

"In 2020, our family welcomed first born, Heath, into the world amidst what many would describe as a dream labour. His arrival was bliss, and we enjoyed the newborn bubble. However, our joy quickly turned to concern when, at just 20 hours old, Heath fell ill" describes Ashley.

The urgency of the situation became evident as doctors swiftly decided that Heath needed surgery. For Ashley and Luke, as Heath's parents, the sudden need for surgery was accompanied by confusion, uncertainty, and immense concern for their newborn. Within only 24 hours of his birth, the family found themselves grappling with a barrage of emotions and questions about what lay ahead for little Heath.

It was during these tumultuous hours that Heath underwent surgery. Three hours later Heath's parents were confronted with the term "Cystic Fibrosis" for the first time. As they absorbed this news, their first instinct was to turn to the internet for information, seeking answers to questions about Heath's future, his health, and the challenges he might face.

For three weeks, Heath remained in the neonatal intensive care unit (NICU), a period marked by tears, anxiety, and a sense of helplessness. Eventually, the diagnosis of cystic fibrosis was confirmed, shattering their preconceived notions about their family's future, and leaving them grappling with a range of emotions.

"It was a really confronting experience" expressed Ashley.

Despite their initial shock and disbelief, Ashley and Luke soon found solace and support in their CF care team, who quickly became an integral part of their lives. It was through the guidance of professionals including their Dr, Professor Jaffe, that they began to see a glimmer of hope for Heath's future.

Ashley said, "Professor Jaffe's reassurance that Heath was born at a time when advancements in CF treatment were rapidly evolving offered us a sense of optimism and relief."

Today, Heath is a vibrant and energetic four-year-old, defying the odds and living life to the fullest. He attends school, plays sports, and enjoys the same activities as any child his age. While CF has undoubtedly presented challenges, it has not defined or limited Heath in any way.

Heath and his family's journey with cystic fibrosis has opened their eyes to the incredible advancements in treatment and care that have transformed the lives of individuals living with this condition. They quickly realised that the generalisations they found online regarding life expectancy and quality of life did not account for the individuality of each person's cystic fibrosis experience. Through their journey, they came to appreciate that the ongoing efforts in advocacy and research are reshaping the landscape of CF care, instilling hope, and paving the way for a more promising future for Health and the 3,730 Australians living with cystic fibrosis.

With over 2,000 known gene mutations of CF, finding effective treatments for all individuals remains a complex and is an ongoing challenge. There is still much work to be done and at Cystic Fibrosis Australia, we are committed to ensuring that every person living with CF has access to the therapies and support they need to thrive.

We hope that everyone living with cystic fibrosis can live long, and healthy lives, unburdened by this genetic condition.

Through our collaborative efforts on both a national and international level, we are working relentlessly to advance research, advocate, support innovation, and improve outcomes for all individuals with CF. From managing the CF data registry to supporting crucial research initiatives, our work is driven by a shared commitment to making a difference in the lives of those affected by CF.

As we reflect on the journey and the progress that has been made to date, we are reminded of the importance of continued support and investment in CF research and care and hope that with your partnership we can continue to strive for increasingly better outcomes.

With your donation, we can continue to fuel progress, drive innovation, and ultimately improve the lives of individuals living with CF.

Together, we can make a difference.

Please donate today and join us in our mission to ensure a brighter, healthier future for all those affected by cystic fibrosis.

