Community Focus supports those living with Cystic Fibrosis
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Welcome to the second edition of Community Focus, and to Spring! My goodness does anyone else wonder what happened to the year?

As the freshness of Spring blooms across Victoria and New South Wales and Christmas decorations start appearing in shops (yes, it’s true) I am quite shocked at how fast this year has flown.

January started with the fight for Kalydeco, which led into the merger between CFV and CFNSW, the rollout of the NDIS and changes to the 5th Floor at The Alfred Hospital, Melbourne, all the while peppered with events and fundraising efforts across both states.

Since our last magazine, Victoria has held its A Night for CF gala ball. This glamourous event was an enormous success. Attended by over 300 people, it raised $43,000 – these funds will be put to research for a cure and support services for people living with cystic fibrosis (CF). Alongside the major events, we have so many wonderful community groups and individuals hosting fundraising events like Crazy Hair Days, sausage sizzles, golf days, bike rides and many more. We do not take these efforts for granted and we are grateful for your support. It is these small efforts by many people that can make living with CF just that little bit easier.

One of the ongoing concerns that comes across my desk is the NDIS. We all know that CF is not regarded as a disability under the NDIS. We also know that some people or families are able to tap into the NDIS by virtue of other issues, but for CF alone it is exceptionally difficult if not impossible. Another burden will be when the mobility allowance is phased out in a couple of years, which will mean that those receiving this allowance will no longer have access to a Health Care Card. These are concerns that affect a small number of people in our community, I want to encourage you to speak to your CF team and social workers to get as much information and advice as you can to determine whether you might be eligible. One key thing to remember is that the NDIS is about disability – meaning that you usually need support from a person or equipment to do everyday things for yourself because of an impairment or condition that is likely to be lifelong. For those few of you who have managed to successfully navigate this maze, please do contact me to let me know how you managed it. We can then pass on relevant information to the community, which may in turn help others.

Over the first weekend in August the 12th Australasian CF Conference was held in Melbourne. Well attended by CFCC members, the program was extraordinary. Some of the big ‘take home’ issues for me were Infection Control and Mental Health. I would encourage all of you to access Consumer Connect (see page 8) to catch up with these presentations by Charles Hayworth and Alexandra Quittner. If you have ever questioned the need for facemasks and gowns, Charles is very clear in sharing his research findings. We should not only be concerned about airborne bugs, but those that stick to surfaces as well! The mental health presentations were a revelation for me – do you know that there is a 30% higher incidence of depression in mothers who have a child with CF, and the mental health of the mother directly affects the physical and mental health of the child? As if mums don’t have enough to be concerned about! Yet, information is power, and now that we know, there are things we can do to help. In Victoria, we have started a small mental health fund (which was made possible by one of our community fundraisers) which will provide small grants to help with the cost of psychological care. Once we have a stronger funding stream in NSW, this will be a priority there too, although we do fund the social workers at Westmead and John Hunter hospitals and they can be contacted for support or referral.

There is not much of the year left, but I implore you to get involved. We have Great Strides (VIC) and Go Red for CF (NSW) coming up in the next few weeks. We need your support to provide services. If you are not aware of the services that both Victoria and New South Wales provide, then please check out the services pages on our website. If you have any questions please don’t hesitate to call the Programs and Support Services team in your state.

As always, if you have any concerns, questions, ideas then I welcome you to contact me directly at ceo@cfcc.org.au, or call the Melbourne office on 03 9686 1811.

Until next time...

Karin Knoester
Chief Executive Officer
A Pilgrimage To Nashville

By Tom Valenta

Wendy Wood has won many awards for the country songs she has written and performed. From Tamworth to Nashville, Tennessee, her music has been acclaimed in recent years.

In 2014 and 2015, she was Nashville Universe Songwriter of the Year. In all there have been nearly a dozen awards and citations in Australia and the United States.

The first song she wrote in 1991 did not win any awards, but is perhaps the most important of her illustrious career. Guardian Angel was inspired by the confronting news that newly-born daughter, Cassie, had been diagnosed with cystic fibrosis.

The mother of a three-year-old son, Jarred, Wendy then lived at Stokers Siding near Murwillumbah in far north-eastern New South Wales. Her husband, Neville is an interstate truck driver who is away from home for weeks at a time.

There were many trips to the Royal Children’s in Brisbane, their nearest CF hospital. With Neville on the road, Wendy would take Jarred, who does not have CF, to Brisbane or Wendy’s mother would travel from Nambucca Heads on the mid-north coast to look after him.

For the past twenty years, Wendy and her family have lived in Tamworth, her spiritual home, where her parents had moved some years earlier. There she has been actively involved with the Tamworth Songwriters Association. Wendy and her friend, Carolyne, have formed a duo called Two Gals and they sing in the local clubs and pubs.

Last year Wendy’s attention was captured by a raffle organised by Cystic Fibrosis NSW. First prize was a trip for two to Nashville! She had won awards, and was in contact with local songwriters, but had only briefly visited Nashville once – in 2010 when floods prevented her from spending time there.

A former CF fundraiser, Wendy purchased an entire book of raffle tickets and one of her numbers came up the winner.

A ‘mother and daughter’ holiday was planned for last November. Cassie was planning to marry in May of this year. But ill health intervened, this time for Wendy. She required emergency surgery and the trip had to be re-scheduled.

The trip was finally made in late May, soon after Cassie and Nathan were married. Nathan accompanied his new wife and mother-in-law. For Wendy it was a pilgrimage, for Cassie and Nathan, a honeymoon.

One highlight for Wendy was a guided tour of the world-renown Gibson guitar factory; others included visiting landmarks such as the Grand Old Opry and the Country Music Hall of Fame.

Cassie and Nathan also travelled to St. Louis, Missouri where they saw heavy metal band, Metallica play live to an audience of 70,000. The concert was their wedding gift to each other.

As part of her prize, Wendy also won a new Gibson guitar which arrived two weeks after she returned from Nashville. It is so special she is almost too scared to play it.

Cassie and Nathan live at Nelson Bay in the Hunter Region where Cassie works in fashion retailing. In May last year, Cassie was prescribed Orkambi and she says it is a life changer for her.

Her doctor told Cassie Orkambi was her last chance at getting on top of her CF as she was allergic to most of the common IV antibiotics used for CF. Within a month her life changed; her skin wasn’t salty; her mucus wasn’t sticky and it was easier to clear.

Cassie says Orkambi has saved her life, It has given her the energy to work a casual job, look after and walk her two dogs and three ferrets.

‘Orkambi gave me the energy to be able to enjoy one of the most precious, love filled days of my life, my wedding day and to enjoy our honeymoon – our first overseas trip.’

Wendy has written and performed another beautiful song about CF. It’s called A matter of life and breath and was inspired by Cassie’s observation that there were no songs specific to adults with CF.

And for Neville, her interstate truckie husband, there is a poignant song called My love he drives the Nullabor.

You can hear all Wendy’s songs at www.reverbnation.com/wendywood/songs
My name is Danielle Eveleigh, I am 29 years old and mother to a seven month old beautiful baby boy who I was lucky enough to carry full term and deliver naturally. I also have cystic fibrosis (Delta508, G551S). Four years ago my life was very different to how it is now and this is my story.

I was diagnosed with cystic fibrosis when I was 14 years old. The signs were ‘missed’ at birth and throughout my childhood, despite always being treated for chest infections, asthma, pneumonia, and this resulted in significant damage to my lungs. After the formal diagnosis, I was admitted to hospital due to infections at least six times a year, for two to three weeks at a time. This cycle became a normal way of life for me from the ages of 15 to 25 years.

In the lead up to my 25th birthday, my lung function was at 35% and I weighed 50kg. There were no signs of improvement in my condition. My medical team commenced the process to have me listed for a double lung transplant at St Vincent Hospital. This process took over eight months and in August 2013, I was formally listed. Three months of waiting went by; I was admitted to hospital for more antibiotic treatment during this time and my quality of life was diminishing. In November 2013, I received a call from the hospital who advised that they had a pair of lungs suitable for transplant. I was rushed to St Vincent’s to be prepared for surgery. At the last minute, the surgeons made the decision not to go ahead with the procedure given the condition of the donor lungs. I returned home and was later admitted to hospital once again for further antibiotic treatment.

While I was in hospital during this time my treating doctor, Professor Peter Wark advised that he had been successful in obtaining access to a new drug, Kalydeco, on ‘compassionate access’ and that I was a suitable candidate for it. Kalydeco at that time was valued at $300,000 per year and I was the only person in Australian with my gene type (G551S) to have access to this new drug. What a change it made to my life! Between November 2013 and the end of December 2013 my lung function improved significantly and I was officially taken off the transplant list. My lung function has now increased to a stable 55% - which it has been at for the last couple of years. Kalydeco has given me a quality of life and the opportunity to live happily with my partner and beautiful baby boy.

The day I found out I was pregnant was Mother’s Day in 2016. All I ever wanted was to become a mother and I could not believe that I had fallen pregnant naturally. Given my CF journey, motherhood was something that my partner and I thought would be a long process with fertility treatments etc. During pregnancy, I was monitored closely through the high risk Antenatal and Cystic Fibrosis team at the hospital. My lung function stayed the same (55%) and I was able to keep active throughout by going to the gym until I was 20 weeks pregnant. Dr Wark believed that I was capable of having a natural birth - and I did. Induced at 38 weeks pregnant, my baby boy was born on 16 December 2016 at 7.06pm.

Motherhood has been an incredible experience thus far. I still have to go clinic every four weeks for review, have nebulisers and physiotherapy twice a day and of course take Kalydeco. However, with the support of my partner, I am enjoying every minute of life with my little boy.
Vertex announced that these are the first data to demonstrate that it is possible to treat the underlying cause of CF in patients with these mutations, which are particularly difficult to treat.

Minimal function mutations are gene changes that leave the CFTR protein minimally functional or unable to function at all. Earlier studies showed that patients with these types of mutations are not responsive to treatment with Kalydeco (ivacaftor), tezacaftor, or the combination of the two.

Two Phase 2 trials studied tezacaftor and Kalydeco in combination with either VX-440 or VX-152, two investigational therapies that are next-generation correctors of the defective CFTR protein.

The trials showed that patients improved their lung function, as measured by percent predicted forced expiratory volume in 1 second (ppFEV1), and lowered the amount of chloride in their sweat, a measure of how well the CFTR protein works.

A Phase 1 clinical trial explored a triple combination with VX-659, which is another corrector. This study showed similar improvements in lung function and sweat chloride analyses.

The trials showed that all of the treatments were relatively safe, with the majority of adverse events being mild or moderate.

“These safety and efficacy data are clear and compelling, indicating significant potential benefit for people with CF from each of these three different triple combination regimens,” Jeffrey Chodakewitz, MD, executive vice president and chief medical officer at Vertex, said in a press release.

“We will be collecting and evaluating additional data from these and other studies and will make a decision on which regimen(s) to take forward into pivotal program(s), which we expect to begin in the first half of 2018,” Chodakewitz added.

Trials showed that all of the treatments were relatively safe, with the majority of adverse events being mild or moderate.

**VX-440**

The Phase 2 study (NCT02951182) is evaluating two doses of VX-440 — 200 mg and 600 mg every 12 hours — in combination with tezacaftor and Kalydeco. The trial includes adult patients who have either two F508del mutations or the F508del/Min combination of mutations.

Among 47 patients with minimal function mutations analyzed so far, the average lung function was found to be improved by about 10-12%. Meanwhile, the amount of chloride in patients’ sweat decreased, indicating improved activity of the CFTR protein.
Researchers noted both of these positive effects in both dose groups (200 and 600 mg). In contrast, those who received a placebo had no changes in these parameters during four weeks of treatment.

The treatment was also beneficial to 26 patients with two F508del mutations who were already receiving treatment with the tezacaftor-Kalydeco combo. These patients were randomized to receive either VX-440 or a placebo for four weeks.

Like the other patient group, the addition of VX-440 to the treatment plan improved lung function by 9.5%. It also significantly lowered sweat chloride levels.

**VX-152**

A second Phase 2 trial (NCT02951195) studied three doses of VX-152 — 100 mg, 200 mg, and 300 mg every 12 hours — together with tezacaftor and Kalydeco. Patients are adults with either two F508del mutations or a F508del/Min mutation combination.

In patients with F508del/Min mutations, two weeks of treatment allowed those in the lower dose group to improve by 5.6% on lung function tests, while those in the higher group improved by 9.7%. Sweat chloride levels also decreased in this study.

A similar result was observed in patients with two F508del mutations: 7.3% improvement in lung function and a decrease in sweat chloride levels.

**VX-659**

The Phase 1 study (NCT03029455) differs in design from the Phase 2 trials as it evaluates increasing doses of VX-659 alone and in triple combination with tezacaftor and Kalydeco in healthy volunteers. The trial also includes patients with the F508del/Min mutations.

As in the other studies, preliminary results showed an improvement of 9.6% in patients’ lung function after two weeks of treatment.

“Patients with minimal function mutations have been waiting for a medicine to treat the underlying cause of their disease, which makes these data, showing pronounced improvements in lung function particularly important,” said Steven M. Rowe, MD, co-chair of a steering committee of global CF experts who advise Vertex on the development of the triple combination treatments.

“It’s also encouraging to see that the addition of a next-generation corrector may lead to substantial additional benefits for patients with two copies of the F508del mutation, who were already receiving tezacaftor and ivacaftor,” added Rowe, who is also a professor of medicine, pediatrics, and cell developmental and integrative biology at the University of Alabama at Birmingham.

All three studies are still recruiting participants.

Melbourne was lucky enough to host the 12th Australasian Cystic Fibrosis Conference over four days in August. The conference ran in two parts – a Lay Conference for community members and a Medical Conference for health professionals.

The Lay Conference was an amazing opportunity for our community to come together, hear from local and international experts, and share ideas on the latest advances in cystic fibrosis (CF) research, care and drug development. In an effort to ensure as many people from our community could attend as possible, CFCC gave away 20 grants to our members to help with the cost of attending.

Don’t worry though, if you weren’t able to attend the conference, you have not missed out. Over 40 hours of footage from the conference – including many of the sessions - is available for viewing (for free!) at Consumer Connect [www.cf livesmatters.org.au/Consumer-Connect](http://www.cf livesmatters.org.au/Consumer-Connect) (you will just need to log in).

It was hard to choose a favourite session since there was so many, but here’s some of our highlights:

- Alexandra Quittner speaking about the impact CF can have on the mental health of someone who has CF, their family and support network and why it’s very important to look after everyone’s mental health.
- Cindy George talking about care partnerships that broaden CF care to not only include the person who has CF and the CF Care Team, but engage the whole community on what it is like to live with CF. She also spoke on how as a community we can help support people with their daily care. This included looking for more objective measures to refine people’s treatment plans and developing a toolbox of different strategies that people can use to suit their individual needs.
- The small group chat session for parents who have a child with CF that is pre-school aged or under – we shared stories and experiences, laughed, cried, and agreed to share contact details so we could continue to stay in contact with each other after the Conference.
- Meeting community members from across Australia and hearing their experiences both at the Conference and at the Lay Conference Dinner.

You may have heard that the 13th Australasian Cystic Fibrosis Conference will be held in Perth in August 2019. We are already looking forward to it!
I attended the 12th CF Conference in Melbourne and although it was very confronting in ways, it was also very enjoyable. I got to meet some wonderful people, and relax and chat at the dinner afterwards.

Lauren Rowe gave an inspiring (sad and funny) talk that was a highlight of the weekend for me.

The speakers talked about lots of promising new treatments and research and gave us hope that our children can now live longer and healthier lives.

Thanks to CFCC for their work and support.

— Barb Hilder (parent)

This was the first ACF Lay Conference I have attended and must say I was impressed by the broad range of presentations and level of speakers! However, my favourite two sessions were the Saturday lunch sub-groups and the presentation by Sonia and Shannon on Sunday.

It was great to learn more about the different aspects of and progress in CF. However, as a parent that’s still relatively new to CF, the biggest bonus of attending the conference was to build my network with other CF mums in an otherwise very isolating condition.

— Virginie Jost (parent)
Exercise and Adolescence

We all know that exercise is a key ingredient to health in cystic fibrosis (CF). It’s then very concerning that, throughout adolescence, the amount of exercise that kids do decreases significantly overall and this fact seems to be worse for girls than boys.

Encourage your kids to keep up, or increase, their exercise, sport and activities during their teenage years. Our advice on how to keep them active and learning? Participate in activities with them and start as early as possible. Get Dad involved! There is heaps of evidence that Dads have the ability to increase activity skills and participation rates in their children and that can only be a good thing.

Mums and Dads need to be exercising, not just to be good role models to their kids, but to manage their own health – physical and mental. Parenting when CF is involved is hard work and you need to be fit to manage it well. Grandparents, aunts, and uncles too. The more of us that get involved and exercise with our kids living with CF, the healthier and stronger our whole CF community will be.

For more information:
The DADEE (Dads and Daughters Exercising and Empowered) program in Newcastle (www.dadee.net.au) has been a world first, groundbreaking program to halt the decline of physical activity in girls and improve the father-daughter relationship.
CFCC Programs and Support Services

Thanks to our amazing and generous funders, donors, and community fundraisers we are able to provide a range of programs and services that support our members who have CF and their families in Victoria and New South Wales. We have highlighted a couple of these services below to give you an idea of what we offer. For a full list of our services, please visit the relevant website or contact us via the details below.

**New South Wales**

**Social Work:**
Members in NSW can access many services in the clinics, hospitals, face to face, by phone and Skype. Our most popular service is to assess each client and discuss their services and then to clarify what financial and other assistance the person with CF, their carer/s and family members may be eligible for. We point people in the right direction, make referrals, assist with forms, information and appeals. It can all be pretty overwhelming but we are there to help you make sense of it and get what you need where possible.

**VitABDECK subsidy:**
Members who have CF in NSW may be eligible to receive a discount on VitABDECK.

*For more information:*
P | 1800 650 614  
E | nswsupport@cfcc.org.au  
www.cysticfibrosis.org.au/nsw/services

**Victoria**

**Counselling Assistance Program:**
Members who have CF in Victoria may be eligible to receive a grant to subsidise the cost of seeing a psychologist or counselling service.

**20% Reimbursement Program:**
Members who have CF in Victoria may be eligible apply for a 20% reimbursement of some of their CF-related expenses.

*For more information:*
P | (03) 9686 1811  
E | support@cfcc.org.au  
www.cysticfibrosis.org.au/vic/member-services
There is a range of government supports and benefits that may be available to you to help with some of the costs of managing your, or your child’s, CF. We’ve listed some of them below...

**Medication expenses**

**Pharmaceutical Benefits Scheme (PBS) Safety Net**

*What it is:* If you (or your family) has spent a set amount (the PBS Safety Net threshold) on prescription medications, the price of medications are reduced for the rest of the calendar year.

*Eligibility:* Everyone

**Low Income Health Care Card**

*What it is:* Reduces the cost of health care, including through cheaper PBS medications. You may also get a discount on electricity, gas and water bills and motor vehicle registration.

*Eligibility:* Income must be below a threshold.

**Ex-Carer Allowance (Child) Health Care Card**

*What it is:* Reduces the cost of health care, including through cheaper PBS medications. You may also get a discount on electricity, gas and water bills and motor vehicle registration if the bills and Card are in the same name. You need to renew the Card each year.

*Eligibility:* You must be aged between 16 and 25 years of age, a full time student, and your parent or carer had a Carer Allowance Health Care Card for you on the day before you turned 16.

**Travel and transport**

**Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS)**

*What it is:* A reimbursement of some of the cost of travel and accommodation if you have to travel to access medical specialist services or specialist dental treatment.

*Eligibility:* You live in NSW and are more than 100km from, or travel more than 200km a week to access, medical specialist services or specialist dental treatment.

*More information:* Email nswsupport1@CFCC.org.au

**Victorian Patients Transport and Assistance Scheme (VPTAS)**

*What it is:* A reimbursement of some of the cost of travel and accommodation if you have to travel to access medical specialist services or specialist dental treatment.

*Eligibility:* You live in Victoria and travel more than 100km one way or an average of 500km a week for one or more weeks to access medical specialist services or specialist dental treatment.

**Mobility allowance**

*What it is:* Assistance with the cost of travel for work, study or volunteering when you can’t use public transport (or if there isn’t public transport near where you live) due to disability, illness or injury. If you get a mobility allowance, you will also get a health care card.
Eligibility: You are aged 16 years of age or older and have a medical report from your doctor confirming you can’t use public transport without substantial assistance because of disability, illness, or injury when traveling to and from home for paid work, voluntary work, study or training, or to look for work (hours spent on these must be above a minimum threshold). You may also be eligible if there isn’t public transport near where you live.

Income support

Disability Support Pension
What it is: Financial support through a regular payment when you are unable to work 15 hours or more a week as you have a permanent physical, intellectual or psychiatric condition.
Eligibility: You are aged 16 years of age or older and have a permanent and diagnosed disability or medical condition (a medical review is required to assess impairment), and meet the income and assets tests.

Sickness allowance
What it is: A payment if you temporarily can’t work or study because of an injury, illness or disability.
Eligibility: You are aged 22 years of age or older and have a job or are a full time student (and get ABSTUDY or Austudy), but temporarily can’t work or study because of an injury, illness or disability (a medical certificate from your doctor is needed), and meet the income and assets tests.

Carer support

Carer Supplement
What it is: An annual payment, paid in July, if you receive carer support such as the Carer Allowance and Carer Payment. It is in addition to the other payments.
Eligibility: There is no need to apply for the Carer Supplement. It will automatically be paid to you if you receive eligible carer support, such as the Carer Allowance and Carer Payment. You can get the supplement for each person you receive Carer Allowance for. Part time carers will receive a part rate of the Carer Supplement.

Carer Allowance
What it is: A fortnightly payment if you need to give additional daily care to someone who has a disability or serious illness or is frail aged.
Eligibility: You care for a child aged under 16 who has a disability or serious illness and lives with you (CF is on the Australian Government’s List of Recognised Disabilities). If caring for a person aged 16 years and older, you must provide constant care in the home of a person who has a severe disability or severe illness or is frail aged.

Carer Payment
What it is: A payment when you are unable to work in substantial paid employment because you provide full time daily care to someone with a severe medical condition, severe disability, or to someone who is frail aged.
Eligibility: You provide constant care in the home of a person that has a severe disability or severe illness or is aged. You must also meet the income and assets tests and not receive any another income support payment.

Bills and utilities

Essential Medical Equipment Payment
What it is: A payment to help with energy costs to run medical equipment, medically required heating or cooling.
Eligibility: You need heating, cooling or certain equipment for your medical needs, or the needs of the person you care for. To claim the payment you, or the person you care for, must have a Commonwealth Concession Card and pay the running costs of the equipment. A medical certificate is required. Some of the eligible equipment includes a parenteral or enteral feeding device, oxygen concentrators, nebulisers (used daily), and positive airways pressure devices.

Other

National Disability Insurance Scheme (NDIS)
What it is: An individualised support plan for people with a permanent and significant disability. The types of things the NDIS may support include assistance with daily personal activities, transport to participate in daily activities, help with household tasks, home modification design and construction, mobility equipment, and vehicle modifications. There is also Early Intervention support for children aged under 6 years.
Eligibility: You must have an impairment or condition that is likely to be permanent; your impairment substantially reduces your ability to participate effectively in activities or perform tasks or actions unless you have assistance from other people, assistive technology or equipment; and your impairment affects your capacity social and economic participation.

To find out more about any of these concessions and benefits, see more options, or if you would like to let us know of others we may have missed off our list please visit our websites at www.cfbuzz.org or www.cysticfibrosis.org.au/vic/concessions-benefits, or contact your services team; Victoria: support@cfcc.org.au or (03) 9686 1811, NSW: nswsupport@cfcc.org.au or 1800 650 614.
Anne Banitskas, Teacher

I met Jo in November 2016 at Dawson Street Preschool during enrolment day.

Jo explained how nervous and worried she was to send Eli to preschool, as this was his first time away from home. Jo was also concerned about how we would support Eli into the program, as he has cystic fibrosis. I asked Jo to write down the main things she wanted me to know about cystic fibrosis in relation to her child. We continued to talk for a while and then Jo said, “I’m feeling more relaxed now about sending him to preschool.” I also did a home visit where Jo showed me how she gave his medication (Creon) before meals, which she mixes with apple puree. Jo was amazing as she helped to educate and support me whilst I learned about CF.

I applied for, and was successful in securing funding for an additional assistant as part of the educator team who helps me to support Eli. I also contacted Cystic Fibrosis Community Care prior to Eli starting preschool to gain further knowledge and confidence so that we could support Eli into the service and attended CF training at the Royal Children’s Hospital too. In Term 1 we completed a risk assessment and communication plan for Eli too.

In order to support Eli’s inclusion into the program, I have taken into account the following:

When planning activities: To avoid water contamination, wet sand and mud as Eli is highly susceptible to infections.

Alternative activities: Playing with delta sand, providing fresh water for water play every 30 minutes, ensuring Eli washes his hands afterwards and making sure he is well hydrated especially during the warmer weather as he can become lethargic and/or require a salty snack/rest.

Most of my planning has been developed through ongoing collaboration with the family. We are both engaged in shared decision making, with respect and value to each other’s knowledge and experience.

Jo Farah, Mother

I first met Anne in December last year at kinder enrolment day. What was supposed to be a straightforward enrolment process, had me extremely nervous because I now had to somewhat handover the care of my child to someone I had never met.

Anne is very open to learning about CF and listening to my concerns and I am honest and upfront about the issues that may arise with Eli. For example, he could suddenly feel unwell at kinder, have a sore tummy, not eat well, be lethargic/tired or worried about a procedure at hospital (which he gets very anxious about). If I come to Anne and let her know what is going on with him, she is better prepared with how to deal with it in the classroom. At the beginning of the year, Anne also attended a training day for teachers at the Royal Children’s Hospital that really helped her get a better understanding of CF.

Anne and I try to identify any concerns or issues we might possibly have and immediately put a plan in place. For example, we found it helps keep a jar of Creon (enzymes) and a stack of apple puree for her to mix the granules at the center. This saves me the worry of having to bring enzymes and apple puree every morning. Anne also came up with the idea of having a chart with a list of foods and how many scoops of Creon he needs with each item. With me willing to be open about CF and Anne’s willingness to learn all she could, and all the support resources that are available, the step into kinder for Eli (and me!) wasn’t as bad as I thought it would be.

Anne Banitskas and Jo Farah work together to support Jo’s son Eli, who has CF. This is their story...
Ryan McCathie said the 13-week program, a collaboration with John Hunter Children’s Hospital and Cystic Fibrosis NSW, looked at whether high intensity interval training could benefit cystic fibrosis sufferers.

“We’ve seen some amazing results already,” he said.

“In the past, the general guidelines for people with cystic fibrosis were just ‘exercise for 30 minutes a day’, with the advice to do more slow, steady exercise.

“We’re doing interval training, so going at 100 per cent for a short period of time, then having a short rest period.”

Mr McCathie, of Hunter Rehabilitation and Health, said he monitored the participant’s oxygen levels throughout the sessions.

Cystic Fibrosis research project looks into interval training

“A lot of parents have felt a bit worried about pushing them to that extra level, but what it’s shown is that pushing them to that 100 per cent effort for a short period of time not only improves their fitness, but improves their airway clearance as well,” he said.

“Doing these intervals, they are finding it much easier to clear their lungs and cough up the mucus and phlegm.”

“Because it’s in a safe environment, we can really push them further than what they are used to.”

Lizzie Walters, 13, has been participating in the exercise project since it began.

She would love to be able to do cartwheels with her friends. Since building up her upper body strength through the program, it now seems possible.

Her mother, Joanne Walters, said her daughter’s fitness and self-confidence had improved, as well as her oxygen levels.

“She is fitter, she is stronger, she has more energy,” Ms Walters said.

“Even in school in PE, and things like that, she’s been happy to participate. She’s been able to do more physical exercise at school, and keep up with her friends a bit more without coughing as much.

“Her oxygen levels have been higher, and they are not dropping as much during exercise, or overnight.”

Mr McCathie said the program participants underwent clinical testing at John Hunter Children’s Hospital before the project to get baseline data. They would be re-tested at the end of the trial.

Those results would be complemented by functional fitness testing within the gym at different stages.

“At the six-week test we saw huge increases in all aspects - their strength, their endurance, across the board,” he said.

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A Night for CF

*A Night for CF* was once again a magical night to remember for the CF community in Victoria.

After being greeted at the door with a spectacular fire show, guests filled the room with a pleasant hum of frivolity. Amid drinks and laughter, people could be seen eyeing off the spectacular range of prizes available at this year’s silent auction, and when nobody was looking quickly popping a bid down. From cheese platters, to accommodation and travel packs, there was plenty to grab people’s interest. The wine wall, another big hit, featured over 150 generously donated wines from among Victoria’s top wineries. That’s 50 more than last year!

Keegan Bakker (Keegs), our newest ambassador once again kept the evening flowing smoothly, introducing our CEO Karin to speak, followed closely by our generous sponsor the East Malvern Community Bank Branch of Bendigo Bank.

Then it was time to kick things up a notch at the live auction where some fierce competition saw friends turn to rivals as they tried to outbid each other for the exciting prizes on offer. Antarctica Flights generously donated a flight package for two, which brought the auction to a roaring crescendo.

Leaving no time for the dust to settle, the Baker Boys once again turned up the heat and got the crowd moving on the dance floor! Finally, when all was said and done, people got some great mementos of the night at our complimentary photo booth!

Thank you to everyone who came to this fantastic night, we had an absolute ball with all of you and have already started our planning for next year! If you are interested in getting a table together for *A Night for CF* 2018, email events@cfcc.org.au.
Great Strides 2017

It's time to get your stride on! Registration is now open for Great Strides 2017.

That's right, everyone's favourite fun run is back in 2017. Join nearly 2,000 people across Victoria by participating in our one of our biggest annual community events, Great Strides.

This year you can ‘stride’ in either Bendigo or Melbourne with both locations planning a festival of activities around the races.

Get a team together and get involved.

You can walk it, you can run it, but whatever you do... don’t skip it! www.greatstrides.com.au

Bendigo

Sunday, 22 October 2017
Lake Weeroona, Bendigo
3km or 6km

Melbourne

Sunday, 29 October 2017
Tan Track, Royal Botanical Gardens
4km or 8km
65k 4 65 Roses Walkathon 2018

Walking 65K is tough, but living with an incurable and life-shortening illness is tougher.

The 65K 4 65 Roses Walkathon was first held in 2008 as a community fundraising event for Cystic Fibrosis NSW. In the nine years since its inception over $1,250,000 has been raised for Cystic Fibrosis NSW and the Children’s Hospital Westmead.

Every year this events grows larger than the one before. In 2017, it raised $463,553 and attracted over 1100 participants. In 2018, we hope to raise $500,000 and attract over 1300 participants.

The 2018 65K 4 65 Roses Walkathon will take place on Saturday 24th February around the famous ‘Bay Run’ spanning the foreshore of Drummoyne, Five Dock, Leichhardt and Rozelle.

For more information please contact Stephen in NSW on (03) 8732 5700.
In its current form, the Barefoot Ball is a highlight on the CFCC calendar. Joining the Newport Kinghorn Racing Surf Academy, CFCC presents a very unique event in one of the premier locations in Sydney. The best part is... it is on the sand!

Just take our review of the 2017 Barefoot Ball from attendee Kate;

“We watched the sun go down over the ocean and wriggled our toes in the sand, while being treated to some fine wine and dining. The entertainment was fabulous too! After dancing away to a big band in the Ball Room, a large group of us then moved to the retro disco at Studio 54, boogying away until the early hours of the morning. The fact that we raised much-needed funds for ground breaking research and important services for families living with the daily challenges of CF makes this night great fun for a wonderful cause”.

Guests can expect an extraordinary night at the 2018 Barefoot Ball. We guarantee it.

For more information on the 2018 Barefoot Ball please contact Stephen in NSW on (03) 8732 5700.
A Community that Cares

CFCC would like to thank the following community fundraisers who have supported them so far this year, raising much needed awareness and funds!

• Frank Jennings for collecting $500.00 worth of donations at his local Soccer Club
• A big thank you to Ellie-May, Clare, Lucy and Holly who held a 'Bits and Bobs' stall at Torquay IGA where they sold wonderful homemade crafts and merchandise. Altogether they raised $401.85 for CFCC
• The students and teachers at Nungurner Primary School for raising $23.00 on their Wear Red Day
• Thank you to Samantha's Childcare & Kindergarten for selecting CFCC as their charity of choice in May and donating $55.50
• LJ Hooker Mooroolbark for holding a sausage sizzle which raised $550.00
• The staff at Hugo Boss Australia who held an internal samples sale that raised $6,071.25
• The students at Lilydale High who raised $227.05 from merchandise sales and tin rattling in 65 Roses Month
• Thank you Swan Hill Women in Racing for raising $327.00 at the Swan Hill June Racing Carnival
• Country Racing Victoria donated $355.94 from the horse For65Roses placing 2nd in its race
• The students at Alkira Secondary College dressed in their favourite footy colours and raised $427.90
• Mariella Kennedy auctioned off her hand-made yarn storage unit online and raised $22.50
• Thank you and congratulations to Paul Kenny, Hamish Watson and Laura Shellie who ran the half marathon at Run Melbourne. Collectively they raised $2,429.84
• The Greives Family for organising a CF Lung Function and raising $3,363.00
• Thank you to the students and teachers at Loreto College for raising $500.60 at their cake stall and sausage sizzle
• Heather Griggs for hosting a Bring & Buy event which raised $1,229.30
• Sandi Warren for coordinating the Family Fun Day on the Green where $16,933.00 was raised to support those living with CF
• Thank you Free 2 Travel who hosted a charity day on 65 Roses Day
• Sarkis Azar and Startrack Courier for raising $626.50 at their Greenacre - Breakfast BBQ
• Gail Brady and Office Work's Call Centre who organised a charity day and raised $620.00
• The Roads & Maritime Services NSW who hosted a luncheon and raised $243.00
• Patricia Ingram and the Wagga Wagga Marketplace Management for wrapping Mother’s Day gifts and raising money on 65 Roses Day. Their grand total was $2,940.00
• A big thank you to Peter Castles and the Wagga Wagga Community for helping to raise $2,194.75 on 65 Roses Day
• Thank you Aimee McLaughlan for raising $200.00 through your Mini Photo Sessions
CF Superheroes, we need you! It takes a community to care for CF and so we are calling on you, our valued community members to come to the rescue.

If you like to host, organise activities or enjoy a creative challenge then why not host your own fundraising event. You, your group or your club can fundraise any way you like. It is ok if you are not into hosting, simply participate in an organised event such as Colour Run or Tough Mudder!

For more ideas please contact events@cfcc.org.au (VIC) or communityfr@cfcc.org.au (NSW).

- Congratulations Will Dempsey and Tom Macken for completing the Canberra Marathon and raising $8,796
- Thank you Sou’Westers Group for their constant fundraising efforts. So far, they have raised an extraordinary $10,962.90!
- Peter and Jennifer May for their outstanding efforts during the Bowral Classic
- Thank you to the Goulburn CF Group for both their ongoing support and for raising $3,800.00
- Terry Green and the Tuncurry Bowling Club for donating $1,105.00 from their fundraising efforts
- Samantha Scales who raised $175.00 on 65 Roses Day
- Patricia Ingram who raised $1,190.00 through her Quilt Raffle
- Thank you Sue O’Donnell and the Department of Human Services Centrelink (NSW) for raising $150.00 on 65 Roses Day
- The student and teachers at Red Bend Catholic College for raising $440.25 through merchandise sales
- Cee Egan and his 65 yarn bomb roses raising $553.59
- All our Rise n Grind Cafes: Café One9, Rockpool Café, Tarn’s Cakes & Café, Michel’s Patisserie – Warners Bay, Quotes Café, Coal Loader Café, The Quick Brown Fox Lismore, The 2093 Postcode Project – Manly Vale & Garden Street Cafe

Are you The hero we need?

CF Superheroes, we need you! It takes a community to care for CF and so we are calling on you, our valued community members to come to the rescue.

If you like to host, organise activities or enjoy a creative challenge then why not host your own fundraising event. You, your group or your club can fundraise any way you like.

It is ok if you are not into hosting, simply participate in an organised event such as Colour Run or Tough Mudder!

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Meet our new staff

Ashleigh Bevan - Administration and Finance Coordinator (NSW)
Ashleigh has come to CFCC with a wealth of experience in administration, logistics and project management. Having served nine years in the Australian Army as an Officer, Ashleigh brings a unique perspective to our team. Ashleigh has led and participated in many fundraising events and campaigns for various charities. In 2016, Ashleigh managed a project for a feature film titled, ‘Charlotte’, which was released on the 1 May 2017. It has gone on to receive official selections and award nominations in international film festivals and won the award for Best Feature Film at the 2017 South Australian Screen Awards. Ashleigh is very happy to be a part of our team and is looking forward to continuing her career path in the not-for-profit sector.

Jessica Brien – Project Coordinator (VIC)
Jessica has come to CFCC with many years’ experience running the Stephanie Alexander Kitchen Garden Program – an Australia wide health promotion program in schools. She has been at the forefront of establishing this program in a school to the point of seeing its effective implementation and growth. Jessica’s background is in Health Sciences; however, she also has a post-graduate degree in Public Health Nutrition and a published article in the Early Childhood Journal of Australia. Having previously had work experience with the Coeliac Society of Victoria and Tasmania, she is very excited to further her work in the not-for-profit community sector. Jessica is looking forward to furthering CFCC’s work in coordinating the peer support program and carrier-screening project. In her spare time, Jessica loves following her favourite Essendon Football Club, swimming, watching the tennis and cooking up a storm.

Renae Ward – Social Worker (Newcastle – NSW)
Renae comes to us as a social worker, with case management and research experience in the hospital sector in Newcastle and Sydney. Since graduating with a Bachelor of Social Work in 2008, her employment has allowed her to pursue her passion of providing support and advocacy to clients and families. She also has previous qualifications in childcare, supporting children and families in Europe and Australia. Renae is enjoying working in the Hunter Region CFCC Newcastle office and looking forward to forging positive relationships with existing clients and the CF community as a whole. In her spare time she enjoys being with her busy family with three children, loves reading and has recently taking up bike riding after many years.

Tessa Sanders – Administration and Volunteer Coordinator (VIC)
Tessa comes to us fresh out of university with a background in marketing and events management. Having recently moved to Melbourne from Sydney, Tessa is full of enthusiasm and new ideas. She is excited to learn as much as she can in her new role and brings with her volunteer management experience that she cannot wait to demonstrate. Tessa aims to step-up the volunteer and speaker program and is looking forward to building positive relationships with CFCC’s new and existing volunteers. In her free time, Tessa enjoys cooking delicious meals with her housemates, going for long weekend runs and trawling through Melbourne’s vintage markets.
Volunteer’s Corner

It has been a busy few weeks for our volunteers! Between wrapping wine for the Ball, folding Christmas cards, talking to community groups and other various jobs, it has been all hands on deck.

If you have not had a chance to sink your teeth into some volunteering lately, do not despair! Great Strides Melbourne is just around the corner. This event is a volunteering extravaganza in which we will require over 100 volunteers to ensure the event goes smoothly and to cheer on the runners and walkers as they make their way around the track.

We are also excited to announce that CFCC Victoria will be having a Bunnings Sausage Sizzle on December 2. We will need expert barbeque masters to step up and volunteer their time to ensure our sausage sizzle is the best Bunnings has ever seen! More information on this coming soon.

As always, we love to hear your ideas and feedback! Drop an email to our Volunteer Coordinator (VIC), Tessa at admin@cfcc.org.au or call on (03) 9886 1811. If you are interested in volunteering in NSW, please apply here cysticfibrosis.org.au/nsw/volunteer_registration

Thank you all for your ongoing support! Keep your eyes peeled for more volunteer opportunities as they arise.

The Tobin Brothers Foundation

and their personal connection to our cause

Established in 1984 to mark the company’s 50th anniversary, the Tobin Brothers Foundation makes annual grants to organisations and individuals whose work can be shown to have meaningful ‘community benefit’.

Since its establishment, the Foundation has made over 288 separate monetary awards totalling almost $500,000. Last year The Tobin Brothers Foundation made a $2,500 grant to Cystic Fibrosis Victoria. This one had an extra special meaning for the Foundation Trustee Michael Tobin as cystic fibrosis is a cause, which has recently, became close to his heart.

Connor Barrett was born in July 2015 in Western Australia and not long after diagnosed with CF. Connor is the grandson of Michael’s colleague and friend Errol Barrett. Both are funeral directors who trained together in Melbourne five decades ago and stayed in close contact ever since. Whilst the Tobin Brothers Foundation had been a long-time supporter of CFV, Connor’s diagnosis gave the most recent grant even more meaning.

“When you know someone personally with the disease and see how it impacts on their loved ones, it’s rewarding to be able to help in a small way,” Michael said. “The cystic fibrosis community across Australia seem to be a very hardworking and passionate group and I hope that will help ensure Connor and all those with the disease live longer and more enjoyable lives into the future.”

A big thank you to Michael Tobin and the generosity of The Tobin Brothers Foundation.

In Memoriam

We pay tribute to the lives of the following Victorians with who have recently passed away:

Stephanie Dundas

CFCC is grateful for donations received in their memory.
Biggar View

By Susan Biggar

I woke early in my hotel room in Sydney, maybe stirred by an internal warning mechanism. Rolling over, I instinctively grabbed my phone—and, as a sign of my age, reading glasses—glancing at the screen. There were a number of messages and several missed calls. But one text, from my brother-in-law, jumped at me. ‘Aidan’s in Stanford hospital. Please call.’

Aidan is my 21-year-old son who is partway through a four-year degree in California. And he has CF.

Rewinding the clock to March 2014, I was with Aidan when he heard he had been accepted to study at his university of choice in the US. It was a momentous occasion for him. But I remember several friends saying to me at the time, ‘I would never let my child live overseas, particularly not with a health issue.’ Was it even my decision to ‘let him go’? At 18, legally and hopefully emotionally, he was ready to be in the driver’s seat, and his dad and I were to become support crew (hopefully not backseat drivers).

This sounds so rational and straightforward, but as all parents know, the transition to adulthood can be thorny and stop-again, start-again. From the sandpit onwards, our kids are taking steps towards independence. Transition is also a long, gradual process for parents, and it may require slowly peeling parental fingers off of the steering wheel; a wheel that CF might give us plenty of reason to cling to tightly.

Aidan is my 21-year-old son who is partway through a four-year degree in California. And he has CF.

If you’re a parent, you may have learned through heartache and tough times in the ED or on the ward that a highly vigilant parent is essential. Like the time you noticed that a drug had been forgotten or the wrong dose was about to be administered. Or when you had to go to bat for a particular approach to IV insertion. We all learn to be pushy and determined and forthright—hopefully in the nicest possible way—about what our children need. So how can we be expected to suddenly abandon ship and stand down on the watch? ‘How will my child manage?’ we ask ourselves. Though maybe the real question is ‘How will we manage?’

Yes, yes, we know about the importance of transition in CF as it has been drilled into us since our babies were, well, babies. We know they need to pass the meds test, have 1-on-1 time with their doctor, and self-motivate on physio. We know the importance of teaching strong self-management and advocacy skills to our kids. But, as a mum who may hold the Australian record for most-questions-asked-in-an-appointment, I wasn’t completely confident about passing the torch to my offspring.

Then Aidan boarded a plane to California. And he managed. He learned to order (and pick up) his meds, to attend appointments (on time), to do physio (er, sometimes…), to do extraordinary amounts of exercise, to eat enough (though never before 8am and often after midnight), to take a friend (or girlfriend) to appointments and to ask questions and even disagree (respectfully) with his medical team.

Nine months later, when he had a major health scare, I offered to fly out. ‘No thanks, Mum,’ he said, ‘I’ve got this.’ And I realised that he did have it. Honestly, though I wanted to be there for me, to ease my own stress and worry, I didn’t think my presence would add value. Plus, it might have robbed him of his hard-earned confidence and independence.

Two months ago, Aidan had emergency surgery while at university. My first instinct, again, was to book a flight. Initially he said no, but then changed his mind, welcoming my involvement. Let’s just say I didn’t need to be asked twice. I know he was grateful for my support in his recovery and I think I was helpful.

I wonder if that’s a good test: Do I want to be there for him or for me? There will be times when our recently-turned-adults really want or need us at the bedside or clinic, but it’s their call, isn’t it? We may not eliminate those harrowing middle-of-the-night calls, but hopefully we can have confidence that their health is in good hands: their own.

Susan Biggar is a Melbourne writer. Married to Darryl, they have three children, two of whom have CF.
Hi Emily,

thank you for your letter. The first thing I would like to say is that feeling down or frustrated about your circumstances doesn’t always mean that you are not resilient. It is absolutely normal and expected to experience some really tough times emotionally when you are managing the relentless demands of a chronic illness.

Your question has however raised the importance of resilience when facing the challenges that having Cystic Fibrosis can bring.

The resilience of an object is defined as its ability to ‘spring back into shape after bending, stretching, or being compressed’. So how do we find our shape again after all the ways that life with chronic illness can pull us taut?

In my experience as a parent of 2 children with CF, as a person living with Type 1 Diabetes, and as a psychologist, these are some of the ingredients that I believe to be useful in the recipe for resilience:

1. **Support**: The connections that you have with others and enlisting their support during difficult times is so important. Sometimes it may not be in our nature to ask for help so it may feel unfamiliar or uncomfortable, but the support of others can provide a crucial step towards our return to an equilibrium in unsettled times. This support can come in many forms, it can be practical or emotional. It can be as simple as just reaching out to someone and sharing that you are having a tough time.

2. **Self-care**: Looking after yourself both physically and emotionally is vital when managing a chronic illness or being the carer of an individual with a chronic illness. It’s important to first know what your recipe for self-care is. This requires an awareness of what activities tend to boost or drain your energy levels. It can help to view your energy like a fuel tank. Check in with those fuel levels, it can be practical or emotional. It can be as simple as just reaching out to someone and sharing that you are having a tough time.

3. **Self-efficacy**: This essentially involves believing in your ability to accomplish a task and achieve a favourable outcome. The ability to effect change.

4. **Permission for emotions**: Sometimes there is a misconception that being resilient means not being upset, or that feeling bad means you aren’t ‘coping’. Having the ability to both acknowledge and express the emotions that are likely to arise when managing a chronic illness is in fact part of being resilient. This is not liking how you feel, but accepting (rather than fighting) how you feel which in turn can ease those emotions. Sometimes there are feelings akin to grief and loss, or there is an anger or frustration around the relentless nature of chronic illness management. All of these emotions make sense in the context of your experience and it is ok to feel this way.

5. **Mindfulness**: A helpful tool in managing the ongoing impact of a chronic illness and building resilience is mindfulness. In a nutshell, mindfulness is about shifting your attention from the thoughts that consistently spin around in your mind to the present moment that you are living in. It also encourages taking an observing and non-judgemental view of yourself and (as mentioned previously) giving some space to acknowledge and express emotions as they arise. A really helpful app that can introduce you to some mindfulness strategies is The Smiling Mind.

These are just a few tips in building resilience, you might find that you have others? Just consider what you might already do that helps you to ‘bounce back’ from tough periods and that will be part of your recipe for resilience.

Resilience is ultimately about flexibility and the capacity to recover in difficult conditions. I suspect that in your journey of living with CF you will find many instances that prove your resilience already.

I love this quote from Nelson Mandela that I feel sums up resilience:

“Do not judge me by my successes, judge me by how many times I fell down and got back up again”

Kirsty is a practicing psychologist and mother of two children, both with CF.
A Word From Lauren

By Lauren Rowe

When I was born in 1990 my parents were told that because the CF gene was discovered the year before, that there would be a cure for me in 5 years’ time. 27 years later and I am not cured, but I am still here and cannot help but see some great comparisons of being a CF kid back then to what it’s like now. I give you my top 10 comparisons.

1. No Internet connection.

There was no such thing as the internet in the 90s. If someone wanted to learn what CF was there was no quick search in Google, but a trip to the local library to search through books. There certainly wasn’t any such thing like YouTube or Facebook to pass the time and connect with friends in hospital.

2. What cross infection?

In the early 90s the risk of cross infection between CF patients was unknown. CF friendships would form at CF camp, clinic and hospital stays. Everyone was clumped together no matter what bug they were carrying. When in hospital, all CF patients and their siblings had access to a buffet lunch and dinner (no tray service), with every dinner consisting of sausages, mushy peas, sausage rolls and party pies. Every. Single. Night.

3. Hospital entertainment.

The hospital entertainment consisted of a huge starlight stand on wheels consisting of a tiny TV screen, VHS player and Nintendo 64. There was only two for the whole ward, so they had to be booked in by the nurses for use. Play therapists were unheard of, so you would have to provide your own fun.

4. Expensive hospital carparks.

In the 90s hospital car parks where so expensive – actually never mind… Some things haven’t changed.

5. Life expectancy.

Being a kid with CF today comes with a greater hope of living to an even longer age than we had in the 90s when the life expectancy was only 20-30 years.


In the early 90s there were zero carer facilities for parents who wanted to stay with their children. As no beds were available, my parents would take turns in sleeping on a hard chair next to my bed.

7. No phones.

If you wanted to make a phone call in the hospital in the early 90s you would have to go downstairs to a communal pay phone. When I did get a phone in my room at 8 years of age, I would have to purchase a confusing phone card and enter lots of digits before the call connected. I got my first mobile when I was 14 years of age and each message would take 20c of prepaid credit.
8. Physio.

While there have been great advancements in physio over the years, the only options available in the early 90s were percussion and exercise. We would have an extremely heavy physio table with steel legs to lug around the house - but it did make a great table for punch and food at parties.


Organ transplant was not even talked about, or at least rarely done when I was a kid. It was a very new and somewhat confronting treatment for CF adults.

10. Smoking.

In the 90s smoking was much more acceptable than it is today. When I was firstborn my parents had to put up a ‘no smoking sign’ on the front door so nobody would light up inside the house. So while there is still no cure 27 years on, it is good to see there has been some change within the CF world!

To hear more great stories from Lauren, please subscribe to her YouTube channel at www.youtube.com/c/giftedlife.
UPCOMING EVENTS

› Vandermade Charity Golf Day (NSW)
   WHERE: Cabramatta Golf Club
   WHEN: 20 October

› Great Strides (VIC)
   WHERE: Lake Weeroona, Bendigo
   WHEN: 22 October

› Express Glass/B&D Charity Golf Day (NSW)
   WHERE: Moore Park Golf Club
   WHEN: 27 October

› Great Strides (VIC)
   WHERE: The Tan Track, Melbourne
   WHEN: 29 October

› Central Coast Charity Golf Day (NSW)
   WHERE: Kooindah Waters Golf & Spa Resort
   WHEN: 10 November

› Traralgon Area Support Dinner (VIC)
   WHEN: 14 November

› South East Metro Area Support Dinner (VIC)
   WHEN: 29 November

Please note these dates were correct at the time of printing but are subject to change