Q&A with Josie Smith, director of the Sight Loss Support Group of Central Pennsylvania

Mike Dawson

Since April, Stage College resident **Josie Smith**, 62, has served as the director of the **Sight Loss Support Group** of Central Pennsylvania. She is legally blind herself, and that is among the factors that motivate her in her job.

What's the role of your organization and what kind of service do you provide in Centre County?

We provide **support** to people who generally are going through vision **loss** for the first time. That can be a rather overwhelming experience for people. We like to bring them here, talk to them and make them realize, that above all else, they're not alone and life definitely goes on if you have **sight loss**.

We try to get people involved in other activities and meet other people with **sight loss**. It makes you realize that you could be happy, you could lead a very full life, even though you can't see what you may have seen yesterday or five days ago.

Peer **support** is a big part of it.

All of what we do is deal with the emotional side. We look at ourselves as a gateway to the services that are available that we don't provide. We'll do referrals to the Pennsylvania Bureau of Blindness and Visual Services, which is a state agency, and we'll refer people to North Central **Sight** Services in Williamsport.

There's a whole network of services there that most people are not aware of because there's no reason to be aware of until they have a need."

Your **group** has some 400 members. How active is your membership?

It waxes and wanes. Sometimes we'll see someone one time, and that is all they need or all they decide to take advantage of.

Losing one's **sight** must be a difficult experience. How do people deal with it?

It's different for everybody, but it definitely can be an unraveling. I know that I have walked out of some doctor's appointments feeling pretty distraught because I've heard things for the first time that weren't very happy and made me realize I had lost a lot and had a lot more to lose. So, it can be a very overwhelming experience.

So, when people come in here, one of the main things we do is make them realize there is a lot of hope and there's a lot of possibility out there.

I'm just amazed that other people deal with it very, very well and other people are in tears.

Josie, you have **sight loss**. What’s it been like for you?

I have retinitis pigmentosa, which is retinal degeneration. I have a significant vision **loss**, but it’s been very gradual over my life.

It’s come on so gradually that it hasn’t been a very emotional experience for me, but the first time I encountered a doctor, he looks in my eyes and says, ‘very interesting for me, but tragic for you.’ You know, you don’t go home feeling too good, and to hear that in your 30s for the first time …”

Prior to your being the director of this organization, you were the programs director in 2008 and served on the organization’s board in 2002. What are some of the rewarding experiences you’ve had while being involving in the **support group**?

I love helping people. When they come, they really don’t know much of what’s out there to help them, and by the time they leave, they know a whole lot more than they did when they first come in. They leave with hope, they have a plan, they have people that they’re going to go see.

It’s just very rewarding to, how can I put this, … you kind of reframe your narrative or your view on the world from going ‘I’m losing my vision and it’s an incredible amount of **loss** if you can’t see anymore.’ You have to find new ways to do things, and it can get you pretty stalled. But if you can change the assumptions and those perspectives to one that’s more hopeful and more optimistic, that’s the most rewarding part.

You said your **sight loss** was genetic, but you don’t know of anyone if your family who has it. Do your son and daughter have any **sight loss**?

I was watching them very, very carefully when they were younger; I was very concerned. They went to see ophthalmologists at a very early age than most kids do. They’re showing no signs, so I think they’re going to be fine.

What are the goals you have as director?

I want to build the resource center. I want to have a lot more accessible technology available to people and adaptive products so people can come in and really sit down and try things out. I had a couple who came in recently, and they had been to the doctor’s office, which was a very positive experience, but it’s sometimes not the most relaxing environment in which to try out products.

This is a more relaxed environment, and they can stay as long as they like.

You can always make it bigger and better.

Once that’s in good shape, then the next piece of the puzzle, or the vision, is we need to do a lot more outreach than we have been because I didn’t fully realize until I started working here, vision **loss** is becoming a very signify public health concern. What just blew my mind is that the vast majority of people are not using vision rehabilitation services. We have more and more people who are becoming visually impaired, and the vast majority of them either don't know about this or are choosing not to use it, so I think outreach is really, really important. And I'm trying to collaborate more than we have in the past with other agencies in the area.

Going back to the resource center here, what do you have on-site that people can stop in and use?

There's a CCTV, we call it a video magnifier. It magnifies any book or piece of paper you put on there. It will magnify it on the screen. There text to speech programs on the computer, scanners where you put a piece of paper and it'll read what's on the scanner. those are the high-tech things.

Those are the high tech, pricey stuff. There's a lot of assistive technology that's very inexpensive. There's a lot of help to get this equipment for people.

Some of the most helpful are the simplest things, like a hand-held magnifier, contrast in colors, like when you're setting your table, using contrasting colors helps tremendously, talk books, large print books.

What does it mean to have **sight loss** and help those going through it for the first time?

Having a vision problem myself, I think it would be hard to do this kind of work if you couldn't relate personally to what people went through. The drive that motivates us and gets us out of bed in the morning is that b/c this is something I care very much about and the personal experience with it has an awful lot to do with it. I feel if we can help people be more hopeful and optimistic and realize that there is a lot of possibility out there living with **sight loss**, then I've made the world a slightly better place.

I was so busy raising my children that my **sight loss** sort of went to the back. I didn't pay much attention to it. Now, it's a little more front and center

What was one of the hardest experiences you went through?

I lost my driver's license in 1993. That was a big **loss**.

I just realized I haven't driven for 20 years, and I don't miss it.

Did you have resources available to you that were like the kinds here at **Sight Loss Support Group** of Central Pennsylvania?

I think I was legally blind for years but didn't know it. I think that's one reason that motivates me to work here and I lived for decades with a vision **loss** without knowing what resources were available. I just tripped over it. I just happened to run into a caseworker when I moved to Bedford, Pennsylvania. … She's the one who told me I was legally blind.
