Practical Leukemia Tipsheet for the newly diagnosed, and their families

Personal note from the author

I hope that you find this document helpful.

I was the CEO of a 25 person management consulting firm, an author of 8 books, and a professional speaker on digital transformation who spoke all over North America. I had a wife, three twenty-something kids, and was active with several not-for-profits. Life couldn't be better.

Then on April 3, 2017, I was diagnosed with AML with Extramedullary Disease - a very aggressive AML.

After several months of chemo (and the loss of 60 pounds) I was told that while the cancer has mostly been killed, it will return quickly, and that the survival rate was... zero. I was then transferred to the Bone Marrow Transplant (BMT) clinic for evaluation to see if I was a candidate for this last chance treatment. Thankfully I was a suitable candidate. Sadly, no one in my family was a bone marrow match. Thankfully, some unknown person on the other side of the world was a "perfect" match. And generously agreed to be my donor.

At the date of this writing, June 2021, I am almost four years post-transplant, and just over 4 years post-leukemia diagnosis. I am still here, and for the most part, I am healthy.

Note: This isn't medical advice, and it could be that there have been changes to the treatment protocols that make part (or all) of these suggestions not relevant to you. It is your choice to follow these ideas, or not, and you do so at your own risk.

That being said, consider sharing this document with those closest to you: it will make a difference!

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Your entire body will be affected by the leukemia AND the treatment: GI tract will be destroyed from mouth to anus, your skin, hair, and nails will be affected by the chemo, your liver and kidneys will be stressed to the max, and you will have short-term cognitive impacts (attention span, mood changes). Everyone is different, but eating as much as you can, drinking water, walking, and following doctor's instructions directly impact your recovery. (The good news is that for the most part, your body mostly returns to normal once the chemo chemicals are gone and your blood counts return.)

I also would like to point out that while the points below were important for me, you are different than I am, and your diagnosis (and treatment) may be very different.

Editorial note: I personally never liked the term "Cancer Journey", as most journeys are pleasant, and AML treatment (and my later BMT) was definitely NOT pleasant and NOT a journey - it was a battle that you fought every single day during treatment and during recovery. I like "Cancer Battle" instead.

It's not just about you

- While you have Leukemia, you are not the only one affected. My wife pointed out to me early on that "I" didn't have cancer, but rather "We" have cancer. It affects your spouse almost more than you: Beyond caring for you, the entire weight of running the home, paying bills, managing investments, taking care of children or elderly parents, and keeping up with their professional responsibilities is on them.
- Assume that you'll need a family member with you quite a bit of the time, to help with meals, listen to medical reports from the doctors, deal with visitors, take laundry back and forth, and most importantly, keep your spirits up. If they can't be there due to COVID, having an iPad set up with Facetime on can be an important substitute – even if they are just sitting there and doing nothing.
- Your caregiver needs to ensure that they also are taking care of themselves, otherwise they won't have the energy (or patience) to take care of you. This means ensuring that they find ways to reduce their stress:
    - Go to more movies, or "binge" more on Netflix
    - Exercise, including joining a gym near the hospital, or using home gym equipment.
    - Attending the (excellent) programs at "Gilda's Club" Toronto. These include meditation, guided trips to the art gallery, etc, etc. Many of these are now offered virtually.
    - Rotating caregiving responsibilities with other family members and friends.
    - Talking to a social worker at the hospital
    - Arranging for a modified work schedule (if possible or necessary)
- Appoint a particular person to be the "main contact" for you - you won't be able to readily take calls or return emails.
- Consider how you'll share the news with your colleagues, clients, suppliers, friends, and family. I did this with some personal emails, some bulk email, personal meetings, as well as a facebook post upon my diagnosis, and then an update a number of months later. Everyone felt that they wanted to help in one way or the other, so I asked them to donate blood. Literally, thousands of donations were made – a real bright spot looking at pictures of them donating.
- If you are religious, have someone reach out to your clergy. They can be incredibly helpful.
- I told people that while under treatment, that I would be unavailable via phone, email, or social media. If people wanted to find out how I was doing, they contacted my wife, who functioned as my gatekeeper.

Room set-up

- If there is any way that you can get a private room, do so. There is less risk of infection from the other patient (or their guests), you'll get a much better sleep, have less contention for the bathroom/shower, and have more highly valuable privacy.
- Get large pictures - I got colour photocopies - to put on the wall; it's amazing how much this affects your attitude on the more difficult days. It might sound shlocky, but a month (or three) in the hospital is different than a few days: having the room look at least a bit more normal is very empowering.
- If your room doesn't have a wall clock, then buy one. My room did have a clock, but it tick-tocked so loudly I couldn't sleep. So I ordered a silent electronic one from Amazon for my room, had it delivered to my hospital room, hung it up, and gave the old one back to the hospital. (I didn't ask for permission - I just did it.)
- You become exceptionally sensitive to cold; if your room isn't warm enough, ask the nurses to arrange for the engineers to turn it up 2-3 degrees.

- I love playing the piano, so rented a good digital piano ($60/month) for the room. It was tight, since the rooms are very small, but I made it fit. While there were some very bad days where I couldn't even get out of bed, playing for an hour or two every day lifted my spirits greatly. (It seems that others enjoyed the music as well.)
- Don't order a phone, nor TV, as the cost was ridiculous. Netflix you could pause, has better selection, and didn't have commercials. News you can get streamed on your computer. The best purchase ever: a new iPad.
- Get a seat pad for the chair: the chairs are very uncomfortable to sit in for long periods of time. And drape a sheet over the back so that your back doesn't stick to the vinyl. Do whatever you can to be in the chair rather than in the bed, to maintain strength.
- What gave me great comfort was heated blankets, particularly when I was fighting infection. I also found that it helped me to sleep. Tip: If you get another blanket and put it on top of the heated one, it stays warm for a longer period of time. During the day, when I was sitting in the chair, I often had a heated blanket on top of me to keep warm.
- I still am sensitive to temperature; I sleep every night with a heating pad and an electric blanket. I have often thought about whether having these would be a good idea in the hospital. They would be, but given how often blankets and sheets were changed (because of soiling) I know it wouldn't ever work out.

Personal Comfort

- Shave your chest and arms: Adhesives and tape (from EKG's, dressing changes for your Hickman line, peripheral blood draws, etc,) are exceptionally painful when removed, as your hair gets yanked from your skin. This pain is 100% avoidable when the adhesive is on shaved skin.
- REQUIRE the nurses to use "paper tape", not plastic tape, whenever they do a blood draw, biopsy, etc. Plastic tape is excruciatingly painful when removed.
- If you need a peripheral blood draw (you will, despite the Hickman line): Ask for a "Butterfly" needle: it's a smaller needle and less painful.
- Bring your favourite shampoo, but if it has much of a scent, you may find it nauseating. Same thing with deodorant. I was so sensitive to smells, I needed to have my wife change her "unscented" deodorant to a different brand.
- Since there is much wailing and crying in the hallway, you might prefer to have the door closed - the crying and screaming is depressing.
- Bring slippers, and SLIP ON shoes.
- Purchase a case of kleenex, as you will be using it quite a bit. The hospital-supplied tissues are too small, and they are no better than cheap tissue paper.
- Bring "nice" regular clothes and wear them: You feel better wearing healthy-person clothes, and Nurses and Doctors treat you better as well.
- When you have a procedure, they will always provide you a gown for you to change in.
- Assume that you will need to launder ALL of your clothes every day, as they will become dirty or soiled every day.
- At night I always wore a hospital gown, as it was easier when going to the washroom. And since it usually became sweaty, it could be changed every night. (If you bring your pyjamas, bring a new set for every night.)

- Buy a Fitbit exercise band or an Apple Watch, and set a daily goal for the number of steps each day. On some days, I wasn't even able to get out of bed, but getting a minimum number of steps walking around the ward is critically important.
- Again, if you don't have an iPad, get yourself one. In the room, I placed my laptop computer on the movable table to watch movies. I used my iPad to read the news, respond to emails, when sitting in the chair. I used my phone when I wanted to text or speak to someone (which was quite rare.)
- Bring a power bar so you have flexibility as to where to plug in your rechargers, computer, etc.
- Download a TON of movies onto your computer, and sign up for Netflix if you haven't done so already. Watching movies is a great distractor from the pain and the nausea, and can sometimes substitute for supplementary pain meds. (I watched EVERY star trek episode in every series, in sequence: it was surprisingly upbeat. Also watched EVERY James Bond movie, in order. Fascinating.)
- Don't expect that you'll have the concentration (or even desire) to read, although people will drop off magazines for you, etc.

Sleeping

- Generally my bedtime was 7:30pm. This was necessary both because of fatigue, but also because you never get a good rest with all of the interruptions and extraneous noises. And that you are woken at 6am for blood work.
- Buy an industrial sized container of earplugs at Marks Work Warehouse: you won't be able to sleep without them. (The loud "Buzz Buzz" alarm from your drug pump due to air bubbles every hour is terrible.) The tiny packs of earplugs from the local drug store cost about 10X more.
- Bring an eye mask, as often a nurse will turn on the light in the middle of the night when they check you or change your meds, and then forget to turn off the light.
- Clicking from the drug pump (sounds like a geiger counter) is terribly loud: moving the speed down a chunk makes it quiet enough to sleep. Ask the nurse if it is possible to slow the pump slightly: don’t do it yourself.
- Purchase two decent pillows. (The pillows at the hospital are plastic and make you sweat. (And aren't comfortable.) Another great investment: when I finally left the hospital, I threw them out.
- The mattress if vinyl, and it gets sticky with only one sheet. When the nurse changes the bed, request that they put two sheets on the mattress for you to sleep on top of, rather than one. I asked them to use two flannel sheets as this was much thicker, and more comfortable. This is separate from the sheet and blanket that cover you.
- I had a problem with profuse sweating at night. They had brown bed pads that were used (I think) for people who had incontinence or diarrhea problems, but I slept on a stack of two or three of them just to sop up the sweat. In the middle of the night I would remove a sweaty one and it would make my sleep far more comfortable (eg I wouldn't be sleeping in a puddle of sweat.)

Safety

- A huge risk is falling. Remember to always be anchored in three places, your two feet, AND something else. For example, in the shower, anchor yourself by holding onto the rail with one hand at all times. When you use the washroom in the middle of the night, hold onto the bed as you walk (and then the wall).

Staff

- The sheer number of people who you will be watching your care is huge:
    - A day nurse and a night nurse
    - Your hemotologist, who is in charge of your cancer treatment and care strategy, and is the "Most Responsible Physician (MRP)" They will come by a few times to see you, but will generally be guiding behind-the-scenes.
    - An Attending physician or nurse-practitioner. These are responsible for your day-to-day health. They will check in with you every day, reviewing your blood numbers, prescribing drugs or other items to be delivered by IV, doing a detailed physical examination. They are hematologists or specially certified nurse-practitioners.
    - Medical residents and Fellows: These are doctors and specialists-in-training, that might see you with your MRP or the Attending.
    - Pharmacists: These are specialists in chemotherapy; they will review the drugs that you will be taking, and sometimes will provide detailed schedules and print-outs. Their job is very complex: As an example, when I was having my BMT, I was on 19 concurrent prescriptions, in addition to the chemotherapy and non-prescription drugs.
    - Other specialists: Since AML chemo (and later, the BMT conditioning regime) are exceptionally harsh, you will experience significant body/organ dysfunction. As things come up, you will be seen by the appropriate specialists. In my case, this meant heart, liver, kidney, and infection-control specialists.
    - Technicians: If you can't get to a test, in most cases a test comes to you, along with the technician. This would include ultrasound, X-ray, EKG, and various others.
- Nurses intimately know what you're going through, and every one of them has advanced certifications that allows them to be a nurse in the ward. Don't hesitate to ask them a question; if they don't know the answer, they will get it for you.
- The nurses are incredible; because you are in the ward for quite some time, you will get to know them and vice-versa. While they are very caring, and generally social, be aware that they have a schedule, and need to take care of many patients - don't be greedy with their time.
- A thank you goes a long way, and will ensure better attention: to the people who bring the meals, the people who disinfect your room every few days, the technicians, the nurses, and the many doctors who will be visiting you.

Health points

- Immediately sign up for the online portal, and provide a key family member user access. All of your test results are there, along with clinic notes etc. Reading these results BEFORE the doctor comes around on their rounds means that you can spend your allotted time asking more meaningful questions about what the numbers mean, what you might expect in the next day or two, etc.
- Write down any questions that you may have, so that you will remember to ask when the doctor comes around. (Because of your treatment, your memory likely will play tricks on you.)
- Many people will tell you about a "revolutionary" treatment and cure. These typically are all "alternative medicine", homeopathic hocus pocus, or other non-evidence-based therapies. People also gifted me many books on how person X used the XYZ approach to treating their leukaemia, and is now completely cured. (I thanked them, then threw these in the trash.) Given the huge amount drugs that

will be in your body, and the risk of unknown side-effects, I strongly urge you NOT to self-treat with anything, other than good nutrition.

- The bone marrow biopsy and the spinal taps are truly not comfortable; every time you have one you may be a completely different experience. On one of my spinal taps I was back to "normal" immediately, while with another I was on my back unable to move, with an extreme headache for 14 days.
- Eating is a real challenge. In two months, I lost 60 pounds; some fat, but almost all of my muscle. Ask friends and family to make some of your favorite foods. If you are Jewish, you can order food (no charge) from Bikur Cholim, which is significantly better tasting than the hospital food.
- It actually became very hard to eat: You have no appetite. Mouth sores mean it is hard to put things in your mouth. And when you eat, you either become nauseous, or it came out as liquidy diarrhea.
- The docs will say not to stress about it, but just eat whatever you can. (I wasn’t stressed about this at all.)
- Mouth care is very important, and exceptionally challenging. You cannot use a regular toothbrush, nor are you allowed to floss. They will give you a mouth wash, which you should use as much as possible, as well as foam swabs to swab over the teeth and gums. There is one toothbrush on the market that I was able to use without pain or bleeding. It is the Sensodyne ProNamel ultra soft brush, although I am sure there are other similar. https://www.amazon.ca/Sensodyne-Gentle-Toothbrush-Sensitive-Bristles/dp/B07F4KQMFC/. Or consider this one, although I haven't tried it: https://www.amazon.ca/dp/B00N32BB46/
- They don't tell you this, but with all the chemo (and if you have a BMT, the radiation) there is a huge dental impact. Not just because you can't really brush or floss, but the chemistry of your saliva changes during the process: I've since had two root canals, and about 12 cavities filled in the year post-transplant. DO EVERYTHING they tell you to do with respect to mouth and tooth care.
- Since much of the molecular studies and cytogenetics is highly technical, you may wish to ask for a geneticist to help you decipher what they mean. For sure check what your results might mean on Google. (In my case, I had some good markers, and some very bad ones.)
- Another huge risk is infection, which can be deadly. Warn anyone who comes to visit that if they have a tickle in their throat, a stuffy nose, OR IF ANYONE IN THEIR FAMILY DOES, that they should not visit. Since your immune system will be zero while you are in treatment, you cannot fight infection: anything you catch can be deadly. (I ended up in the ICU, by the way, and was dogged with many infections.) Since they will ration (or prevent you from having) Tylenol, the fevers, shakes, etc are terrible. (The reason why they often prevent you from taking it is that the Tylenol might mask your symptoms.) The one upside to COVID and fewer visitors is a dramatically lower risk of being infected.

Financial issues

- Contact your insurance agent to start the process for payments from any Long Term Disability, Critical Illness, or Business Interruption insurance. These coverages are usually paid from the date of initial disability, but since it takes a while for them to process the claim, the earlier you take care of this the better.
- If you are in Canada, and are under the age of 65, go to the government website to apply for CPP Disability Payments. This is about $1200/month, and is payable if you are completely disabled (which you now are.) It is paid retroactively FROM THE DATE THE FORM IS RECEIVED, NOT FROM THE DATE OF DISABILITY, so you need to get this started asap. Of course, you fully will intend to getting back to normal, but given these payments are available for those who qualify (and you will, if you have leukemia), there is no reason not to get this “free” money.

- Depending on how you are doing after the treatment, you will likely be very weak, unable to walk very far, or stand for long periods of time. You can have your family doctor fill out a form to get you a temporary "Disabled" pass for your car, and then have your spouse or friend submit it.
- The cost of parking at the hospital is outrageous. If your spouse (or a friend) is coming to the hospital every day, consider alternatives:
    - There are discounted long-term passes that are available: ask about them at the hospital.
    - Depending on the season, there may be free street parking nearby.
    - Consider using public transit instead - it's more convenient and direct. (Not recommended during COVID, as anything caught on transit may infect you.)

After you're home

- When you are released from home, you will be on a very strict "outpatient" schedule. In my case, this meant two clinic appointments each week, with time getting a blood test beforehand. In addition, since your body is in a recovery mode, there will be many tests that you will need to take – which often will mean another day or two each week driving to the hospital. (Eventually your appointments will be weekly, then bi-weekly, monthly, and eventually, annually.)
- The hospital will provide plenty of documentation when you are released: who to call if something happens, what to watch out for, and detailed instructions on how to avoid infections from food. (On this front, everything from foods to avoid, how to wash foods that you can eat, what you shouldn't have when you eat out, etc.)
- Your job at home is to recover: this means forcing yourself to take walks, especially at the beginning when you are at your weakest. You'll never get stronger sitting on your rear end.
- A good practice when someone says that they wish to come over: ask whether they, or anyone in their family, has the sniffles or a sore throat – if they do, then the visit should wait. When "healthy" people come over, try to visit outside, to reduce the risk of infection even further.
- We had arranged a stand-up hand disinfectant dispenser to be at our front door, so anyone coming into the house immediately could disinfect.
- If you tend to get cold, purchase a high-quality electric blanket (for the night), and a heating pad (for the day).
- Vaccinations: The conditioning that is required pre-transplant obliterates any of your built-up immunity, and also obliterates any of your childhood vaccinations: literally, you are a blank slate. Within the two years post transplant, you will begin taking all of your childhood vaccinations again. (Note that some vaccinations – *live vaccines* – you will not be able to take, so you will need to rely on herd immunity to avoid getting sick.)
- A year or so after my transplant, I somehow contracted Chicken Pox, even though no one I knew actually had a case of it. This put me in the hospital for two weeks. (I also had Chicken Pox as a child!)
- While COVID has been bad for society, there is a silver lining: more people are aware of the dangers of infection, and they may have a better understanding of your new sensitivity to it. In my case, except for my wife, no kissing, hugging, or handshaking: the risk of infection is just too high for me.
- Remember that your recovery will not be a straight line: It will be a zig-zag, with a number of set-backs along the way, along with great improvement with just about everything. At the time of this writing (about 4 years post-transplant) my new normal is not exactly like my "old normal" (I have fatigue, sensitivity to temperature, and a few other minor things), but I am living a full and satisfying life. Without Leukemia.