

## LOOKING AFTER YOURSELF PROTECTING YOUR MENTAL HEALTH

Mental health is a vital part of overall wellbeing. We can attend to it like we would take care of our physical bodies - if we sprain a joint we use ice and heat and then rest. The same applies to our mental health. The health of our minds can feel harder to care for as it is not as visible, not as obvious as our physical health. Sometimes it can be trickier to find things to 'do' that can help.

It might be helpful to remember that challenging times can also be an opportunity to nurture resilience - it's how we go about responding to the challenge that is key in transforming a difficult experience into one that gives us strength in the future.

## TOGETHER FOR SHORT LIVES

Together for Short Lives is here to make sure the 99,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours. We are a lifeline for families who care for vulnerable and seriously ill children. Getting the right support can make a lifetime of difference. And that's what we're here for.



**HELPLINE: 0808 8088 100**



**INFO@TOGETHERFORSHORTLIVES.ORG.UK**



**WWW.TOGETHERFORSHORTLIVES.ORG.UK**

## SPECIFIC SELF-HELP FOR FAMILIES WITH SERIOUSLY ILL CHILDREN

For families caring for a seriously ill child, time and physical space can be limited, particularly if you are caring round the clock for your child, often as well as looking after other siblings.

Even if you have very few minutes to yourself in the day and your time is taken up with the needs of others, it is always possible to try and carve out some time that is just for you. You might need to set some boundaries to make it happen.

## COPING WITH ISOLATION

Another issue faced by families caring for seriously ill children is isolation. Having a child with a life-limiting or life-threatening condition can be an isolating experience, in the long



hours spent caring for or thinking about your very ill child and often feeling unheard. Sometimes the many appointments that you have with different professionals can be overwhelming and you may feel alone with the enormity of the responsibility.

When we are isolated we can often feel very alone, maybe even lonely. It's good to think about the difference between these two.

Loneliness is often more about a disconnection with yourself. This of course impacts on our ability to connect with others – if we're not caring towards ourselves it can be difficult to reach out and be this way with others. Aloneness differs from loneliness, in that it embodies a choice and is therefore a more empowered state. Loneliness is about losing yourself, whereas aloneness is often about finding yourself – being alone can sometimes be glorious! Some tips for managing isolation step by step:

**Accept the reality of the environment** – this is what's happening and nothing can change this right now.

**Embrace your feelings** – try not to judge feelings as positive or negative – just feel, if you can. There may be some deep feelings but this is perfectly normal, you are allowed to feel, and you have permission to find it difficult. You might want to write down the emotions that you can recognise, this can help you to move on rather than getting stuck.

**Be aware of how loneliness can appear in the body** – possibly by noticing physical sensations such as a faster heartbeat, shallow breathing, tightness in the chest, emptiness in the stomach, pins and needles in the legs and arms. When we know to look out for sensations we can notice them and then let them pass us by – feelings in the body will come and go if we let them. This in turn can help us cope with them.

**Transform isolation into alone-ness** – it can be an opportunity to reconnect with yourself and to rediscover the things that make you, you.

**Practice self-care** – when we spend a lot of time caring for other people, we can forget to extend that same care to ourselves. It can be useful to remember to give that care back to ourselves. It can be difficult to get this started in a life that is already full of the needs of other people, but we can benefit so much from carving out a space to take care of ourselves.







## SOME IDEAS FOR IMPROVING WELLBEING

### Connect with people – reaching out to friends and peers

Keep in touch digitally. If you are feeling worried about not having enough to say it can help to meet up to do something, like have dinner together, watch a tv show, do a quiz, play a game, talk about a book, do some yoga or other exercise. If you don't feel confident with digital communication tools there are plenty of guides available to show you what to do, for example:

- [Zoom](#)
- [Facetime](#)
- [Skype](#)
- You might like to seek online peer support, for example by joining the Together for Short Lives' private [Facebook group](#).
- If you prefer, you can try writing letters or postcards if video chat is not your thing, or if you don't have computer access. It is also good to meet with friends and family outdoors when this is possible.

### Eat regularly and stay hydrated

Think about your diet – there is a strong link between food and mood. If we give our physical bodies the things they need to best function, our minds have a better chance of staying healthy too. Be mindful if you have a tendency to overeat – the stress of isolation may leave you reaching for the biscuits a bit too often! Drink water regularly.

### Try to keep active: 'Move your mood'

Similar to food, moving your body can have a significant impact on your mood. Physical activity is possible at multiple points in the day. It's not about having an



intense exercise regime, but doing what you enjoy and doing things that work for you and your body. You can get active outdoors or at home – cleaning/dancing/walking up and down stairs/doing seated exercises and stretching/doing online workouts/sitting less.

### Get as much sunlight, fresh air and nature as you can

Being outdoors has a profound impact on mental and physical health. Of course this is much harder if you are a full time carer to a vulnerable child, but it is still possible.

- Spend time with the windows open and be near the open windows
- Arrange a comfy place to sit near the window
- Look at pictures of nature and get inspired
- Listen to natural sounds – there are free downloads of waves or birdsong

[British Library Sounds](#)

[Spotify](#)

[Nature Sound Map](#)

- Bring in flowers or plants from the garden
- Grow seeds, watching your positive impact whilst connecting with nature

### Take care with news and information

It can be difficult to find ways of connecting with the outside world that don't make you anxious. Find trust-worthy sources and filter out those that are sensationalist or which aren't helpful. Feel empowered to switch off if you find certain newsfeeds or online groups upsetting or anxiety provoking. You can change what you follow on Social Media, even if only temporarily.



**FAMILY FACEBOOK GROUP:**

[WWW.TOGETHERFORSHORTLIVES.ORG.UK/FAMILIES-TOGETHER-SUPPORT-GROUP](http://WWW.TOGETHERFORSHORTLIVES.ORG.UK/FAMILIES-TOGETHER-SUPPORT-GROUP)





## Spending time at home

If you've been a full time carer for a while, spending all your time at home will probably be normal for you. Even so, it can be helpful to have a think about your relationship with your home space.

- Decide on your routine – this can be difficult if your routine is decided by the care needs of a seriously ill child, but where possible, waking up and going to bed at the same time can be helpful for everyone. When someone has care needs it can be useful to try and develop a rhythm, so that the 'administration' tasks get done in a certain time frame each week – things like the washing and organising, the cleaning of specialist equipment, the ordering of medication and supplies. It's this rhythm that can make the complexity of the task eventually feel more manageable.
- Find ways to relax and be creative – for example you might like to try arts and crafts/colouring/mindfulness/music/writing/ yoga or meditation
- Keep your mind stimulated – it can be helpful to undertake activities like reading/ listening to podcasts/watching films or documentaries, downloading an app to learn a new language and doing puzzles and brain teasers. Your local library may have information about online resources and activities. You could also look at some of the educational resources online such as Future Learn or Open Learn.

[Future Learn](#)

[Open Learning](#)



**FAMILY SUPPORT HUB**

[WWW.TOGETHERFORSHORTLIVES.ORG.UK/GET-SUPPORT/](http://WWW.TOGETHERFORSHORTLIVES.ORG.UK/GET-SUPPORT/)







## Recognise what you are offering – appreciate your gifts and efforts

With such an all-consuming caring role it can be easy to lose sight of the tremendous thing you are doing. Sometimes we can find ourselves living with a kind of ‘giving fatigue’, where we’ve lost touch with the power of giving – we’ve given so much but had an emotionally complicated return. By this we mean that sometimes those we give to can’t thank us in the way they would like to, or in the way we need to hear. It can be hard to retune our sense to take on board the ways that your child and other family members are thanking you. This can leave us in a place where we aren’t in touch with the gift of giving – the sense of our power and strength in continuing to give. We might instead feel the opposite – dis-empowered or drained by our gifts, rather than emboldened and fortified by our choices.

The question is how do we reignite this? How do we get back in touch with the power of giving?

- Start by giving to yourself. Giving yourself some time and space. Give yourself a special dinner. Give yourself a spa evening. Give yourself an hour with your favourite book. Give yourself a drive in the car with music blaring.
- Recognising your continuing gifts of care and attention to your children and spouse.
- Saying thank you to those that give to you. Sometimes in saying thank you to others we can actually begin to say thank you to ourselves too.  
Sharing your insights: This can help remind you of your expertise, and all that you’ve learned through giving. You might find it helpful to engage with some of the family actives run by Together for Short Lives.
- Compliment someone/extend kindness and support to someone unexpected. When we are kind to others we are better open to be kind to ourselves.

## Emotional First Aid

If you're feeling anxious

- Make a safe space in your home
- Have a handful of comfort activities that you know can calm you down – puzzles/ cleaning/organizing/deep breathing

If you're feeling claustrophobic or trapped

- Open doors and windows, sit on your front step or in the garden
- Try to see the sky – it can give you a sense of space
- Regularly change the rooms you spend time in if you can

If you're worried about feeling lonely

- Think about ways to connect with people in your life – looking at pictures of people you love gets you thinking about them
- Listen to a chatty radio station or podcast or even an audio book if your life feels too quiet that day

If you're feeling despondent

- Try to move your body, get up and leave the room. See if you can find something to do – make a cup of tea, water a plant, wipe a surface
- Reach out and let someone know how you're feeling - a friend, a partner, a relative. Or if this doesn't feel comfortable, contact Samaritans or Mind
- Try to be kind to yourself. Try to avoid giving yourself a hard time for feeling this way. It's ok to be struggling







## HELPFUL ORGANISATIONS

[Breathing Space Helpline](#)

NHS Living Life: 0800 328 9655

[Penumbra](#)

[Citizen's Advice](#)

[Carers Trust](#)

Helpline: 0300 123 2008

[NHS Inform](#) / Helpline: 0800 224 488

[Counselling Directory](#) / Helpline: 0333 3447 990