

# Information for Adults Living With Acute Lymphoblastic Leukemia (ALL)

## Amanda (LLS Information Specialist)

I'm Amanda. I'm an Information Specialist at the Leukemia and Lymphoma Society.

Information specialists are master's level health professionals who talk to patients and family members over the telephone, online, or by email, and we are able to discuss with patients and family members their diagnosis, their upcoming treatment, as well as resources such as financial assistance, things going on in the community, and support.

## Marci (ALL Survivor)

My name is Marci and I was diagnosed with ALL in 2014.

For it to come on so quickly. Like I wasn't sick before that; it happened so immediately that it just almost seemed surreal. And I didn't know very much about leukemia, but the doctor sat down with me and went through all the different types of leukemia, and the subtypes of leukemia, and my different options I would have depending on which type of leukemia I was diagnosed with.

## Daniel Pollyea, MD, MS

Acute lymphoblastic leukemia is a type of a cancer. It's a cancer that affects the bone marrow. The bone marrow is the organ in your body that's responsible for making all the cells of the blood. So it has to make the red blood cells that carry oxygen, make you feel strong. It has to make the white blood cells that fight infection. It has to make the platelets that clot the blood. All that's the responsibility of the bone marrow and the bone marrow, as you can imagine, is an enormously complicated place. And just like anything that's really complicated, whether it's a machine or a computer, or our bodies, mistakes can occur. And mistakes actually happen all the time in our bodies. They take the form of mutations that occur in the DNA of a cell. So almost every cell in your body has this information set packaged up in the form of DNA in the nucleus of the cell. And this instruction set tells that cell everything it needs to know; what kind of cell it should be, where it should go, what it should do, how long it should live. All that's information that's given to it by the DNA.

So you can imagine if a mutation occurs in the DNA of that cell, it can push that cell down a pathway toward a cancer. And that's essentially what happens in the bone marrow of a person afflicted with ALL. These mutations accumulate, they arise and accumulate in the DNA of a cell, and they push that cell down a pathway where they overpopulate one particular type of cell. And that one particular cell just crowds out the whole bone marrow and usually spills out into the peripheral blood and prevents the bone marrow from being able to make the normal healthy white blood cells, so people are prone to infection. It prevents it from making the normal red blood cells, so people get anemic, tired, fatigued. It can sometimes impair the ability to make platelets, so people can have bleeding complications. So all of those are the sequela or the complications that can occur from ALL.

## Marci

When I checked in to the hospital, the doctors went over the different types of leukemia and some of the different treatment options, but it took a couple of days before they were actually able to diagnose what type of leukemia I had. But as the information came in, my doctor would sit and go over with me what that meant and where my options were.

## Dr. Pollyea

This diagnosis of acute lymphoblastic leukemia can be overwhelming. It's a disease that most people don't know anything about before they're diagnosed, have no experience with. Most people don't know anybody who's been diagnosed. And patients and caregivers and families need to really rely on the treatment team to

provide answers to questions both small and large. And that's where the Leukemia & Lymphoma Society comes in as well. It's a tremendous resource for patients and their families.

## **Amanda**

Information specialists get all sorts of different questions from patients who are newly diagnosed. The most common questions are, "What is my diagnosis?" "What does this mean for my life?" And we're able to explain to them what to expect from most common treatment. Another important question that we often get is, "What's the financial burden going to be? Are there any resources to help me?" We will be able to go over different resources both locally and nationally that may be able to assist in that area. The third category that people ask about a lot is support, "Who will understand what I'm going through?" We're able to connect patients with support groups, both in person and online, so that they have someone else to talk to who's gone through this experience.

So information specialists are able to discuss with family and patients the diagnosis of ALL as well as different treatment options. We're able to help the patient and family from diagnosis all the way through survivorship. And this can mean helping them with clinical trial searches, providing educational materials, discussing treatment options, as well as connecting them to their local LLS chapter so that they might access some support resources.

Many children who are diagnosed with ALL will enter into clinical trials, while this is less common in adults. Clinical trials are a vital part of cancer treatment. They help the doctors to discover what the next best treatment is going to be.

## **Dr. Pollyea**

Pediatricians have been working on this disease for a long time and have had unbelievable success through years and decades of work, and we've gotten to the point where there's a very, very good chance when a child is diagnosed with ALL that they'll be cured. On the adult side we have not been as successful historically, and there's a lot of reasons why that may be. Biologically, the disease is different, and there are features of adult ALL that make it more resistant to treatment and historically more likely to relapse, and less able to cure. But the pediatricians have also historically been very aggressive, using lots of different chemotherapy treatments, and prolonged regimens that has resulted in a lot of great success.

On the adult side, for many years we didn't think that adult patients could withstand such intensive treatments. More recently we've come around on the adult side, to mirroring what the pediatricians have been so successful with, and we've been adopting a lot of their protocols to our adult population in the hopes that we'll be able to replicate their success in our population, and those studies are ongoing, but the early signs point to a lot of optimism that that we are going to be able to, hopefully catch up and someday do as well as the pediatricians have done with ALL.

Marci had a disease with the Philadelphia chromosome and was able to take advantage of a targeted therapy with one of these kinase inhibitors, and we think may have turned a, historically bad prognostic feature into one that has really enormously helped her with the respect to being able to be eligible for a kinase inhibitor that can be really effective when chemotherapy may not be.

## **Marci**

Once they knew that I had Philadelphia chromosome-positive ALL leukemia, they prepared me to go on that TKI inhibitor. And we had to wait a couple of days to see if it was actually going to start working. And lucky for me, my numbers started to immediately drop and I was over the course of about two months able to get into remission from this TKI inhibitor.

But because it's still so new and they don't have long-term results for this, that was when we talked about the option of doing a bone marrow transplant. It sounded kind of counterintuitive to make me more sick in order to get me better, but because I'm young and healthy, it was really the only way to get a cure.

## **Dr. Pollyea**

Stem cell transplants are still a really important component of ALL treatments for some patients, and can be a crucial factor in our ability to cure this disease. We're really evolving as to who we recommend this intervention for. Historically, because of our lack of success with most ALL patients, that was the recommendation for pretty much anyone who was felt to be a candidate that could tolerate a transplant. But we're really evolving in our understanding of who would be the most suitable candidates for a transplant and currently, we're using minimal residual disease testing as our litmus test for who would be the best candidate to need a transplant. So, patients who complete some component of their treatment and have no minimal residual disease, may potentially be able to be cured with no transplant and just further chemotherapy and maybe some maintenance chemotherapy-type regimens. Whereas some patients who achieve a morphologic remission after a certain number of cycles of chemotherapy, but not a remission on a minimal residual disease level, those may be the best candidates to send on to a transplant because of the low likelihood that they have of being cured without that intervention. And again, this is all information that the pediatricians have really led the way on. They've showed this in a number of really well designed studies. And in the adult population, we're working on validating whether these are relevant to our patients as well.

## **Marci**

The hardest part of being diagnosed with leukemia is the effect that it's had on my husband and my children. I live in a small town in the mountains, and had to come to the city to get my treatment. So, besides having to have a mother that had leukemia, I also had to be away from my family for a long period of time.

## **Dr. Pollyea**

Support for patients going through this ordeal is crucial, can't emphasize enough how much a person will need to rely on their support system when they're going through the diagnosis, treatment, implications of this disease. That support can come from anywhere. There are no rules about where it should or could come from. It can come from a patient's family, friends, community, co-workers, all these are resources for patients that need to be drawn on in this time of real need and that's something that we encourage a person to seek out and we help them seek out. It can be difficult for some people to ask for help. A lot of people at the time of their diagnosis, they're accustomed to being the helper. And it can be very difficult for people to step back from that role and say, "I'm going to need to be the person that's okay with asking other people for help." And that reversal, depending on the person, can be a big challenge and something that they actually need quite a bit of help acknowledging and getting through.

## **Marci**

Because I had to be away from home, my husband had to try and be the rock, and the one that was there to keep our kids in as normal of a lifestyle as he could. For me, I just looked at it as a job, and just did what I had to do. And I kind of took each day as it came, and did what I needed to do to get through this. For him, it was a lot harder because he wasn't there every day, and trying to deal with our kids and their emotions, and him and his emotions, being a little bit more removed was hard.

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## Dr. Pollyea

Caregivers are so important when their friends, families, loved ones are going through this ordeal, but they are not robots, they're not machines. They're still people, and they have a lot of needs that we all need to take into consideration. And there can be significant challenges for a caregiver with the downside of not a whole lot of people are asking how they're doing, that's not often the focus. And that can be very, very difficult for a caregiver to be so needed by somebody and not have their own support system potentially be in place. So that is something that needs to be given lots of consideration and attention by the treatment team, and the whole community because there are real challenges there for those very important people who are being relied on so heavily.

## Amanda

Many of the calls that an information specialist takes will be from the caregiver, as well as the patient. We want the caregiver to know that we're there to support them just as much as we are the patient. They often feel alone because the focus is on their loved one who's going through treatment, so we're able to connect them with just as many supports as we are the patient.

## Marci

Knowing that I was diagnosed in a day and age where there's been so much research, and so many great things to work towards the cure of leukemia, at least I was lucky enough to be diagnosed at a time when there's so much available out there to help for a cure.

## Amanda

A diagnosis of ALL can be very overwhelming as you go into the hospital for your initial treatment. Oftentimes, patients receive a lot of services in the beginning, but they don't necessarily have the time to cope with their diagnosis. Whether you're in consolidation and getting treatment at home, or you're years out and into remission, LLS is there to provide the support that you need.

Information specialists are available over the telephone at 1-800-955-4572. You can also email an information specialist at [infocenter@lls.org](mailto:infocenter@lls.org).

You can chat live with an information specialist by going to [www.lls.org/information specialists](http://www.lls.org/information specialists).

Let us be there for you.