Living Beyond Cancer Podcast Transcript

Cancer Survivors with Disabilities

Guest: Dr. Lesley Cottrell, Jennifer Tenney, and Jessi Wright

Lauren Hixenbaugh (00:02):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh, the Coalition Manager for Mountains of Hope. Living Beyond Cancer is a series of podcasts, created for cancer patients, survivors, and their caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and is produced by the West Virginia Cancer Institute's Cancer Prevention and Control. Today, we're recording in multiple locations, so please forgive any of our tonal differences. Today's topic is focused on the needs and overall quality of life, for cancer survivors, that have experienced a disability, during or after treatment. This topic was chosen because data shows that many survivors experience long-term side effects of cancer and cancer treatments. To help us better understand this topic, I've invited some experts. It's my pleasure to introduce today's guest, Dr. Lesley Cottrell, Jennifer Tenney, and Jessi Wright. Thank you all for being with us today and fitting it into your busy schedule. We'll just get started by introducing ourselves and your role at the Center for Excellence in Disabilities.

Dr. Lesley Cottrell (01:06):

Well, I'll go ahead and get started. My name is Dr. Lesley Cottrell, and I appreciate the opportunity to have this discussion today. I'm the Director of the Center for Excellence in Disabilities, at WVU and a Professor in Pediatrics.

Jennifer Tenney (01:23):

My name's Jennifer Tenney, and I also work at the Center for Excellence in Disabilities, in Morgantown, and my role is as the Primary Investigator, for the Work Incentives Planning and Assistance Grant, which is a Social Security funded grant, that helps people understand how their Social Security disability benefits will be affected, when they go to work, after having a disability.

Jessi Wright (01:46):

I'm Jessi Wright. I oversee our State Assistive Technology program. You can also think of that as Assistive Tools, which just funds different devices or techniques, to help people maintain independence, after a disability or continue to work, all those kinds of things.

Lauren Hixenbaugh (02:04):

I think it's pretty safe to say that we have a panel of experts here. I'm excited to dive into today's topic if everybody's ready. Then we'll kind of get started with the basic, which is, what does the word disabled actually mean, and should we be using a different term?

Dr. Lesley Cottrell (02:19):

I'll go ahead and get us started on that. I think, to me, the word disabled is often used as a description, right. In the English language and across languages, we need these terms, to describe people and put them in certain categories or ways to remember them by. I think it's not necessarily the word disabled but how it's used often, that gets us into certain ways of someone uses that term to set someone off to the side or as a reason for not doing something. I think that's where we get into it, or if we use that term to solely define an individual, that's where we get into some issues. But we talk a lot, at the Center and beyond, about person-first language, and the whole purpose of that is again, not to define a person by the disability itself, and rephrasing things, slightly, make a big change. We can go through that a little bit more, but I think, just to answer your question directly, as a descriptor, it's fine, but we really need to pay attention to how we use that word.

Jessi Wright (03:38):

To build on that, I think there's a lot of people who after a medical diagnosis or an accident or even aging don't consider themselves as having a disability. These short-term impairments or just those things that come with aging, of hearing and vision, they don't realize that that does fall under disability categories, and there is assistance out there for those kinds of things. Even those temporary disabilities still qualify as a disability, so there's just more education that needs to be put out there, on disabilities, and what that means, and then also in reducing the stigma.

Jennifer Tenney (04:19):

Yeah, Jessi, I think the biggest thing is reducing the stigma around the word disability and being disabled. Like Lesley said, about person-first language is really important to remember. The big saying in the disability community is label jars, not people, so to remember that people are people first, and their disability does not define them.

Lauren Hixenbaugh (04:42):

Great information. I'm glad you guys talked about the stigma. In researching this topic, I came upon a statistic that says, roughly 40% of cancer survivors, in the US, who are at a working age, will experience long-term effects of cancer and cancer treatments, such as productivity and the ability to do the work, so how do we improve this quality of life for survivors and their families?

Dr. Lesley Cottrell (05:05):

Well, Lesley, I think Jessi and Jennifer were talking about that a little bit. I mean, the idea that everyone wants to be independent in the activities that they do, and so as we go through some transition, whatever that transition might be, and we experience a limitation in one activity, we want to have self-confidence, that we could get back to that activity. It might be a little different, using something else to help us do that, but we strive for independence. So I think, for all of us to help someone who's going through that, we don't all have self-confidence, particularly when we go through that. More people are resilient than others. And so for us to say, let's go back, and let's see. You really want to do that activity. Let's see what we can do, to get you back to that point.

Again, it might look different. We might be getting it in a different way, but how can we help facilitate that for you, instead of having that perception? That's it. We're done. You've experienced this. You'll never go back to that level of independence. That's where we falter, I think.

Lauren Hixenbaugh (06:14):

Sometimes I think that's what happens with the word disabled. People hear that word, and they say, oh no, I don't have that independence anymore.

Jessi Wright (06:23):

And kind of with what Lesley was saying, too, when she very specifically said, what do you want to do, so making sure that we're being person-centered. A lot of times, we end up a case management or different professionals working with that individual, and they have an idea of what they should be doing. A lot of times, it is appropriate, but there is also that person, and meeting them where they are currently at and building on that, rather than talking around them and making the decisions that you feel are best for them, the person needs to be involved, in order to feel empowered, so that they can work on that independence.

Jennifer Tenney (07:08):

I think another important thing about the independence piece and thinking about cancer survivors, who experience a disability, comes into the work arena, which is where I focus my professional career. But having cancer and experiencing a disability, due to that or because of the side effects of chemo or whatever, doesn't mean that you don't have the ability to work and be productive and be independent and have the things that you had, prior to your cancer diagnosis, if you want those things. Like Jessi said, we want to definitely be person-centered and understand what the cancer survivor or the person with the disability wants most, but I think it's really important to remind people that, especially because so many young people experience disabilities, that work is not out of reach for them, and everybody has the ability to contribute, in some way, via volunteer work or paid work, and with assistive technologies and lots of assistance from your employer and maybe some of those service agencies out there, you can definitely get a lot of help, to go back, to do maybe not necessarily what you were doing beforehand but find something that you love, which is really important for all people.

Jessi Wright (08:36):

So with everything we just discussed, it really comes down to the first step, which is education, letting people know that resources exist, that this isn't the end of the world, that there are ways to go back to what you were doing or maybe find new things that you're interested in, so we really need to hit that piece because that's when they're feeling their lowest. Their life has just been turned upside down, and they don't know the resources. They've never needed them before, potentially. So without that piece, they never make it to us, to get assistance to maintain independence.

Lauren Hixenbaugh (09:14):

So one thing you just said, Jessi, was kind of a question I was going to ask you about them finding a new identity. So how do they do that? How do they find a new identity, beyond survivor, beyond the role of employee? How do they find that new identity?

Jessi Wright (09:30):

So with what I do in Assistive Technology, people will come, and they will say, "Well, this is my diagnosis, and these are the things that are going on with me." But that's not what I want to know. I want to know, what do you want to be able to do? Let's just forget your diagnosis and be you, so that's your identity. What do you want to be? What do you want to do? So it's that empowerment piece, that you don't just have to have a label and be put in a box, like Lesley was saying earlier, with using the term disabled. No, you are still you, so reminding people, that they are whoever they want to be, and we have the tools to help them achieve that and maintain that because this might have turned their lives upside down. And maybe they don't want to do these things that they used to do, and they have a new insight to who they are now. And how do we achieve that? So it is a matter of simply working with the individual, where they are and ignoring a diagnosis, for the most part, because everyone and I don't care what diagnosis it is, there are different pieces to that. Everyone still has different strengths and different weaknesses, so at the end of the day, it's irrelevant. You are who you are. What can you do? That's what I want to know more than anything. What can you do? Because we're going to work with those strengths and build you up. That stuff you can't do, not so relevant. What can you do? What do you want to do? And that's how we make things happen.

Dr. Lesley Cottrell (11:01):

That, right there, is not just for the individual but for family and friends, because whatever the transition it is, if we define our identity ... It's not just that we define our identity by what we think. It's by what others think too, and especially during those types of transitions and experiences, we often need assistance from others, at least initially. We value their input, and their thoughts, and their ideas about what's going on, and it's important that they have this same approach for that individual, and they're encouraging that individual to take that approach. It's not an automatic one. It's not a natural one for us. We always think of someone else, so I would say that same thing that Jessi just mentioned needs to be shared with family and friends.

Jennifer Tenney (11:52):

I think, too, it's important, Lesley, to talk about the transitions like you were just saying, a transition from not having a disability to having a disability, but like you said, we all go through transitions, whether it be a transition from middle school to high school, or high school to the working world, or high school to college or a vocational school. Everybody experiences transitions in their life. And this is just another transition. And like every other transition in life, there are people that are available to help you get through that transition, and family and friends are definitely one of the biggest support systems that a person has, to help them get through that transition, whatever type of transition they're going through.

Dr. Lesley Cottrell (12:41):

I'm glad you said that Jennifer, because it's not minimizing any of those transitions. Many times, we stumble on those things. Someone might say, "Well, having cancer is very different than going from middle school to high school." Absolutely, it's a different type of transition, but it can block someone. It can be very significant for that person, at that point in time, so in general, I think exactly, I would agree with you. But whatever it is that's new about that transition, that requires those new resources, a new way of thinking, and that we're often not experiencing one transition, but we're experiencing multiple ones, so if it's a mother of young children, who's going through a cancer diagnosis and treatment, it's not just that cancer diagnosis and treatment and what follows, but how to do that and be a mother and complete those motherly activities. So it's complicated stuff, but yeah, absolutely. I'm glad you said that. It's normalizing but not diluting the fact that it is a transition.

Jessi Wright (13:44):

And when we talk about those transitions, the built-in ones, in school and things like that, you plan for those. You see them coming. And when we get into things like this, you don't. Nobody plans to have cancer. It's not on your bucket list. That point, someone is already overwhelmed. They are trying to find resources that they've never had to find before, while they're also worried about their health and wellbeing, their family, and all of these other things. And that's why it's great to be able to reach out to one place and then let them help you get connected to the other resources. And we can do that, at the Center, and I'm sure you can do that too, with the Cancer Institute, and just helping people identify those resources because if you have to do all that searching yourself, when you're also just trying to search, to find out your survival rates and all of that very critical information, it's overwhelming. And if we can work with people at the front-end, when we're talking about this is what you're going to be going through, yes, at the end, there may be some tweaks we have to look at, but we can get some ideas to help ease some of that anxiety, when you come out of this, you're going to need things. Let's make sure they're in place and help in that way as well.

Lauren Hixenbaugh (15:14):

That's great information. And we'll get into resources a little bit more. Both organizations here, the Center for Excellence and Disabilities and Mountains of Hope, both have a plethora of resources available, and I definitely want to get into that and make sure that we're getting out our hard work and efforts to everybody. But one of the other transitions that I was thinking about, while you guys were talking, is the financial piece. So that's a huge transition, and as Jessi said, it's not something that you planned for. So when I was researching this topic a little bit, I did find a ton of resources. I think Jennifer's going to talk about SSI versus SSDI and give us a little bit of information on how people can work through this new financial transition that they're going through.

Jennifer Tenney (16:11):

Yeah, Lauren, it is a huge financial transition, that you may find yourself in, going from having a job to not being able to have a job while you're going through your cancer diagnosis and treatments. And you may come out of those treatments and not be able to work anymore. There are options for you, to draw disability benefits from the Federal Government, everybody knows, and that's hard about Social Security, but there are two Social Security disability programs, Social Security Disability Insurance, or SSDI, and Supplemental Security Income, or SSI. Both of those programs do give money monthly, to the person, to help them pay for food, and shelter, and the other things that they may need in their lives. They are very different, though, in the way that you become eligible and the amounts of money that you can get. When you're on Social Security Disability Insurance or SSDI, somebody's worked in the past, so it could be you. It could be a deceased spouse. If you have a disability, prior to the age of 26, you could also draw, as a disabled child, off of a parent who is deceased, retired, or disabled themselves. So somebody did some work, and so there's variations in the amount of money that a person receives on Social Security Disability Insurance, but the average check is about $850. I've seen SSDI checks at $100. I've seen SSDI checks at $2300. There's a huge range in the amount of money, and it's all dependent on how much you worked in the past and what type of job you've had. Now SSI is different. SSI is for somebody who either has never worked or who may have worked some but not enough to be eligible for that Social Security Disability Insurance system, so one is an insurance system, and SSI is supplemental income, to help you pay for food and shelter. And SSI is Federally tax-funded, and it is for people who have low income and have low resources, meaning that you don't have a lot of assets and things that you own. In fact, for SSI, there is a resource limit of $2000 a month in stuff that you own and cash in the bank, to be eligible for SSI. The nice thing about these two programs, as well, is that they come with health insurance. Both of them do. SSDI comes with Medicare. Unfortunately, there is a 24-month wait for Medicare, once you become eligible for SSDI, and I really don't have a good reason why. There's never really been a reason why there's a 24-month wait, but there is Medicare insurance.

Jennifer Tenney (19:22):

And Medicare's your basic, they pay 80%. You pay 20%. You have hospitalization coverage, outpatient coverage, prescription drug coverage. And you pay for some of those services, just like you would any other type of private health insurance. SSI comes with Medicaid immediately, so the first thing you're eligible for SSI, you're immediately eligible for Medicaid. And Medicaid pays for most things. The nice thing about Medicaid, as well, as it also can pay for personal care services, which Medicare doesn't typically pay for, so if you are needing those personal care services, after going through your diagnosis, or in the middle of your diagnosis, SSI and SSDI are not exclusive of after you have cancer. You can definitely apply during the process because what Social Security is looking at is not only do you have a disability that affects your daily living and is expected to last longer than one year or end in death, but they're also looking at the workplace. Do you have the ability to work, and in 2020 make approximately $1260 before taxes, a month, which to give people a reference, 40 hours a week, at minimum wage, is about $1255 a month, so you're looking at, do you have the ability to work, full-time, at minimum wage. If the answer to that is no, then you can be eligible for those programs during your treatments, during the time that you're going through getting these treatments done, and having new disabilities diagnosed, and those sorts of things, so the thing I want people to know is that there are options, so you're not going to lose those incomes completely. Now it does take time, unfortunately. Now folks with cancer diagnoses, depending on the diagnosis, it would depend on how quickly a person can get on benefits. Unfortunately, right now, the average wait to get on Social Security benefits, after going through the appeals processes and things like that is about three years. But like I said, for lots of different cancer diagnoses, it's a lot shorter of a time span, so you don't have to wait as long. But the key to all of this is to really just make sure that if you know that you're not going to be able to work, for an extended period of time, to go ahead and apply right away, because the worse they can tell you is no. And if they tell you no, you can appeal. So that's, I guess, my takeaway for this portion is definitely there's help. There's medical insurance. You can get medical insurance. You don't have to worry about preexisting conditions with either one of those medical insurances. They'll cover everything that you need to be covered.

Jessi Wright (22:33):

So in additional to the income, when you are transitioning into these disabilities, there may be things that you need, like equipment. You may need a shower chair when you get home. You may need just different tools, to maintain independence. And insurance may cover some of those things. Durable medical equipment can generally be funded, which would include shower chairs, bedside toilets, some of those kinds of thing. We could run into other things that aren't necessarily funded or are going to take longer to get funded, but you need them right now. So when it comes to those devices or those tools, that may help with independence, that's something that we are able to assist folks with. We do loans of equipment, and the loans have multiple purposes. Some is to try, to see if this is going to be the right thing for them. And that might be a memory and cognition aid because I know that memory gets impacted a lot, when we go through chemo and things, so what tools are going to be best for them and then, finding out what those are and if there's funding available for those. Or it might be a short-term thing. You don't know how long this memory issue is going to last. It may start to come back. Do you really want to invest a lot of money in something that you may not need later, so having that short-term loan. We also have a reuse program, so equipment gets donated to us, which includes durable medical equipment, like the shower chairs and things, also power wheelchair, and all kinds of different walkers, and things like that, that we're able to then clean up, refurbish, and get them back out to somebody for free. And that might be they're able to order some of that through their insurance, or Medicaid, or Medicare, but they have to wait. This could be serving as that piece until they can get their own. Another thing, too, is communication. If at any point, the treatment or the cancer is impacting their ability to communicate, communication devices are essential. Communication is a basic human right, and we need to make sure that no matter what situation it may be, we can provide good communication for the individual. We do have communication devices here, but then we work closely with the speech program here at WVU has a clinic, trying to get them assessed, so they can get what they need to communicate their wants and needs. And insurance will generally pay for communication devices as well, so as things come in, we also do try to help people get connected to funding sources, because we know, especially here in West

Virginia, we are a high disability and an impoverished state, so we need to make sure that we have those external resources to help people.

Dr. Lesley Cottrell (25:29):

I'm sure that would be really helpful, Jessi, in terms of Mountains of Hope and other resources of support groups, start to get what you can during treatment and afterwards and being able to, particularly if you couldn't, if you didn't have that communication, having that opportunity, so you're saying, at any point in time, if they need that if that would help with their recovery.

Jessi Wright (25:55):

So the way our program works, too, is we serve all ages and all abilities, so anybody can use our program. There's no requirement to have a disability, so when they first get that diagnosis, and they're thinking, okay, what am I going to need, they can start trying out some things there. What's going to fit in my house? What'll fit in my tub, for me to shower appropriately? And having those conversations and borrowing devices, to see how well they're going to work. That's actually really great to do, especially if we're thinking, okay, I might have some cognitive issues. Let me try this device out and try to get familiar with it now so that maybe it won't be so hard for me to figure out when I really need it, or I can look at it now, maybe develop some cheat sheets, or guides, so that if I do struggle, I have something there to support me, so it is a good thing to look at across the board. And your needs change. Everyone's needs change almost daily, so with a disability, especially of that kind, the things that cancer brings, you may see improvements. You may see declines, as time goes. It's a constant evaluation of what do I need right now.

Lauren Hixenbaugh (27:06):

I like that Lesley brought up the word support. So we've talked a lot about what folks might need, but then there's the aspect of support, and what do these individuals need in that area? Mountains of Hope does have a Facebook support group, for individuals, caregivers, and their families. It's been a really great environment. We've had some really supportive conversations on the Facebook page, but beyond that, is there anything else that those folks might need?

Jessi Wright (27:41):

It's really interesting right now, just due to the COVID situation, that it's really opening folks eyes to how to still be engaged at a difference, so this really getting rid of that social isolation. And I know that a lot of folks who are going through chemo, they do have to kind of isolate, because they may have compromised immune systems. This is all pre-COVID. These things were already concerns, so now we have COVID, but this is really opening our eyes to other things that are out there, to keep us connected. So we're seeing support groups popping up, national support groups, state support groups, that are doing these things via video conferencing, so that you can really get connected across the board, with lots of different people and have conversations, to find out what else is available to you but provide that support, and it's expanding now, with the way we're now using technology.

Dr. Lesley Cottrell (28:43):

And I think those support groups are very helpful because you hear people ... And again, we're not going to do it naturally. Unfortunately, that's not how we're made, but to hear someone saying, take some time off, shut those voices down, shut those concerns down, and just take some time for yourself. There's a lot of resources, and it might be mindfulness activities. It might be just sitting out and enjoying the sun for 10 minutes, so there's that social interaction, and then there's that just focused calm, pay attention to yourself, and turn off the worries, in a way that I think would go hand-in-hand with that. And there's a lot of resources that where you will list, Lauren and you guys have on your website, as well as some of the other assistive technology, that Jessi has, for recreation and for health and wellness, but that's a huge piece.

Jessi Wright (29:43):

I should have said and recreation, health, and wellness. That's something that frequently gets overlooked. We look at all these critical needs. Can they be independent at home? Can they cook? Can they do their daily living activities? Can they go to school? Can they be employed? But at the end of the day, what do we do? We work so that we can get money so that we can not only pay the bills but so we can go play. And everyone should have that opportunity. That goes into that person-centered piece. What do they want to be able to do? What's going to increase that quality of life, because many times, with cancer, comes depression. And if we can make sure we're focusing on that quality of life and that independence, what do you want to be able to do? What is going to bring you out and make you feel full with your life again? And we have all kinds of fun things, including adapted tricycles and things, so people can get out and be engaged, with their families, with their communities, with the environment, so looking at that kind of support, as well, and making sure we're connecting with recreation and just meaningful activities.

Lauren Hixenbaugh (30:56):

So as we talk about support today, one of the groups that we haven't talked about, and they might be listening to this podcast, is the family member, the caregiver. What resources do they need, long versus short-term? Let's talk about those folks for a minute.

Dr. Lesley Cottrell (31:17):

I was just going to say, it's interesting. The more you talk about these issues, the more consistent the message is, I think. When you first start talking about disability, you think difference, kind of full circle to when we started here. And it's really not, so for the families, it's pretty much, to me, very similar things. You need respite, but as a family member, as a caregiver, you're doing just as much. You're invested, mentally, just as much, and so all the health and wellness idea and the restfulness are the same for families. Outside of what we've already talked about is understanding ways to support someone else. Don't forget yourself, because you can't really do that effectively if you haven't been taking care of yourself.

Jessi Wright (32:11):

Self-care is very important, and there are support groups for the families and care providers, so those are great to get connected with. And then, I'm always tooting the horn about assistive technology, because I think it's great for everybody. But there are pieces of technology, that not only supports that individual with the disability but also makes life easier on the caregiver. If we can increase that independence, for the individual with the disability, that's less work the caregiver has to provide, which generally makes everyone feel a little bit better. You're maintaining your independence, and the caregiver also gets to free up some time and do other things, while enjoying the fact that you have some independence. So there's a lot of pieces in there that can assist those caregivers. I do think that again, there's this education piece that needs to happen. We tend to, when we have someone in our circle, who has an illness, or a disability, we want to hover. We want to take care of everything, we sometimes forget that person-centered piece of what do they want. What do they need? And I've seen this happen where someone is coming in to help you clean your house, and they left. And you have no idea where they put your dishes because they're not asking you what would you like this to look like. How do you want me to do this? Because at the end of the day, this is your space, and what is going to work best for you? So there definitely needs to be open communication, just some education, on how to support.

Jennifer Tenney (33:53):

I think a lot of education, too, comes with knowing the resources, like we've been talking about, just being aware of what's available, as a caregiver and a family member, so that you can assist the person with the disability, in applying for services and supports that they may need, because they may be overwhelmed. They may be too ill to fill out the actual application or to make those phone calls, so that might be hard for them, so just to also be aware of the resources that are available, so that people can get the help they need, not only as the person with the disability but the caregiver and family member, because as Jessi was saying too, there are support groups for caregivers and family members, as well. And I think that's important, along with knowing the resources. That's one resource for folks, family members, who are going through the cancer with the patient and the survivor.

Dr. Lesley Cottrell (34:56):

Yeah, so with this, I think there's a pendulum, right? And many of us fall into extremes at some point. It may not be every day, but on one end, it's I'm going to do everything for you. You even start to hear, at some points, this language, like the person with the disability is a child. You hear that kind of interaction. Let me do the ... You don't want to be on that end. You don't want to have them completely dependent, in every way, right? They might be completely physically dependent, but in every way, you definitely don't want to treat them ... especially as a spouse, partner. You want to watch that interaction, so it doesn't become a dependent kind of parent feel to it either, right? The quality's very important for that independence. And on the other side, in terms of total independence, you don't want the family member to get lost, with the partner to get lost, so yes, you might need to reconfigure that kitchen, so that they can reach the plates and things of that sort. But everything doesn't have to be about that person with the disability. The child, the partner, the spouse also has a say in this, so keeping it right in the middle and trying to find that is where you want to ... And you won't have every day like that but checking it, talking about it, how can we get it back is going to be key.

Jessi Wright (36:31):

It is. It's key for everyone because that provides a sense of normalcy. And it tries to get you back to everyday life, because when it does if you're that person, if you're that patient, with the diagnosis, you don't want the world to revolve around you. You want your family to still have a normal life, so when you can get to that balance of realizing, I'm going to still need these things and these supports, but we're going to include this as an all-inclusive-family thing, that is a much stronger support than customizing everything to fit that individual's need and potentially making them feel like a burden. That's what we want to avoid. So with the Assistive Technology program here, we do have demonstration labs. Now COVID has kind of put a kink in how we operate, but we do still allow people to come in and see what we have, and to get hands-on demonstrations of equipment, because many people do not know what is available. It could be something as simple as an electric stapler if you don't have the strength to push down on a stapler. We have that, so a lot of times, people come here and just generate ideas. So now we're doing things right now is people can call and make an appointment, to come in. We're doing groups of no more than two, so if they need to bring a support person with them. And we just do our best to show them whatever they might need and give them an idea of just what is out there and how many things are available. And we're lucky right now in the world because there's so much change in how manufacturers are making things and being more inclusive, that now not everything has to be special ordered. We're now being able to get off the shelf technologies or just changing a mindset of you know what? That is an off-the-shelf technology, but it can be used for somebody with a disability, to overcome an obstacle.

Jessi Wright (39:03):

But you have to have that knowledge to think outside the box, and as an AT person, what we are is professional problem solvers. You give us a situation, and our job is to figure out how to help you do that. So absolutely, we encourage people to come in, because assistive technology truly encompasses everything. We even have farm and garden equipment, so that people can be out there, still doing these things they enjoy, or maybe that's their employment option if they have arthritis or mobility concerns. We have the recreation. We have the work. Maybe you just need computer access and something to read out to you, because you're having a little trouble using computers and being able to read text. Those things are available, so yes, we still have a lab that's open and lots of stuff in it, that we like to make sure that people know it's available. We are going to be creating a video tour of the lab and posting it on our website so that people can get a better idea because assistive technology is not a common term. And people just don't realize what all it can encompass and how much it can help them of all abilities.

Jennifer Tenney (40:17):

Jessi, I think it's important to note, as well, you talked a little bit about employment, that WVU is also associated with the Job Accommodation Network, which is a national network, that's located here in Morgantown. We're very lucky to have them here, in Morgantown, to help us with the job accommodation, that does the same thing that Jessi and her group do, on a national level. And you can go to their website and put in whatever job you're doing and whatever accommodation or problem you're having, and they will generate ideas for your job, so that we have that option, as well, for those who may be listening, that are not in West Virginia. And Jessi, I believe there's an AT program in every state, right?

Jessi Wright (41:07):

You are correct. Just like there's a Center for Excellence in Disabilities, at least one in every state and US territory, the same goes for the Assistive Technology programs. We all do the basic same things. We all provide equipment loans. We all demonstrate equipment. We all do trainings and awareness events. We all have for use. These are all Federally mandated things we must do. Now everyone may have a different type of equipment, a different focus, because every state has a different population that they're serving, and they want to meet the needs of their state, but it is very good to know that even ... We serve West Virginia, and I say we serve birth to dirt, all ages, all abilities, as long as you're here in the state, but if you are leaving the state ... Maybe you're just here receiving treatment, or maybe you're moving ... these resources are available in every US state and US territory. We can provide that information if they need help finding it. You can also just Google search state AT program, California, and it's going to come up.

Lauren Hixenbaugh (42:07):

Thanks for saying that. That's a really good thought, that people might just be here briefly, so they can go to their home state and find these resources. So as we begin to wrap up today, I just want to take a moment and revisit some points for our listeners. So if listeners remember one tip, out of today's podcast, what would that be? What would you hope it would be?

Dr. Lesley Cottrell (42:29):

For me, I think I would hope that they would know that wherever they are, in West Virginia, southern part, northern part, you don't have to be close to Morgantown at all, that you could reach many resources and that, in many instances, we're trying to make a lot of this one-stop shop, right, so you have less coordination that you have to deal with. So for instance, for just the CED, we have several offices throughout the state. There's one in Big Chimney, just outside of Charleston. There are 80 plus staff throughout the state, in each region, that you could reach out to. One of our primary resources, if you're not sure, or there are multiple programs that you want to learn more about, that's related to this, you can go to our website, WVU CED. That will have every single program listed there, that we have, with contact information, or you could call the main number, and there'll be a person there, asking you questions, who can help connect you to the right program and get you started.

Dr. Lesley Cottrell (43:47):

There are multiple programs. There's programs that will work together so that again, you don't have to coordinate. And then, of course, all these programs outside of CED, the wonderful thing about this podcast, we learn a lot more, from Mountains of Hope, and other providers, and hopefully, likewise, and it's a shared process so that we can make those connections, to not just our programs but to other programs, and they could do the same. Jessi, do you want to talk about Assistive Technology?

Jessi Wright (44:17):

So because Assistive Technology isn't just talking, we actually have concrete things, it does become a little more complex. Our lab is located here, in Morgantown. We don't have another lab in the state. We do have some subcontractors that we work with or agencies that we partner with, that may have technology, so we try to connect to those. But we have wheels. We are willing to travel. And COVID has definitely presented some challenges with that, but it's also presented new opportunities, by thinking outside the box. Now we can do distance demonstrations if somebody wants to see equipment. If they want to video in and I give them a personal tour of our lab, so they can really get an idea, we can do that via distance as well. We are also seeking funding for a box truck so that we can load up almost the whole lab and take it all around the state because a rental car ... I've got a couple suitcases of equipment. I can only bring so much, and you're not going to get a full picture of what all this can be. So we are building because we do realize that we cover an entire state, and we're not really centrally located up here in Morgantown. So we try to get out there as much as possible. We're having more barriers, with that, without awareness events, due to COVID, but if there's a need, we try to meet that need. If someone needs us to get down to their area, we'll try to get that worked out, or if they're coming up to Morgantown because they already have an appointment scheduled here, we want to meet that need. We don't want them to have to come back. We want to be as easy for them to work with as possible. Folks are already going through enough. We don't need to over complicate their life. We want to try to make this a convenient stop, so we try to work with people's schedules if they are in town, but if they're not in town, when we're on the road, we try to post that on our Facebook page and our website, to let people know where we're going to be. So if they're like, oh, they're going to be in my area. I wonder if they can stop in and show me these things. That's what we're here to do. We're here to serve the state, and we're going to do that in any way that we can find possible.

Jennifer Tenney (46:36):

Just to echo off what Jessi was saying about being able to find a way, with the financial piece that my program does, we typically do most of our stuff over the phone, recognizing that a lot of West Virginia doesn't have broadband access or good internet access, but we still could also do FaceTime. Most everybody has a smartphone, out of necessity, so we can do FaceTime. We have partners throughout the state, so we partner with the Division of Rehabilitation Services, so if you can get to a Division of Rehabilitation Services office, you don't have to get services from them, but they will still connect you with you, and you can sit in one of their offices and, talk to us on the phone, and get that financial piece or any of the other pieces from the Center. We have those partners, throughout the state, so if you can just get to one of those partners, that may be in your area, if we aren't coming to you anytime soon, then that's probably the best way to reach us if you don't have the ability to do it straight from your home.

Lauren Hixenbaugh (47:46):

Great. Thank you all for sharing those points. I do want to go back to our resources, just for a moment. If you want to find out more about all of the CED's resources, you just need to go to their website, just www.cedwvu.org. You can also visit moh.wv.gov, and our resources page, and find out about these specific programs that are listed there. And then we did talk a little bit about our Living Beyond Cancer Facebook support group, so all you have to do is type in Living Beyond Cancer. Search for it. It will pop up, and you can join our supportive environment and talk with other cancer patients, survivors, and their caregivers. Living Beyond Cancer would really like to thank each and every person that came today and listened to the podcast and especially our speakers, Dr. Lesley Cottrell, Jennifer Tenney, and Jessi Wright. Again, thank you all for joining us.

Jessi Wright (48:47):

Thank you.