

From Me and My Friends, to You and Yours Chronic Illness

A Foreword

This From Me and My Friends to You and Yours resource aims to cover chronic illness and disability more generally. With a multitude of conditions falling under these categories, it is impossible to cover each and every one separately. However, the experience of having any chronic illness, mental or physical, as a young person holds certain shared experiences. These can be incredibly challenging but also very valuable. The content shared throughout can also be applied to, and used by, those who are currently undiagnosed. It aims to equip you with the tools to initiate conversations with your peers, and know that you are not alone in this.

Putting this resource together was a large team effort, drawing upon the experiences and expertise of many young people with long term health conditions, mental health conditions and disabilities. The LUNA Project would like to extend a big thank you to everyone who took the time to share their advice and experiences.

You can find condition specific From Me and My Friends, to You and Yours resources here:
<https://www.thelunaproject.org.uk/from-me-and-my-friends-resources>

Our Science Communication resources, which explain the science behind different conditions, can be found here:
<https://www.thelunaproject.org.uk/science-communication>

Key Definitions

Chronic illness - A health condition which lasts over 12 months. They cannot be cured but can be managed

Disability - A physical or mental illness which limits someone's life activities and/or mobility.

Neurodivergent - A difference in mental/neurological function, the opposite of neurotypical

SEND - Special Educational Needs and Disabilities, used if a child has a disability or learning difficulty that means they need education support

Flare - A period of increased chronic illness symptoms

Pacing - A set of coping strategies and skills that improve quality of life and manage energy for people with chronic illnesses

Comorbidities - Conditions that commonly occur together, may be linked but aren't always

Baseline - A chronically ill person's "normal" or regular symptoms and energy levels

Accessibility - Everybody being able to access an environment equally without barriers

Ambulatory Wheelchair User - Someone who uses a wheelchair but can still walk (i.e. is not paralysed)

Autoimmune - A disease caused by someone's immune system attacking their own body

Stimming - Self-stimulating behaviours, eg repetitive movements or sounds, used by neurodivergent people to regulate sensory input

Fluctuating - Variable; changing pattern of symptoms or overall health

Relapse - The return of symptoms after a period of improvement (remission)

Brain Fog - A chronic illness symptom marked by being unable to concentrate, think clearly, or find words

The world of chronic illness, disability and long term health conditions is full of new vocabulary that sometimes feels like an entirely new language to learn. We've put together a list of key terms and definitions that you will see used in this resource and beyond! Obviously, this is not an exhaustive list but should provide a good starting point for you and your peers.

How does your chronic illness affect you:

Physically?

The physical impact of chronic health conditions is far reaching and each person will be uniquely impacted by their condition. Even when two people share a diagnosis, their symptoms and presentation may differ. We asked the LUNA community how they were impacted physically by their condition(s) and these were some of the common responses:

- Sometimes my anxiety manifests itself physically with tremors, nausea or muscle twitches.
- Struggle to nourish and hydrate myself adequately due to symptoms associated with food and drink.
- As the day progresses my ability to concentrate decreases.
- Get fatigued after a short time and therefore need to rest frequently.
- I struggle to participate in conversation unless the person is facing me directly.
- Interrupted, unrefreshing sleep due to pain and other symptoms.
- The weather can impact symptoms, often making them worse.
- Using different mobility aids for different days.
- I injure myself frequently and therefore have strategies to minimise and manage them.
- Constantly having to adapt to changing symptoms.
- Struggle to walk/stand for long periods of time.

Mentally?

Despite the fact that long term health conditions are often characterised by physical symptoms it is important that we don't underestimate the mental impact they can have. Dealing with a chronic illness/disability can at times be incredibly challenging mentally. This is a completely normal reaction and you will never be the only one finding this hard. Many people with chronic illnesses also have diagnoses relating to their mental health which can be equally as tricky to navigate. When we asked the LUNA community how their condition(s) impact their mental health they said:

- Body confidence issues due to bloating, weight loss/gain and visible differences.
- The incredibly dangerous nature of my conditions has given me severe anxiety.
- Feelings of frustration at both my situation and my body.
- Burnout excessively having to constantly think about my health.
- The uncertainty of how I am going to feel from one day to the next is incredibly anxiety provoking.
- Worries about how it will affect my future too: will I be able to live independently, work or have a family?

- My relationship with food is affected significantly due to GI symptoms and this is mentally exhausting.
- Pacing is incredibly hard to do, particularly when people are asking you to join in.
- Can feel sad or upset when you can't do something, or something feels more difficult than it is for your peers, particularly if this is something that you enjoy.
- Feelings of isolation, sometimes I accidentally distance myself from people as it feels easier to keep things to myself.

How does your chronic illness affect your life?

Missing Out

- My illness limits the number of things I can do in a week.
- I spend weekends resting so miss out on social things.
- I can't join in with very long days or very physical activities like sports.
- Tasks take me longer, so I have to prioritise. More often than not, that means missing out on things I want to do.
- I only attend school two days a week.
- Sometimes the stimulation of socialising is just too much to cope with.

Medical Stuff

- Treatments and appointments take up a lot of my time.
- Frequent hospital admissions.
- I have to carry emergency medications and medical supplies.

Planning

- I constantly have to plan ahead.
- Routine and pacing are pivotal for me to be able to manage.
- A lot more thinking and planning is needed - this can be tricky because my body is very unpredictable!

What do you wish your friends knew about your chronic illness?

- My chronic illness isn't my fault and I can't help it - if I can't come to an event or see you, that's not personal and it upsets me too.
- Sometimes I won't engage in conversation or reply to texts but that doesn't mean I don't like you, it likely means I'm not well enough to be on my phone.
- It's not awkward or rude to talk about my disability - in fact, I like that you care!
- You see me at my best, not at my worst, so don't assume how sick I am from what you see.
- Chronic illness fluctuates and so do my abilities - sometimes I will walk and other times I will use my wheelchair.
- The nature of chronic illness is incredibly unpredictable - we can appear fine one minute and be in hospital an hour later.
- My chronic illness impacts every aspect of my life and takes up a lot of mental energy!

How can your friends help with your chronic illness?

- Don't be afraid to talk about it or ask questions - I avoid bringing it up because I don't want to bother people but it's nice when someone asks.

- Think about accessibility - it means a lot if someone does this before I do.
- It's not going to go away so please don't tell me to "get well soon."
- Invite me to things even if you don't know if I can come - let me decide what my body is capable of.
- Tell me about what you're doing so I don't have to find out via social media.
- Find me chairs, carry my bag or push my wheelchair but make sure you ask first!

What would you say to someone whose friend has recently been diagnosed with a chronic illness?

- Be supportive in the knowledge that you don't have to fix them - let them know you're there for them.
- Continue to include them in activities, and offer accessible alternatives so that they are not left behind.
- Even if they don't reply to messages, keep reaching out because it really does mean a lot.
- Research and learn about the condition - some questions can be answered by Google.
- Know what to do in an emergency situation: do they carry emergency meds or wear a medical ID bracelet?
- Don't get offended if they cancel plans at the last minute. It isn't personal! Chronic illness is very unpredictable.
- Be patient with them and let them know you're still there. It does get easier over time, and together you will figure out how to deal with this.

Get Involved!

We would love to get as many people involved in creating these resources as possible! If you are a young person living with chronic illness, mental health condition, disability, or long term health condition, and would be interested in making a similar resource based on your experiences, we would love to hear from you!

You can email us at thelunaprojectuk@gmail.com or find us on social media @thelunaprojectuk.

Find out more

You can find more information about the work we do, our resources and opportunities to get involved on our website: <https://www.thelunaproject.org.uk/>