

EMOTIONS WHEN YOU'RE LIVING WITH A TERMINAL ILLNESS



If a time comes when the aim of your treatment is no longer to cure you, how do you even start to deal with that news? It's normal to feel a range of emotions, or just totally overwhelmed.

There's no right or wrong way to deal with this. You might decide to accept the prognosis and make the most of your life, focusing on the things you want to do – maybe to make a bucket list and plans with people you love. Or you might want to carry on living your normal life as far as you can and not think about it too much. Maybe you can't accept the diagnosis and want to explore other options. Or you might feel as though you just can't cope.

It can be a combination of these feelings from one day to the next. There really is no right or wrong way to feel or deal, but you don't have to go through it alone.

Handling emotions

Getting bad news about your illness can be frightening. You're bound to feel lots of uncertainty and might have questions, like when and how your body will change, the effect it will have on your relationships and exactly how much time you have left. Not having answers can be frustrating and upsetting.

It can help everything to feel more manageable if you break down these big unanswerable questions and think about things in smaller chunks. Take it a step at a time and make small goals for yourself. You can still tackle bigger issues, but you don't need to think about everything at once.

Take it a step at a time

You could veer from one emotion to another, day to day, or even minute to minute. You could feel distressed, scared, angry, frustrated, lonely, guilty or in denial about what's happening.

Take some time to find your feet. You will adapt, and often those intense feelings will get less overwhelming over time. That's not to say you won't have bad days, but the devastation you feel at first will lift. You'll find that the really crap bits will go alongside moments of happiness, positivity and laughter too.

It can be liberating to blog or vlog about your fears and how you feel.

The thing about staying 'hopeful' or 'positive'

Being hopeful doesn't mean living in denial. Hope is an important part of being human. You can accept that your cancer isn't curable and still have hope. It's about redirecting it.

If you hope to visit somewhere you've always wanted to go, contact an organisation who could help you make this a reality. If you hope that you're able to do the stuff you enjoy for as long as possible, make a plan with your care team and palliative specialists.

It's also important to find a balance. The people in your life might be willing you to 'keep fighting' or not let it 'beat you'. Although it's coming from a place of love, it can be difficult and make you feel guilty. Or maybe you're putting pressure on yourself.

This 'battle' narrative isn't always helpful. There's nothing wrong with accepting your prognosis – by admitting that your cancer is terminal, it doesn't mean that you've lost, failed or are giving up. You can still go forward with positivity and hope. You could view this as a new chapter, or an opportunity to live life to the max. You could focus on having special times with the people you love. Some people find it empowering to plan for the end of their life or funeral.

Opening up to people

It can help to talk to someone about how you feel – someone in your care team could lend a listening ear so that you can vent and get everything out.

You might feel that nobody else can understand what you're living with. Even the people closest to you might not get it at times, and that can be frustrating. Try to be patient and open with them. The QR code below links to more advice on talking to your loved ones, including siblings and partners.

If you or they are finding it hard to talk about your diagnosis, it can help to talk to someone less close to you, like a counsellor or your Young Lives vs Cancer worker if you have one. Your doctor or nurse can help you find support, or you can search for counselling services in your area.

Talking to other people who are in a similar situation and hearing how they cope with their feelings can open up valuable support and friendships. Your doctor or nurse might know about local support groups for people who are living with a life-limiting illness, or even the same condition as you. For example, Shine Cancer Support (shinecancersupport.org) have support circles for young people living with an incurable illness.

If you're not ready to chat to other people, healthtalk.org has videos and written interviews of people talking about their feelings when told they had a life-limiting illness.

When and how to get extra help

If you have prolonged, intense feelings that start interfering with day-to-day life, then these could be signs of depression and anxiety. Look out for:

- Sadness or crying all the time
- Feeling irritable or frustrated
- Not being able to enjoy anything
- Change in sleep routine
- Lack of concentration
- Feeling helpless or worthless
- Recurring thoughts of death or suicide.

It can be hard to tell if it's a natural response to your illness, or depression. Either way, it's always good to share this with someone. Talk to your doctor or nurse – they could adjust medical treatments to make symptoms more manageable, or help you find therapies like counselling, complementary therapy and support groups.

Contact us for support, Monday to Friday:

Phone: 0300 303 5220 (9am–5pm)

Email: getsupport@younglivesvs cancer.org.uk (9am–5pm)

Live chat at younglivesvs cancer.org.uk (10am–4pm)



Scan the QR code for more support and tips on talking to loved ones

Young Lives vs Cancer helps young people and their families find the strength to face everything cancer throws at them. We've been there before. We'll face it all, together.