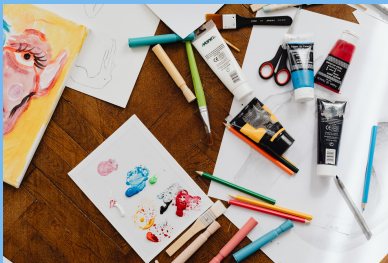


Pediatric Illness & Mental Health:

Stories for Patients and Their Parents & How Art Therapy Can Help



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My Story

My name is Grace, and I created this booklet to share my story and the stories of others with the hope of encouraging new patients and parents alike. Four other students and myself are sharing our stories with you. We all hope that our stories can help you get through both the easy days and the rough days.

I was diagnosed with chronic kidney failure when I was two-and-a-half years old. At the time, the closest children's hospital was an hour away from where I lived, so we did a lot of driving. I was away from home a lot, and when I was old enough to go to school, my parents decided to homeschool me because I would miss too much school with all of my doctors' appointments. It wasn't the original plan, but

I ended up being homeschooled all the way through high school. I think that was one of the best choices my parents made for me. When I was around 6 years old, my illness came to a point where the children's hospital we had been going to at Albany Medical Center was no longer able to treat me. We were referred to Boston Children's Hospital, and have been going there ever since. The renal (kidney) transplant team has become like family and they know me well. They like to tell me that I'm a little bit famous in the renal department. I'm 21 now, and I still see most of the same doctors at Boston Children's that I did when I was little. In the 19 years since my diagnosis, I have also dealt with Grave's disease, which is a thyroid disorder, seizures, been on hemodialysis,

then peritoneal dialysis, and back to hemodialysis. I have had apheresis treatments, two kidney transplants, and many other surgeries and procedures. MRIs, ultrasounds, IVs, catheters, a feeding tube; I have done most of it. I spent a LOT of time in the hospital in the past 21 years. I've been both inpatient and outpatient more times than I can count. My doctors and nurses came to know me so well, that one of my hemodialysis nurses could look at me and tell if I was going to have a seizure. There are several doctors and nurses that I will always remember because of how much they truly cared about me and I am so grateful for them. They have always done their best to make sure that I had everything I needed, including one of my favorite things: art supplies. I was constantly drawing, painting,

or some other kind of craft. They even let me paint the windows of my room when I was inpatient. I think if I hadn't had those art projects to do, I would have spent most of my time in bed sleeping or watching tv, which isn't a bad thing, in moderation, but not the best day in and day out. I did not participate in "official" art therapy, but for me, art was my therapy. It still is. That is why I am minoring in it here at college, and why I want to be an art therapist. I want to show people how art can help them the way that it helps me. It has always given me something to focus on other than my illness, or even difficult times unrelated to my health. It is such a valuable tool that I believe people dismiss because they think art requires talent, when that is not the

case. If anything, artistic talent can develop the more time you spend making art. It is a learned talent. I think the most time I ever spent doing art was in 2019, when I had my second kidney transplant. That kidney is the one I have now, and it came from a deceased donor, because the type of kidney disease I have was too aggressive to risk someone's healthy kidney. Today, I am the healthiest I have been since before my diagnosis. All of my medical conditions are under control. I'm no longer on dialysis. I have medications I have to take every day at a specific time, I have to get labs once a month, and I have a check-up with my renal team every three months. There are still bumps in the road every now and then, and I know there always will be, but I am so much better than I was and for that

I am forever thankful.

Art is still something I am passionate about. I love creating things, whether that be for myself, for other people, or just to create.

Art is expressive, at times without us even trying. I want to use this passion for art to help other people who are in the same place in life that I once was. That is where the inspiration for this booklet came from. I truly hope that it is helpful and inspiring for everyone who reads it. <3.

-Grace Utter, current Gordon student
& BCH patient

What is art therapy?

Art therapy is a therapeutic technique that incorporates creative methods of expression through visual art and media. It originated in the fields of art and psychotherapy and may vary depending on the program or therapist. Art therapy can help improve cognitive and sensory motor function, self-esteem, self-awareness, and emotional resilience. It may also help resolve conflicts and reduce stress. There are many different approaches to art therapy, but they all have the same general purpose: supporting mental health in hard times, including physical illness.

Patient Story 1

I was in the hospital frequently for chronic GI issues and a rare tumor. The hardest parts for me were being away from my family and friends and coping with surgeries. Something clinicians did for me that helped make things easier was that I had one nurse who would braid my hair or stay with me at night when my parents couldn't be there. They would also find me playdoh to keep me entertained and the best movies.

I participated in art therapy while I was in the hospital. It was helpful for me and helped keep my mind off of the difficult things I was going through.

-Jenna-Marie

Patient Story 2

I was in the hospital for a hemorrhagic stroke. The hardest parts for me were not understanding what was happening to me, and loneliness. The nurses were very encouraging and helped me be more comfortable by playing music in my room. Getting visits from my friends and family was something that was really helpful while I was in the hospital. I was not able to participate in art therapy because my injury made it difficult to do anything requiring fine motor skills, but if I could have done it, I think that art therapy would have been beneficial.

-Grace P

Patient Story 3

I was in the hospital frequently for Type 1 Diabetes Mellitus. The hardest part for me was the mental and emotional toll. This particular chronic illness is so finicky!!! If my blood sugar is too high, I am irritable and often unexplainably angry at everything until it settles back into range. If my blood sugar is too low, I feel like my whole body is vibrating like an electric toothbrush. In those moments, I am so anxious, uncomfortable, and vulnerable. I feel as though I could fall apart and dissolve. Those are the moments when my separation anxiety is through the roof. Having T1D also affects my sleep. Some nights I'm just a straight up insomniac!

I was diagnosed on November 27, 2017. My care team at Boston Children's Hospital allowed my parents to hold my hands for a lot of the scarier blood draws, IV insertions, insulin injections, and finger pricks. My mom slept overnight in my room with me. The nurses gave me these really cool socks that I still have! They did little things, probably insignificant things that made me weep. I felt like someone out there really cared for me (and this was aside from the comfort I was finding in my relationship with Christ!). For instance, something I loved was that they had customizable menu requests. A favorite of mine was these amazing fresh fruit cups that you could order with your breakfast. One day, I was craving just a bowl of strawberries, so I wrote a note to the cooks in the kitchen ON

MY MENU asking if I could please have just a few extra strawberries. The cooks in the kitchen prepared not one, BUT TWO bowls of cut up strawberries just for me. I didn't think they would even notice, but it made me weep! I'm even tearing up right now remembering it. Those cooks are my favorite story ever. I would do anything to thank them personally and tell them I love them.

I didn't participate in art therapy while I was in the hospital, because I was too lethargic at the time. There is a possibility it could have been helpful for me. I was doodling in the margins of my Bible, as I still do to this day, but I'm not sure if full blown art therapy would have been helpful. I tend to be a verbal processor and I don't really like structure that much, unless I get to dictate what said structure will look like.

-Grace C.

Patient Story 4

I was diagnosed with neuroblastoma, a rare childhood cancer. The treatments I had as a child caused some deformities and issues for me later. During high school I ended up having to go back to the hospital for some major procedures to address those issues. I was in and out of the hospital all through college. The hardest part about my hospital experience was not understanding what was happening or what would happen next. My time in the hospital was from 6 months old all the way up through some of my toddler years. I underwent a lot of painful surgeries and very uncomfortable treatments.

My body would feel really awful, and most of the time I didn't know why. Because I was so young, I had no autonomy over things being done to my body, making me frequently feel tense and fearful of what might come next. My communication was also very limited so I could not communicate the way that I was feeling about these unpleasant and painful procedures. The only expression of fear, anger, or depression that I had at my disposal was crying. I realized quickly that this didn't get me out of treatment and made everyone else in the room feel sad, so I became very good at not shedding tears.

Obviously, as an infant, and as a toddler, it was near impossible to grasp what cancer is or chemotherapy or surgery, etc. However, we don't give young kids enough credit for what they can understand and remember. I knew I was sick. I knew that when my parents' faces looked distressed that it had to do with me. I knew which hallways and rooms meant I was going to have a CAT scan, a blood draw, or surgery (even though I didn't know what the purposes of those things were). I knew which people were doctors, which were nurses, and which were interns. I think it is important to have as much conversation as is appropriate with

kids who are suffering from illness and to give them space to lose it at times. Tears are part of kids' processing what is happening to them and how they feel about it. In my experience, slipping into survival mode made processing my trauma much harder later on. I cannot stress this enough!!!! Clinicians that took the time to pop their heads into my room to say hi on their rounds, or who visited me to play for a little bit without having an agenda or performing any procedures made all the difference in the world!!!! There was one intern who frequently came to say hi to me and make me laugh while on his rounds. Over the course of my time in the hospital, he probably put in some of my IVs, or helped a doctor out with a procedure

I didn't like. However, all I remember of him was that he was kind. Whenever he was in the room, I knew that things would be ok because he was there. I had another doctor who did all of my blood draws. I HATED blood draws! I was always very nervous to get my blood drawn, but the doctor that did my blood draws and lab work was my absolute favorite. She was a HUGE support for my parents during my treatment. They always loved seeing her, which made me feel better. She always told me what she was going to do before she did it, and she always told me when it was going to be over. Sometimes we would count down the time the blood draw would take.

She would always let me play in her office before any blood got drawn and she visited me often outside of that room or her office. She even came to a few of my birthday parties at my house! I didn't always know what was going on, but I did know the difference between being just another patient versus being loved and cared for deeply by those that were handling my physical care. I trusted those doctors even in moments of fear and pain, because I knew that I was getting a hug after and a visit later that would have nothing to do with cancer. Even though I didn't have words to say how I felt, I felt seen by them.

Laughter and fun really helped me get through my time in the hospital.

Nothing about being in the hospital is fun. When you are there for extended periods of time, it is not hard to slip into depression. I had been blessed with an awesome family and church friends who came to visit. A few core people always knew how to put a smile on my face. Joy and laughter is the best medicine of all. I did not participate in art therapy. I think it would have been beneficial if I had, especially since I did not have the ability to speak well. It would have provided a different avenue for me to express emotion. I was pretty young so I am not sure what methods there are for including young toddlers in art therapy. All I can say

is, I wish I had had some kind of psycho/emotional therapy as soon as possible during or after my treatment. I did not receive any kind of psycho/emotional therapy until my junior year of college! My parents definitely would have put me in counseling if they had known how much my cancer experience had affected me. However, as I said earlier, I learned quickly that my pain and suffering caused others to feel sad or to suffer, so I learned how to mask my emotions and suppress them very well.

-Current Gordon Student

A Nurse's Perspective

I have been a pediatric nurse for six years. I have seen art therapy be beneficial many times for my patients in many different ways. This includes painting, clay work, crafting, coloring, and more. I think it's beneficial for everyone if a person was to explore it. I think it's a wonderful way to provide distraction in a stressful environment and provide the patient with a positive distraction. Art can help us get lost in another world almost, give us something to focus on other than our reality. This can be very beneficial for children going through a hospital admission,

certain procedures, treatments and therapies. It's also a way for anyone to express themselves and their thoughts in their own way uninterrupted by anyone else. You can be your true self through art, or unload stress onto paper, or even express your happiness, hopes and dreams! If I could tell new patients one thing, it would be this: You are stronger and braver than you know and you have a crew of people supporting you through it all. From your family to your health care team, even if you are willing to accept it or not. I want them to know that they are safe and can be open about how they are feeling, it can help us best take care of them as a whole including body, mind & soul.

I would tell parents this: let your child express themselves. It's okay to be scared, it's ok to be sad but try to find comfort in their child's bravery and resilience. It's also okay to not be okay, it's never easy seeing your child be sick. Ask for support, ask for a shoulder to lean on, seek out ways to unwind. Most importantly, take care of yourself so you can be your best for your children, take breaks and do something for yourself. In pediatrics your child's team is here for you too.

-Shantel, current pediatric nurse

Tips From Patients

1. Don't suppress... Easier said than done. I've had treatments that have followed me into my adult life and I still struggle not to suppress my emotions about them. Survivors' guilt is real and it's heavy. You feel sorry for feeling sorry because you know others have it worse. Or, you feeling sorry makes others feel sorry for you so you hold it all in. As someone who has had it a lot better and a lot worse than so many others, please don't. Grieve your losses. Have a good sob fest over them. Cry angry, ugly tears, and tell someone that you trust that you're not ok. It's okay to not be ok. Something that has helped me in this area is to ask myself "if someone

else had been through all the exact same traumas I have, would I see them the way that I see myself? Would I hold them to the same unrealistic standards? Would I make them do the same emotional lockdown that I make myself do? Would I tell them to suck it up because others have it worse?"

2. Don't stay there, stay engaged... When you've been in the hospital for a long time, or even in and out of it a lot, your life starts to feel like it revolves around it. I had to quit a job that I loved because I just wasn't available enough between hospital visits and recovery times to stay on the schedule. While all my friends went off to college, I had to take a gap year because I didn't want to have to miss school when I had to be in the hospital.

You spend, days, weeks, and months inside the same four walls, and sometimes it feels like life outside is just passing you by. It can make you feel disconnected and depressed. If you're already grieving your losses (and not suppressing *cough*), then it can get you in a rut really fast. Find something that gets you out of that rut and that gives you joy. Do something that interests you or that you've never done before. Pick up Duolingo and try to learn a language while you're in a bed or a waiting room. Ask someone to bring you a sketchbook and figure out how to draw. Drawing was almost as helpful as journaling for me. Learn that instrument you've been putting off learning. You have the time now.

If you are completely unable to do any of those things, ask a friend to visit you or call you to tell you all the tea that's going on in the spheres of the world you can't reach at the moment. Staying invested and engaged fights the fog of depression and the feeling of being trapped.

3. Learn to advocate for yourself.

Sometimes it feels frustrating to have to advocate for yourself, especially when it feels like your needs are obvious or should be thought of by others. This can have some elements of truth, but it still means that you're not getting what you need if you don't express what you're needing. People often rush to your aid when you receive a diagnosis or experience your first couple of days in

the hospital. Yet after a few weeks, they can forget that your illness or time at the hospital is still just as difficult as it was in the first few days, maybe even more difficult now. If company is what you need, then it is ok to ask a close friend if they can come and visit you. If fresh air and sunshine are what you need, then ask if there is a way for you to spend some time sitting outside. If counseling is what you need, ask for that too. I never did and I wish that I had.

4. Find others who understand you and your situation. I wish I had had a support group of people who had also suffered from childhood cancer. I still wish to this day that I had a friend to rant to

that would respond with "ugh! SAME!" instead of an empathetic "I'm so sorry." Both are SO important and needed at different times, but relatability is the key to not feeling lonely in your suffering.

5. Have grace for yourself and your body. Your body is working hard and has been through a lot. Your mind and heart have too, maybe even more so than your body. Thank your body for everything it's bringing you through and take good care of it while it's healing. Don't beat yourself up for the ups and downs of the grieving process or try to silence your thoughts and emotions. Healing is not instantaneous, or even a linear trajectory. I wish it were, but it will be a whole lot smoother if you have patience with yourself and treat yourself with

kindness and respect.

6. Never compare yourself to others.

7. Have patience.

8. Rely as much as you can on people around you.

9. Identify a recovery goal.

10. Focus on achieving that goal and always take things one step at a time.

11. Ask for ice chips (+ elbow braces if you have IV catheters in for longer periods of time).

12. Bring a comfy pair of pajamas to wear once they tell you that you can change out of your hospital gown - you'll want the comfort!!

13. Bring baby wipes. These are super versatile and great for wiping your face, hands, armpits, and whatever parts you might want to feel clean when

you don't have the strength to shower!

14. Don't be afraid to ask for prayer. We had families all around the world on their knees, praying for my recovery from the difficulties of hospital life. It was so comforting to know I was being bathed in prayer.

15. Tell your story! Even if it's hard to talk about, or you think there's no way your story could help someone else, talk about it. I was so surprised at how many people were encouraged in their faith because of my testimony. It truly is a blessing.

16. Walk or wheel around. Sometimes hospitals have some really cool spaces and it's a better view than your own room.

17. If there is a garden or a courtyard, try to get out and enjoy the plants and sunshine.

18. See if the nurses have any fun things they like to play or any recommendations (they know the best places and best food).

19. If you feel up to it try to participate in the activities they have scheduled for patients. You might just make a new friend that you can compare experiences with.

20. You can always ask the kitchen for some of your favorite foods. When it was time for me to try to eat again, the kitchen made me my favorite breakfast of bacon and gluten-free and dairy-free pancakes. They also can give you extra jello.

Advice For Parents From Patients

1. Make sure to take time for yourself too. Make sure you eat, sleep, and shower. Ask the nurses for a parent tray or go out for thirty minutes to change and eat. Your child is in great hands. My favorite memory was actually when my parents weren't there.

2. Hey parents, I get it. This is your precious baby that is in the hospital. I know it's scary, we're scared too! But please don't be helicopter parents, okay? Our medical care team is on top of it! We will tell you if we need help advocating for

ourselves or if we need you to do anything in particular. The best gift you can give us is a little bit of silence. We will be okay.

3. Just be there... My parents did not get everything right and they definitely made some mistakes that caused my recovery to be more difficult, but they were always there. I never once went into any of my procedures alone. They basically lived at the hospital with me. In every good and horrible memory I have of those years, I am never alone. Either one or both of them is hugging me tightly to their chest. If that wasn't possible, then they were holding my hands. If that wasn't possible, they were

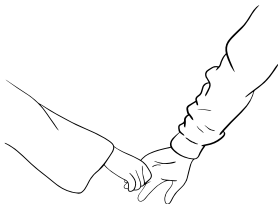
standing in the corner speaking to me softly, "Everything will be ok. I am here. I love you. It's ok sweetie!" The power of those moments far outweigh anything they said or did that made obstacles for me later on. It was the most important thing they could have done and did for me. In my more recent visits to the hospital, I see kids in their rooms alone all the time. It breaks my heart. I want to go in there myself to play with them, hug them, ask them how they're feeling, sit there while they rest, or hold their hands when they're scared. I get that parents have to work, and some parents have their own medical traumas that make it difficult for them to be there 24/7.

Personally, I struggle to understand not being there for your kid, but I do realize that people have reasons for not being there 24/7. If you can't be there, PLEASE arrange for someone that the kid loves and trusts to be there. If there was ever a time that my parents couldn't be at the hospital with me, they would arrange for my grandma or my aunt to come. I was never alone and that made the healing process 100 times easier than it would have been otherwise.

4. You may have noticed that Tip #2 and Tip #3 contradict each other. Ultimately, you know your child best. They may be the type of kid who likes alone time and would be very happy to have a little time to

themselves, even if that's just to take a nap. If your child is one that wants you there as much as possible, do your best to be there. If you cannot be there, have another family member or friend your child loves and trusts be there with them while you aren't able to.

5. Always encourage and support your kids as much as possible, even when it's hard.



Resources

If art therapy is something that you would like to learn more about, here are some resources you might find helpful. You can also reach out to a social worker or child life specialist wherever you receive your medical care.

American Art Therapy Association:
arttherapy.org

- Art therapist locator
- Research
- Publications
- Career center & more!

You can also find this booklet online at www.gordon.edu/counselingwellness

Created by: Grace Utter
Kidney Transplant Recipient
Gordon College Center for
Student Counseling and Wellness
Student Intern
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