

SUMMER 2014

A MAGAZINE FOR KIDS WHO HAVE CF AND THEIR

SIBLINGS

ROZEE

COWPOO COOKIE:

WE SHOW YOU HOW TO
MAKE YUMMY BISCUITS
PAGE 28

SIBS' CAMP

HEIGHTS AND
FLIGHTS 2013
PAGE 15

COP A LUNGFUL OF THIS

YOUR LUNGS
ROCK, LOVE 'EM!
PAGE 18



**CYSTIC
FIBROSIS**
Western Australia

ALL
AWESOME!

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ON THE FRONT
COVER:
Marc at the 2013
CFWA Sibs' Camp

PRINTED BY:
Image Source
P. 08 9380 8906

DESIGN:
Function Creative
functioncreative.com.au



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produced for CFWA. Articles or
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of the editor or those of CFWA.

EDITOR'S LETTER

Well it's been a while since we last had an issue of Rozee for you. Almost a year in fact!! You are all probably grown up by now and raising your own children - ha ha !!

In this issue we are very excited to bring you a few more interviews with siblings and people who have CF, not just from Western Australia but from other parts of Australia too. In fact, there are kids all around the world going through similar things to you!!

We also wanted to look at lungs in this issue as well as provide some ideas for what to do if you don't feel like eating but know you should.

A big congrats to Paige who won an iPod Touch in the survey response draw from the last issue. We hope she enjoys it, maybe she will put some "One Direction" tunes on the iPod, like Charlie on page 17 who you will see LOVES "One Direction" A LOT.

We are always looking for feedback, ideas and young people to contribute to the magazine, so if you would like to be involved let us know!! Contact us at the details on this page.

Have a wonderful long summer holiday. We hope you relax and have lots of fun in the sun!! Don't forget those salt tablets (if you have CF) and of course sunhat, sun cream, drink plenty of water and salty drinks (if you need to)!

Bye for now,

Natalie



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KYLIE'S STORY

I live in Melbourne and was diagnosed with CF as a toddler. I went to university and after graduating I started working as a primary school teacher. I am also working as the ambassador for CF Victoria, raising awareness and spreading the word about CF. I also like going to the gym, travelling, and achieving incredible things. I am very happy to say that I got married a short time ago, too.

Do you have a question you would like to ask Rozee? You can send your question anonymously if you wish or ask that your name is not included when the question is published.

Email your questions to education@cysticfibrosiswa.org or write to Rozee (CFWA) at: Rozee Magazine CFWA PO Box 959 Nedlands 6909



ASK KYLIE & JANETTE

QUESTION: I AM 12 YEARS OLD AND WANT TO FIND OUT MORE ABOUT MY CF. I HAVE GOOGLED CYSTIC FIBROSIS ON THE INTERNET BUT FIND IT HARD TO UNDERSTAND WHAT THE INFORMATION MEANS AND SOME OF THE INFORMATION I HAVE FOUND HAS MADE ME FEEL WORRIED. HOW DID YOU LEARN ABOUT YOUR CF AND WHAT DO YOU DO IF YOU DON'T UNDERSTAND SOMETHING OR FEEL WORRIED ABOUT WHAT YOU LEARN?

KYLIE:

I have to agree that some of the information you find on the internet can be a bit worrying and it can also be out-dated. There are plenty of other ways to find out about CF. We didn't have the internet when I was growing up, so I had to rely on my parents, doctors and friends as sources of information.

My advice is to always ask your parents and talk about CF with your family and if they don't have the answers or information you require, the doctors and physiotherapists will definitely be able to help you. The doctors and physios have always provided me with all the important information about CF throughout my life.

I remember when I was about your age; I would always make sure I had one question to ask my doctor at every appointment. So next time you are due for a check-up, make sure to write down some questions and your doctor will be really excited to answer these or reassure you about any worries.

Friends with CF are another good information source, but just remember CF affects everyone differently. Learning about CF is something that you will do for the rest of your life because there are always going to be advances in treatment and medications.

For this issue of Rozee, we are very lucky to have two adults with CF, from Sydney and Melbourne, providing advice for us.

JANETTE:

Most people with CF want to find out more about their condition and how it might affect them. I have looked for information about lots of different things to do with CF in the past. Googling is great as it will give you lots of information quickly but some of it will be hard to understand and some of it won't be correct or up to date. It can be hard to know where to find helpful information. I have found that the state and national CF association websites from Australia or overseas from the USA, UK, Canada and NZ are good places to start. They will have lots of information that is easy to understand and might even have links to other useful and trustworthy websites too.

Sometimes I have been worried about what I've read too, so I've always found someone to talk with about the information and how I'm feeling. I encourage you to do the same. Your doctor is probably the best place to start. You can even bring along a copy of the information so your doctor can see what it says. They can tell you what information is correct and current and whether or not it applies to you. You might find that what you're worried about is not a concern for you now and you can put it out of your mind. It's your doctor's job to answer any questions about your health in a way you can understand. Sometimes another member of your care team might be better able to help you like your physio, dietician, social worker or clinic coordinator.

If you are still worried, your parents, a friend or a friendly social worker can listen to how you're feeling. Sometimes just talking about worries is all people need to feel less worried. There may be other things you can do to help you feel better too, like going for a walk, doing something fun, watching a feel good movie or having a hug.

It's important to remember that most things are often better than what we fear they will be. It's also important to remember that everyone with CF is different - we all have different CF symptoms and can be more or less affected than other people we know. The information you read will apply to most people with CF - but not all people with CF.

Good luck looking for information! If you look in the right place and talk about any worries you should end up with the information that is helpful.



JANETTE'S STORY

I live in Sydney and am a 30-something year old

with CF. I am married to a 40-something year old who also has CF. This makes us a little unusual! We put a lot of effort into looking after our health and with a little bit of luck thrown in, we both manage to stay reasonably well. We have two lovely Kelpie dogs who are the light of our lives and whom we love.

I work full-time as a genetic counsellor. In my current role, I meet with pregnant women and their partners to discuss their ultrasound results and their options for further tests in pregnancy and if they would like more information about the health of their baby. I enjoy my job but it can be stressful and emotional at times.

MEET THE MEMBERS

GABBY, OLIVIA AND JARED LIVE IN GEELONG, WHICH IS A LARGE TOWN AN HOUR FROM MELBOURNE AND ALSO HOME TO THE GEELONG CATS (IF YOU ARE A FOOTY FAN). THESE SENSATIONAL SIBLINGS LIVE ONLY 15 MINUTES FROM THE BEACH AND THE OTTWAY FOREST.

GABBY IS 9 AND HAS CF, OLIVIA IS 11 AND JARED IS ALMOST 13. THEY HAVE A YOUNGER BROTHER AARON, BUT HE WAS A BIT TOO YOUNG TO ANSWER ROZEE'S QUESTIONS.

GEELONG HAD IT'S OWN GREAT STRIDES RECENTLY AND NEARLY 300 PEOPLE CAME. THEY RAISED OVER \$15,000. JARED & OLIVIA HELPED OUT ON THE DAY.



Jared



Olivia



Aaron



Gabby

DO YOU LIKE HANGING OUT WITH YOUR BROTHER/SISTER? WHAT DO YOU DO?

Gabby: I like playing basketball with them and I like dancing with my sister.

Olivia: Yes I do, Gabby and I usually do tricks on the trampoline. Also sometimes we play basketball.

Jared: Yes, I do like to hang out with Gabby. She is really nice, sometimes funny and enthusiastic. The things Gabby and I do are shooting hoops, jumping on the trampoline and jogging around the block to help her with her physio.

HOW WOULD YOUR FRIENDS DESCRIBE YOU?

Gabby: Nice, friendly, playful and funny.

Olivia: Funny, energetic, nice, enthusiastic.

Jared: My friends will probably describe me as sporty, a little bit funny, nice and good at games.

WHAT MAKES YOU PROUD OF YOUR SISTER/BROTHER?

Gabby: My sister practices dancing all the time and does competitions and Jared wins a lot of swimming competitions.

Olivia: How Gabby can have so many needles without crying and I know I wouldn't be able to do that.

Jared: I'm proud of Gabby because she never complains about doing physio and takes over 30 tablets a day.

WHAT IS YOUR FAVOURITE THING TO DO IN YOUR SPARE TIME?

Gabby: I love doing flips on the trampoline and also playing Barbies and playing teachers.

Olivia: Practicing my dancing and my acrobatics.

Jared: Well in my spare time I shoot hoops, swim, play games like Minecraft and read.

WHAT IS THE BEST BIT OF ADVICE YOU HAVE BEEN GIVEN?

Gabby: Believe in yourself.

Olivia: You can either dream your dreams or go out and chase your dreams.

Jared: Never give up.

IF YOU COULD MEET ONE FAMOUS PERSON WHO WOULD IT BE AND WHY?

Gabby: "One Direction" because I love them and they are cute and their songs are awesome.

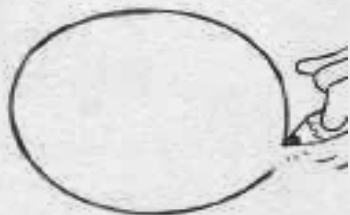
Olivia: Sophia Lucia because she is an amazing dancer and she is so determined to get better at everything she does even though she is amazing.

Jared: I would like to meet Hugh Jackman because he sounds like a really nice guy and he is the best actor in the world in my opinion.

HOW TO DRAW AN ELEPHANT

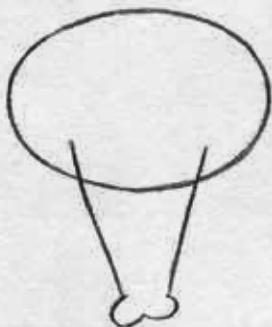
STEP 1

Draw a circle.



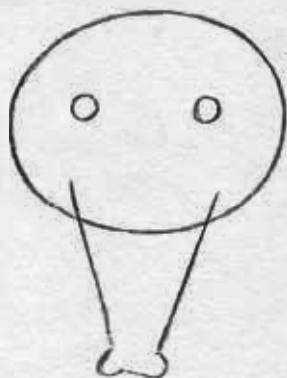
STEP 2

Add a trunk.



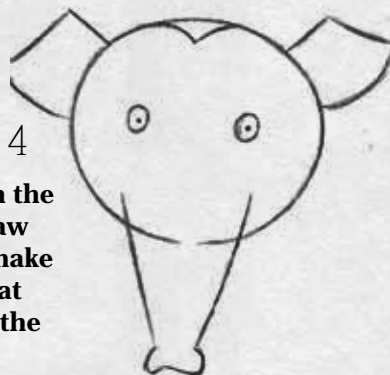
STEP 3

Add two small circles for eyes.



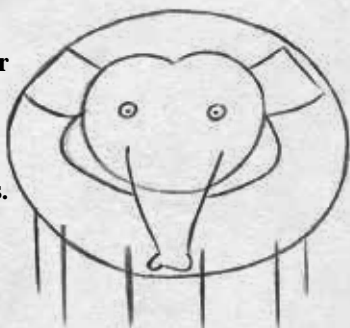
STEP 4

Put dots in the circles, draw ears and make a triangle at the top of the head.



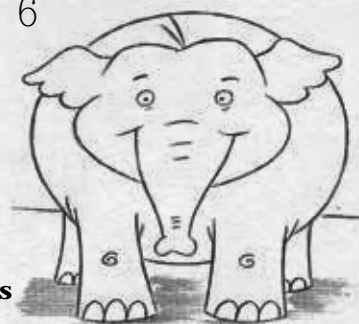
STEP 5

Draw another larger circle around the head. Add wider cheeks. Add 6 lines for legs. Rub out top part of head.



STEP 6

Draw in details for legs. Add tufts of hair on top of the head. Add details for trunk.



There's your elephant!

GAME ON!

New additions to our Wii games collection, available for loan to members.

Here is a brief review of the games:

1. JUST DANCE 3

Like Just Dance 1 and 2, this has a mix of old and new hits which everyone in the family will have fun dancing to. If you are feeling a bit bored of your normal exercise routine, doing several of the dances in this game will get you moving. Ask your brother, sister, mum or dad to do a few tracks with you. Aim to do this for at least 30 to 45 minutes to get your heart pumping.



2. BIG BEACH SPORTS

This game takes a while to set up your character. The games don't really give you a work out at all, and you could play them by sitting down. This would be ok to pass some time, but definitely not good for a workout.



Fitness



Fun



Fitness



Fun



If you don't already have these games and want to try them out, please call us at CFWA or email equipment@cysticfibrosiswa.org for more details.

Woven Sun

If you are sitting somewhere like in a hospital or even at home, bored out of your brain, and you like a bit of craft, this activity will certainly pass some time.

Adapted from "Michele made me" craft blog.

STEP 1:

Trace around the plate onto the card. Cut out the circle. Repeat Step 1 and cut out a second circle which you can put aside for later on.



STEP 2:

Using a ruler and pencil, rule four lines like spokes on a bike wheel, that go across the circle straight through the middle.

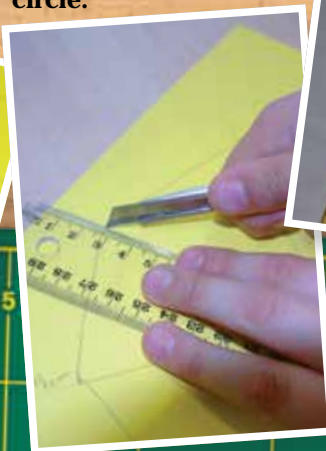


WHAT YOU WILL NEED

- ☐ CARD
- ☐ SEVERAL BITS OF BRIGHTLY COLOURED STRING OR WOOL, ABOUT 60CM IN LENGTH
- ☐ A PLATE ABOUT 20CM IN DIAMETER. YOU CAN GO BIGGER BUT IT DEPENDS ON HOW MUCH WEAVING YOU WANT TO DO.
- ☐ PENCIL
- ☐ RULER
- ☐ PAIR OF SCISSORS
- ☐ HOLE PUNCH
- ☐ STANLEY KNIFE - YOU WILL DEFINITELY NEED PARENTAL SUPERVISION TO USE THIS
- ☐ SOMETHING TO LEAN ON WHICH DOESN'T MATTER IF IT IS CUT.

STEP 3:

Measure 1.5cm from the middle of the circle around the spokes and connect the dots to make an even smaller circle.

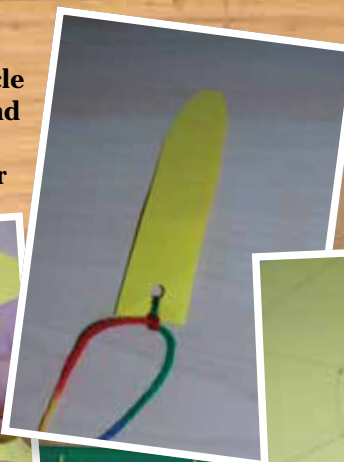


STEP 4:

Parental supervision required for this step: Using a stanley knife, cut slits along the spokes of the wheels, but start from edge of the smallest circle and end at the edge of the middle circle.

STEP 5:

Make a needle by cutting out a small rectangle from the card. Make one end round and put a hole punch through the other end. Tie some wool onto the needle.

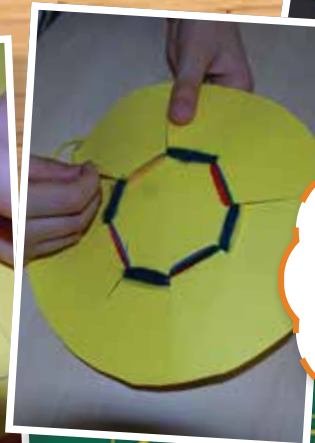
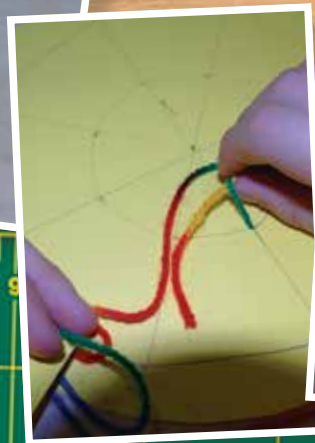


STEP 6:

Leave a bit of wool hanging out at the start and then thread the needle under and over the slits very close to the small circle in the middle. Go around as many times as you want using that colour. Once you want to change to another colour, thread back to where the yarn is hanging, untie the wool from the needle and then tie a knot. (Make the knot on the other side of the circle.

STEP 7:

Repeat Step 6 with as many different colours as you have. You may like to do a pattern or have an explosion of colour, until you have filled the circle to the edge (where you have drawn the outer circle).



STEP 8:

Match the other circle to your woven circle and using a hole punch, put holes around the edge of both the circles.

STEP 9:

Thread a darker coloured piece of wool through the holes around the edge, tie a knot at the back leaving two equal sized strands which you can use to hang up your amazing creation.



Note

You can use other materials e.g. coloured plastic bags, cut into thin strands.

If you cut out a large circle you may not want to complete the weaving in one sitting, it might take you a while.



HAPPY CAMPER

Every year CFWA runs a Siblings' Camp for brothers and sisters of people with CF. The camps go for 2 days and there are lots of fun activities organised each year. The camps are open to siblings aged 8 to 16 years.

Q: HI ASHLEIGH! TELL US A LITTLE BIT ABOUT YOURSELF (HOBBIES, WHERE YOU LIVE, FAVOURITE THINGS YOU LIKE TO DO, WHAT WOULD YOU LIKE TO DO IN THE FUTURE?)

A: I am 12 years old and I am the youngest in my family. I love spending time with my family and I have a brother who is 14 and he has CF.

I am an outdoor person; I love to go fishing and camping. I live in South Hedland which is 15 minutes out of Port Hedland. I love to read and jump on our trampoline. When I'm older I want to be a marine biologist.



Q: HOW MANY SIBLING CAMPS HAVE YOU BEEN ON AND WHAT MADE YOU WANT TO COME ALONG FOR THE FIRST TIME?

A: I have been on three Sibs' Camps; the 2013 one is my third. My mum used to tell me about the camps when the information came in the mail. She used to read out to me all the fun the kids had from the CF magazine.

I wanted to attend when I was 8 and 9 years old, but we lived in Broome and mum wouldn't let me or my brother travel on a plane by ourselves. So when I turned 10 mum let me go and it was awesome.

Q: WHAT WAS YOUR FAVOURITE ACTIVITY ON THE CAMP?

A: All the activities are super fun but I would have to say I like the flying fox the best because you can go upside down and it's awesome. I also thought the Lost Pilot activity at the 2012 camp was fantastic and I really enjoyed it.

Q: HAVE YOU FOUND THE CAMPS YOU'VE BEEN ON HELPFUL?

A: Yes it helps me understand more about CF and how to cope with new changes. It's all done in a fun way. It is also nice to know that I am not alone and other people have family members just like my brother.

Q: WHAT WOULD YOU SAY TO SIBLINGS THINKING ABOUT COMING TO THEIR FIRST CAMP?

A: You will love it - trust me, it's exciting! You will meet new people and no one on the camp will make fun of you. If you have a problem you can talk to the camp leaders. They are all really good, nice, friendly and really helpful. The other campers are just like you, they too have someone in the family with CF and it is nice to meet kids just like yourself. The activities are so much fun, I can't wait for the next one.



Q: IS IT DIFFICULT BEING A SIBLING OF SOMEONE WITH CF? WHAT ARE THE NEGATIVES AND POSITIVES?

A: Yes it is quite difficult being a sibling of someone with CF. We live in South Hedland and my brother has to fly to Perth every 3 months for his check-ups. That means mum usually has to take him so she is away from home for a few nights. With all the different medications my brother is on, it can get very confusing, and some of the medication makes him very cranky and unbearable at times →

→ -that would be the worst part. I hate seeing my brother sick.

The positives are that I get to go on Sibs' camps. It has given me an opportunity to write in the Rozee Magazine and I also get to eat some of the yummy food my brother gets to eat.

Q: DO YOU HAVE ANY TIPS FOR YOUNGER SIBLINGS WHO HAVE A BROTHER OR SISTER WITH CF?

A: If your brother or sister are on medications that makes them cranky, stay away from them, but offer them support if needed. Ignore their behaviour, they can't help it. Always think positive about things and be thankful you are healthy.

Caitlin's just hanging around.



Run Holly run!



Oscar getting involved!



The 2013 gang!



heights & flights

Sibs' Camp '13

The Siblings' camp is held every year and is especially for kids who have a brother or sister, or even a parent, with CF. It is two days packed full of fun, excitement and adrenalin-pumping activities that you may never have had the chance to do before. You will make lots of new friends and meet other kids who know what it's like living with someone with CF.

The 2013 camp was at Woodman Point, right on the beach near Fremantle. 21 kids aged 8 to 16 attended. The theme was 'Heights and Flights' so we had lots of games and activities based around this theme.

The Scitech team came and did a special show, teaching everyone about the science of flying; battling gravity and the laws of physics to fly balloons, aeroplanes and rockets!

We were able to do rock climbing

and a ropes courses inside 'The CUBE', which

is a very cool indoor roping facility that includes high ropes and abseiling. We went on the flying fox from the top of 'the CUBE' that was 10 meters high and 120 meters long!

We spent some time in the ocean learning surf lifesaving skills such as performing rescues and playing flags. Then it was time to test everyone's teamwork skills by attempting to build rafts from some plastic bollards, planks of wood and ropes. The real test came when it was time to set sail in the ocean - luckily all the rafts stayed together and floated.

During the evening, Robbie the magician came and performed some amazingly unbelievable acts leaving everyone gobsmacked!



Learning some surf life- saving skills.

YOUR FEEDBACK FROM THE CAMP:



What was your favourite activity & why?

- ★ My favourite activity was the flying fox and raft building because I thought I couldn't do the flying fox but I did, and the raft building because we worked as a team.
- ★ The cube because I love to climb, the magic show because he tricked us all and the flying fox because you could go upside down.
- ★ I liked the magic show because there was a box with nothing in it then a real bunny appeared.
- ★ The flying fox because it was high up and fast.
- ★ The rock climbing because I could make it to the top.
- ★ The magic show, it was amazing.

What did you think about the goody bag you received?

- ★ I thought that the t-shirts and the goody bags were the BEST!
- ★ Great. Very, very, very great.

Did you learn anything that will help you in the future?

- ★ How to get over your fears.
- ★ To take challenges.
- ★ That I can do anything, as long as I set my mind to it.
- ★ I learnt how to tie a spider knot.

Would you come on a CFWA Sibbs' Camp in 2014?

- ★ Yes I would because no matter what we do it's always fun and worth coming to.
- ★ Yes because it's so fun and you get to meet new people.
- ★ Yes because it is fun and exciting.

THERE'S ONLY ONE DIRECTION FOR CHARLIE

CHARLIE IS A 12 YEAR OLD WHO HAS CYSTIC FIBROSIS. SHE IS A HUGE FAN OF 'ONE DIRECTION' AND WHEN HER MUM PUT HER 'MAKE-A-WISH' APPLICATION IN, WHICH WAS TO SEE THE 'ONE DIRECTION' CONCERT IN PERTH AND MEET THEM BACKSTAGE, IT DIDN'T SEEM THAT IT WAS GOING TO BE POSSIBLE. BUT LUCKILY THE MAKE-A-WISH FOUNDATION WERE ABLE TO MAKE CHARLIE'S WISH BECOME A REALITY.

TELL US ABOUT YOUR "ONE DIRECTION" EXPERIENCE CHARLIE?

I was at school and a teacher announced over the PA system that my "Make-A-Wish" had come true and I was going to see "One Direction" in concert and meet them backstage. My mum had received the news and asked if they could announce it over the PA. I screamed and cried because I was so happy.

When the day arrived for us to go to the concert, a limo came and passed by my house, but then it turned around and parked in my

driveway. Everyone in my family was excited especially my little brother Ben. A man stepped from the limo and rolled out a red carpet. He gave me a cord so I could play music from my Ipod in the limo and I chose "One Direction". Mum was being weird trying to sing along!!

My mum, my nan and I all got to ride in the limo to the "One Direction" concert. When we got there the backstage crew escorted us to the Green Room (the place



MAKE-A-WISH.

How to apply

You will need to ask your parents to either download an application form from the website www.makeawish.org.au or ask at your hospital if they have any forms, or you can call 1800 032 260 to speak to someone or email wishes@makeawish.org.au to ask for a form to be posted to you.

Once the form has been filled out, your parents will need to ask your CF nurse and doctor to fill out parts of the form too. You may also want to include a letter you have written about your wish.

There are four types of wishes that begin with:

I wish to be...

I wish to go...

I wish to meet...

I wish to have...

The most common wishes that children make are for a computer, cubby house or a trip to the Gold Coast.

Once your application is sent off, the Make-A-Wish Foundation will keep you posted about things by phone and emails. Your application will be handled by a staff member working over east, however if your Make-A-Wish is happening in Perth, a volunteer from Perth will also help your wish come true.

Allow time for your wish, as it can be a lengthy process depending on what your wish is.

**THERE'S ONLY
ONE DIRECTION
FOR CHARLIE**

where the famous people hang out before they start their performance). Six body guards came to the room first followed by the "One Direction" band members. I didn't really know what was happening. They were in the corner and there were other kids there too waiting to meet them. We all lined up to see them. I got my photo taken with them and I was introduced to them by Jess a volunteer from the Make-A-Wish Foundation.

The concert was loud but good. I screamed. I got to see them do the sound check too. There were only 100 people there at that point. We were only 6 rows from the front.

HOW LONG HAVE YOU LIKED ONE DIRECTION FOR AND DO YOU HAVE ANY FAVOURITE BAND MEMBERS? I have been into "One Direction" for about a year and a half. My two favourites are Loui and Niall. They are the cutest.

WHAT OTHER THINGS ARE YOU INTERESTED IN Other things I am into other than "One Direction" is soccer and playing the drums.

WHAT WOULD YOU LIKE TO DO WHEN YOU ARE OLDER?

When I am finished high school I would like to be a personal trainer.

COP A LUNGFUL OF THIS

LUNGS HELP YOU BREATHE. THE END.
NOT!!

THEY DO SO MUCH MORE THAN THAT!!

Did you know that you breathe about 20,000 times a day? You do this so that your lungs get oxygen into them. Oxygen is one of the gases found in air and every single cell inside you needs the oxygen you breathe in for energy!

Lungs are like two spongy bags inside your chest. They are extremely important as they supply the oxygen to the cells in your body. Each time you breathe in, air travels down your windpipe (trachea) which splits into two, giving each lung some oxygen.

Your lungs are filled with bronchi, which are like spongy tubes that branch into even smaller tubes called bronchioles, a bit like the way a tree has branches. Then like leaves attached to the branches or like bunches of grapes, there are tiny bubbles called alveoli on the end of the bronchioles. There are about 300 million alveoli in your lungs. The alveoli are covered in tiny blood vessels and oxygen travels from the alveoli into the blood vessels where it is carried around your body in your blood.

While oxygen is being carried around in your blood, your lungs also get rid of carbon dioxide (which is the waste product) when you breathe out. Plants do things the opposite way around and suck in carbon dioxide and produce oxygen.

LUNGS AND CF:

The human body is made up of about 50 billion cells which are so tiny they can only be seen through a microscope. There are different types of cells in the body with different jobs to do. For a cell to work properly in the body, there needs to be a balance of salt and water. It's like each cell has a security guard with instructions on how much salt and water is allowed in and out of the cell.

In a person with CF, the cell security guards have the wrong instructions, so they let too much water into the cells and so there's not enough water outside the cells. This is what makes the mucus in the body so thick and sticky.

The mucus clogs the airways in the lungs (the bronchioles and bronchi) which makes it hard for oxygen to get through and into the blood stream. That's why some people with CF can get out of breath more easily. The mucus in the lungs is also an attractive place for bacteria to hang around which can cause chest infections.

That's why it's so important to do the daily thing that perhaps, if you have CF, you don't like having to do, PHYSIO!! If you are doing your physio each day you are really helping to slow down damage to your lungs and to cut down the risk of infections.

What actually happens when you are doing your physio routine is that you are getting air behind the mucus and this helps to push the mucus up your trachea (windpipe) so you can spit it out.

Even though doing physio can be a bit of a drag, it really needs to be a part of your daily routine, like brushing your teeth.

OTHER THINGS TO DO TO LOOK AFTER YOUR LUNGS:

Everyone should look after their lungs, not just people with CF, so things like avoiding smoking and exercising regularly are good for all members of your family to do.

EXERCISE:

Lots of investigations have been done which prove that exercise has many benefits for everyone and particularly for people with CF. Regular exercise for people with CF can help to clear mucus from the lungs, build up muscles and strength, improves your posture and helps your lungs to work better, plus exercise can make you feel good.

Exercising most days, doing a sport or something else which makes you huff and puff, is a great way to help your lungs. The more fit you are, the stronger you will feel and the better your body will be able to cope if you get sick.

It is most important though, to pick a type of exercise that you really enjoy and want to keep doing; it could be yoga, dancing, running, football, tennis, trampolining, skipping or netball, as long as it gets your heart pounding and makes you huff and puff. Make sure you are eating lots of calories to give you the energy you need to exercise. If you want to know more about the different types of exercises that you can do, you might want to talk more with your parents, as well as your CF physio, who can give you lots of advice on the best types of exercises to fit in with your life.

Your local CF organisation might also be able to provide some funding towards exercise equipment, so it may be worth asking your parents to look into this too.

Remember to make sure you have water and salty drinks like Gatorade and take your salt tablets with you when exercising, especially in hot weather, and also to let your sports teacher or team coach know about some of the things you may need to do while exercising e.g. spitting up mucus, going to the toilet, or letting them know if you are tired and don't feel up to doing things at full capacity. This may be something your parents have already spoken to your teachers about.

MEDICATIONS:

Having to do nebulised antibiotics can be time consuming and annoying, but the reason why you may have to do this is because the medications such as the hypertonic saline are helping to thin the mucus so it's easier to clear, or Tobramycin which helps attack bugs in your lungs.

AVOID CIGARETTE SMOKE:

It is well known that cigarettes are bad for you and the reason is that they contain almost 5,000 different types of chemicals, with about 69 known to cause cancer and other diseases. Smoking cigarettes is more risky, but breathing in second-hand smoke is not ideal either. Smoke

from cigarettes contains irritants that cause inflammation of the airways, which is something that people with CF don't need, as their airways are already inflamed and affected by thick and sticky mucus.

Many studies have shown that people with CF who are exposed to second-hand cigarette smoke tend to have more regular and serious lung infections than those people who are not exposed to cigarette smoke.

COLDS:

People tend to get more colds in winter, not because of the colder weather but because we are usually hanging around indoors more often with other people. And when people cough and sneeze, germs spread through the air. It is impossible to avoid colds and other viruses, but you can reduce the risks by making sure you wash your hands before eating, use hand gel throughout the day, avoiding putting your hands near your eyes or mouth and stand well away from someone who looks like they have a nasty cold.

So you can see there is quite a lot involved in how the lungs work, and as you already know, if you have CF you do have to work quite hard to look after your lungs. Just remember there are a team of people helping you to look after your lungs such as your parents, your siblings, your close friends and also your CF medical team. All these people need to look after their lungs too!!

I KNOW I NEED TO EAT LOTS, BUT I DON'T FEEL LIKE EATING.

If you have CF and you need to take enzyme capsules to help with digesting your food, you may also find that there are times when you don't always feel like eating the high calorie foods that you need to eat. Sometimes you might just feel like eating fruit and vegetables or even nothing.

The thing is, most people with CF really do need to eat more calories in their day than other people. This is because quite often, the lungs in a person with CF have to work extra hard, so more food is needed for energy. Also the pancreas in the digestive system is often blocked by mucus so it makes it more difficult to digest food.

Lots of studies have been done which have shown that eating all those extra calories helps the lungs in a person with CF to work better and to fight infections.

This may sound fantastic to people who don't have CF, but it can be really quite tricky if you don't always feel hungry. (This can be common for people with CF).

Here are some tips to use if you don't have much of an appetite which you can share with your parents if you think some might work for you:

☐ Put your meals on a larger plate, which will make your meal look smaller, so it looks like you don't have so much to eat.

☐ Use short, fat glasses for drinks like milkshakes, so it will seem like you have less to get through.

☐ Salty or sour tasting foods can be better to eat than fatty or fried foods if you are feeling sick.

☐ If you feel sick, try things like crackers, dry toast, vegemite, lemon tart or flat lemonade.

☐ Eating regular small meals (e.g. 6 meals a day) may work for you, instead of 3 big meals.

☐ If you are not feeling too hungry some foods that are easier to eat are things like milkshakes, soups, puddings, custard, small sandwiches and breakfast cereals.

☐ Try to eat at regular times each day such as eating every 3 hours, so you avoid missing meals. If you keep skipping meals that can make you even less hungry.

☐ Keep snacks within easy reach so you can grab something whenever you need to. If you need to eat more at school, ask your parents to chat

with your teacher to see if you can have some snacks handy on your desk to munch on. If you and your parents can explain why you need these extra snacks, your teacher and the other students, in most cases, will be very understanding. Your body needs the extra calories in the same way that other people have dietary needs e.g. people with diabetes need to keep things like jelly beans on hand, and people who are allergic to nuts need to avoid coming into contact with them.

☐ Ask your parents to take some handy snacks for you when you go out e.g. muesli bars, boxes of sultanas etc. so you can have a munch while you are at your swimming lessons or while driving in the car to visit friends.

☐ Try to avoid drinking lots while you are eating as that can fill you up, but remember to have drinks in between meals.

☐ Exercise is really good for you in many ways, but it also can increase your appetite, so keep this in mind and eat extra food if you are playing sport or exercising.

LEMON PUDDING

(easy but you might need assistance from your parents for some bits)

Ingredients:

2 cups (500ml) single pouring cream
½ cup (110g) castor sugar
1/3 cup (80ml) lemon juice
raspberries, blueberries or strawberries to serve

Equipment:

4 (180ml sized) cups, glasses or ramekins
saucepan
wooden spoon
measuring cups or scales



What to do:

1. Pour cream and sugar into a saucepan over a medium heat. Bring to a simmer, stirring occasionally.
2. Allow the mixture to simmer for 6 minutes or until the level of the mixture has reduced slightly.
3. Add the lemon juice and simmer for a further 2 minutes.
4. Pour into 4 glasses, ramekins or cups and put into the fridge until set.
5. Serve with fruit eg raspberries, blueberries or strawberries.

Taken from "Fast, fresh, simple" by Donna Hay.

☐ If you haven't got into it yet, try your hand at a bit of baking or cooking (obviously check with your parents that this is ok – you might need mum's or dad's assistance while you are learning). There are so many amazing recipes out there in books and online. Maybe your parents have some yummy dishes that you could help

them prepare. Being able to cook is a very handy skill to have (it can take a bit of practice) and if you're able to cook or bake a few delicious snacks or dishes, your family will be very grateful and impressed. (You might get out of doing other chores!!)



HAVING A SIBLING WITH CF: COMMON FEELINGS AND THOUGHTS

Brothers and sisters are very important. They keep us company, have fun with us and sometimes teach us things. You probably love and care lots about your brother or sister and they probably help to teach you to be more patient, and understand that everyone is different.

You may experience lots of different feelings about having a sibling with CF, sometimes good, sometimes not so good. Having a brother or sister with CF can sometimes make life more complicated. Some common feelings are listed below.

WORRY

You might worry about the future and what will happen to your sibling. Sometimes you might worry about asking new friends over to your house as you might have to explain why your brother or sister is coughing, doing physio or taking medication.

EMBARRASSMENT

You might feel embarrassed about your brother's or sister's

appearance, such as if they have a PICC line in or they look skinnier than other people.

You may feel embarrassed when strangers stare at your brother or sister when they cough, or when people ask lots of questions about them.

GUILT

You may feel guilty that your sibling is unwell and you aren't. You may even sometimes wish that you were sick too, so you could get more attention from your family.

JEALOUSY

You might feel jealous of your sibling if they are getting lots more attention from your parents and others. In some families the child who is ill gets more presents, and more people make a fuss of them. It can seem that people are not as interested in the things that you do.

ANGER

You might feel angry if you have to miss out on planned activities due to hospitalisations, or that your parents are at the hospital a lot with your brother or sister. You might feel angry if you are asked to do more household chores than your sibling.

Feeling angry with your brother or sister is normal. This happens in all families. Ask your friends this and they'll say they get mad at their brothers and sisters too sometimes.

SADNESS

You might feel sad when you think about your brother or sister being unwell or when it seems like no one else understands what it is like to be a sibling of a person with an illness like CF.

You may also think that your feelings don't matter to anyone else, that you are not as important as others in the family.

IT'S OK

Having these feelings is not a bad thing - it is ok to feel angry, frustrated, sad or embarrassed. In fact, most brothers and sisters (and adults too) will have these feelings at different times, it's just a part of life and being human.

YOU ARE NOT ALONE

There are lots and lots of children who know how you feel - other siblings can understand the good and not so good things you might feel about having a brother or sister with CF.

Other siblings share many of the feelings and experiences that you do.

Many siblings also have very close relationships with their brother or sister. They share fun times and are able to be just like any other siblings.

POSITIVE FEELINGS AND EXPERIENCES

PRIDE: For your brother or sister 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.

BEING ABLE TO ADAPT TO CHANGE EASILY: You may have learnt from your brother or sister that sometimes plans have to change due to your sibling having to go to hospital, or doing extra CF treatments at home. Being able to accept changes and adapt easily is a great skill to have for later on in life.

BEING MORE MATURE: Growing up with a brother or sister with CF can help siblings learn to be more grown up than some of their friends. This can be a good thing. Some things you have learnt will really help you when you're older.

Which of these have you learnt from being a sibling:

-  Being understanding of people who are different.
-  Knowing a lot about medical things.
-  Being a responsible person.
-  Helping your parents with extra chores.
-  Feeling glad to be healthy and able to do things.

WHAT CAN YOU DO IF YOU WANT SOMEONE TO TALK TO?

You don't have to manage things on your own if you are feeling worried, angry, guilty etc. There are people who can give you advice or a different point-of-view which can really take the pressure off your shoulders.

➔ **MAKE A LIST OF PEOPLE YOU CAN TALK TO IF YOU FEEL ANGRY OR SCARED.** This could include your mum or dad, grandma or grandpa, a special aunt or uncle, a friend or school counsellor.

➔ **YOU CAN ALSO CALL KIDS HELPLINE ON 1800 551 800 FOR A CHAT.** They run 24 hours a day, seven days a week and are for 5 to 25 year olds. They are also online at www.kidshelp.com.au



➔ **IF YOU FEEL LEFT OUT AT HOME, TALK TO MUM OR DAD ABOUT HAVING SOME SPECIAL TIME** with just you and them.

➔ **TRY TO FIND OUT AS MUCH AS YOU CAN ABOUT CF** - from parents, teachers, books, CFWA or other people who take care of your brother or sister so there is no confusion about what is going on. If you don't understand something or are worried, it's really important that you speak to your parents about it.

➔ **THERE'S ALSO YOUNG CARERS WA WHICH HAS A GREAT WEBSITE AND ALSO OFFERS DIFFERENT KINDS OF SUPPORT FOR YOUNG PEOPLE WHO HAVE TO HELP CARE FOR SOMEONE WITH AN ILLNESS.** They run camps, art classes and other activities. Find out more details from their website at www.youngcarers.net.au

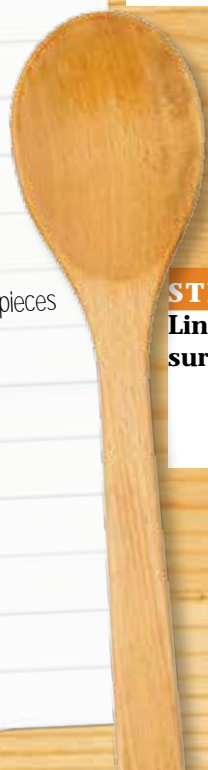
➔ **LIVEWIRE PROVIDES FREE, SAFE AND FUN ONLINE COMMUNITIES FOR FAMILIES AFFECTED BY SERIOUS ILLNESS AND IS FOR 10 TO 21 YEAR OLDS.** Their website is www.livewire.org.au

How to make: A Cow Poo Cookie

What you'll need:



- ☐ 250g packet of plain biscuits
- ☐ a large plastic bag
- ☐ wooden spoon
- ☐ 150g butter cut into pieces
- ☐ rolling pin
- ☐ 18cm round cake tin
- ☐ 150g plain chocolate broken into pieces
- ☐ mixing bowl
- ☐ choc drops
- ☐ small saucepan
- ☐ a handful of raisins or sultanas
- ☐ cooking foil
- ☐ desiccated coconut
- ☐ green food colouring



STEP 1:

Put the biscuits in the bag. Make sure the bag is sealed and crush biscuits into tiny pieces with the rolling pin. Put crumbs into the mixing bowl.



STEP 2:

Line the cake tin with foil, make sure it goes to the edges.



STEP 3:

Put the butter and chocolate in the saucepan and heat gently. You may need an adult to help with this step. Stir until chocolate and butter is melted. Pour into the mixing bowl.



STEP 4:

Add in half the choc drops and sultanas.



STEP 5:

Spoon the mixture into the cake tin and press down with the back of the wooden spoon. Make circular patterns on the top. Put the biscuit in the fridge to set for at least 2 hours.



STEP 6:

Add food colouring to the coconut and mix. Put around the edge of a serving plate.



STEP 7:

Take biscuit out of fridge when it's set. Take out of the tin and place on the serving plate. Sprinkle the green coconut on the top for grass, with a few choc drops and sultanas (for flies).



STEP 8:

It looks a bit yuck but tastes really YUM!!!



A DAY IN THE LIFE OF...

JORDAN

HI My name is Jordan; I live in South Hedland, WA. I was 15 in November and I have CF. I have a sister named Ashleigh and she is 12 years old.

I have a pet German Shepherd dog named Akeera, she is 4 years old and thinks she is still a puppy. Akeera loves water and doesn't care what kind of water she swims in.

I am employed casually at Brumby's and I work there a couple of days a week.

My main hobby is gold detecting which I have to get up real early for, if I want to go. also play touch rugby once a week which I love and it is best when I get a tri or two.

I enjoy fishing and camping too.

MY USUAL DAY STARTS LIKE THIS... |

My mum usually wakes me up in the morning. I take my Cipro antibiotics (because that has to be taken on an empty stomach) then I start my physio and finish with nebulised antibiotics (this can take up to 45 minutes to 1 hour).

Now I have to have breakfast, which normally consists of a bowl of cereal and a large glass of extra protein milk, or my mum will cook me some eggs and make me an extra protein milk drink and then I have to take lots of enzymes and vitamins.



MY SCHOOL UNIFORM



YUM



Then I get ready for school. School starts at 8:05am and either mum or dad take me or I catch the bus (which I have to be at the bus stop by 07:30am) and that means getting up even earlier so I don't miss the bus.

School finishes at 2:15pm and I catch the bus to the shopping centre where I work.

I start work at Brumby's at 3:00pm and finish at 6:30pm. Mum or dad picks me up.

I am starving by the time I get home from work so I grab my enzymes and we all sit down and have dinner. Sometimes I get to bring left over cakes home.

I have my shower, let my dinner go down, do my homework and relax before I start my physio and nebulised antibiotics all over again.

At around 10:00pm, I take my Cipro once again and I go to bed.



BOOK:

What's up with Beth? Medikidz explain Cystic Fibrosis

If you're aged between about 9 to 15, this is a good book to explain various things about cystic fibrosis in an interesting way using cartoon characters.

Ask your parents to contact your local CF organisation to see if they have any copies available or else you can find the book online through websites such as Amazon, Book Depository etc.



To borrow this book or other books from the CFWA library ask your parents to either email education@cysticfibrosiswa.org or call 08 9346 7333. To see what books we have you can also browse online at <http://cflibrary.org.au/>

PHONE/ IPOD APPS: (FREE)

Remember to check with your parents about downloading any apps through iTunes!

POCKET FROGS (FREE)

You can make new frogs, look after them and make tadpoles. The frogs have different habitats which you can change. You get a gift each day in the menu.

Compatible with iOS 4.3 or later. Use with iPhone, iPad and iPod touch.



CF BUDDY IPHONE APP (FREE)

This app keeps you occupied while you do your physio exercises. You can design your own buddy and your parents set up what type of physio routine you do. Each time you do your physio you gain points which you can spend in the shop to add more features to your physio buddy.

Compatible with iOS 5.1 or later. Use with iPhone, iPad and iPod touch.



ON YOUTUBE

EVAN TUBEHD (www.youtube.com/user/evantubehd)

This is a family friendly website with videos on YouTube by a young boy, Evan, who reviews toys, visits different places and makes things. His sister also reviews a few toys too. If you like Angry Birds, Mine Craft, Skylanders or Star Wars you will love this guy and his reviews.



Rozee is looking for young people to contribute to this page. If you would like to be a regular reviewer or just want to give us a couple of ideas for books, games and items on YouTube, contact us at CFWA.

Lungs Word Puzzle

p o m a w h n p e g c b y x e
 o u r j n e q x o k c p m u h
 f e g l g t e g n w a h u q t
 a h d y u r i h a r c v c r a
 e z x i c n e b e p s v u n e
 s o i i x t g h i y u a s e r
 c v s p l o t s n o a c d b b
 h e k b y o i b v t t l a u q
 l c b y i o c d m s p i a l r
 j x h s c a r b o n l p c i e
 e b y b r o n c h i o l e s c
 d h k w a k g v x r g q e e a
 p u p i l o e v l a x h l r v
 c a l e w i x b t l m l q k i
 g c s r a v v t p t s d q t g

alveoli
 antibiotics
 breathe
 bronchioles

carbon
 cells
 dioxide
 exercise
 lungs

mucus
 nebuliser
 oxygen
 physiotherapy



FREAKY FACT OR FICTION?

An American man, known as The Texas Snake Man held ten live rattlesnakes in his mouth by their tails in 2006.

He also sat in a bathtub with 87 snakes for 45 minutes in 2007.

Fact or fiction?

Answer:

Fact !!

Taken from "Freaky Fact or Fiction World Records" by Dianne Bates

Jokes to have up your sleeve:

Knock knock
 Whos there?
 Beets!
 Beets who?
 Beets me!

Q. There were four cats in a boat, one
 jumped out. How many were left?
 A. None. They were all copy cats.

Q. How do you fix a broken tomato?
 A. Tomato paste!



**Cystic Fibrosis Western Australia would like to acknowledge
the support of Telethon for helping us bring Rozee to you.**