

# Chronic Illness and Bereavement

**“Grief is difficult for everybody, but there's an added complexity when you're chronically ill because, as we know, for a lot of us, stress is not the best thing for our bodies, and grief is surprisingly stressful. It's upsetting and it's difficult, so it can have a real impact on your physical health.” - Ella**

This resource and the accompanying podcast were created by a group of chronically ill young people who have experienced bereavement. We came together wanting to share our experiences of the complexity of grief when you are chronically ill as we couldn't find anyone else talking about it. If you are a young person reading this, it might feel like you are the only person who is experiencing this, we promise you are not alone, and we hope that reading/listening to our experiences is helpful and makes you feel seen and heard.

**“Personally I found really hard to navigate is grieving for people that you have never met before, even if it's, you've had two conversations, you've replied to each other's messages, or you haven't even spoken in a couple months and then seeing or hearing that someone has passed away and it's like, I don't really know... I've had it before where I don't really know if I'm allowed to grieve it, because I've not met that person.” Abigail**



## Community Grief

Community is important for everyone, and online community can be a lifeline for many of us living with chronic illness. Social media is a really important space for connecting with people with similar experiences, forming friendships, and seeing representation. When someone in the community dies it is an incredibly difficult and complicated experience.

You might be physically isolated from the other people who knew your person because they are online too, and the people physically around you might not understand why you are grieving. If you have experienced this, your grief is real.

## Grief impacting your body and illness

Grief has a physical impact for everyone, but this can be more complicated if you already live with a chronic illness that causes physical symptoms. It can be complicated and stressful trying to work out what is a change to your physical health or a new symptom, and what is the impact of grief, so it is important to look after yourself the best you can.



**“You are allowed to grieve, and you should give you're taking yourself time to grieve. Despite the fact that you might be aware that it may influence or increase your symptoms and cause a flare up, it shouldn't put you off of grieving, because grieving is important, it's natural thing and a natural part of the process. So I wish that's something that someone had told me, back at the start of my grief journey was to give grief its own time and acknowledge, whilst also acknowledging the impact on my body in itself.” - Ryan**

## Timelines are complicated

With both chronic illness and grief, you can find yourself wanting a timeline (when will I feel better?). Neither have a timeline, and just as chronic illness can significantly impact traditional life timelines like education and independence, this can also extend to your grief journey. You may not be well enough to grieve at the time, or a change in your physical health may trigger grief. It is okay to grieve at a different pace to others around you.

**“Anyone's grief journey can feel like, not a mess, but not a straight line. Not as planned out as all these visuals say. And then you put chronic illness into the mix and the unpredictability of your body. And even when you may think, ‘Okay, I'm getting to this side of it, my thoughts are now like this.’ And then your physical health can go downhill, which can also then bring your mental health down as well.” Abigail**

## Medical Spaces

**“A lot of death happens in medical environments. And for a lot of us in chronic illness, those medical environments don't have the best memories. So having to go back to those environments can be very, very difficult. So, give yourself some grace with it. If you've got to go back into a hospital, give yourself five minutes outside before you go in, and just take a minute.” Beth**



This resource just touches the surface of the experience of chronic illness and bereavement. Scan the QR code to listen to our episodes on the Grief in Common podcast.



This project is a collaboration between Teapot Trust and Winston's Wish. To access more resources, support, get involved, or give feedback, please get in touch via <https://www.talkgrief.org/> and <https://www.teapot-trust.org/>

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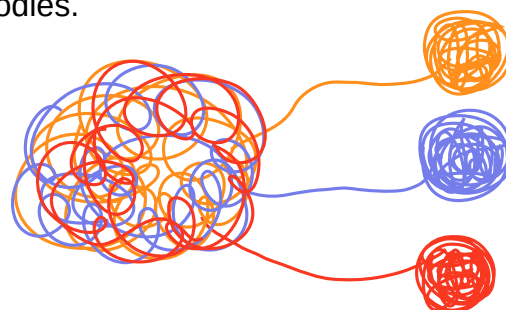
# Chronic Illness and Bereavement

This resource and the accompanying podcast were created by a group of chronically ill young people who have experienced bereavement. We came together wanting to share our experiences of the complexity of grief when you are chronically ill as we couldn't find anyone else talking about it. We hope this is helpful for you, whether you are a healthcare professional, teacher, youth worker, carer, or other person supporting us, to understand our experience and how you can best support us through a really challenging time.

## Understanding our experiences

Chronic illness and bereavement are both complicated physical experiences. It can be hard to understand, untangle, and manage the affect of grief on our bodies.

**“Grief is difficult for everybody, but there's an added complexity when you're chronically ill because, as we know, for a lot of us, stress is not the best thing for our bodies, and grief is surprisingly stressful. It's upsetting and it's difficult, so it can have a real impact on your physical health.” Ella (episode 1)**



Grief can also affect our experience of being in a medical setting, treatments, our feelings about our illness, and feelings about our futures.



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**“I knew my friend when we were both going through a lot of hospital treatments, and then she slowly got sicker and she passed away. The treatments that helped to get me better were ultimately what contributed to her death. I'm aware that it's not the most common situation, but I also know I'm not the only one in this situation. If you put young people who aren't in school in a ward together, they'll make friends with each other.” Ella**

We explored the experience of chronic illness and bereavement more in Episode 1, and we would recommend having a listen to that.

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## Supporting us

### Listen to us

**“One of the most useful things you can actually do before sitting down and having a discussion with a young person, with topics surrounding their chronic illness and their grief, and how both of those things might be affecting their lives, is to recognise with them, verbally, that you are not an expert in either of these things and you might say something wrong, but try and reassure them that you are coming from a place that cares and that wants to get this right.” Beth**

### Acknowledgement goes a long way

**“For me, the biggest thing was that acknowledgement and people recognising that impact and that my fears weren't completely unfounded, that I wasn't being hysterical or panicking about things that were worst case Scenarios and would never happen because I'd seen the worst case scenario happen. So yeah, actually just it was so simple to just acknowledge the impact it had on me.” Ella**



### Your Words Matter

**“Just take a moment and say what you're about to say in your head before it comes out of your mouth. Because we can all trip up on our words and be a bit clumsy and say stuff that isn't great, but that can be really affecting for somebody who's going through grief. Say it to yourself first and go, ‘Yes, this is definitely what I'd like to say.’ Because that is something so small that takes just a second, but can have a really big impact.” Beth**

### It is okay if you are not the right person to help

**“If you're not the right person and this is not the right place to have that conversation, it is also okay to leave it for the right person in the right place. Like, it's absolutely fine to include in their discharge letter, like, a link to Winston's Wish, or direct them to someone who can help them in that way.” Ella**



### A note for young people...

**“If someone does say the wrong thing, know that it likely is not from a malicious place. We're not good at talking about grief... give yourself a bit of a break about something someone has said to you if it's really upset you.” Ella**

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