Each day is a gift, but, that day comes with different challenges with which I have to cope; these challenges are in addition to every day-to-day stress from living in this modern world. Many people, of course, do not understand and we survivors must teach them that, although the treatment may have ended days, weeks, months, even years ago, we still have many issues – physical, emotional, mental – from having cancer and subsequent treatments. Just because we “look good and/or well” does not necessarily mean we feel “normal.” Autologous transplant 2002 – now 58 years old

Feeling good

• Generally feel really good. Exercise regularly, jog, yard work, etc. The transplant is becoming more of a distant memory which is how I prefer it to be. Autologous transplant 2006 – now 55 years old

• For the second consecutive year, I forgot about my transplant anniversary. It is good to be able to concentrate on life & not illness after 8 years. Allogeneic transplant 2005 – now 65 years old

• I would like to blame my BMT for going bald, gaining weight, and losing foot speed, but, that was happening for a long time before my AML. If the word “cure” is ever used here, I consider myself in that club. I was lucky to be treated at the Hutch and luckier still that I came out as well as I have. Allogeneic transplant 1997 – now 59 years old

• Fighting cancer and winning the battle contributed to who I am today. Coming face-to-face with death gave me greater appreciation for life. I wouldn’t change anything. Autologous transplant – now 57 years old

Finally feeling good

• I am very grateful for these extra years and don’t spend too much time thinking about “waiting for the other shoe to drop” - but it is in the back of my mind, sometimes. My life has returned to normal for the most part – at least by most appearances, and as time goes by I forget sometimes and let the little annoyances creep in and “get” to me. Some days I am very frustrated – my memory is shot and I find it difficult to function at my previous mental capacity. But I look normal, so people think I’m the same as I was before I got sick – this can be frustrating. On the other hand, after 8 years, it appears that the chronic GVHD has given up – so, I’ve been off prednisone for 5 months and in a couple of weeks I’ll stop taking the last of the antibiotics. It
was so awesome to finally take pills only once a day! How liberating! Allogeneic transplant 2005 – now 55 years old

- Lucky thirteen! After 10 years of meds. & issues, the last three years have been peaceful & smooth. I now only see hematologist/oncologist once a year, leaving plenty of time to just live life & I am so very grateful. Allogeneic transplant 2000 – now 42 years old

- I got off prednisone last year and I believe I will be able to taper off of MMF after the summer!! After 15 years of these drugs, I am ready. Allogeneic transplant 1998 – now 65 years old

- I would do this all over again. I can walk without falling or leaning to the right. I can think again! I can read – I have a new & different life. Not as many friends and I like spending time with me again. It took a couple of years to feel pretty good – but now I think I’m suffering the side-effects of steroids & chemo – my neck hurts always because of compressions and my bones are getting weaker – I miss exercising. But, I don’t miss MS. Autologous transplant 2010 – now 55 years old

- Overall health seems better even though I just had a pacemaker installed which I think has helped with my day-by-day functions. Just opened a pizza restaurant… I’m 68, soon to be 69, late starter. Autologous transplant 2006 – now 68 years old

- It took a long time, but, I feel great! Autologous transplant 2007 – now 48 years old

### Wish I had been told

- There were many things that have taken me by surprise since leaving after my transplant. I was not made aware of the things that could happen with my treatments! Examples: 1) NO sexual desire – wasn’t warned that could happen with treatment. It has put a strain on my marriage; 2) NO education about “chemo brain” or the “post-menopausal brain fog.” Being aware of these, I may have been able to do something about them hitting me so hard. It sucks to go around feeling like you have no clear idea of what you are doing because you forgot & can’t remember. Allogeneic transplant 2011 – now 30 years old

- I am encouraged by the increased focus on the psych. aspects. Regarding this topic, virtually every BM transplant patient I have discussed this with agrees that a greater awareness of what was to come would have been helpful for patients & support. Obviously, it has become a greater focus for FHCRC & SCCA and I am sure this will help alleviate these challenges moving forward. Autologous transplant 2005 – now 54 years old

- I think the staff (doctors included) need to be more aware and concerned about the financial burdens of the transplant patient. Before saying that tests have to be sent to SCCA, they should consider whether the patient will have to pay for these tests and help the patient explore the costs involved. Adding financial strain and concerns on top of dealing with cancer and recovery from a transplant is very difficult for patients and their families. Allogeneic transplant 2012 – now 69 years old

### Thanks to caregivers

- My girl --- was the key to me making it this far. You have to have a good caregiver and I have had the best. Allogeneic transplant 2012 – now 60 years old
• 15 years! Wow! Although it seems like such a distant memory...I could not have done it without the love & support of my wife. Allogeneic transplant 1998 – now 46 years old

• Today is my 55th birthday. I was 26 and my son was 5 months old when I was diagnosed with CML. I missed his first steps, but, prayed for enough time to be able to see him graduate. Not only did he graduate HS & college, he has grown into a beautiful, successful young man. My husband, who was only 24 at the time, stood amazingly, steadfastly by my side with a new baby and a very sick wife. We recently celebrated our 30th anniversary. Life is good!...no, Life is Great! Allogeneic transplant 1986 – now 55 years old

• I’m blessed with my health, my wonderful husband who was my caregiver – always there for me... Allogeneic transplant 1999 – now 59 years old

Grateful to be alive, but…..

• Being diagnosed with a secondary cancer sucked. I finally “forgot” about being sick & then this happened. I always knew it would happen, but, it was still a shock. Allogeneic transplant 1999 – now 34 years old

• This has been an extremely taxing and eventful 10 yrs. After 8 surgeries, most dealing with the aftermath of GVHD or its treatment, I’m thankful that I still have the constitution to keep plugging away. I never dreamt that I would still be dealing with GVHD this long post-transplant. Allogeneic transplant 2003 – now 56 years old

• I am still here. You guys are the best. But sometimes, with all these problems that slowly keep happening, it sucks. Autologous transplant 2001 – now 42 years old

• It has been 7 long, tough years with chronic GVHD – osteoporosis, etc. Would I trade the experience for not having it, No Way! It’s better than the alternative. I’m thankful to be alive! Allogeneic transplant 2006 – now 68 years old

• The experience has left him with sort-term memory/learning issues. He was super smart & school was easy before. Now, he has challenges reading & remembering. Pediatric Allogeneic transplant 2011 – now 10 years old

• Definitely, eyes affect me & the problems effects greatly impact my mood. The dry mouth & other problems with swallowing – almost choked twice – yikes! have me worried quite a bit. The best thing is my support structure around my family. At times I am extremely resentful toward the world. However, I remember some of the friends I made in Seattle that weren’t so lucky as I. Pediatric Allogeneic transplant 2001 – now 27 years old

• I have never regretted my transplant. I’ve had 24 years I thought I’d never have! It was not a big shock when they told me I was in stage 5 kidney failure, I just would like to know what happened to stages 1, 2, 3, 4 – it is what it is. I hope to have a kidney transplant as soon as possible (makes eyes, hips and kidney just spare parts). Allogeneic transplant 1989 – now 61 years old

• The most frustrating issue that I have since my transplant is my not so good memory. But the good news is that I can remember the fact that my memory isn’t as good as it used to be and concentrate on one task at a time. Autologous transplant 2005 – now 55 years old
I used to have a somewhat healthy sex life. Now it is nonexistent. I get very depressed about that. Allogeneic transplant 1999 – now 52 years old

I am glad I had the transplant, but, because of the radiation, I have had 3 cancers. Because of the sarcoma cancer in my leg, my life has changed forever. The cadaver bone replacement broke. I don’t want to amputate or get a rod put in my leg as I can stand and pivot, walk a little with a walker, and walk up and down my stairs. So, using a wheelchair is challenging, hard, degrading, and very annoying. I am grateful I’m alive, but, I’m not very happy. I’m mostly depressed. Allogeneic transplant 1999 – now 52 years old

Compared to how things were 21 years ago, life is great. However, the surge of basal skin cancers is starting to freak me out. I just had the 12th one removed/treated & I’m 34. I’m frustrated because no doctor can really tell me why. They tell me the radiation caused it…is their guess. (I’m also fair-skinned & freckled). I’ve since started wearing a hat & jacket whenever I’m near the sun & I feel like one of those “mole people.” Is there anything else I can do to stop these? MOHS surgery is not cheap! I’m happy to be alive, don’t get me wrong. Just…frustrated. Pediatric Allogeneic transplant 1992 – now 34 years old

I have PTSD in relation to transplant. Any medical issue (even a bad cold) scares me and I get flashbacks to leukemia. I almost feel like I’m getting a deathly illness. Just having the skin cancers removed sets me off with uncontrollable tears while I am having the surgery. Allogeneic transplant 1987 – now 58 years old

In this year’s responses from patients there are some regarding sexual dysfunction – is it normal? Will it ever return? This is always sort of “taboo” and I’m glad you address it candidly. Rest assured, a significant # of post-tx patients are dealing with that for sure. Please ease everyone’s minds and print the actual % of people indicating sexual dysfunction. Misery loves company! Allogeneic transplant 2005 – now 53 years old

I was married in April 2012 and then I was diagnosed with thyroid cancer in Dec. 2012. I had a thyroidectomy in Jan. 2013. I have no doubt that this was a secondary cancer caused by my transplant 13 years out. I had actually stopped worrying about this happening. I was more angry than I was scared. It was like reliving everything and starting from scratch. I now wonder how many more times I will do this. Allogeneic transplant 1999 – now 35 years old

I am glad I had the transplant, however, there is not a day that goes by that I do not have pain, mostly in my lower extremities. My memory is poor, my vision is not so good (I prefer reading large print books) and my legs hurt a lot of the time. Getting up from a sitting position requires more effort. We just returned from France and I was able to cope, but, found I needed to take oxycodone a couple of times a day. Autologous transplant 2010 – now 67 years old

The two issues I face, as a result of GVHD, are “dry mouth and dry eyes.” They sound so innocuous, it’s almost like self-pity to mention them. However, I’ve had to be fitted for scleral lenses often in an effort to get the correct fit and the lenses get dirty or start to hurt my eyes as they become drier throughout the day. I take Restasis, but who knows if it even helps. But my life is always balanced by the fact that I am alive and in spite of the eye and mouth problems, life is good. Many wish they had my problems because theirs are much worse! Allogeneic transplant 2001 – now 66 years old

I have continued issues with shortness of breath when exercising as well as muscle cramping. I have had osteopenia since late 1990’s & probably still have it. I have had to have basal cells removed regularly since around 2010 (2-3/year). But, who’s complaining! I’m alive and feel great. Allogeneic transplant 1997 – now 59 years old

I am constantly doing word puzzles and brain games to help with my short-term memory and brain “fog.” Will these memory problems be with me for the remainder of my life? My termination of employment was
partially due to my memory and problems with stress-induced confusion. I worked there for 16 yrs. I guess I just finally got so bad – they let me go. Allogeneic transplant 1982 – now 57 years old

Reactions to the questionnaire

- I can’t decide how I feel about this questionnaire. It’s only my second one, but, it sort of forces me to pull up and quantify every issue (emotional/physical) I have and results in me feeling a little worse about things than before. I also begin worrying again about relapsing and remember so clearly the feelings when I was first diagnosed and was told I needed a transplant. Maybe I am repressing these feelings the rest of the time and haven’t really confronted them yet? Maybe they will never go away and will always rear-up when there is some ”trigger?” Because the rest of the time, I feel healthy, capable, happy and really just satisfied with my life. Although, when I have these “triggers” of memory, I sometimes feel that I should be doing more with my life, since my time might be limited. Allogeneic transplant 2010 – now 38 years old

- I am so grateful to have another year to be filling out the questionnaire. I always look forward to the “comments” section and loved the new “resilience” form. There have been many obstacles in the past 17 years post-transplant, but, all worth overcoming to be here with my beautiful family! My heart is filled with gratitude for all you have done & continue to do. Thank you, Fred Hutch! Allogeneic transplant 1996 – now 50 years old

- Another year has passed, as this LTFU questionnaire reminds me. I’m still here, still in remission, and still grateful for the many blessings in my life. Time is a precious gift. Please continue to share the comments from respondents. That’s my favorite part of the annual questionnaire. Autologous transplant 2010 – now 59 years old

- These questionnaires and the comments make me feel inadequate at times. In many ways, the CML, the transplant, the years of relapse, etc. did not make significant changes in my life. I went back to the same job that I’d had for 20 years & I’m still there. My kids are grown & I did most of what my peers did except for the year off for the transplant. I’m not more religious or spiritual or a better person and I feel badly about that, but, can’t get around it. That said, it’s delightful to be alive, to be working, traveling, writing; to be reasonably healthy and happy. This year we all – my donor sister & her husband, my husband, our 2 daughters – went to Italy/Sicily for 2 weeks, walking ten or more miles a day and enjoying each other and the adventure. Allogeneic transplant 1997 – now 68 years old

- I enjoy reading comments from other survivors - it helps me with my own thoughts. I am very thankful to all who helped me during that very difficult time and I am very thankful for my donor and my wonderful family who took care of me. Allogeneic transplant 2005 – now 52 years old

- I am also thrilled that the questionnaire is now online to complete. The online version was easier to complete and only took less than ½-hour total (even including the time it took to include my medication list). Thank you, thank you...loved the enhancement. Autologous transplant 2002 – now 66 years old

- One of my favorite things to see each year are the comments from past patients. I love seeing the dates --- especially the ones from 25-30+ years ago. Gives me hope-a goal! Allogeneic transplant 2006 – now 41 years old

- Thanks for doing the resilience questionnaire. I waiver back and forth between, “Wow, I’m resilient; look what I went through and how I’m doing now! I’m like Superwoman!” to “Man, (sigh and collapse on the couch) do I really have to cook today? I just can’t do it.” Allogeneic transplant 2005 – now 38 years old
• (My wife) has asked me to complete your questionnaire because she is afraid that if she were to do it, it could bring back too many painful memories and that she would not be able to emotionally handle this process and might increase or intensify her nightmares.  Autologous transplant 2007 – now 58 years old

• 19 years since BMT for acute myeloid leukemia.  Some made it and others didn’t.  Survivor’s guilt.  Hard to read some thoughts and comments from people who have a hard time.  Allogeneic transplant 1993 – now 39 year old

• I look forward to and dread this questionnaire in equal measure.  Dread because it focuses my attention on areas where I’m not feeling well, and I also feel badly for feeling like I’m not doing very well when I know others are doing worse than I am.  I look forward to it because reading others’ comments helps me to feel like I’m not alone and others are dealing with the same issues.  The one thing I always feel is gratitude.  Allogeneic transplant 2006 – now 40 years old

Many things I am thankful for

• I am grateful every day that I am here to walk my dogs, gaze at the stars, laugh with my family and friends and dream of a future.  Allogeneic transplant 2008 - now 34 years old

• My family and I celebrated the 10th anniversary of my successful stem cell transplant on… My wife, four children, their spouses and our six grandchildren thank my unrelated donor for these ten years.  Allogeneic transplant 2003 – now 69 years old

• My life has become so much better in many ways since —2008.  I am more aware of what I eat, I exercise more by walking & working out, I enjoy golfing, hiking & other things we do.  I enjoy my relationships with my children and friends more.  My wife and I have become closer and more in love after only 32 yrs. of marriage.  My church means more to me now and I just enjoy every day (even if it is raining & cold).  As far as my cancer coming back, my attitude is:  if it is to be, let it be – and give me the strength and dignity to accept it.  Autologous transplant 2008 – now 71 years old

• It’s July 28th and I’m sitting on my deck in the sun, albeit with lots of sunscreen and a hat, enjoying a wonderful weekend in Seattle.  I can’t believe it has been 19 years since my BMT at Fred Hutch.  This December---marks the 25th anniversary of the day I heard my name and leukemia/lymphoma in the same sentence.  It’s been an amazing experience, not just the medical aspect, but the interaction with all the people I’ve met.  Being diagnosed with cancer of the blood was not in my life-plan, and to be honest, it stinks being a cancer patient.  Being a cancer survivor is something else altogether.  Like Dr. Seuss said,”oh, the places you’ll go and the people you’ll meet.”  Autologous transplant 1994 – now 63 years old