CYSTIC FIBROSIS NZ

For Billy and his family, even Christmas can quickly turn upside down

Each December invitations for festive gatherings roll in, but for April and Charlie, they have to ask themselves: Can we risk it?

As the world gears up for celebrations together, Billy's family begins planning their own quiet, careful version of Christmas.

As the holidays near, most of us picture laughter around the table, sticky fingers from Christmas treats, and children racing to open presents under the tree. For April and Charlie, parents to four-year-old Billy and his 6-month-old sister Poppy, Christmas looks very different.

Billy was diagnosed with cystic fibrosis before he was even born, an uncommon occurrence that left the family and their clinicians navigating unchartered territory. Of course, Billy's birth brought joy, but also a new reality of routines, physiotherapy, hospital visits and constant vigilance.

The festive season often means large gatherings with friends and family, Billy's family must always check if anyone has been unwell. "We have to reiterate how important it is for Billy as we almost ended up in hospital for his first Christmas", says April. "People don't always understand, or label us as over-the-top, but for Billy it could mean another hospital admission, more irreparable damage to his lungs, and more heartache seeing him so unwell".

Billy's countless hospital trips and medical procedures have left him traumatised. He's had surgeries, various blood tests, lines and nasogastric tubes inserted, extra vaccines and so many rounds of antibiotics, that April has lost count.

"Sniffles and mild colds are an inconvenience for most, but for Billy they could be life-threatening, leading to unwanted treatments, medications and long term damage" Mum, April.

Your $25 donation can cover parking costs for one day during an unexpected hospital admission, keeping the family together with one less worry.

When staying safe means staying away

Even a trip to see Santa requires careful planning. "We tend to see him during the middle of the day and at the start of November to avoid all the kids and heavy foot traffic," April says.

The hardest part is keeping up-to-date with Billy's medications, his treatments like sinus rinses, nebulising, daily physio, and also advocating for Billy among family and friends, to keep him well. People still try to share their food or drink, kiss him or turn up to gatherings sick.

No one wants to miss out on the celebrations, but April and Charlie have found themselves having to leave gatherings due to others attending while they are unwell.

There are so many things that most people don't need to think about that are daily challenges that Billy faces, not being able to be a real kiwi kid jumping in puddles, playing with mud and swimming in public pools.

Three years in a row Billy has received a paddling pool from various family members, and while this is a wonderful gift for most kids, the risks posed by a hose and stagnant water mean Billy is unable to enjoy such a gift - the risks are too high.

Shaking things up: new traditions and celebrations

Billy's family have had to adapt and create new and different Christmas traditions, creating a whole weekend of decorating, singing carols, making hand-made decorations for their grand parents, all while wearing matching Christmas outfits.

"We try to ensure that we make up for the all the events and activities that Billy has to miss".

"This year we are not seeing any of the family and have decided to take the kids to the beach and enjoy the day!"

Billy misses out on so many traditional Christmas activities, even simple things like making the Christmas jam and mince tarts.

Gifts with meaning and purpose

CFNZ help every year with Billy's Christmas present through the Breath 4 CF Grant. A grant which removes barriers to physical exercise, and is a really important part of treatment and wellbeing for anyone living with CF.

"Last year he received a balance bike, this year it will be a pass to the trampoline park. It's fantastic as we see the joy of Billy receiving something we may not be able to afford ourselves and also helps with his lungs too".

You can help fund a Breath 4 CF Grant for a child this Christmas with a donation of $150

"CFNZ are a godsend over the Christmas period - being able to receive the support to navigate the stressful holiday season makes a huge difference as well as seeing your kid open a really cool present on Christmas day that will help improve his daily health".

"Until you're living it, you don't realise how much a condition like CF changes everything" says April. "It's not just the medical side; it's the grief for the life you thought your child and your family would have. The ongoing burden of worry and isolation can be crushing."

Joy and magic packaged differently

But there is hope, and you can help bring it to families like Billy's this Christmas.

CFNZ helped provide April and Charlie with a community that understands, offering not just practical everyday support and financial help, but also compassion, connection, and advocacy for life-changing treatments like Trikafta.

"CFNZ has helped us feel seen, understood, and less alone in a world that often can't comprehend what we are going through." April says.

Your gift this Christmas helps CFNZ be there for families like Billy's, providing one-to-one Social Worker and practical support, ensuring no one faces cystic fibrosis alone.

While Christmas may look a little different for Billy and his family, your generosity can make sure it's still filled with joy and hope.

With heartfelt thanks and warm wishes

The CFNZ team

CYSTIC FIBROSIS NZ

Your gift this Christmas helps families like Billy's find hope and support through every challenge.

THIS IS THE DIFFERENCE YOU CAN MAKE

$25 provides one day of parking, keeping families together during unplanned admissions these holidays

$50 helps our fight for life-changing medicines access so that families like Billy's can worry less, and particpate more

$150 provides a Breath 4 CF Grant for a child, to promote exercise and lung health as part of daily treatment, as well as providing joy and fun moments

Give a gift of your choice to help support and provide hope to families like Billy's

YOUR GENEROUS GIFT

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If you choose to become a regular donor one of our team will be in touch to confirm the details.

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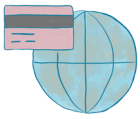

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Your generous donation can make all the difference.
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