

## A letter to my past self



Dear Laura (your past self),

You will have just received the diagnosis. Jack is only three weeks old and the words 'cystic fibrosis' are the scariest you've ever heard. Today is the worst day; the hardest, most terrifying day of your life, and I only wish I could lessen the pain you're feeling.

But I can offer hope. Read that sentence again: today is the worst day.

A CF diagnosis is not what it used to be. Advances in medicine mean that the outlook for children like Jack is more hopeful than ever. You must believe the doctors when they say this. Since that day, things have got better and better. I'd be lying if I said it was all fun and games, but things have never sunk as low as that first day. There have been days where you've wobbled, or worse just crumbled. But reflecting on it all, I realise that none of these bad days were caused by the effect of the condition on Jack's health. He is a joyful, healthy, beautiful and robust little boy (you'll never get tired of being told he's next in line to play for England Rugby because of his size). Thanks, in many ways, to Jack's amazing CF team, a year on, he is thriving.

What that brilliant medical team can't prepare you for is that the hardest days to come will be triggered by external factors; the stuff you can't control. Strangers in coffee shops will ask why you're giving apple sauce to your three-month-old baby. You will run out of medicine just before the weekend. You will go out for the day without the Creon® and have to turn back, no matter the plan. And, unavoidably, your friends and family will make well-intended but heartbreakingly outdated comments about CF.

If I could give you one piece of advice to help manage these ups and downs, it would be this: look after yourself first. Maintaining Jack's CF routine is a marathon, not a sprint, and in order to keep the routine going and spirits high, you need to have considerable inner strength, so that the things you can't control don't completely derail you.

Here's what I've learned to do...

- **Build a network.** We have a wonderful pharmacist, a nurse I trust implicitly, and I lean on family and friends when I have a rough day.
- **Share the load.** We have trained a couple of loved ones on Jack's routine which means we can have a break. This has also helped close family and friends understand more about his condition.
- **Make physio fun for everyone.** Jack and I listen to nursery rhymes, sing together and, as he's grown older, watch his favourite TV programmes. Depending on my mood, I might listen to a podcast or my favourite music through an earphone, meaning that I, too, look forward to this peaceful time with my boy. You might be pleased to hear that Jack now sees the physio ball and squeals with excitement.
- **Do things just for you.** This is the most challenging one... I have worked hard to carve out time to do things just for me. A night away with friends, a massage, a long walk – these moments, no matter how small, fill my cup, refresh me, and enable me to return as a better mother.

The airplane oxygen mask analogy has never been truer – place the mask over your own mouth and nose before assisting others. Managing your self-care is something you're going to have to focus on to keep things afloat. It requires conscious planning to attend to your own needs and to make that time a priority. You may get it wrong before you get it right (in fact, you almost certainly will) but you'll figure it out, you'll learn the importance of it, and this will help to sustain you through the joys as well as the uncontrollable bits of life with your perfect little boy.

Soak it all up, life only gets better from here,

Laura x

(your future self)

**P.S.** That pain I mentioned at the start, the one so fierce it keeps you up at night? One year on and I can reassure you that it's almost disappeared; replaced instead by a new-found determination and resilience that, prior to Jack, you didn't know you had.

Published: July 2024  
Review due: July 2027