

Amy Johnston (25), from the Wirral, was 24 when she was diagnosed with breast cancer in May 2020 during the COVID-19 pandemic. She was helped by Teenage Cancer Trust's Youth Support Coordinator Franki.

She said: "As I was diagnosed with breast cancer during the height of the COVID-19 pandemic, I had my diagnosis and treatment alone. I think it is so important for everyone to have someone with them during their cancer journey, but perhaps more so for younger people. Older people have more life experience and are more equipped to deal with it. For a lot of young people diagnosed with cancer, it will be the biggest thing in their life to date and at the minute most have to go through it by themselves. Lots of families fully shield with the young person after their diagnosis because it's not safe for them otherwise, so they should be able to go into hospital with them too.

My cancer journey started in May 2020. I had been getting dressed one day and when I pulled a top over my head, I found a lump in my breast. I was scared and called a friend who works at a breast clinic. She told me to go to my GP. We were in the first lockdown and my appointment was over video, which was weird in itself as I had to take my top off for a stranger.

The GP said it was probably nothing to worry about as 24-year-olds don't really get breast cancer, but she referred me to the breast clinic for an ultrasound. Before my appointment, I spoke to friends who work in health care who said it was probably hormonal or a cyst, and a cyst would show up on the ultrasound.

I had to go to the ultrasound alone due to the pandemic. I was initially ok with that as I thought it was nothing, but when the radiographer said that it wasn't a cyst, I burst into tears. They said there was an 80 percent chance it was breast cancer. I was so upset that one of the nurses said: 'I wish I could give you a hug'. She held my hand as that was the most she could do.

I was taken for a biopsy and a mammogram and I was so upset and crying so much that they led me through the back routes of the hospital because they didn't want to lead me through the main corridors.

Less than a week after my first GP appointment, I was diagnosed with triple negative breast cancer.

Two weeks later I had a mastectomy. Again, I had to go in alone and my dad couldn't even walk me into the waiting room, despite the fact that he had self-isolated with me. We said goodbye in the parking lot. We were hugging and crying a lot.

I'd never had major surgery or gone under aesthetic and it was such a scary thing. I was walking into the biggest surgery of my life completely by myself. I struggled with that as a 24-year-old, I can't imagine young people having to go through something so big alone.

I never met my oncologist, they only chatted to me over the phone, and when he told me on the phone that I might go into early menopause and that the treatment might affect my ability to have children I burst into tears. I knew I wanted children in the future, but I hadn't thought about it that much and I didn't know it could be taken away from me.

Luckily, I had time to preserve my fertility, but I put so much pressure on myself as I thought it could be my only chance to have children. I found it hard to inject myself, so to start with my aunt, who is a nurse, came round in full PPE to give me the injections twice a day in our garden.

But I soon became a pro at it. I had to go to all of my appointments by myself again, and obviously it was all new to me. They didn't have any COVID-19 at the Liverpool Women's Hospital where I was having my fertility treatment and there was someone who almost acted like a bouncer outside to make sure that no-one was going in when they shouldn't. During one appointment they found that one of my ovaries wasn't stimulating eggs and there were only six egg sacks. I thought: 'Is that all? Will I only have six chances?' I felt there was not enough happening, and I burst into tears. Again, I had to go through that by myself without my boyfriend or family around.

They prolonged my injections for a couple of days, and they managed to get 16 eggs. Because I found out I had the Brca1 gene, I want the eggs screened so I don't pass it on – I want it to end with me. But that means I have about half of the amount of eggs to work with when the time comes as there's around a 50 percent chance of me passing it on to my children.

I had to have that surgery by myself too and it felt quite invasive. I was a young woman by myself with my legs up in stirrups while seven or eight medical professionals stood that end talking to me. I thought: 'This is so weird; can you at least come and stand by my head'.

I started my chemo at Clatterbridge Cancer Centre a few weeks later at the end of June. I had to go in by myself, which was frightening. During the first week I was itchy and had a slight rash, but it didn't seem too bad. About four minutes after the next dose was administered, I turned to a nurse and told her that I felt sick. She saw that my face was bright red, and she knew I was going into anaphylactic shock, so she pushed the emergency button and then suddenly I was surrounded by lots of nurses. I could still breathe, but I felt like my breath wasn't going anywhere. My tongue and face were starting to swell, my heart was beating fast and I had back pain.

They stopped administering the chemo, put something through my picc line and then in three minutes I was fine. But it was really scary and the closest that I had come to death. I wanted my dad with me, and I really missed having anyone there. I had to stay for an hour so they could keep an eye on me, and I had taken a book in to read but I wasn't going to read when I had nearly died, and I just sat staring into space.

I called my dad to tell him what had happened, and it was another tough thing for him to deal with. You want to be there for your child when they go through something like that.

They changed the chemo I was on and I had it four times every three weeks and then four times every two weeks. The second drug made me feel really nauseous and sometimes even just having a shower was a big achievement and I would lie on the sofa for the rest of the day. It was very isolating and when I felt bad, I would have loved to have had friends to come and sit and talk to me. Because I was shielding, the only way I would have been allowed to see them would be by getting up and going for a walk, but I didn't feel up to that. My boyfriend isolated for two weeks so he could stay with me for a bit, but he couldn't do that forever and we've not been able to see each other much.

Normally he or my dad could have come to chemo with me, and chemo was when I really missed having someone with me as I was sat there for a few hours by myself on an adult ward. Everyone was a lot older than me and they would say: 'Oh, you are so young'. It came from a good place, but it felt odd that they felt sorry for me because I was younger.

After the initial scare, things suddenly slowed down during my chemo. Everything had moved so fast up until that point and I almost didn't have time to think. During chemo I started contemplating what was happening to me. I was referred to a therapist who specialised in working with young people with cancer. I found it good to speak to an outsider who wouldn't molly coddle me and say: 'You're so brave' or 'You're being a super star'. Sometimes I didn't feel particularly brave and I wanted to just say that. My dad and my boyfriend had a lot to deal with already, so I didn't want to put more on their plates. The therapist was also able to speak to them when they were struggling, and they didn't want to upset me by talking about it.

Teenage Cancer Trust's Youth Support Coordinator for the area – Franki – had gotten in touch with me before I started chemo. She wasn't able to come and see me because of COVID-19, but she called me every couple of weeks to see how I was doing. It helped to have someone who I could speak to about cancer, but sometimes I was tired of talking about cancer and we'd have a general chat. She still calls me now and it's nice to know that I can talk to her too.

Before the pandemic, Franki used to organise events where young people with cancer could get together and support each other. That moved to online sessions and it was good to be able to meet other young people in similar circumstances.

We did lots of crafts sessions together via online calls and it was nice because there was never an awkward silence. You don't feel the need to talk all of the time because you are all working on a craft project. Franki started conversations and people joined in when they wanted to.

You have a lot of time on your hands during treatment, and even more while you are shielding and can't see other people, so it was good to try out lots of different things that I might not have tried before, like candle making and clay modelling. There was something really therapeutic about working with my hands and being able to squish the clay down when things went wrong and to be able to start over again. I made a little platypus which I painted afterwards.

It was nice to be able to talk to other young people with cancer, but I only came across another young person with the same type of cancer as me by accident on a Facebook group. I am starting up a website where young people can chat, and it gives me something positive to focus on. It's called the Young Cancer Action Network or YouCAN.

I finished my chemo in November, and I got to ring the bell, but I did that by myself too. They offered me the chance to take a bell outside, but it was horrible weather, and I didn't think people would want to stand outside in the rain while I rang a bell. Because the Brca1 gene means I am more at risk of the breast cancer returning, I will have a double mastectomy when non-urgent surgery starts again."

On Christmas:

"The drug I had for my last lot of chemo made me feel really sick. I hadn't seen my nana or uncle for months, so I wanted to feel well enough for Christmas so I could relax. I did feel a bit better, but I had to deal with low energy and tiredness. I'm slowly starting to build my fitness back up."