

SUMMER 2019

A MAGAZINE FOR KIDS WHO HAVE CF AND THEIR SIBLINGS

# ROZEE

Why do I have to do Physio?

A day in the life of Dylan

Adventuring With CF

Meet Cara & Isla

Learning to relax

Camp Kulin 2018

Go Red for CF



CYSTIC  
FIBROSIS  
Western Australia

ALL  
AWESOME!

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**ON THE FRONT COVER:**

Holly with sister Jamilla and her  
mum and dad at Uluru

**PRINTED BY:**

Picton Press

🖱 [pictonpress.com.au](http://pictonpress.com.au)

**DESIGN:**

Function Creative

🖱 [functioncreative.com.au](http://functioncreative.com.au)



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# Editor's Letter

Welcome to the 7th edition of  
Rozee magazine!

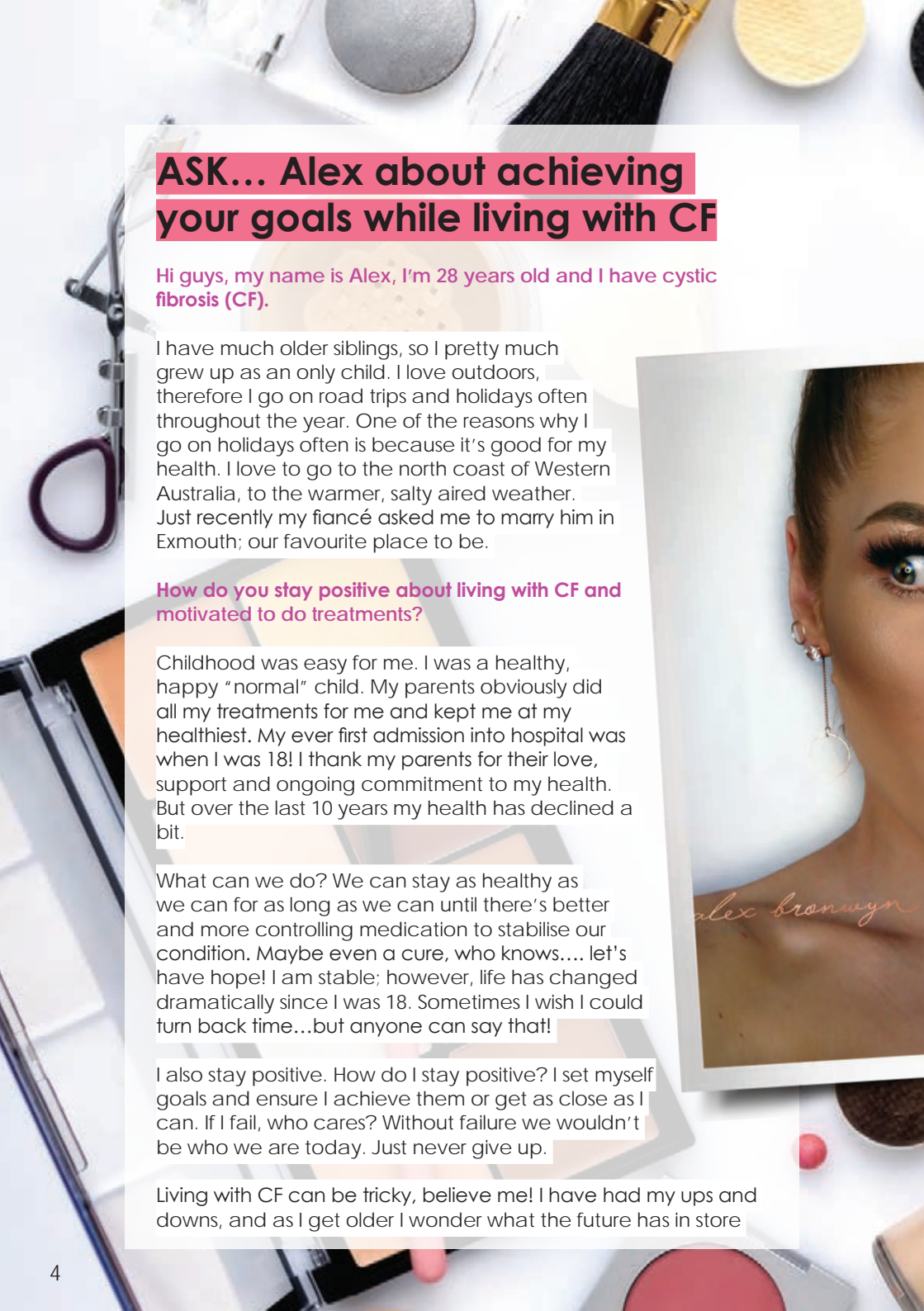
In this edition we hear from Alex, an adult with CF, who shares how she achieved her dream of being a make-up artist and how she juggles CF with work. We also learn all about the importance of physio and the different kinds of physio that kids do. We share some relaxation techniques that might help you stay calm during medical tests and how to talk about your worries with someone you trust.

We hear lots of great stories from kids with CF and their siblings, including interviews with sisters Cara and Isla, a 'Day in the Life of' Dylan, Holly's adventures through the Northern Territory, Kiah's first admission at PCH and Toby sharing a bit about his physio routine.

There's lots of fun stuff too, like learning to make slime, a recipe for pizza buns, puzzles, jokes and games!

Bye for now,  
Gillian and Natalie

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## ASK... Alex about achieving your goals while living with CF

Hi guys, my name is Alex, I'm 28 years old and I have cystic fibrosis (CF).

I have much older siblings, so I pretty much grew up as an only child. I love outdoors, therefore I go on road trips and holidays often throughout the year. One of the reasons why I go on holidays often is because it's good for my health. I love to go to the north coast of Western Australia, to the warmer, salty aired weather. Just recently my fiancé asked me to marry him in Exmouth; our favourite place to be.

**How do you stay positive about living with CF and motivated to do treatments?**

Childhood was easy for me. I was a healthy, happy "normal" child. My parents obviously did all my treatments for me and kept me at my healthiest. My ever first admission into hospital was when I was 18! I thank my parents for their love, support and ongoing commitment to my health. But over the last 10 years my health has declined a bit.

What can we do? We can stay as healthy as we can for as long as we can until there's better and more controlling medication to stabilise our condition. Maybe even a cure, who knows.... let's have hope! I am stable; however, life has changed dramatically since I was 18. Sometimes I wish I could turn back time...but anyone can say that!


I also stay positive. How do I stay positive? I set myself goals and ensure I achieve them or get as close as I can. If I fail, who cares? Without failure we wouldn't be who we are today. Just never give up.

Living with CF can be tricky, believe me! I have had my ups and downs, and as I get older I wonder what the future has in store



*alex bronwyn*



A close-up photograph of a woman's face. She is holding a blue inhaler to her nose with her right hand. The inhaler has a white label with the word 'SMOL' and some smaller text. She has red lipstick on and is looking towards the camera. The background is slightly blurred, showing some makeup products.

for me. All I know is that I have a supportive and loving family and fiancé, and that they are there for me no matter what.

**Can you tell us about how you achieved your dream job as a makeup artist? And how you manage CF and work?**

I had always wanted my own business but never knew what. After many years of trying different things and studying; personal training, massage therapy, hairdressing, accounting, bookkeeping and the list goes on, I finally found my niche; makeup!

It started as a hobby three years ago and I've now turned it into a part time/casual business as a professional freelance makeup artist and social media influencer. This means I use my large following on social media (Instagram) to show my audience my makeup work and also share what it's like living with CF, with the hope to raise awareness. With such a supportive audience, it keeps me motivated and driven to stay healthy and work towards my goals.

Deciding to quit my office job and do only makeup was a challenge. But, the best decision I have ever made! I couldn't be happier. I have freedom. And freedom makes me less stressed which gives me a little more quality of life, which is a necessity living with CF. I worked smarter, not harder, to get where I am today, and by concentrating on that I am successful. I am so proud of what I have achieved. Anyone can do this. It's your choice to never give up. Because I have the freedom, I am able to manage my CF well! I can do my treatments when I need to and have the time off to recuperate when I need to. This is so important too, to ensure

that you keep on top of your treatments. AND because I share that I have CF with my clients and social media followers, they all understand what I am going through, and are so supportive.

# A DAY IN THE LIFE of...



Hi, my name is Dylan and I'm nine years old. My family includes me, my mum Karen, my dad Alan, my brother Ben and our dog Gizmo.

My hobbies include playing soccer, tennis and running, as well as playing on the PlayStation and pranking my brother!

A standard Tuesday for me looks a bit like this...



**PEP- Five sets of 20**  
(if unwell mum makes me do a couple more).



**Morning fitness**, which is running around the oval.  
(Today I did it seven times.)



**Breakfast.** I also take my inhalers, nasal spray and lots of tablets.



**Classroom work** and I also eat my brain food (veg and fruit).



**I leave for school** with my brother and we usually take our scooters.



**Recess time.** I eat crackers and cheese, a muesli bar, and take Creon, and if it's warm I'll also take a salt tablet. Then I go play games with my friends.



**School starts**, organise for the day.



**More classroom work.**

# DYLAN



**Lunch time.** Usually a ham and cheese sandwich, apple juice and sometimes popcorn, and I have my Creon too.



Tonight I have **soccer training**.



## STEM

(Science, Technology, Engineering and Maths).



**Dinner**, inhalers and lots of tablets.



**Scoot home** with my brother. Have a treat, fruit and some rice crackers with my Creon and salt.



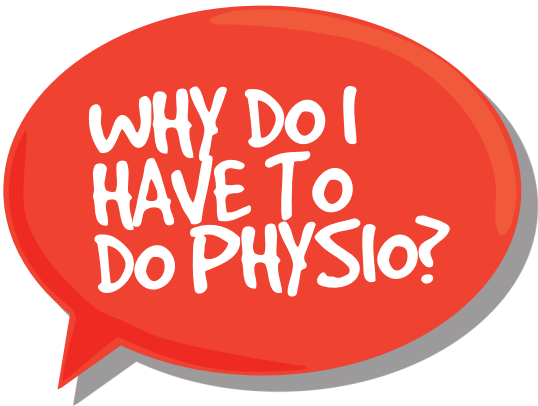
**Shower**, homework and nebuliser.



**More physio.** Either three or five sets depending on how well I am.



**Read in bed.**  
Then Zzzzzz



## WHY DO I HAVE TO DO PHYSIO?

When you have CF, physiotherapy, or physio for short, is something you have to do every day to help keep you healthy. Everyone has mucus in their body. Mucus is a thick liquid that is made by some parts of your body, like your nose and lungs. People will often get lots of mucus when they have a cold. Mucus has a very important job in the lungs, which is to clear germs and things like dust from the air to keep your lungs clean and healthy. If you have CF, your mucus is much thicker and stickier than normal, and physio is needed to help loosen and clear the mucus otherwise it can build up and cause problems with your lungs.

When you do physio, you might use huffing and coughing to clear the mucus. If you don't cough up mucus, that doesn't mean physio isn't working. Physio helps move the mucus from the small airways which is very important. This reduces the chance of infections and improves your lung function, meaning you will feel better. If you don't do physio the mucus will stay in your lungs and create a perfect breeding ground for germs and bacteria, which can make you feel quite sick.

There are different types of physio. You may have used some or all of these methods:

## Percussion

As a baby or small child, your parents and others, like maybe your grandparents or even a Homecare Worker, would do your physio, using percussion or 'pats' on your back and chest.

As you get older the technique you use changes so that you can start to do physio by yourself and not need to rely on someone else.

## PEP

PEP stands for Positive Expiratory Pressure. You might do PEP through a PEP mask, mouthpiece, bubbles or a vibrating PEP, like a flutter. It works by breathing out against a resistor, which helps get air behind the mucus to push it up to your larger airways where you can clear it more easily.

## Huffing and Coughing

Huffing is a breathing technique that should be a part of all physio routines and you can even use it when you exercise. It helps to move mucus as well.

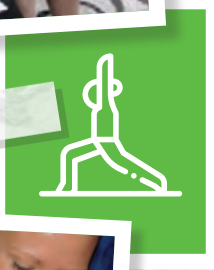
## Exercise

Is also a really important part of physio, it keeps your body fit and strong and helps to make you feel happier too!

Sometimes, despite all your hard work, you might get a drop in lung function or get a bug and have to go in to hospital for an admission. This doesn't mean you've failed. Unfortunately, sometimes these things are unavoidable.

It can help to know that you aren't alone. In WA there are over 200 children with CF. They all need to do their physio everyday too.





## Toby Talks About His Physio Routine

Toby is 7 years old and shares a bit about his physio routine at home. Toby also has one of our homecare workers, Ishbel, come out and help him with physio a couple of times a week.





## What kind of physio do you do Toby?



I do Ventolin then Hypertonic Saline for 10 minutes. After a 5-minute break I do PEP. This is usually 3 sets of 20 breaths when I am well and 5 sets of 20 when I have a wet cough.



## How do you pass the time when you do physio?



I pass the time by watching Netflix or YouTube on my iPad. Sometimes I like to tease Ishbel (my Homecare Worker) hehehe.



## What do you do on days you don't feel like doing physio?



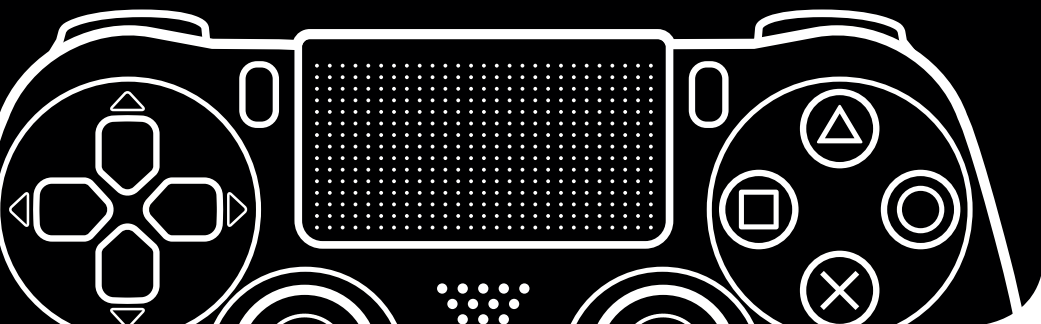
When I don't feel like doing physio, mum reminds me how much I need to do it, so I just do it. Sometimes I make deals with mum - if I do my physio properly I can get a treat at the shops or buy a new game for my Xbox.



## How do you feel after you've done physio?



After physio I feel annoyed because I have to wash all my physio gear. Sometimes I feel worse as physio loosens up mucus and then I cough more. But mostly I am relieved that it is done, and I can get on with my day.





# Kiah's

## First Admission at the New Children's Hospital!

**Perth Children's Hospital (PCH) has officially opened and we were able to have a chat with 13-year-old Kiah, who was one of the first cystic fibrosis (CF) patients to be admitted back in June.**



**How has your first admission at PCH been?**

Good. It's a lot prettier and brighter. I think everyone seems a lot happier.

**What can you tell us about the hospital?**

There are so many cool things around the place. Like the sensory lights on level 4 that change colour when you move. There's also a massive interactive screen on the ground floor and lots of wooden climbing sculptures around- I loved the whale shark the best.

The gym is massive and has beautiful views. There is also Livewire, a mini cinema, a library where you can actually loan books, and there is Wi-Fi now too!

**What's some of the major differences from Princess Margaret Hospital to PCH?**

The food is better and there are so many more options for your meals. You actually order all your meals on the TV. There are also lots of cafes that have yummy food. The supershakes from Threepenny are really good.

**What would you say to kids who will be coming to PCH for their first admission?**

It's amazing! It's a happier place to be.





## IN MY CHAIR PROGRAM

**Have you heard about the Stitches Bear in my Chair program?**

This program helps you stay connected with your class mates and take part in school lessons while you're in hospital.

**So, how does it work?**

When you are having a hospital admission, you and your school can sign up to take part in the program. Your school will be sent a Stitches bear, who will sit in your chair at school to represent you while you're in hospital. They will also get an iPad so that they can video call you during lessons.

You will also get an iPad to Facetime your class, as well as a small Stitches Bear and a Stitches Bear in my Chair t-shirt.

If you're interested in being part of the program during your next admission, your parents can get in contact with the School of Special Educational Needs: Medical and Mental Health (school hospital), who coordinate the program. The phone number is 9340 8529 or email [ssenmmh@education.wa.edu.au](mailto:ssenmmh@education.wa.edu.au)



# ADVENTURING WITH CF: TRACKING DOWN BRUMBIES IN CENTRAL AUSTRALIA

*By Holly*

**H**olly is a 13-year-old girl living in Albany, WA. She also has CF.

She loves sport and home schools with her older sister Jamilla. They both enjoy horse riding.

In 2016, my family decided to plan a trip to see brumbies in their natural habitat. We decided to go to the Northern Territory after watching a video "The Desert Brumby". We planned to go in June 2017, but we received a call from PMH (Princess Margaret Hospital) saying I had to go to into hospital as I had grown *Pseudomonas* in my lungs"



I spent three weeks in hospital to get rid of the bugs. We started to plan our trip for the end of August. Unfortunately, my lung function didn't improve after the hospital admission and it didn't look like we would be able to go on our trip. I worked really hard doing all my treatments to improve my lung function, so we would be able to go on our trip. We travelled to Perth to see how my lung function was going. It improved marginally, and we spoke to my doctor, Dr Wilson, about still going on our trip. As I had been doing such a good job at home and promised to continue whilst away he let us GO, Yay!

In order to continue my treatments on our trip we had to pack lots of medicine and equipment. Two of my medicines, Pulmozyme and **Tobromycin**, needed to be kept cold so we had to borrow a car fridge off my Uncle Lee. My dad brought an inverter for my nebuliser. Finally, we set off across the Nullarbor on the 27th of August.



On the first few days we did up to 1100km/day! The road was long and straight and on the sides of the road there were a few shrubs, but mostly bare and orangey and rocky. My sister Jamilla and I got a bit bored, but to keep ourselves amused we read books, played games and slept. One of our few stops was at the Great Australian Bight. There were huge drop off cliffs next to the ocean. Another stop was at Cooper Pedy, where they have opal mines and an underground museum and underground houses. The opal mines were a bit ugly, like big piles of dirt. There were hundreds of piles of dirt with holes next to them, but the opals were really pretty.

*Most nights we pulled off the road and drove down a path and dumped our swags. One morning we woke up and our swags had frost on them!*





It took us four days to get to Alice Springs. We stayed at the caravan park and the next morning we went to Desert Springs Wildlife Park. We watched a bird show that was amazing then we went around the park. I started to feel a bit hot and tired, so I got an ice cream and Jamilla and dad kept going whilst mum and I had a break. I felt a bit better, so I got dressed in some cooler clothes and went to find Jamilla and dad. My favourite thing was the bird show. After that day we headed out to the West McDonald Ranges to see the gorges.

We went to Standley Chasm, Ellery Creek Big Hole, Serpentine Gorge, Ormiston Gorge, Glen Helen Gorge and Redbank Gorge. All the gorges were so beautiful, they looked like a big slice through the world. We went swimming in all of the gorges that had water. The water was like ice, so freezing!

After travelling in the West McDonald Ranges we went to Kings Canyon. It was a half day walk and you had to start before 10am because of the heat. We went across bridges and climbed rocks, it was really hard work, but we got through it. It was also really hot and long, the cliffs were really huge with big drop offs. On the other side of the cliff were some people that waved to us which was really cool. It was a great walk but so tiring.

We then headed to Running Water Yard to find the brumbies. Running Water Yard is on the Finke River, pretty much in the middle of nowhere. We camped there for three nights and saw lots of brumbies. They were really cautious. We saw different harems, most had a stallion a couple of mares and at least one foal. They were magnificent, particularly the stallions. They were lots of different colours.

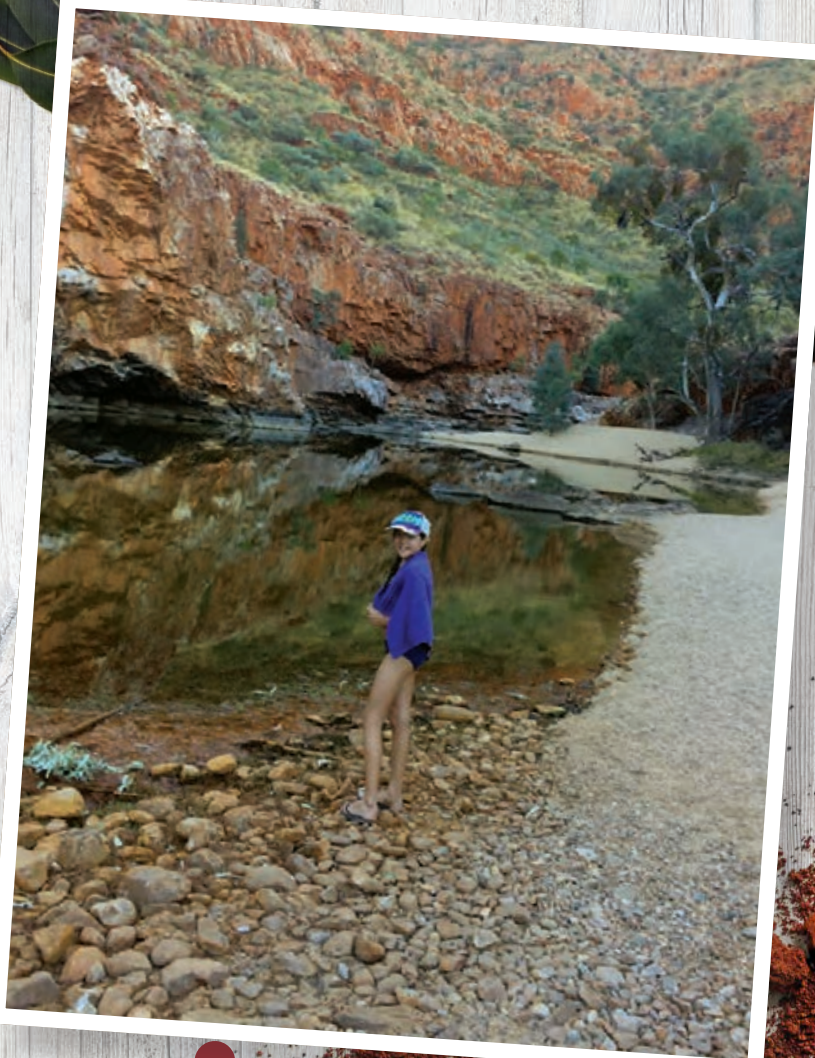
After that we went to Uluru. We went on a camel ride, my first but by far the best. You could see Uluru from the camels. Camels feel very different to ride than horses. It was weird at first but got better. It was really scary when the camels got up with their front feet first and when they go down they get down with their front feet first. That same day we walked around Uluru. Let's just say Uluru is so amazing and beautiful, it is massive. Then we went to the sunset viewing to watch the sunset. It was so amazing and awesome. After watching the sunset, we went to a place called Outback Pioneer BBQ.

*We had crocodile, kangaroo steak, an emu sausage and a buffet salad. I loved the crocodile the most. The emu sausage was a bit weird.*

it tasted a bit bitty and the kangaroo steak was very nice. After that we went back to camp and set up for bed. The next morning, we set out to go to the Olgas. They look a lot like sand in the desert; wavy also a bit like coral. After that we started heading home on the Great Central Road. It was a long drive on red dirt. We saw brumbies crossing the road which was really cool. We also saw lots and lots of camels on the sides of the road.

We were all very excited to get back after three weeks.







# MEET THE MEMBERS

## Cara and Isla

Cara and Isla are sisters who live in Perth and both have CF. They also have an older sister Skye who doesn't have CF. We chatted to Cara and Isla about how CF affects their lives, staying motivated to do physio, their hobbies and dreams for the future.

**Hi girls, can you tell us a bit about yourselves? What are some of your favourite things to do?**

**CARA** I'm Cara and I'm 9 years old. I like playing on my iPad and the Ps3. We really like playing Crash Team Racing.

**ISLA** I'm Isla and I'm 6. I like playing tennis, gymnastics and doing art and crafts.

**What is something special about having CF?**

**CARA:** We have to take more meds than others and sometimes we have to go into hospital. Last time I went to hospital I even had to go to school with a PICC line in.

**ISLA** I need to have Creon with food. Also, people can't borrow my things at school, so that I don't catch germs.

**What are some of the tricky parts about CF?**

**CARA** All the doctor's appointments take such a long time. And also, I really don't like blood tests.

**ISLA** Going to hospital.

**Do you have any tips to help other kids to stay motivated with physio?**

**CARA** Get a distraction, like an iPad. Or sometimes, when our homecare worker comes I would do bubbles then as a reward I would get to go for a swim in the pool.

**ISLA** Make things out of paper, drawing or colouring books.

**Learning to swallow tablets can be hard. Can you tell us how you learnt to do this?**

**CARA** It was really hard. Sharon (the nurse from Cystic Fibrosis WA) came out and helped us. We started by practicing swallowing M&M's and Smarties and worked up to bigger sized lollies. Now I can swallow my vitamin D and I take my Vit ABDECK with a scoop of yoghurt and I crush my salt tablets. I don't need to take Creon.





**ISLA** I can swallow my Creon now. I used to have it with apple puree which was yummy.

### **How do you manage CF and school?**

**CARA** I get questions from the other kids like 'what is CF?' sometimes, which I find hard to answer. The ladies from CFWA came and spoke to my class about CF which helped with some of the questions.

I manage most of my CF at home, like physio and medications, and I don't need Creon.

**ISLA** I take my Creon with recess and lunch at school. Mum and dad put it in my lunch box with the food that it goes with.

### **What would you like to be when you grow up?**

**CARA** I wanted to be an air pilot but not anymore. I'm not sure at this stage.

**ISLA** I really want to be a teacher, but I also want to be an artist.

### **WHAT IS YOUR...Favourite singer/music?**

**CARA** Taylor Swift

**ISLA** Ed Sheeran and Taylor Swift

### **Favourite food?**

**CARA** Mangoes, especially mango smoothies. Oh, and homemade onion rings

**ISLA** Onion rings

### **Favourite thing to do in your free time?**

**CARA** iPad (the Slither game)

**ISLA** Draw, iPad (Dancing Line game)

### **Favourite colour?**

**CARA** That's a hard question. I quite like a really bright orange and a light yellow.

**ISLA** Black, white and grey

### **Favourite TV show/movie?**

**CARA** Despicable Me movies

**ISLA** Despicable Me 3



# GO RED FOR CF

AT SCHOOL

Feel like you want to raise awareness about CF and raise some money for Cystic Fibrosis WA too?

You can help by encouraging your school to Go RED for CF! For a gold coin donation, your classmates and teachers can join in the fun and wear something red to school for the day.

## How to get started:

1. Ask your parents about hosting a Go RED for CF day at your school. You can then speak to your teacher to get the school on board.
2. Your school can register their fundraiser online at [www.cfwa.org.au/get-involved/fundraising/](http://www.cfwa.org.au/get-involved/fundraising/) and we will send them all the details.
3. We can provide your school with a Go RED for CF Starter Pack, posters, a certificate and more to help your Go RED for CF Day be a success.



COOLIN IN KULIN!

## *camp kulin 2018*

This year we took a bus and headed 3 hours East to Kulin which is a small wheatbelt town (population 300) and home to the fantastic Camp Kulin.

Camp Kulin has gained national and international recognition for its program and we could easily see why with all activities focused on team building, confidence, persistence and perseverance. And did I mention FUN!

Tanya our camp leader played so many great games, everyone got involved and helped each other. Some of the highlights included: Giant Foosball, Dodgeball, Circus Tricks, Giant Hungry Hippo, Blind Maze and our Drumming performance.

Check out the video that one of our participants made from camp this year – go to [cfwa.org.au/what we offer/member events/sibling and offspring camp](http://cfwa.org.au/what-we-offer/member-events/sibling-and-offspring-camp). We also got to pay a visit to the local museum which housed some really old vintage cars and trucks. On our last night we had a quiz night ‘Tanya Style’



which involved lip sync battles, dancing, toilet rolls, newspaper and ended with Ric being crowned Camp Kulin King!

What a great couple of days we had, because of the distance we decided to extend our stay and got to spend 2 nights and 3 days at camp. We asked all our camp kids if they enjoyed staying the extra night and 100% said YES so dependent on funding, our Sibling & Offspring Camp just got longer

A Big shout out to MAZDA Foundation who funded our camp this year. THANKYOU X

The Sibling and Offspring Camp is for kids aged 8 to 16 with a parent or brother or sister with CF. The camp gives you the chance to meet other kids who know what it's like to have someone with CF in their family, share stories and make new friends. If you haven't been to camp before and would like more details, contact Paula on [services@cfwa.org.au](mailto:services@cfwa.org.au) or telephone 6457 7333





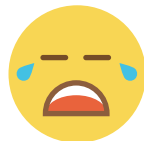
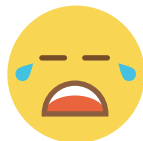




# LIVING WITH



# SOMEONE WITH CF



Having a brother, sister or even a parent with CF can sometimes mean that over time you may experience many different feelings, like worry, embarrassment, guilt, jealousy, frustration or even sadness. It is very normal to have these feelings, and it's also important to understand why you might feel them.

## WHY DO I FEEL...

### Worried:

You may worry about them sometimes. You might worry about the future and what will happen to them. It might help to tell your parents or someone you trust about your worries. Even though they may be worried too, it is ok to ask them questions. They can tell you what is happening and explain things to you.

Sometimes you might worry about asking new friends over to your house as you might have to explain why they are coughing or doing physio. Here are some things that can help:

- Tell your friends about your sibling/parent before they visit.
- Explain that they have an illness and that they have to do special treatments to keep their lungs healthy.
- Talk to friends about some of the good things as well as the difficult.

### Embarrassed:

You might feel embarrassed about their appearance. Such as if they have a PICC line, they cough lots or they look skinnier than other people.

### Guilty:

At being “normal” and healthy. You may feel guilty that your sibling/parent is unwell, and you aren't. This is quite common and is important to talk to someone you trust about these feelings.

### Jealous:

It might feel like there is a lot of attention on the person with CF. In some families, the child who is ill gets more presents and more people making a fuss of them. It can seem that people are not as interested in the things that you do. It is normal to feel jealous when this happens. The suggestions below may help:

- Talk to a parent or friend about it.
- Ask your parents to tell relatives and friends to be fair with gifts and attention, for all the children in the family.
- Ask your parents if they can set some time aside each day to spend a bit of special time with you, maybe playing games, making things, chatting, watching TV, having a hug.
- Ask your parents if they know any other children like you. Maybe your parents can arrange for you to meet other children who have a sibling or parent with an illness (like CFWA's Sibling and Offspring Camp!).

## Frustrated or angry:

You might feel angry that normal life is disrupted when your sibling or parent has to go into hospital. You might feel angry that it's 'all about them'. Feeling angry is normal. Ask your friends this and they'll say they get mad at their family too sometimes. Here are some things that can help you calm down:

- Count slowly up to 10.
- Walk away and come back when you are feeling calm.
- Go in to another room and listen to music or watch TV.
- Spend some time doing something relaxing - reading, drawing, making things, going for a walk.
- Tell your parents that you feel angry and need help to get calm.
- Write a story or draw a picture about how you feel.

## Lonely or sad:

Sometimes you might feel sad because your sibling or parent is ill, or you might feel like no one else understands what it is like to be in a family of a person with a chronic illness. If you feel sad, some of the suggestions below may help:

- Have a cry; many people feel a bit better after a cry.
- Write or draw about your feelings in a notebook.
- Ask a parent for a chat or hug.
- Tell your parents or someone else you trust that you feel sad.

Lots of kids miss their sibling and parents when they have to stay in hospital. Some kids get upset about the treatment that their sibling or parent needs to have. Some of the suggestions below may help:

- Tell them you really miss them when they need to stay in hospital.
- Make a special card for them.
- Get someone to take you to the hospital often to visit.
- Make a calendar to count the days until they're home.

## BEING PART OF A FAMILY AFFECTED BY CF ALSO MEANS THAT YOU MAY ALSO EXPERIENCE POSITIVE FEELINGS AND EXPERIENCES SUCH AS:

- **Pride:** for your sibling or parent for how well they are able to cope with their illness.
- **Being closer with the family:** You may feel very close to your family because you all have to work as a team to live with CF on a daily basis.
- **Being more sympathetic:** You probably have a greater understanding of what it is like for other people to suffer or to experience something that is really difficult to live with.

## WHAT HAVE YOU LEARNT FROM LIVING WITH SOMEONE WHO HAS CF?

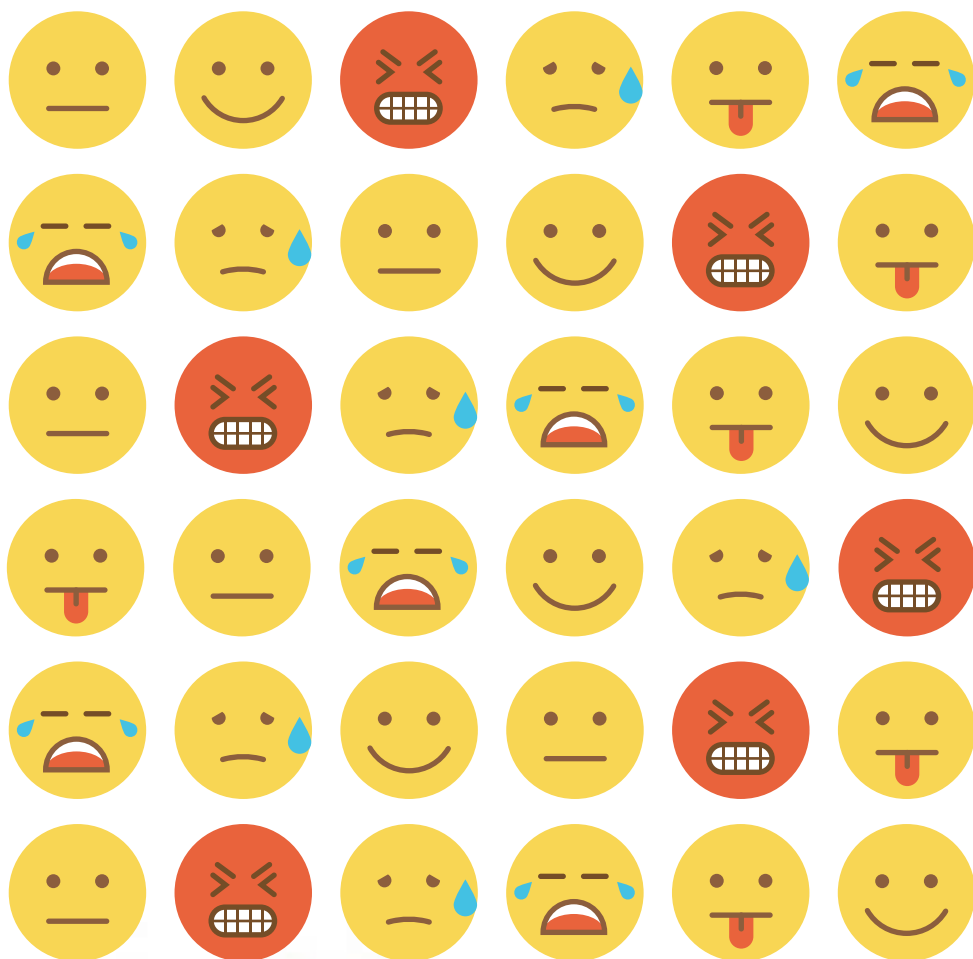
Being understanding of people who are different?

Knowing a lot about medical things?

Being a responsible person?

Feeling glad to be healthy and able to do things?

Other things? What are they?





# Who to talk to

Whether you have CF, or have a family member with CF, you may sometimes have difficult feelings or questions that you are nervous to ask. Despite your nerves, it can really help to talk about these feelings with someone you trust. The first step is finding someone you can be honest and open with and who can help you. Could this be your:

- **Parents**
- **Grandparents**
- **Aunt/uncle**
- **Older sibling or cousin**
- **Doctor or someone else on the CF team**
- **A teacher or another school staff member, such as the nurse or student support person**
- **Another adult you trust e.g. Homecare Worker**

When starting a tricky conversation or talking about difficult feelings, getting started can be the hardest part. Try these tips:

## **Pick a good time and place to talk.**

Any time you're together can work. For example, when you're walking the dog, helping with the dishes, or in the car. On the phone could be a good option too as then you're not face-to-face and it might not feel as nerve wracking.

## **Think about what you need.**

Do you need the other person to just listen and understand what you're going through? Or do you want advice? Or do you need answers?

## **Think of what you'll say.**

You can get started by saying things like:

"I need to tell you about a problem I'm having."

"I'm worried about something."

"I need your advice about something."

Once you get started, whoever you're talking to will listen and talk too. Most of the time you will feel much better after talking about your worries and speaking truthfully. If you don't feel better, or feel like your answers weren't answered, there are also some websites that can provide information or someone to talk to.

## **cystic Fibrosis WA**

(CFWA)

The CFWA website has a page for young people with CF, aged 12+ with lots of information about living with CF.

**W:** [www.cfwf.org.au](http://www.cfwf.org.au)

**CFsmart**  
cystic fibrosis education program







## cfSmart

CFSmart is a website for teachers, parents and school aged kids. If you go to the website, you can click on the 'students' tab and choose either high school or primary school. It has resources and information you might find useful about CF.

**W:** [www.cfsmart.org](http://www.cfsmart.org)

## Livewire

(AGED 12+ ONLY)

Livewire is a website for kids aged 12 to 20 years with a chronic health condition/disability and their siblings. It was created to make a community for young people like you, who are dealing with some tricky stuff and can do with a crew who understand and offer a little extra support. Livewire has chat rooms, blogs, competitions, articles and their very own TV channel, LivewireTV. You can swap stories, ask for ideas, and talk about whatever's going on in your life. Chat rooms are run by Livewire chat hosts who are always there to listen, support discussions, and provide support without judgment.

**W:** [www.livewire.org.au](http://www.livewire.org.au)



## Kids Helpline

The Kids Helpline has a heap of information for young people aged 5 to 25 years, to help you work out any issues you might be facing, like dealing with emotions, getting along with family, feeling alone, feeling worried, cyber bullying and much more. They also have a free telephone counselling service and email option if you feel like you need to talk to someone.

**W:** [www.kidshelpline.com.au](http://www.kidshelpline.com.au)  
**PH:** 1800 55 1800



A person is shown in a yoga pose, specifically the Urdhva Dhanurasana (Upward Bow Pose), with their hands clasped behind their head and feet on the ground. The person's silhouette is dark and is superimposed over a background of a dense forest of tall, thin evergreen trees. The sky is a pale, hazy yellow, and there are small, dark, bird-like silhouettes scattered across it. The overall mood is serene and peaceful.

# Learning To Relax

Learning  
To Relax  
During  
Medical  
Tests

# During Medical Tests

Most kids with CF have to go to hospital or have medical tests like needles, PICC lines or port flushes done at some stage. This can make you feel worried, nervous or scared. There are different things you can do which help distract your brain from what's going on and can make you feel calmer and less worried.

You can practice these at home as much as you like, in fact, the more you practice, the better.

## 1. *Calm Breathing*

- Step 1:** Sit or lie in a comfortable position. Close your eyes and relax.
- Step 2:** Take a deep breath in by breathing in through your nose.
- Step 3:** Let it out slowly through your mouth. You can make a hissing sound (ssssssssss) if you like. Try and relax your body while you are doing this.
- Step 4:** You may want to say the word “calm” in your mind while you are breathing out. You may notice that as you breathe out, the scary feelings seem to go away.

## 2. *Muscle Relaxation*

This works best if you are able to sit in a comfortable chair, but you can also do them while in bed. You will need to squeeze tight the muscles in each of the following body parts, hold it while you count to 8 and then relax it.

### **Hands**

Pretend you have a tennis ball in your left hand. Squeeze the ball really hard. Count to 8 while you squeeze, then let go and relax. Let your hand and arm go all floppy and soft. Doesn't it feel good now? Take the ball in your right hand and do the same.

### **Arms**

Pretend you are a weight lifter. Your arm muscles are very strong. Flex your muscles and show us how big they are. Hold this position while you count to 8, then relax. See how good your arms feel when they relax.

### **Shoulders**

Pretend that you are having your morning stretch. Stretch your arms right up to the sky, as far as you can reach. Count to 8, then relax. Let your arms drop down to your sides and relax. Notice how good they feel when they are soft and floppy.

### **Jaw**

Pretend that you have just bitten into a hard biscuit. Bite down on it. Use your neck and jaw muscles. Then relax. You still haven't managed to bite some off. Have another go and bite really hard. Now relax as the biscuit melts in your mouth.



## Face

Pretend that a little butterfly has landed on your nose. Try to get him off without using your hands. Screw your nose up really tightly and count to 8. Great, he has flown away. Oh, no, he has landed on your forehead! Wrinkle up your whole face and count to 8. Great, he has gone for good now. Relax. Your face now feels smooth and relaxed.

## Stomach

Pretend that you are trying to button up a pair of jeans, but they are too tight around the waist. You squeeze your tummy muscles in while you try to do up the button. You just can't get them done up. Relax. Try again. Suck your tummy in tightly and count to 8. Relax. See how good your stomach feels when it is relaxed!

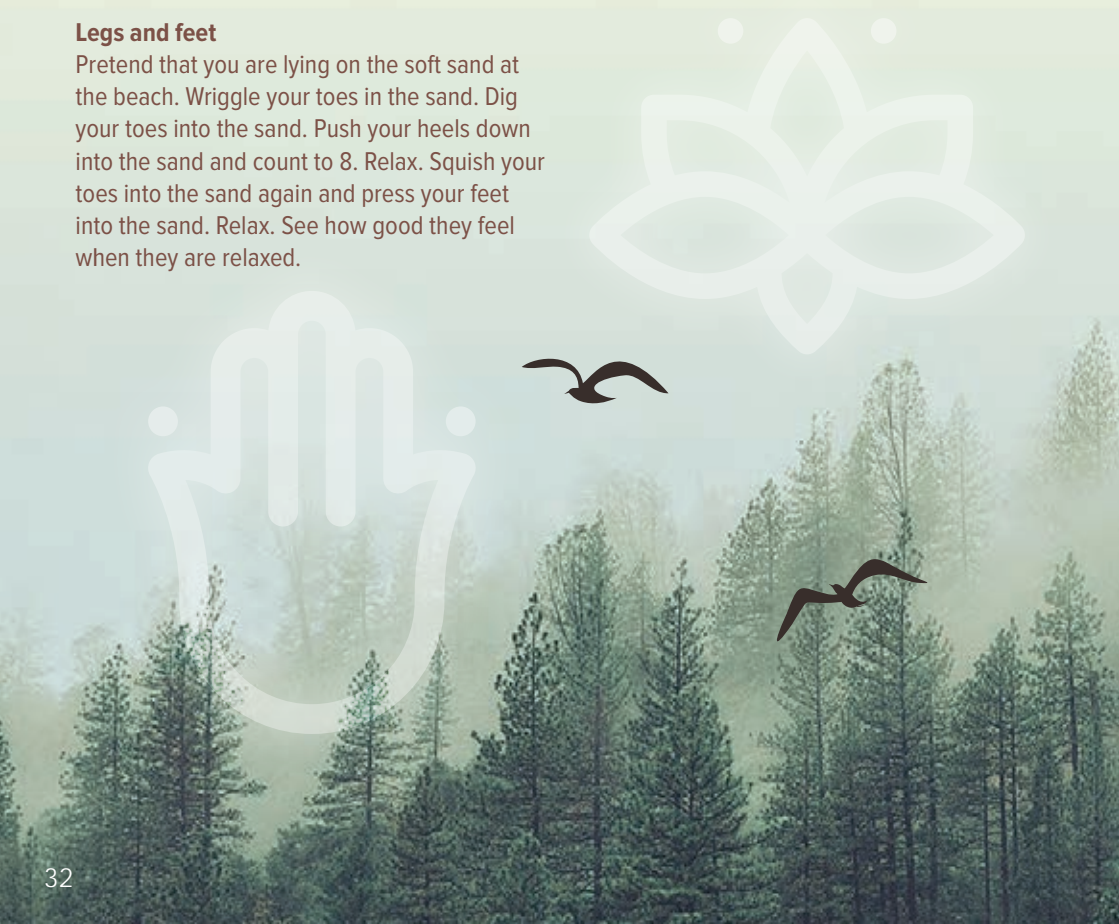
## Legs and feet

Pretend that you are lying on the soft sand at the beach. Wiggle your toes in the sand. Dig your toes into the sand. Push your heels down into the sand and count to 8. Relax. Squish your toes into the sand again and press your feet into the sand. Relax. See how good they feel when they are relaxed.

## 3. Mind Pictures

You can make a mind picture by using your imagination to focus on pictures in your mind. Close your eyes and let your muscles go all soft and floppy. Imagine a place that is warm, safe and makes you feel happy. You could imagine that you are at the beach, swimming under water, in a garden, in fairyland, at the circus, on an island, in space, at the zoo or in a jungle. Pick a space that you find relaxing and think...

- What can you see?
- What are you wearing?
- Who is with you?
- What are you doing?
- What can you smell?
- What can you touch?
- What can you hear?





## 4. Busy Brainwaves

Keep your mind busy during a test, such as:

- Look at the pictures and paintings on the walls and ceiling and think of a story to go with them.
- Read a book
- Watch television
- Listen to music
- Draw a picture
- Write a letter or story
- Play a game or do a puzzle
- Play cards
- Blow bubbles
- Play with your toys
- Talk to the nurses



## 5. Positive self-talk

Positive self-talk can help you to handle difficult situations. When you feel scared, nervous or angry you can help yourself to feel better by using positive thoughts, like:

Instead of saying “I don’t like this doctor because he put a drip in me” you could say,

“This doctor did a good job. I needed to have a drip so that I can have the medicine to make me better.”

Another example might be: “Hospital is ok, there are some fun things to do here”

rather than “I don’t like hospital.”

These techniques are from the KKind team. KKind can also provide support during hospital admissions if you are feeling scared or nervous. You can ask your nurse about them.







CRAFTY

CORNER

# MAKING SLIME

It seems everyone is obsessed with making slime at the moment. Fold it over and pop it like Silly Putty! Stretch it and knead it like pizza dough! Squash it through your fingers! It's a fun activity to do at home, and we've found a great recipe for you to try.

## BEFORE YOU START

Before you do anything, you need to ask for your parent's permission and help! Slime making is a chemistry and involves a chemical reaction between the ingredients being mixed, so it's important that you read the directions, use the correct ingredients, measure accurately, and have a little patience if you don't succeed the first time. Remember, it's a recipe just like baking!

You might also not have all the required ingredients at home, so this might require some slight pleading for your parents to take you to the shops.

## FLUFFY SLIME SUPPLIES

'Little Bins for Little Hands' has a heap of slime recipes and ideas. We have chosen a basic one to start with. Fluffy Slime.

- White Washable PVA School Glue
- Foam shaving cream
- Saline solution
- Baking soda
- Food colouring (optional)
- Bowl, measuring cups and spoon

1



Measure and add 3-4 generous cups of foam shaving cream to a large mixing bowl.

2



Next, add a few drops of food colouring (if desired) and gently stir to mix colour. Then measure and add 1/2 cup of white glue and gently stir to combine.

3



Add 1/2 teaspoon or so of baking soda to mixture and gently stir.

4



Lastly, measure out 1 tablespoon of saline solution and add to bowl.

5



Whip the mixture to activate the slime. It will begin to pull away from sides and bottom of bowl.

6



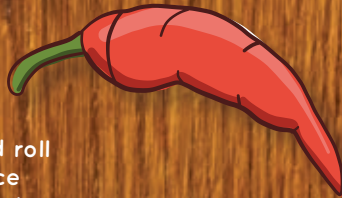
Pick up your slime and knead it until smooth and stretchy and no longer sticky.



# How To Make... Easy Pizza Buns

\*NOTE: Ask your parents for help with cutting ingredients and using the grill. This recipe is so easy and is a great lunch time meal. You can make the pizza to suit your tastes by changing the toppings as you wish.

## Ingredients



- 1 large wholegrain bread roll
- Tomato paste/pizza sauce
- Shredded mozzarella or cheddar cheese
- Meat, such as ham and/or pepperoni
- Vegetables of your choice, such as capsicum, mushroom or cherry tomatoes
- Herbs of your choice, such as oregano or parsley

## Instructions



*Step 1:* Preheat oven grill to medium.

*Step 2:* Cut bread roll in half and place face up on a lined baking tray.

*Step 3:* Spread a spoonful of tomato paste over each half of the roll.

*Step 4:* Sprinkle over cheese and any herbs you want.

*Step 5:* Add other toppings such as meat and vegetables.

*Step 6:* Place tray into grill and cook for 5-10 minutes, or until cheese is golden and melted. Keep an eye on it.





# PUZZLES & STUFF

**Jokes to have up your sleeve**

**Q: How can you tell a vampire has a cold?**

**A: She starts coffin.**

**Q: Why did the student eat his homework?**

**A: Because the teacher told him it was a piece of cake!**

**Q: Why can't Elsa have a balloon?**

**A: Because she will let it go.**

**Q: What's worse than finding a worm in your apple?**

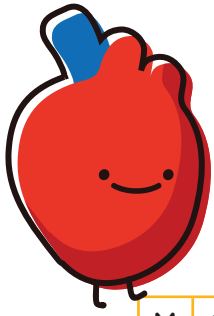
**A: Finding half a worm.**

## QUICK QUIZ

1. In the movie 'Finding Nemo', what is the name of Nemo's father?
2. What is a herbivore?
3. Name the vowels
4. How many years in a decade?
5. When you mix red and blue paint together, what colour does it make?
6. What school does Harry Potter attend?
7. Who sings 'Blank Space'?
8. What city are the AFL team the Swans from?
9. Where in your body would you find the aorta?
10. Who did Prince Harry recently marry?

ANSWERS (upside down) 1. Marlin, 2. An animal that only eats plants, 3. A E I O U, 4. Ten, 5. Purple, 6. Hogwarts, 7. Taylor Swift, 8. Sydney, 9. Heart, 10. Meghan Markle

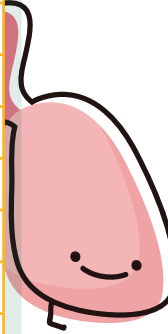




# Word Search

Try and complete our Human Body themed word search!  
Words can go up, down, forwards, backwards or diagonally.

M	G	A	R	H	P	A	I	D	I	O	C	M	E
E	L	C	M	V	E	F	F	T	D	L	N	B	I
I	R	H	E	A	R	T	O	R	S	P	I	L	H
S	P	N	G	E	S	C	K	E	X	S	W	A	J
T	T	A	I	Y	T	J	L	G	I	K	G	D	U
O	K	J	L	R	U	K	Q	N	H	N	P	D	S
M	O	B	F	P	N	I	U	I	D	I	T	E	U
A	H	W	U	E	O	D	B	F	E	S	A	R	G
C	M	C	E	A	I	N	M	S	S	Z	O	D	A
H	D	S	X	C	N	E	D	L	U	N	G	S	H
B	Z	R	E	A	L	Y	T	L	T	Y	Y	R	P
S	W	U	S	V	I	Y	T	M	R	E	U	B	O
J	I	R	O	O	E	W	J	F	U	C	E	F	S
Q	T	O	N	G	U	E	W	H	R	Q	L	O	E
P	S	H	T	P	F	C	K	I	A	U	K	S	O
A	L	D	G	Y	M	M	B	J	H	T	N	R	E
E	Y	E	P	O	S	A	E	R	C	N	A	P	C



<input type="checkbox"/> ANKLE	<input type="checkbox"/> HEART	<input type="checkbox"/> NOSE
<input type="checkbox"/> BLADDER	<input type="checkbox"/> KIDNEY	<input type="checkbox"/> OESOPHAGUS
<input type="checkbox"/> DIAPHRAGM	<input type="checkbox"/> KNEE	<input type="checkbox"/> PANCREAS
<input type="checkbox"/> EYE	<input type="checkbox"/> LIPS	<input type="checkbox"/> STOMACH
<input type="checkbox"/> FINGER	<input type="checkbox"/> LUNGS	<input type="checkbox"/> TONGUE



