

Arachnoiditis Survivor: A Portrait of Resilience against Patient Harm in America

Tips & Ideas for your Personal Interview and/or telling your story.

Your Story: (These responses will be used in Art For Arachnoiditis Publications. *Portions of the interview may be published in the book, website, or displayed at the exhibition. Impact of the project is greater when a specific name is attached to a story. However, you have the option to remain anonymous for this project.*)

If you have already written or published your story in a public forum, please provide the link here and we will use that version for project purposes. _____

or attach your file in an email to sheilalynnk@yahoo.com subject: Arachnoiditis Survivor My Story .

Please add any of the following details which are not already described in your current story.

A few tips to guide you through it IF this is your first time telling your arachnoiditis story (you are not required to answer these questions. These ideas might help you decide what you would like to share about your arachnoiditis experience and what might be useful to other survivors and/or readers trying to understand what it means to live with arachnoiditis.)

IN YOUR OWN WORDS:

- **Can you explain how you got arachnoiditis?**
- **How has arachnoiditis affected your physical abilities? What portions of your body have been affected?**
- **Please tell how this has made you feel about yourself.**
- **How does this affect the way you interact with the people around you?**
- **On the really awful days, what people/places/things/experiences/memories bring you back from the edge?**
- **What kind of support/ assistance/guidance do you receive from your medical community? Are you satisfied with it? Do you have a team of care providers working together to help you adjust to this condition? If so, how did you find them?**
- **What assistive devices, if any, do you use to make it through your day? Who pays for them?**
- **Describe your work life/productivity~ Are you still employable? self-employed? working with Vocational Rehabilitation Services to determine employability with arachnoiditis? adjusting to permanent disability payments?**
- **Do you have children? are you able to care for them independently? How has arachnoiditis affected your parent-child relationship?**

It may also be helpful for you to keep a journal (for yourself) and then refer back to it for specific details.

- **Keep a journal to describe your current daily activities for a 24 hour period** (and/or complete a five day journal of your activities)
- **include items such as:** when you wake up, sleep, leave your house, describe side effects you cope with due to medications(initials only) & how often you take them, how often you have to ask for help, does anyone stop in for a visit (initials only), how often you use social media on the internet, your pain level, things that relieve your pain, things that make it worse, describe something that inspires you or a moment of joy in your day, something you do for somebody else, tell what entertains you or distracts you from your pain~music, movies, books, a child, a friend, etc. Include anything else that you would like the public to know about your experience as an arachnoiditis survivor.
- **Pain Journals** are also known to be useful in determining what triggers your severe pain and what brings relief.

Your story can be sent via email to: sheilalynnk@yahoo.com subject: Arachnoiditis Survivor My Story. Or via USPS to the studio.

For inclusion in the Arachnoiditis Survivor Project, your original consent form with your signature must be mailed to: Sheila L. Kalkbrenner, Arachnoiditis Survivor Project, SheilaLynnK Art Studio, 345 South Main Street, Wellsville, NY 14895.