

SUMMER 2021

A MAGAZINE FOR KIDS WHO HAVE CF AND THEIR SIBLINGS

ROZEE



The Power of Positivity

First ever SIBS day out

Hospital in the Home

Salt & Vitamins... But why?



CYSTIC
FIBROSIS
Western Australia

ALL
AWESOME!

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Editor's Letter

Welcome to the 9th edition of ROZEE Magazine!

This is Gillian's 5th edition of ROZEE and Maggie's 2nd – and its our second edition working together!

In this edition, we have an awesome interview from Amanda who is an adult with CF. She tells us a little bit about how she lives a very full life and makes the most out of all her opportunities.

We also have lots of great stories like what a day for Montanna looks like and meeting our members Ben and Jordan. We know this year has been a bit wild and crazy, so we have included some tips on how to be positive even when you aren't feeling like it.

There's lots of fun stuff too, like making a rose stamp, a delicious and fatty recipe for brownies, and a fun emoji quiz!

We hope you enjoy this edition of ROZEE and you have a wonderful Christmas!

Bye for now,

Gillian and Maggie

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Ask... Amanda



Amanda is an adult who has CF, she just turned 50 years old and works as a nurse. Amanda lives with her husband Kevin, two dogs – Lucy and Ben – and a cat named Gus. She enjoys cooking, reading, travelling, gardening, fishing, and going out on her boat.

RoZEE was lucky enough to have a chat with Amanda. She tells us a little bit about how she lives a very full life and makes the most out of all her opportunities.

What is something unique about you?

For the past 18 years I have lived in remote areas of Western Australia. I lived on Rottnest Island for a year and then moved up to the Kimberley Region. I have lived in some extremely remote Aboriginal Communities and towns in the Kimberley Region. The Kimberley weather (which is very hot!) and the distance can be quite challenging when living with CF but with the flexibility and willingness to help of the CF Team at Sir Charles Gairdner Hospital, I have done this successfully.

Why did you decide to become a nurse?

I kind of fell into nursing in my early 30's. I was travelling and ended up in Fitzroy Crossing, a remote Aboriginal town in the Central Kimberley. I met the Dean of Notre Dame University who told me I should be a teacher as I had developed a program for the Aboriginal kids where they got to use the pool if they went to school. I told him I was a Drug & Alcohol Counsellor/Educator and he then advised me about nursing. As the days went by the idea kept popping up in my head until I enrolled.

What steps do you take to achieve your goals?

To achieve goals, I write myself a list at the back of my diary at the start of each year. Everything from travel, personal goals, work goals and financial goals. I also set myself a weekly list of tasks and goals. I must admit, I have several things on the go at any one time.



With such a busy life, what motivates you to keep up with your treatments?

I make sure my treatments are done daily so that I do not get unwell. There is nothing worse than feeling chesty and coughing throughout the day when I do not have to by not doing treatment. Upon saying this, I'm not perfect and sometimes get too tired to do my nebs so I try to do them early rather than later in the evenings. All my daily tablets are in a lunch container under the coffee table and I put all my daily tablets into a bowl in the morning to ensure they are all taken. Nebulisers are done in front of the TV and I try to schedule them at the same time so that it becomes routine. Netflix, iView and SBS is my go-to when having treatment.

What advice do you have for kids (and/or their siblings) that have CF?

Live life! Do not let CF stop you doing anything you want to do in your life. That is, do not let CF define you! Do not skip your treatment. Allow your treatment to fit in with your life. A great way to do treatment is watch Netflix or your favourite recorded shows. This is your time, so make it work for you. The key is to stay as healthy as possible, take all medication and treatments so you can live life as much as possible. I know it is time consuming and boring, I have been there, but doing treatment and taking your medication will give you a better quality of life. Trust me, the older you will look back and thank you down the track!



A DAY IN THE LIFE OF

MONTANNA



Hi, I am Montanna and I am 17 years old. I have my mum and my dad, my older sister and my younger brother in my family. I enjoy working, going to the gym and catching up with my friends when I'm not working. This is what my Wednesdays normally look like:

7:00am: Shower then physio
(Bronchitol, Pari-pep 10 sets of 10, Tobi Podhaler)

7:30am: Breakfast and tablets

8:15am: Drive my brother and I to school

8:45am: School starts

10:50am: Recess

11:10am: School work

1:00pm: Lunch

1:40pm: School work

3:30pm: School finishes and I drive my brother and I home

4:00pm: Eat afternoon tea and do my homework

5:00pm: Arrive at the gym. I usually do a 20-minute run on the treadmill

5:30pm: Go to a pump class (weights class) at the gym

6:30pm: Pump finishes and I get changed and ready for work

6:45pm: Drive from the gym to work

7:00pm: Work starts

10:00pm: Work finishes and drive home

10:15pm: Shower, eat, physio
(Bronchitol, Pari-pep 10 sets of 10) and homework

10:30/11pm: Tobi Podhaler and bedtime



Taking your tablets each day is an important part of your routine, but do you know what you are taking and why?

Salt

Do you take salt tablets or liquid?

A lot of people like you, who live with CF, probably take salt to help stay healthy. You may take it once a day or even more, especially when the weather is warm or if you have been exercising or running around outside. When you get hot and sweaty you lose more salt in your sweat, a lot more than people without CF.

If you don't replace the salt you lose, you can get dehydrated. When you are dehydrated the mucus in your body gets even more thick and sticky and is harder to cough up, and this can get infected and make you sick. It can also make your tummy sore and make it difficult to go to the toilet and can sometimes even cause a blockage.

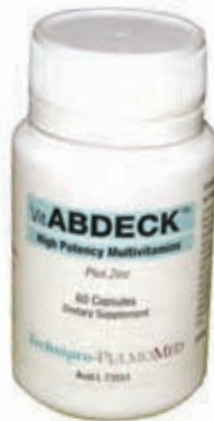
If you are dehydrated you might have a headache, feel a bit dizzy or just feel tired. Your mouth might feel dry and you might even see some little salt crystals on your skin. The colour of your wee can tell you if you are dehydrated. If it is dark yellow you are dehydrated, and you need more salt and water. When your wee is pale yellow you are hydrated. This means you have enough salt and water in your body, and this is how you want to keep it.

Did you also know that people living with CF often don't feel thirsty quite as quickly as people without CF, even if you have been sweating and losing a lot of body fluid? So, it is also important to drink plenty of water throughout the day and to drink more often when it is hot or if you have been exercising.

Now you know why you take your salt replacement and why you need to remember to drink plenty of water, even if you don't feel thirsty!









Vitamins

Do you take multivitamins?

Many people with CF need to take a vitamin replacement. The most common one in Australia is called VitABDECK. Because of CF, your body may find it difficult to digest and absorb all of the nutrients in your diet, particularly fats and fat-soluble vitamins. Extra fats and vitamins are needed to help keep you healthy.

The fat-soluble vitamins are vitamins A, D, E and K. These vitamins have many functions.

- + **Vitamin A helps with your sight and is great for night vision.**
- + **Vitamin D helps keep your bones and teeth strong. It also helps your immune system fight infection.**
- + **Vitamin E protects the cells in your body from damage and has an important role keeping your red blood cells healthy.**

- + **Vitamin K plays a big part in clotting your blood when you are cut or injured.**
- + **Vitamins B and C are water-soluble vitamins. The vitamin B group is made up of 8 vitamins which are also important for good health. They help release energy from the food you eat, they keep your nervous system healthy and help keep your skin and eyes in great shape.**
- + **Vitamin C is important in keeping your body tissues, such as your gums, bones and blood vessels in good condition. It also helps your body fight infection.**

Wow, who knew how important vitamins were in keeping you well!

Remember, every tablet you take has a special function. Ask mum or dad about some of the other tablets you take and find out how they help to keep you healthy.



Hi, I'm Jordan and I'm 22 years old. I work as a Nightfill Captain at Coles and DJ on the weekends, and I have CF.

What advice would you give to other kids who have CF?

balance of everything in your life. How to do that is up to you. I personally like to make a list or schedule so I can tick things off I need to do one at a time.

How would your friends describe you?

I guess my friends would describe me as easy going. I'm always down to do stuff no matter what and hate staying at home.

What is the hardest thing about having CF?

The hardest thing about having CF for me is people don't understand my struggles (not that they are very bad at the moment), but I choose to keep it a secret from everyone, so sometimes it can be frustrating not being able to explain things, but that's my choice I made personally.

What's your favourite thing to do in your spare time?

My favourite thing to do in my spare time is making music. I'm learning to produce, mix and master music as one day I'd like to release my own. It's really time consuming and there's so much to learn so it can keep me busy for hours.

Where is your favourite place in the world?

My favourite place in the world so far that I've been to would have to be Lord Howe Island. It's an island quite far out to sea off the east coast. It's so special to me because it's quite untouched as they only let a certain amount of people there at a time, and there's hardly any buildings there. There's really good you can climb the small mountain that's there as well.



MEET THE MEMBER:

JORDAN



PRESS PLAY

MEET THE SIBLING BEN

If you haven't been to Sibs Camp before, it's a great place to let loose and make friends. This year at camp, we had the fantastic opportunity to interview one of our veteran campers. Ben is 10 years old, in year 5, and has an older sister who has CF.

Are you having fun at Sibs Camp? What has been the best part?

I am having lots of fun. So far, my favourite part has been archery. I have never done archery before and I picked it up really fast.

What are some things you like to do in your spare time?

I like to play soccer, ride my bike, and meet up with friends. My favourite movie is Harry Potter and my favourite TV show is the Simpsons – so I like to watch those in my spare time too.

What is your favourite subject in school?

My favourite subject is English because you get to express your feelings in a different way.

What's it like having a sibling with CF?

It's exactly like having a normal sister but she does some extra stuff like physio. It can be hard to explain because I don't know what it's like to not have a sister with CF, but I'd say it's good having a sister with CF.

What advice would you give to other kids that have a sibling with CF?

You should support them and try to encourage them to do the right things. Make sure you are positive and tell them they are doing good when they do what they are supposed to. Be positive.

What do you do that makes you proud of yourself?

I always try to do the kindest thing that I can and always help other people if they need it.



**I LIKE TO PLAY
SOCCER, RIDE MY
BIKE, AND MEET UP
WITH FRIENDS.**



CRAZY DAY

A lot of things changed because of COVID-19, but it also created a chance to be creative. For Ruby and her mum Mesha...they went a bit crazy!

You may have heard about events like 65 Roses Day or Crazy Hair Day, where people raise money or spread awareness about CF at their school or in their community. This year, a lot of people had to stay home from school or weren't able to go to events because of COVID-19, but that didn't stop Ruby and her mum Mesha from coming up with a creative spin on Crazy Hair Day. This incredible mother and daughter team designed and modelled a variety of hairstyles across the month of May – including a plait rainbow, cupcake buns, a unicorn horn and our personal favourite – roses! They raised over \$750 and helped to increase awareness in an incredibly fun way. Thank you Mesha and Ruby!

If you are interested in doing your own Crazy Hair Day or you have another creative idea for your own fundraiser, contact our team on events@cfwa.org.au or phone 08 6457 7333 for information and a super cool support pack!



#CRAZYHAIRDAY
crazyhair.com.au

 **CYSTIC
FIBROSIS**
Western Australia

An A-Z of Cystic Fibrosis

A

Antibiotics - medicine used to treat infections.

B

Bacteria - bugs or germs that cause infection. Bacteria, like *Pseudomonas*, can make people with CF really sick.

C

Cough - some people with CF will have a cough, usually when they are sick.

D

Digestion - this can be tricky for people with CF because of the thick mucus in their intestines and pancreas.

E

Enzyme - a very important medication taken with food to help digestion.

F

Food - people with CF need to eat more food in a day because their body doesn't digest it properly. They also use more energy, particularly when they are not feeling well.

G

Gut - the gut can cause lots of trouble in CF, including constipation, diarrhoea, tummy aches and really smelly wind.

H

Hospital - people with CF visit the hospital for clinic appointments. They may also be admitted for extra treatment if they get sick.

i

Infections - germs can cause infections in the thick, sticky mucus in the lungs.

J

Jumping - jumping and bouncing on a trampoline can be a great way to loosen mucus and a fun way to do extra physio.

K

KKind - a program at Perth Children's Hospital (PCH) to help kids who might feel nervous or worried about having a procedure.

L

Lungs - the lungs fill up with air when we breathe and are one of the main organs affected by CF.

M

Mucus - people with CF have thick, sticky mucus that builds up in the lungs and digestive system.

Nebuliser - a device used to help breathe medication into the lungs.

Osteopenia - is when a person's bones are weaker than they should be. It is most common in older people with CF.

Physio - chest physio or airway clearance helps loosen mucus in the lungs and airways so you can cough it up.

Quench - quench your thirst with lots of water or drinks that have electrolytes like Hydralyte, especially on hot days.

Running - exercise is really helpful for people with CF. It helps keep the lungs clear and keeps you fit and strong.

Sweat test - a test that helps diagnose CF. People with CF have a higher amount of salt in their sweat

Tablets - antibiotics, enzymes, vitamins and salt tablets are all important to help people with CF stay healthy.

Understanding - having CF, or someone with CF in your family, can make you more understanding of other people's differences.

Vitamins - vitamins A, D, E and K don't get absorbed properly so people with CF need to take a multivitamin supplement each day.

Water - people with CF are more likely to get dehydrated, which means they don't have enough water in their body, so it is really important to drink lots of water.

X-ray - used to take a picture of the lungs and look for any changes.

Yawn - people with CF can get tired from doing all their treatments or when they don't feel well so they need to get lots of sleep every night.

Zen - practicing yoga, mindfulness or meditation is very good for everyone and can be used to help get through procedures that might make people feel nervous.

The CF Trust in the UK have even made a short video with their own A to Z of CF. Click here (youtube.com/watch?v=AVg24S_pSmo) or google 'The A to Z of cystic fibrosis' to watch.



NO DARE TOO GREAT FOR SIBS CAMP

This year, 26 siblings and offspring as well as 5 CFWA staff members travelled to Dare Adventures in Dwellingup for the 2020 Sibs Camp adventure!

Sibs Camp 2020 started bright and early at the CFWA office to catch a bus to Dwellingup. The bus ride was full of laughter, games, singing, and decorating camp bags. The camp itself had many great activities like a commando course, raft building, archery tag, and team building activities. One night, the campers braved the night and did a bush walk in complete darkness – no torches allowed. We worked so well together, we set a camp record for the fastest night walk ever completed. On our final day, we visited a tree adventures course which had lots of climbing, obstacles, and flying foxes galore! There was lots of fun had, friendships created, and many wonderful memories made at Sibs Camp 2020.

Sibling and Offspring Camp is for kids aged 8 – 16 years who have a parent or sibling with cystic fibrosis. The camp is a great way to meet other kids who know what it is like to have someone with CF in their family. If you haven't been to camp before and would like more details, contact Paula on services@cfwa.org.au or telephone 08 6457 7333.

Thanks to Lotterywest and Telethon for supporting this important event.





Hospital In The Home



What is HiTH?

HiTH stands for Hospital in the Home. It is the abbreviation we use when we are talking about having your regular hospital treatments in the comfort of your own home. We will explain a little bit more about what that means below.

When you have CF and get an infection, you need to do extra treatments to get better. This could mean taking extra medicines, like antibiotic tablets or nebulisers, or increasing the amount of physio you do to help clear mucus. Sometimes, even though you do lots of extra treatment, you still might need to be admitted to hospital to help you get better. Most people with CF will need a hospital admission at some stage.

When you go into hospital to treat an infection in your lungs, you will get intravenous (IV) antibiotics. This means the antibiotics go straight into the bloodstream so they can work more quickly. You will also get a chance to talk to all the members of your CF team and fine tune your treatment.

Once you are stable and have had the chance to review your treatment with the team, you might be able to be transferred to Hospital in the Home, or HiTH. When you are on HiTH you get to go home and sleep in your own bed and see your family, friends and your pets while you are still getting all your hospital treatment. You might even still be able to go to school!

While you are at home, the HiTH nurses and physios will come to your house to give you your antibiotics and do your physio. You will even get an afternoon visit from CFWA every day to help with your second physio session. Every week you will need to go back to the hospital for a review and the doctors will decide if you stay on HiTH or get discharged. Some people might have to go back into hospital from HiTH if things aren't working for them at home.

If you live a really long way from the hospital, you won't be able to do HiTH from your home, but you might be able to stay with a family member who lives closer to the hospital, like an aunty or grandparent, or even a friend. There are lots of things for your CF team to consider before deciding if HiTH is right for you, so if you have any questions make sure you talk to them about it.

THE POWER OF

Did you know that being positive can help you be healthier? It's true, science backs this up!

Everyone experiences a range of feelings and emotions like sad, happy, angry, fearful, and joy. It's normal to not be positive all of the time but if you can look at a tough situation and find a positive lesson in it or be able to see positivity in the future, you are what's called an optimist. The opposite of an optimist is a pessimist. A pessimist will find the "bad" in any situation.

If you have CF, being an optimist is important because feelings of love, gratitude, joy and general cheerfulness help bring down feelings of stress and anxiety. Stress and anxiety are now well known to make health issues worse.

Don't worry if you think you might be a pessimist, because no one is born a pessimist or an optimist. You can change your thinking and learn to be more positive!





Tips to being more positive:

Take 5!

Take a little break for yourself and make time each day to send loving thoughts to people important to you. Writing or drawing can help you to focus your thoughts. A fantastic thing to do is to think of 3 things you are grateful for each day.

Help Others

It feels great helping other people! Ask someone you know and trust if they could use a hand with something or find your own special project like looking after an animal or tending a garden.

Appreciate WOW Moments

There can be lots of WOW moments that we just haven't noticed, like the beauty of a spring day when the flowers are blooming or the joy of playing with a pet. What are some of the things that make you feel good?

Achieve Goals

How good does it feel when you achieve a goal that you've set for yourself? It helps make us feel more confident to try new things. If you've got something big you want to achieve, setting small goals to get there can be helpful and make you feel good along the way.

Sharing Positivity with Others

Sharing positive things with someone else like a funny movie, a nice walk outside, and hugs will double the positivity in your life.

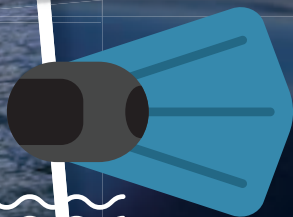
Try New Things

Use your strengths. If you like singing, join a choir. If you like to dance, join a dance team. You could even try something new where you are meeting new people and learning new things.

Practicing Positive Affirmations

It's ok to have negative thoughts but try not to dwell on them; accept them and let them go. Affirmations help us to refocus those negative thoughts and turn them into positive self-talk. Affirmations need to be short and in the moment. Some positive affirmations to try out are "I am a good friend", "I am unique", "I am smart", "I am kind", "I am safe".

Sometimes it helps to talk to somebody about your worries, maybe a family member or a friend. CFWA are here if you need someone to talk to so contact us on servicesmanager@cfwa.org.au.



FIRST EVER SIBS DAY OUT

One of our favourite events every year is our Sibs Camp because we get to have fun with siblings and offspring. This year, we were extra lucky because we got to hang out with everyone an extra time!

We all had such a great day on Sunday 1st March at our first ever Sibs Day Out! The Rotarians of Perth kindly donated their time and their boats and took us to Rocky Bay on the Swan River, where we rafted up together and enjoyed a day on the water.

We had stand up paddle boards, giant inflatables and kayaks to play on. Everyone joined in the fun and we all enjoyed a scrumptious sausage sizzle lunch cooked by the CFWA CEO Nigel.

Events like Sibs Day Out are a great way to connect and form new friendships. We hope to host more events like this, so if you are interested in attending sibling and offspring events, keep your eyes peeled!



crafty corner: Celery Rose Stamps



Supplies:

- celery stalk
- Knife
- Paint (any colour you'd like but red and green are a good place to start)
- A paint tray or bowls to hold paint
- Paint brush
- Blank paper or tea towel for stamping

Instructions

1. Gather all your materials
2. Cut the end bit of celery off from the rest (ask for help from a trusted adult if you need permission to use a knife)
3. Prepare your paint by setting it out in different bowls or a paint tray
4. Apply the paint on to your end bit of celery using a paint brush
5. Stamp the rose stamp on to your paper or tea towel this might take a little bit of practice so keep trying.
6. Paint leaves on to your roses and add any embellishments - be creative!

Get Creative: for more crafts and ideas visit Kiwi.com where this craft was adapted from

We love roses and can't wait for you to try out this rose stamp using the end of a piece of celery! You can use this stamp on paper to create a work of art or stamp a tea towel as a personalised gift. Best of all, you can use the rest of the celery for a yummy and healthy snack.

1.



2.



3.



4.



HOW TO MAKE AVOCADO AND PEANUT BUTTER BROWNIES

These brownies are a yummy treat that is tailor-made for people with CF. The recipe was created by a mum in Western Australia who has a daughter with CF, so you know they are high in fat and delicious too!

*** This recipe uses some sharp tools and a hot oven so make sure you have the supervision of a trusted adult*

Total Time: 35 Minutes

Servings: 16

Ingredients:

- 400 g avocado
- 125 g natural, smooth peanut butter
- 100 g butter
- 2 tsp vanilla paste
- 2 tsp baking powder
- Pinch of salt
- 2/3 cup cacao powder
- 1/2 cup coconut sugar
- 80 g dark baking chocolate

Supplies:

- Food processor
- Baking tin
- Baking paper

Instructions:

1. Preheat the oven to 180 degrees
2. Line a baking tin with baking paper
3. Place all the ingredients except for the dark chocolate into a food processor and blitz until smooth
4. Cut the chocolate into small chunks and stir through the batter
5. Pour the mixture into the baking tin and bake for 25-30 minutes
6. Remove the brownies from the tin and allow to cool before cutting into pieces

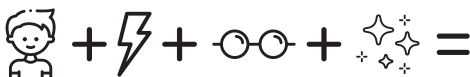
*** Recipe and photos from Cookingfattyfavourites.com*



GUESS THE MOVIE FROM THE Emojis















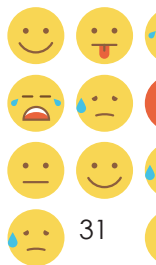








1. Frozen 2. Star Wars 3. Harry Potter 4. Charlie and the Chocolate Factory 5. Cloudy with a Chance of Meatballs 6. How to Train Your Dragon 7. Lion King 8. Finding Nemo 9. Happy Feet 10. Cars



Did you enjoy reading ROZEE?
Do you have CF or have a family
member with CF? Do you have
a story to tell? Let us know and
you might just see yourself in the
next issue of ROZEE Magazine!

