

A chat with the LUNA Project

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I was sixteen when I was diagnosed with a chronic illness. Sitting in the hospital waiting room, being the youngest there by at least 40 years, I have never felt more alone. The nurses gave me pamphlets about support groups and chatted to me about medications with names I still find it hard to pronounce, with side effects that would make me feel worse than I already did. People tried to be sympathetic but ultimately it was easier to not give them a reason to be. Some of those that I would consider close, if not best, friends aren't aware of this diagnosis five years later. Nothing could have prepared me for the alienating thoughts I would have, compelling me to isolate myself from friends and family. And yet, as alone as I felt, I wasn't. According to the Association for Young People's Health 23% of 11-15 year olds report having a long term illness or disability.

So why do so many young people still feel like they are going through this alone? This was one of the foundational questions in setting up the LUNA project. The LUNA Project, *Learning to Understand Needs and Abilities*, is a charity aiming to support and raise awareness of young people with chronic illnesses, disabilities and long term health conditions. They run workshops and school outreach sessions to encourage young people to feel safe in having conversations about disability and health conditions, while also running a podcast and blog to allowing the individuals living with these conditions the opportunity to tell their own story. I had the honour of chatting to Ally Lloyd, one of the co-founders of the LUNA project, and Laura McCafferty, LUNA's research development head, about their experiences of living with a long term health condition.

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What inspired you to set up LUNA?

AL: We set up Luna, just over a year ago. Myself, Beth, and Ross, two of my close friends, we'd had a really quick, crazy year with our health, disability, chronic illness stuff, and we felt very much this was all happening inside our little bubble. It felt like no one really knew about this stuff, but it must be happening to loads of other people. We had these realisations that one of the only reasons why things were going okay for us was because of supportive friends. We had taken that for granted until we talked to other people who were in similar situations, and they said that one of the things they found hardest about having a chronic illness was that lack of supportive friends. We decided that this felt like something that we need to share, and explore, and find ways to include more people in the conversation.

What impact do you think having a chronic illness has in trying to build these supportive relationships?

AL: It's difficult because there can be this feeling of being slightly different to your peers because you've had these experiences, all the hospital trips and appointments and procedures are the things that someone in their 60's would be going through, not someone in their late teens or early 20's. Trying to have those conversations with people who have no experience with that can be quite difficult. And because of being unwell, you can be absent from lectures or social events, the places where you're often building friendships.

LM: Because of my chronic illness, I can't drink alcohol, and having that conversation with people, especially when you're at Uni, where going out drinking is such a big way to meet people, it can be hard when people ask why you're not drinking. I find it hard to talk about my chronic illness to people I've just met and even sometimes people that I've known for a long time! So, sometimes it's easier to lie about it, make up some excuse about why I can't attend, which is quite bad on my part but it stops people asking me questions. Sometimes it can feel like the understanding isn't there, so I find it easier just to kind of brush it off and say that I've got a family event or something.

AL : I totally agree! It's weird because often it's one of your first interactions with people. You end up feeling like you should be having quite an intimate conversation about something that is really personal to you because, on the one hand it's not that deep and it's not a big part of who I am but on a day to day basis it has a huge impact on your life and so it does end up coming up a lot. When it's things like, 'Do you want to come and do this', or, 'Why weren't you here yesterday?', you end up in a situation where you have to have this very vulnerable conversation with someone that you barely know. It can be a lot easier to say, I was just, you know, just busy, or whatever.

Going with that, do you think over recent years there has been an increased social awareness surrounding long term conditions?

AL: I would say around me it feels like there is, but maybe that's biased. I only became ill a couple of years ago and since then I have been having more and more of these conversations. And statistically, if you're in a group with five people, and you mentioned something to do with having a chronic illness or a disability, the chances are that in that group, someone will say, 'Oh, my flatmate has this' or their boyfriend, and it's actually not as lonely as you think it is. It just requires one person to start that conversation. In recent years, I kind of realised that they are more common than you think and as I got more and more confident, I've been that person, starting those conversations!

LM: I agree, once you start you find out that many people do know about chronic illnesses and disability. I do think there is still a stigma, if people haven't been exposed to chronic illness and disability. In my experience, the idea of relapsing can be quite foreign to people. If I tell them I'm sick, and then a couple months later I tell them I'm sick again, they can kind of get lost. But when you start having those conversations people quickly pick up what you're talking about, and are quite willing to look it up themselves. So in that sense, things are definitely getting easier and people are a lot more willing to take the initiative to learn.

Living with a chronic illness, how has that impacted your relationship with your body, particularly in this world of social media which feels, at times, so focused on aesthetics?

AL: I would definitely say it's had a big impact. Before I was ill, I had quite a practical relationship with my body. I did a lot of gymnastics which I loved and I was very much like 'Who cares what it looks like? I can do all these amazing things!'

LM: When you're living in a body that has failed you so many times, and not allowed you to do the things that you want to do, it's hard to love it like that. And in terms of aesthetics, I've got ulcerative colitis, and which means I can lose or gain a lot of weight in quite short periods of time because of the medications I am on. And it can feel like you're not living in your body. When you look in the mirror or you're looking at pictures, you don't look like you and it can be quite hard to learn to love your body when it's constantly shifting like that. It's like, on one hand, sometimes I feel foreign in my new body but on the other hand, chronic illness has kind of liberated me from thinking about how my body looks. It's getting me this far and it works. I'm a lot more comfortable with my body and I think part of that has to do with my chronic illness. So, I guess I'm grateful for that.

AL: There have been times where I've been really ill and been in hospital and nurses are helping you shower and get changed and you just can't be self conscious because for them like it's not a big deal. All day, every day they're seeing different bodies and at first I was like "Oh my gosh, this is so weird", but in some ways it was kind of liberating because for them it's not a big deal so why should it be for me?

Looking at social media, and this kind of wave that we're having now of self love and self acceptance, do you think that it's providing a space for people with disabilities and long term illnesses?

LM: I think so. One of the things I'm noticing on social media is disabled people taking back their own narrative. There's a lot of 'Inspiration Porn'*** which can be quite harmful, portraying disabled people as only useful when they're someone to be inspired by. It produces the idea that disabled people should overcome their disability, rather than society be made accessible for them. And on social media I'm seeing a lot more disabled people taking control of their own narrative in the sense that they're the ones posting, they're showing what disability looks like and all these amazing things that they can do, while [also] showing the reality of disability and the ways that society can be made inaccessible. And I feel like it really helped someone like me when you have such a strange relationship with your body, seeing these other people posting on social media and talking about the same things that you feel, the same things that you go through. I think it's definitely helping people to start conversations. I think we're in a good place, in terms of social media, I think it's getting better.

AL: There's not one kind of disabled body image on Instagram. Like there's like a whole heap: queer disabled people, disabled people [of colour], people with invisible illnesses, people with

very visible disabilities. It's wonderful and that representation is a really huge thing and often I think it's not even people having overt conversations about their relationship with their body but just seeing that people like them exist.

What is something that you think able bodied people should be aware of in supporting their peers with a long term illness or disability?

LM: If my colitis is playing up, and I may not be able to go clubbing or something, or go out somewhere that we originally planned on, sometimes they'll stop inviting me. It's nice to be included, and for people to try. With chronic illness and disability, there's some things we can't do but there's a lot that we can do! And, it's nice if we don't have to be the ones constantly pushing to be included. For example, if I'm sick and I can't leave the flat, it's nice for friends to offer to come around and watch a movie or something. Just to make it feel a little bit less lonely because chronic illness can be quite lonely.

AL: It really doesn't take a lot to show that you've thought. If you're going out with your friend who uses a wheelchair, before you suggest a cafe just have a quick Google and see if it's wheelchair accessible, and don't suggest it if it's not. Or if you're going out with your friend who's hard of hearing, pick somewhere or pick a time that's going to be quiet so you can chat. Otherwise you get in a situation where you make a suggestion, and they end up feeling like the problem because they have to say, "Oh, that's actually not going to work for me. Can we do something else?" If you were going out with a friend who was vegetarian or vegan, you wouldn't be like, oh, let's go to the steak house - just taking that a little bit extra thought. And just listening and doing your own research. Don't wait for them to give you all the information, because like that can be a big emotional burden on them, when there's so much information out there on the internet about literally everything and anything.

For more information about LUNA and the work they are doing, as well as ways that you can get involved, visit their website www.thelunaproject.org.uk and follow their Instagram @thelunaprojectuk !

*www.youngpeopleshealth.org.uk/wp-content/uploads/2019/09/AYPH_KDYP2019_Chapter6.pdf

**'Inspiration porn' is a term coined in 2012 by disability rights activist Stella Young to mean the portrayal of people with disabilities as inspirational solely or in part on the basis of their disability.