

# TWO STEPS FORWARD

*Embracing life with a  
brain tumor*

SAMPLE CHAPTER



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This book is not intended as a substitute for the medical advice of physicians. The reader should regularly consult a physician in matters relating to his/her health and particularly with respect to any symptoms that may require diagnosis or medical attention.

## *Twenty Two*

# BEING A PATIENT

### ***On a positive level, I have learnt to:***

- Be my body's own advocate
- Love and appreciate the small things in life and be grateful for them
- Live each day as it comes
- Learn to put things into perspective
- Know and truly respect my body

### ***Notes to self***

*These are some notes I made for myself during my recovery—my learning points—which I have printed out and put in my office as a reminder to myself. I thought they may be useful to share.*

1. Be your own advocate! If something does not feel right, seek medical attention until they can resolve the issue and you feel comfortable and adequately satisfied with the resolution.

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2. Take each day as it comes. It could even mean take each hour as it comes, especially in the beginning. Know that each person has a unique experience with the condition and also post-surgery.
  - a. Look at your days and week ahead and make sure it is not chaos, with no time for quiet for you and your brain.
3. Listen to your body and your brain. Mental fatigue can be as crippling as physical fatigue. They are closely linked and feed off each other.
4. There may be a 'new normal' you need to find. It does not mean a 'lesser normal' but something new—and it could be better! Mine is.
5. Identify the triggers that may cause you to feel fatigued or off-kilter. Try to minimize your exposure to them. If you have no option, be mindful that it may fatigue you, and plan how to work with it.
6. As a parent, spouse, partner, or in any other relationship, try to find five minutes each day when you are feeling at your best, when you can connect with this person and create positive memories. Store them up.
7. Keep an objective 'eye on yourself'. As you get stronger, keep track of any negative behaviors that are able to morph back into positive behaviors e.g. mommy monster. It is easy to get stuck in a rut. Remind yourself, as you get stronger, to 'check in' on yourself regularly.
8. Make peace with yourself and with others about your abilities. This may still need to happen long after you first think it would.
9. Once you are stronger, think about whether you are pre-conditioning your mind about what your body can do, given the

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past experience you have had. Can you try things again and see if you are able to do them now? You might surprise yourself!

10. Know that you might look and seem to be totally recovered on the outside, but on the inside you might still be recovering, and that some parts of you might never recover to the exact same person you were before surgery. This is okay. Don't run from it: embrace it.

### ***What I asked my neurosurgeon about my condition after I was diagnosed***

I found it useful to keep a list of questions and a diary of my symptoms in the beginning, after my diagnosis, so that when I saw my doctor, I had all the details in one place. Also, it is useful to take someone with you to see your neurosurgeon/neurologist. You might forget exactly what the doctor said, or forget to ask one very important question.

This is a list of questions I put together in the beginning, when I saw the various specialists:

- How much experience do you have with this condition? i.e. how many patients do you see with colloid cysts each year?
- How many patients with my condition have you operated on?
- What is your current opinion on treatment of the condition?
- Does this opinion go along with what happens worldwide?
- Do I need MRIs to monitor the condition? If so, how often? How does this match worldwide opinion?
- How do you determine when to do surgery?
- At what size do most people need the colloid cyst removed?

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### ***Surgical questions***

- How long would I wait until surgery, if you recommend it?
- How long does the operation take?
- What type of operation do you perform?
- Time in hospital and which wards (ICU)
- Post-surgical rehabilitation, if required
- Medications
- Risks during surgery
- Key challenges after surgery
  - Acute (in hospital and after discharge)
  - Long-term
- How long does it take to go back to work/school?
- How long to get 'back to normal'?
- Post op follow up
  - MRIs
  - Neurosurgical appointments
  - Rehab appointments

### ***What to do before surgery?***

*This is the type of information I would have liked to have before surgery—it is not a medical opinion. Unfortunately, because my surgery was more unplanned, I did not have much time to prepare, so we did not get around to doing all of these things.*

1. Ensure the 'house is in order'. Meaning if you have bills to pay or things to sort out, put it in place before the surgery.

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2. Think of all the things you normally do each day and allocate them to someone else, if they still need to happen: e.g. work responsibilities, walking the dog, paying the bills, taking care of children. Let them lapse if you can.
3. Make a few meals and freeze them or reach out to friends and family to bring over meals for the first few weeks. By the end of each day you might not be up to cooking a gourmet meal, but you will need good nutrition to recover.
4. Write a list of all your important accounts and their passwords. Your brain will be focusing on healing, not remembering the multitude of passwords we all have to keep these days!
5. Ensure you have a power of attorney in place if necessary, and create or update your will. This may seem morbid, but any surgery, even minor surgery, carries risk.
6. If you have kids, organize some fun play dates for them after your surgery so you know they are happy and having fun. It allows you to relax when you know the kids are taken care of.
7. Chat to your close friends and loved ones about your recovery. Let them know that it may take some time before you are back to doing everything. Let them know you have no idea what it will be like for you and that each day will be one step at a time.
8. Figure out how and to whom information will be sent out about your surgery and post-op recovery. People will always want to know that you are safely out of the operating theatre and making a good recovery, but you don't want to be inundated with calls in the acute stages.
9. If you have any form of disability insurance/critical illness or income protection insurance and intend to exercise it after surgery, this is the time to look into what needs to be done with regards paperwork and applying for it.

***What to take to hospital?***

1. Super comfy pajamas and socks
  - You will most likely be in hospital gear for a day or so after the surgery, then you can change into something more comfy and familiar. There is nothing like your own PJ's.
  - Sturdy pair of slippers for your 'walks' through the ICU when you are getting up and mobile.
2. Toiletries
  - Take some nice lip balm or Vaseline, as your lips get so dry, especially after surgery.
  - Hand cream.
  - Take your prescription medications to the hospital and they will tell you what you can or cannot take.
3. Neck pillow
  - I found this invaluable. My mom said to take my travel neck pillow into hospital and it was great—just another position you can get your head into post op.
4. Reading material
  - A book may be hard going after surgery, depending on how tired you are. So a magazine may be nice to glance at if your body and brain allow.
5. Notepad and pen
  - It's nice to write something down if you want to ask the doctor or nurse a question, or anything else that comes to mind. Don't tax your brain with trying to remember it, or being frustrated when you can't.
6. Something personal



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- It is nice to take in something personal and comforting to hospital, but not anything that can get lost or that is valuable.
- For a child, a nice stuffy toy is lovely. However, note, that I was very happy with the stuffy bunny my Mom bought me for my stay in hospital too!

### ***What to expect after surgery***

*This is information I think may be useful to have after surgery, it is definitely not a medical opinion. Please seek medical advice if you are concerned about any of your symptoms and follow any advice given to you by your medical team.*

This is the hardest part to write, as everyone has such different experiences after brain surgery (or after any surgery). My list includes questions asked on a regular basis in our group as well. I have found, however, that often after any surgery, the advice you are given regarding recovery may differ in its thoroughness, regardless of where you had the surgery. So, here is my two cents worth, based on my individual experience:

#### **1. My stages of recovery**

##### *a. Acute recovery (<3 months)*

- Rest, rest and more rest!
  - The extreme fatigue I felt in the acute phase took me (and us all) completely by surprise. I did not realize that I would be sleeping for anywhere up to sixteen hours a day for the first four weeks. I would nap two or three times a day and sometimes just lie in bed and read (if I could manage

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that part). Things like going for a doctor's visit, or chatting to someone for too long definitely needed a nap afterwards.

- *Rule of thumb*: Sleep till your body cannot sleep any more! It all benefits the brain and your healing process. There seems to be no time limit on this phase of sleeping.
- Doctors visits
  - Write down any questions for your doctor in a notebook so when you get there, you can remember them all (my memory was not stellar in the acute phase)!
  - Have someone go with you for your first few visits. I found this useful so that I could remember exactly what was said to me, or if I forgot to ask an important question I had been meaning to ask.
- Medications
  - Post surgery there seemed to be a never-ending medication regime, from Keppra to dexamethasone to anti-nausea pills. Some post-op medications can increase fatigue, but they are necessary, so it is a wicked cycle. Take everything that is prescribed according to your doctor's recommendations and call them if you have any questions.
  - Some of the medications made me sleep, some made me stay awake, some gave me mood swings and some made me eat like

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a beast. But they all served their purpose and pulled me through my recovery, so I took them all as prescribed. That is the main thing!

- *Rule of thumb:* Keep track of what you need to take and when (or even better, get a caregiver to do so). Keep a diary so you know if you have taken your meds or not. Believe me, you might not be able to remember, and under or overdosing is not an option!

#### *b. Recovery (3-12 months)*

- In general, I found this went in ups and downs or two steps forward and one step back.
- Be patient. Be patient with your body and your brain. On the days that you are feeling good, don't try to run a marathon. Embrace the feeling, but don't overdo it. You will get there through baby steps, and you and your body will be happier for it.
- I still had to nap every lunch time until I was twelve months post op. Even at eighteen months post-op, I sometimes needed a nap if it had been a busy weekend or day. I have learned to be in tune with my body and know its limits. Napping means my brain was in need of a 'recharge' in order for it to perform at its optimum.
- Continue to respect your body (and brain!) for what it has been through and know it

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will come right. It might be slightly different from before but if you embrace that, rather than fight it, the path is that much easier.

### **2. Hair or no hair?**

- a. To be honest, this did not cross my mind, given the unplanned nature of my operation.
- b. Depending on the type of surgery you have, you may have a neat small incision-patch behind your hairline or you could have a more shaved appearance if you had a full craniotomy. If you have enough time, ask your surgeon what to expect.
- c. If you usually get your hair colored, and if you have time to do so before surgery, do it. It might be a while before you can do so again, and post-op you might not want to expose your scar to chemicals for a while.
- d. Keep a beanie/toque handy, especially if you have surgery in fall or winter. There is something very comforting about having your head wrapped warm and tight. I slept with a beanie for months after my surgery and even now, when the weather changes and my head aches, it is very comforting to put my beanie on.
- e. Your hair will look bizarre after surgery, as it may have been wrapped up tight in a bandage for days. I looked like I had had a perm and was a brunette (and I am a blonde) from all the surgical disinfectant they had put on my scalp. The picture my husband took of me was a classic. The first hair wash is memorable to this day!

### **3. Sleep**

- a. The amount of sleep my body needed to recover was astounding. No-one really explained to me that I

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would sleep ten hours or more at night and then fluctuate between napping and being awake for an hour at a time in the beginning.

- b. Given that the way your brain heals is to sleep and switch off all non-essential functions, lots of sleeping in the beginning makes sense. You may even find your body still needs to nap up to one year or more after surgery. Everyone is different in what they need.
- c. I only stopped napping at lunchtime about one year post op.
- d. You may also suffer from insomnia depending on your post-surgery medications. I found that the dexamethasone gave me insomnia at night and so did my elevated cortisol, even though my brain just wanted to sleep.

#### **4. Pain**

- a. Post op
  - I was told prior to my surgery that the brain itself has no pain receptors, so the pain would be more from the incision and craniotomy.
  - Indeed, the actual pain from the surgery was real but not unbearable. I had oxycodone for the headache (ache in the head, literally) immediately post-op. When I was discharged, I had Tylenol for the pain and oxycodone if things got really unbearable. I rarely had to use the latter.
  - I had pain post-op from the IV lines and arterial line in my arms.

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### b. Headaches

- Because I never had headaches or migraines until I was diagnosed with a colloid cyst, I thought they would just go away after surgery.
- Unfortunately, I still get migraines, even two years post op. It is just part of life. I have my daily preventative migraine medication and know that extreme fatigue and some foods will set it off. I just work with it instead of against it.

### c. Pain around scar and incision site

- The strangest thing was when, about two weeks after surgery, I actually ‘felt’ my head. It felt like it had craters in it, bumps, craters and ridges. Wow! This was an interesting adventure. Even two years out, it sometimes feels like it may have changed shape a bit, or an area might irritate me for a day or two.
- As I continued into my recovery and the area around my incision started to ‘wake-up,’ I had feelings from pain to numbness to just plain old aching. This seems to be what most people encounter, but obviously contact your doctor if anything seems out of the norm.
- Even now, cold and changes in weather make my head ache. I feel I can predict a weather change myself! So a beanie is still very useful if it is cold.

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### d. Neck and Back Pain

- I think given the weird positions you are often put in for the actual brain surgery, sometimes your neck or back may feel a bit painful and stiff during the acute recovery period.
- Also, if you are less mobile during your recovery, your body tends to feel it. If permitted, a gentle short walk each day is a good option. Walk with someone down the road and back, just to keep your body moving. It will also be good for the soul and, as you see yourself get stronger, good for the motivation.
- A hot or cold pack on my neck or back was useful as well.
- I started to see my massage therapist and chiropractor after consulting with my neurosurgeon and this helped alleviate the pain.

## **5. Driving**

- a. Depending on where you live, some countries/states have laws which do not allow people to drive for up to a year after brain surgery. Check with your doctor if there is any such legal issue in your jurisdiction.
- b. I was given clearance to drive once I was off all pain medications and anti-seizure medications, and when I felt able to do so. This was about two months post op.
- c. I actually didn't drive until four weeks after I was cleared to do so. I did so when it felt right to do it, and I started off slowly.

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- d. It is not only your life and but also others who are involved when you drive. Make sure you are ready and feel competent. I held off on driving long distances or driving at night for a while longer.

### **6. Memory**

- a. Well yes, that topic of short-term memory is tricky, as it seems a lot of people with colloid cysts suffer from memory issues before surgery. I did, but not in any extreme way, apart from when I developed hydrocephalus.
- b. After surgery, I felt like my short-term memory was not great. I compensated by ensuring I kept note of things I needed to do, lists and so forth to keep the wheels moving. I felt like a goldfish in many moments! This passes, with time.
- c. I also started playing brain games such as Lumosity on my iPhone to challenge my brain and give it some homework. I still challenge myself now to remember what I have to do the next day, instead of just looking at my calendar. One-year post op I noticed a big improvement in my short-term memory, Now, at two-years post op, I would say it is back to normal.
- d. My long-term memory still has gaps in it even to this day but nothing that is detrimental to my functioning.

### **7. Moods**

- a. Fatigue, and frustration with the fatigue and prolonged recovery, can make one feel more impatient and 'fragile' at the end of the day. Mood swings can also be related to the extreme change that has hap-



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pened, as well as to medications. Your body and mind are adjusting to just having had brain surgery!

- b. Keeping an eye on your moods and state of mind is a good thing. Keep an open channel of communication with your family physician about this if you feel you are struggling more than you anticipated. Seeing a therapist or psychologist is another tool to assist in recovery after such a surgery.

### **8. Stamina**

- a. As you progress in your recovery, you will hopefully notice changes in your stamina and ability to do things. It may be something small like being able to climb the stairs at home without feeling exhausted.
- b. If you feel your stamina is not where you think it should be, chat to your family physician. Major surgery can have an impact on the way your body functions.

### **9. Stress/Lack of confidence**

- a. My ability to deal with stress and my general lack of confidence has been a challenge since my surgery. This was not an issue for me before my surgery.
- b. A good friend said to me, we all head to the doctor for a sore throat but yet when we are under extreme stress we never seek help to chat to someone about it.
- c. If it means seeing a therapist/psychologist, or whatever it takes for you to feel more confident in your abilities as well as less stressed, look into it. I started seeing a clinical therapist and it made a tremendous difference to me. It taught me to be more in tune with my body as well as my mind, a great life lesson in so many ways.

## **10. Vertigo and imbalance**

- a. Having struggled with vertigo prior to surgery, I thought it would be a thing of the past after surgery, but it was not.
- b. Speak to your family physician about options to assist you if you find that vertigo is impacting your daily life. It can be debilitating and incredibly tiring.
- c. Vestibular physiotherapy helped me tremendously; over months my brain learned to counteract the ‘false messages’ it was getting regarding my imbalance. This website offers a good explanation of vestibular rehabilitation therapy: <https://vestibular.org/understanding-vestibular-disorder/treatment/treatment-detail-page>

## **11. Return to work/school**

If you know the date of your surgery and are able to prepare for it in advance, speak to your work place in advance about your return-to-work plan. Discuss with them the fact that you are not 100 percent certain about the time frame of your recovery. Most neurosurgeons will be able to give you an estimated date for return to work, and that will be important for your workplace to know.

The most important part of your discussion will be regarding gradual entry back to the workplace. You may be able to go straight back to normal work hours; however, it might be a better option to start with a gradual entry. This may mean part-time hours for a week and gradually increasing your hours until you are back at your original schedule.

The same discussion or rationale should take place for a return to school or university. A work setting usually involves a high level of focus and attention, which places high demands on the brain.

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This can result in a very tired person, either half way through the day or at the end of the day. Keep the channels of communication open between you and your work colleagues or boss on your progress on reintegrating at work—it is important to your success!

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*Thanks for reading, I hope you enjoyed it! With gratitude Claire*

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