

Creative Connections

30-Word Stories

You can watch the video of this discussion at: youtu.be/Sg7zd2hc5_0

[00:00:04] **Ireland Thomas:** All right, folks. So, today we are going to do a 30-word session about creative writing and about SRNA and what it means to us. SRNA for me I know that it's been a great resource. It's been something that's connected me to my community and has made me feel like I'm seen and heard and a part of something larger than myself, something that's more of a family unit. So, I'm talking today about like taking our stories which are so large sometimes.

[00:00:36] We go through a lot when we have rare diseases, or we know somebody that's impacted by a rare disease. And we're going to be talking about how we can like create a 30 word, just tiny little blurb that shows what our story is like so that people that are outsiders to the illness can see it and then be like, "Wait. I understand it. I get it." For a lot of people, they try to put their story down and it becomes thousands of words, because it's so much it weighs upon people, but sometimes when you're showing it to like friends or family, they might not have time to read something that's long.

[00:01:12] A lot of time if you can make it brief, if you can make it have that same impact, that same punch, even when it's not that same 1,000-word piece, that's amazing. It's something that you can show to people. It's something that matters and you can make other people realize that it matters just as much as you know that it matters. I'm just going to launch into it. I have my screen shared. I could show you what it's like to write.

[00:01:39] For me as a creative writer, most of the time I go about it in a couple different ways, like you can go about it as like a narrative as in this is the story. We start at point A, and we get to point B, or you can do it more poetic using language that's like talking about how much it hurts, but you can use abstract language. So, I'll use both as an example here. Right now, I'll start here.

[00:02:07] So, I'm going to start by writing about the ways that SRNA has helped me personally and I know that it was an organization that saved me when I was a kid. I was 10 and 11 and my mom found it online and we were able to connect with other people that had my rare disease, because they hosted camps once a year and that was what was there for me.

[00:02:28] So, I'll write now and afterward you can always go over the word limit and then narrow it down after. So, I'm just going to write a little blurb. You can follow along and start writing your own, just 30 words that talk about what it means that you found SRNA and how SRNA has helped you as a person. So, for this session, I have it here and let me check my word count. Tools, words. This is a little bit over the word limit. So, I can narrow it down.

[00:03:07] "SRNA's camp saved me. I can't articulate it any other way. I was alone in this until I found out so many others were alone in this and then no one was alone. We were young and we were lost, but we were together. Then no one was alone." See, you could just take it and if it is getting a little bit over the word count,

you could just narrow it down the words a little bit. "SRNA's camp saved me. I can't articulate it any other way. I was alone in this, but then no one was alone.

[00:03:33] We all were lost, but we were together." And then another way to go about it. You can do more poetic language. That's a little bit more my speed about anything you want. You could do it about the rare disease stuff or you can talk about SRNA and the way that it helped you. I would say that if you're going to do abstract language, sometimes it's good to start out with a bang. Start with talking about pain, talk about what you went through and then rise it up into more positive into the joy of finding connection, of finding people.

[00:04:10] Despite it all, it is worth it. But despite the pain that you've gone through there are still good people out there that do want you and do take good care of you. Hi, Ilona.

[00:04:22] **Ilona:** Hello.

[00:04:23] **Ireland Thomas:** Hey there. Hi. So, this is the "30 words Creative Writing" session. I could talk about what 30 words means. Would you like to write a bit today?

[00:04:36] **Ilona:** Sure.

[00:04:38] **Ireland Thomas:** Sure. Perfect. Yeah, I'm admitting Marlene as well. Hey, Marlene, how are you doing? Let me just talk about this. So, I was thinking this session, it's mostly about writing about the ways that SRNA has helped you or your medical journey. And we're narrowing down what is a thousands and thousands of words story down into just 30 words.

[00:05:04] Because sometimes when you're trying to show it to other people, when you're trying to articulate your past and everything that you've gone through, the best way of going about it is to try and have something brief that you could just show people and be like, this is my experience. This is what happened to me.

[00:05:22] So, right here is where I have the prompts and then you can build your own 30-word story of how SRNA has helped you or about how having a rare disease has impacted you. So, for me, I wrote this little blurb that was around 30 words. This one was like 45 and then I narrowed it down a bit.

[00:05:44] **Ilona:** Really? So, those two sentences are 30 words. Wow.

[00:05:50] **Ireland Thomas:** It would just be this one.

[00:05:53] **Ilona:** It is 30 words?

[00:05:54] **Ireland Thomas:** Yeah.

[00:05:54] **Ilona:** Wow. Okay.

[00:05:56] **Ireland Thomas:** And I was talking about how, so when I was a kid when I was 10 or 11, I had my diagnosis for a bit, and I had not found anyone who was like me before because we're all very rare. It's not very likely that we'll run into people that are having our same condition or even just even a similar condition sometimes. So, I was talking about how the SRNA has this camp that they run every year. And that was the first time that I met someone that was like me. That was my age. So, just talking about like in what way did you find SRNA? In what way has it helped you?

[00:06:34] **Ilona:** Okay.

[00:06:34] **Ireland Thomas:** And it's okay to go over the word limit, but like you can always edit it down later and narrow down 45 words into 30 words. Yeah, there's plenty of space for, of course, you can always write whatever you'd like. I was thinking also. So, this is more of a narrative form in that it goes from point A to point B. It shows a journey of being alone and then finding people.

[00:07:04] SRNA's camp saved me. I can't articulate it any other way. But there's also more abstract, poetic language that we can use to articulate what happened and what we faced. So, I usually go about that saying with a bang, what's the feeling and then go more into how SRNA reached out, how it combated the most difficult feelings that I faced with a rare disease.

[00:07:35] **Ilona:** I'm typing into the chat. Is that what we're doing?

[00:07:37] **Ireland Thomas:** Yeah, absolutely.

[00:07:38] **Ilona:** Okay, let's see. I'm trying to think. SRNA...

[00:07:45] **Ireland Thomas:** So, it's just these 30-word blurbs kind of like this where you just talk about what you faced. This is another one. "Despair, but then light. Although I was blind, I could see it. Although I was numb, I could feel it. Although I was pained, it was all made worth it." Where you just talk about that most core feeling, you're able to narrow it down, because otherwise we can always just go off the rails talking about all the medical visits, all the hospitalizations, all the pain, the misery of it.

[00:08:16] But there are moments of light and there are moments that you could just capture, make it smaller, make it manageable, make it something that you could show to another person and summarize exactly how you felt, exactly what it's like. The solution that you found in SRNA or the solution that you've found to the pain that you did find in having a rare disease.

[00:08:41] That's just kind of the way I go about it. I think anything that you do face in life you could always turn it into something beautiful, because that's what makes life worth it. It is the beauty, the gold that you can find in ashes. It's not always the end. There's always something new. There's always something worth your time, always something worth living for, and writing is a good way to set yourself down and say I'm going to go and look for that. I'm going to look for a reason. I'm going to look for connection and community, and SRNA is one big batch of gold. It's something that is full of life and love, and care. So, that's kind of how I look at it.

[00:09:27] **Ilona:** That's not 30 words, but still, I mean, that's the biggest thing for me was that I felt like, of course, you always feel like you're the only one and then when you see that there are other people out, I mean, you don't take joy in the fact that other people are struggling. But when you realize there are other people out there struggling and you hear their stories of, like that they, what am I trying to say? Sorry, that they not only survived it, but they were strong enough to make it through or whatever, like, wow.

[00:10:03] **Ireland Thomas:** Do you mind reading it? I'd love to hear it in your voice.

[00:10:08] **Ilona:** It just says, "SRNA opened the world of warriors which helped relieve the feeling of loneliness."

[00:10:15] **Ireland Thomas:** I like it. It's good. Gosh. Yeah, I think that that's right on the money. SRNA, it felt like home when I was lost. It felt like a place that I could land, finally a soft place to land.

[00:10:35] **Ilona:** Well, the thing about SRNA was they weren't pinpointed only to one disease. When I learned that they supported and funded so many diseases I was just like, "Wow."

[00:10:54] **Ireland Thomas:** Well, it's like, it's otherwise it's we're all kind of orphans in this where none of us are main--we're not mainstream, we're not popular. So, we might as well band together and be like one thing, one group, because it's the same sensation of isolation.

[00:11:16] **Ilona:** That's what I was trying to--isolation, that's a good word, yeah.

[00:11:21] **Ireland Thomas:** Yeah, it's that same--

[00:11:25] **Ilona:** And isolated and loneliness, yeah, I'm going to do that.

[00:11:25] **Ireland Thomas:** Yeah, go ahead.

[00:11:32] **Ilona:** "Feeling of--"

[00:11:36] **Ireland Thomas:** "--isolation and loneliness." That's a good way to put it.

[00:11:40] **Ilona:** And loneliness, yeah. And that's because of all the Zoom stuff and everything. I mean, meeting people in person is 100%, that would obviously be most people's choice. But when you don't make it available, like these Zooms and these meetings, I mean, this was kind of nice just to talk to other people and not explain everything. You don't have to explain why you're tired or you didn't look active today as you normally are.

[00:12:16] **Ireland Thomas:** Yeah, and that's exactly why I love it. So, you're in a room or even virtually you're in a room with people and you don't have to explain yourself. That's why the camp was really great for me too, because I was so used to kids running around the playground and expecting me to be able to follow and keep up. But that was not a thing.

[00:12:39] So, being around a group of kids that were also not super physically capable and people that didn't ask me why I needed to sit down, why I needed to take a breather is nice. People are just understanding, they understand so much more after having gone through the situation, which is hard, and I wouldn't wish it on anybody.

[00:13:06] **Ilona:** Especially a child or a young adult. I can't even imagine. I mean, I understand how hard it is for me. And at 50 years, I've worked; I've lived my life normally or my previous normal. And so, I mean, just being a child or being a young adult, and just kind of trying to find your way. I can only imagine how difficult that must be.

[00:13:32] **Ireland Thomas:** It was hard. I mean, I didn't have much of a, like I always say, life A and life B, because you have life A before diagnosis, life B after diagnosis. Since I didn't have a life A really, I didn't have much to mourn, because it's kind of just been like this. And all things considered, I'm in a relatively good spot with my NMO. It's really well managed. The treatment that I'm on is nice. I'm happy and healthy. I'm a college student. By any metric I'm doing okay.

[00:14:03] **Ilona:** That's great.

[00:14:05] **Ireland Thomas:** But it's still something that haunts you. When you have it, it's something especially with relapsing conditions. What condition do you have?

[00:14:16] **Ilona:** I have NMO.

[00:14:16] **Ireland Thomas:** Yeah, then you get it. Yes, with relapsing conditions it's kind of just it's over your head a lot. But we grow and change and manage and sometimes the fear fades a bit which is nice.

[00:14:30] **Ilona:** Well, when I talk to other people that struggle with NMO and that are within my age range, they say all the time some of them suffered with this from very early on. So, they'll say to me, I luckily have no issues with my vision, meaning I still have full vision. So, they'll say, well, you know, I never had that.

[00:14:55] So, I don't know what I'm missing and I'm thinking to myself, oh my goodness like, yeah, wow. I don't know if it's worse not having it like you said and then not realizing what you're missing or haven't had it and then it's gone for whatever period of time or circumstance. So, then you have to adapt as to how to move forward.

[00:15:21] **Ireland Thomas:** Yeah, I think that with illness, it's way more cons than it is pros. But I do think that it enables us to have a greater empathy for people around us, because it's something that completely changes your worldview and how you view disability, how you view people. Like this could happen to anyone.