Interview with Pip

This interview was submitted on March 10, 2022. Names have been changed for privacy. Pip is a 34-year-old, Cis-female, and is single, no children. Pip has sickle cell anemia and restrictive lung disease and is an oxygen wearer.

What is sickle cell anemia?

Sickle cell anemia is one of a group of inherited disorders known as "sickle cell disease". It affects the shape of red blood cells, which carry oxygen to all parts of the body. Red blood cells are usually round and flexible, so they move easily through blood vessels. In sickle cell anemia, some red blood cells are shaped like sickles or crescent moons. These sickle cells become rigid and sticky, which can slow or block blood flow. This means your body can't get enough oxygen and this causes extreme fatigue and pain, and other symptoms. There's no cure for most people with sickle cell anemia, although treatments can relieve pain and help prevent complications associated with the disease.

Learn more at Mayo Clinic.

What is restrictive lung disease (RLD)?

RLD causes a decrease in the total volume of air that the lungs are able to hold. It is often due to a decrease in the elasticity of the lungs themselves or caused by a problem related to the expansion of the chest wall during inhalation. Symptoms include cough, shortness of breath, wheezing and chest pain.

Learn more at **Johns Hopkins Medicine**.

1. What is your disability called?

Pip: Sickle Cell Anemia and Restrictive Lung Disease (I'm an oxygen wearer).

2. Have you found any GWA content that includes your disability?

Pip: Sort of. In the way of Chronic Pain (the main staple of sickle cell disease). None for people who are on supplemental oxygen though.

- 3. If writers made content about characters with your disability, would you want:
 - The speaker is nondisabled, the listener has your disability
 - The speaker has your disability, the listener is nondisabled
 - The speaker and the listener both have your disability
 - I do not want GWA content about my disability
 - Other (please explain)

Pip: I'd like for the listener to have my disability and the speaker to be non-disabled. As I am also a writer it is something I also want to incorporate in some of my writing. Especially for those of us with pulmonary disorders and who use oxygen and Cpaps like myself.

- 4. If you are comfortable sharing, what type of NSFW content do you want to find on GWA?
 - A) Kinky sex, vanilla sex, or both?
 - B) What gender tags are you looking for?.
 - C) What romantic pairings are you looking for?
 - D) What sex acts are you looking for?
 - E) Are you looking for more content that includes sex toys?
 - F) What kinks and fetishes are you looking for, if any?
 - G) Other (please explain)
 - H) I prefer not to say say

Pip:

- A) Kink or vanilla: Both, I appreciate variety and exploration.
- B) Gender tags: F4F or F4NB
- C) Romantic pairings: dating, married & D/s
- D) Sex acts: oral, vaginal, masturbation (both solo & mutual), anal
- E) Sex toys: Actually, though I don't mind sex toys, my preference would involve more toys for external play (crops, cuffs, blindfolds, sexy dice etc) and less for use during intercourse. So fewer straps, dildos and the like. I think the art of using one's whole body to please your partner is kinda becoming a lost art of sorts. That's just my perspective though.

- F) Specific kinks and fetishes: D/s, MD/lg, FemDaddy/lg, matrimonial (I think sex as a married couple is insanely hot), and role-play, these are my top 5
- G) Other: As far as liking individual, specific kinks, the ones that stand out for me are; spanking, biting, kissing, teasing/denial, and general body worshiping. Is dirty talk a kink? Lol Anyway, yeah those are the ones that stand out.
- 5. Do you refer to your disability by a shortened or different word? For example, many paraplegics call themselves "para", e.g. "I'm John, I'm a para."

Pip: For Sickle Cell Anemia, we in the community use either SCA or Sickle Cell Warriors. For Restrictive lung disease, it's just RLD.

6. Are there any online resources for learning about your disability, including having sex with your disability, that you recommend for writers?

Pip: Links for intimacy issues/practices related to SCA and RLD:

- <u>SCA</u>
- RLD/COPD

7. If sex for you is different or more difficult than for non-disabled people, why is that? Are there things a new partner might not understand about you at first when it comes to sex?

Pip: Sex with sickle cell can sometimes exacerbate pain in SCA carriers cause moderate episodes of joint pains and sometimes pain within the sex organs; priapism in persons with penises and pain in the mound area of people with vaginas.

With both SCA and RLD, stamina or lack thereof is the most pressing issue. Certain positions can cause moderate to severe tiredness. There can also just be a general lack of sex drive, not for wanting. We may be in the mood and just unable to perform.

Also, trying to have sex with an oxygen line on can be...comical at times, I've never done it with mine on but, from friends I've heard it can be a good laugh with the right partner.

8. Do any sex aids exist to help people with your disability?

Pip: I don't think anything outside of a nice rub down to help joint discomfort in SCA patients after sex and make sure you have inhalers and your O2 line nearby after for RLD patients.

9. People google very specific questions about disabled people: like:

"Can paralyzed people have sex?"

"Can autistics feel love?"

With regards to romance and sex, do people make assumptions about what your life is like and what you can and cannot do in bed?

Pip: Being someone who is into "lifestyle play" (BDSM) and a submissive, having a chronic illness that causes frequent pain episodes that can be insanely severe with SCA. People automatically assume that any and all types of play that incorporate corporal punishment or positions in bondage are automatically out. However, as long as you have open communication with your partner and a specified guideline in how you play with each other, we can enjoy "lifestyle play" like anyone else, even with mild restrictions.

10. What should writers include in order to describe your disability accurately? What is the best way to describe a person like you, in a porn script, ensuring that your disability is not erased and the script is for people with your disability?

Pip: Mentioning certain symptoms can be helpful during scripts with "check-ins". Mentions of used aids (inhalers, oxygen, cpap) making sure the disabled listener (or speaker) has support for daily lifestyle accommodations.

11. What should writers avoid when writing about your disability?

Pip: Pity. Writers should avoid pity, I can't speak on speakers with disabilities but, listeners(at least in my case) I don't want pity. Sympathy, emotional vulnerability is quite fine but, I don't want to be felt sorry for. Also, I personally don't want everything to be taken too seriously about either of my illnesses. I've been through more than

most before the age of five, been closer to death more times then I can count and things that have kept me sane is the love of family and friends and LOTS of laughter. Even after months in hospital admissions, when I couldn't cry anymore, I laughed.

12. Tagging is how people find content. For example, for a paraplegic I'd tag it:

[SCI] [paraplegia] [wheelchair] [disabled listener] [interabled relationship]

What tags would you choose for your disability?

Pip: [Interabled relationship], [Sickle Cell Disease] (as there are different hemo types other than Sickle Cell Anemia), [RLD], or [Lung disorder], [Cpap] and/or [Oxygen(O2) therapy]

13. About "person-first language" and "identity-first language", there is a big push in the medical community and schools, and from parents of disabled people, to never say the word "disabled". For example, they tell us to say "he's a man with paralysis" or "she's a woman with autism". Yet many disabled people say that they do not like this and get annoyed that people treat "disabled" like it's a bad word.

The question is, if we write content for your disability, it needs to be tagged so you can find it. What type of tagging do you prefer?

- Person-first like [person with a disability] [person with SCA]
- Identity-first like [disabled listener] [SCA listener]

Pip: Again, I will not speak for others but both are fine with me. Disabled is not and shouldn't be a bad word. But, I do understand the need for Person-first identity with some.

14. A common piece of advice from articles about writing for disabled people is, "Ask disabled people what they want, then write that". That leads to a different problem: how does a writer meet disabled people to ask them? Are there any online communities you recommend that welcome questions from non-disabled people?

Pip: I mean...this is Reddit so, I'm sure there are a few or, maybe writers and disabled participants can start our own subreddits within GWA specifically for that kind of interaction with both disabled and non-disabled mods.

15. Please choose a pseudonym to protect your privacy. What shall I call you? (You can use your Reddit name if you prefer.)

Pip: Pip is fine.

16. **If** you want me to include your age (or age range), gender, preferred pronouns, relationship status, and whether or not you are a parent, provide that information here.

Pip: Age 34, Cis-female, single, no kids

17. Do you have other thoughts you would like to share about this?

Pip: Lol, I think my messages have said it all:)