

SUMMER 2018

A MAGAZINE FOR KIDS WHO HAVE CF AND THEIR SIBLINGS

ROZEE

**A Day in the Life
of: Brandon**

**What is
a PICC-Line?**

**Going to School
with a PICC Line:
David**

**What is
Cross-infection?**

**Crazy
Hair Day**

**Sibling and
Offspring Camp**

**How to Make:
A Smoothie Bowl**



**CYSTIC
FIBROSIS**
Western Australia

**ALL
AWESOME!**

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Disclaimer

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Editor's Letter

Welcome to the 6th edition of Rozee!

In this edition, we learn all about PICC lines- what are they, what activities can/ can't you do with one in, and we even hear from an adult with CF about her experiences with PICC lines.

We also talk about anxiety. Anxiety is very normal and common for many people to experience. It can be described as butterflies or a knot in your stomach. We talk about what you can do to minimise and cope with these feelings.

We have some member interviews, including Brandon from York, who shares a day in his life, as well as a couple of interviews from kids who went on our Sibling and Offspring Camp.

There are also lots of fun sections, including a craft activity, puzzles, and a recipe. So, take a look inside!

Bye for now,

Gillian

P.S. We hope you have a wonderful Christmas and happy school holidays too.



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and Stuff



Ask...

Katrina about
CF and PICC lines

Hey guys! My name is Katrina, I am from Bunbury, I am 26 yrs old and I have cystic fibrosis (CF). I was diagnosed a few days after birth. I have 2 older brothers, but thankfully they are not even carriers. Growing up, my parents tried to make things fun for me, like reading a good book to me while I was doing my nebulisers or airway clearance. Sometimes my brothers even snuck in to listen.

I learnt that if I didn't take my medication or do my physio, then I wouldn't feel so great and would have to miss out on doing things, so I made sure I did them all the time. I still get sick of doing it sometimes, but I would rather be healthy and be able to do things like travel the world, hang out with friends and dance. Because I keep myself pretty healthy, I have been able to travel to America, England, France, Bali, Fiji, Solomon Islands and soon I'm off to Cambodia. So, no matter how much you hate it, just do it and find ways to make it fun, so that you can enjoy doing what you love.

Sometimes I have to have a hospital visit and get a PICC line put into my arm so I can get better.



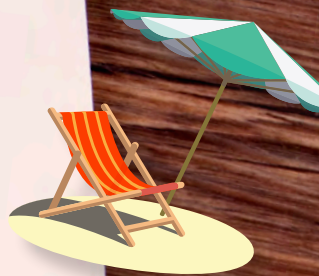
A PICC line is a long line they put in your arm that they can put medicine into a few times a day for 2-3 weeks. If you are able to, it can be done at home once the line has been put in. If you go home with the line in, you must be very careful to look after it, protecting the area and making sure you don't bump it or get it wet.

When I was younger they used to put me to sleep to put the PICC line in, but now I have to stay awake, so I had to find ways to make it easier for me to get the drip put in. The last time I was in hospital was one of the best experiences. I took time before they took me to get it done, to sit and listen to soothing music.

I also talk to God and ask Him to help it go smoothly, as pain free as possible and to calm the nerves inside, I find this helps me. I always have my mum by my side and she holds my hand (yes, even as an adult). The ladies doing the job were really nice and assured me it wouldn't take long and she would try to make it less painful. Then me and mum put in earphones and watched a comedian on her phone, this really helped to take my mind off what was happening. And it was all over in about 15 minutes.

So just think of ways that make it easier for you and ask your doctor if it's possible to do them. Sometimes we need to go into hospital so it's important that the process is as easy as possible then when we come out we can continue enjoying life.

From, Katrina



A DAY IN THE LIFE OF...

BRANDAN



Hello there, my name is Brandon and I have CF. I am 14 years of age and I live in York. I go to York District High School and I am in year 9. I have a younger brother called Cameron. I have a younger sister called Addison, who also has CF. I have 3 step brothers and 1 step sister all younger than me. I live with my Mum and Step Dad. I love watching and playing football, I also enjoy playing basketball and swimming. This is my normal Friday...

7:00

I wake up and hear Mum, Cam and Addi talking and the dogs barking at the birds then the birds squeaking at the other birds.

7:05

I get out of bed and get dressed into my school clothes, then say hi to everyone and make my breakfast which is normally coco pops with my Calogen. Mum has already got my tablets out for me.

7:30

I do my flutter physio for 20 minutes, which gives me time to watch some of a movie on the TV.

8:05

Cam, Addi and myself get our bikes, we say bye to our dogs, Koda, King and Jess, then we ride to school. School is only a 5-minute ride down the road.

8:20

I hang out with my mates before classes start and we talk about what's happening on the weekend.

8:40

I go to my form class which is Avon 1. This is where we get our names ticked off.

8:50

Science is my first class for today. I don't mind Science.

9:40

Next is English, where we read 'Jasper Jones' and we also talk in class.

10:30

MORNING TEA! Mum packs the best snacks. I usually have cakes, chips, biscuits... which I take between 2-3 Creon 10,000 for my snacks, but that also depends on how much I eat. Taking tablets at school is easy since going into high school. The school allows me to have them in my bag without having to take them in



front of a teacher. It gives me more freedom when I can eat as well. My mates and I have a few snacks then go play some footy.

10:50

It's time to go back to class. This is my favourite time of day – 2 periods of sport. As we only have a small school, we go over to the rec centre to do all our sports. We get all the sports equipment from school and carry them over to the basketball courts to start our game.

12:40

LUNCH TIME! A variety of cold sausages, cocktail onions, cheese, gherkins and olives is on the menu in my lunch box today. I usually take Creon 25,000 at lunch, due to the amount of fat in it. Today I had to take 3. I have my lunch then we go and play footy.

1:15

After lunch we have cadets. Cadets involves the whole secondary school for the last 2 periods of the day. The year 9s (which is me) head to the fire pits and we have to cook sausages and then get to eat them. Every week we do different things. We go on camp once a year.

3:00

School is finished and we ride back home while we talk about our day.

3:10

We have arrived home. Mum has set us chores that we do which include getting fire wood, cleaning our rooms, feeding the animals and checking for eggs.

3:30

Cam and I have a little kick of the footy or shoot some hoops.

4:00

Matt gets home so I hang with him while Cam and Addi are playing together.

4:30

I get ready for footy and head down to the oval.

5:00

Footy training starts. I do a lot of training so Mum won't make me do another session of the flutter. I find keeping fit is a more fun way to do physio. We have only lost 1 game this year, so we are training hard. Its been 20 years since the under 16s York team has been in the grand final.

6:15

After the 16s training session, I stay behind to train with the resses and league footy team.

7:30

time to head home, have a shower and eat my tea while catching up with mum. I haven't seen her since this morning, so we have the events of the day to catch up on.

8.30

I head to bed as I have a game of footy tomorrow. Cross fingers we have another win.



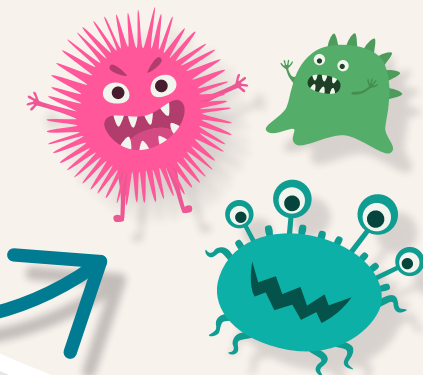
What is a PICC line?

You might have heard of PICC lines, or maybe you've even had one. Lots of children and adults with CF need to have a PICC line at some stage in their life.

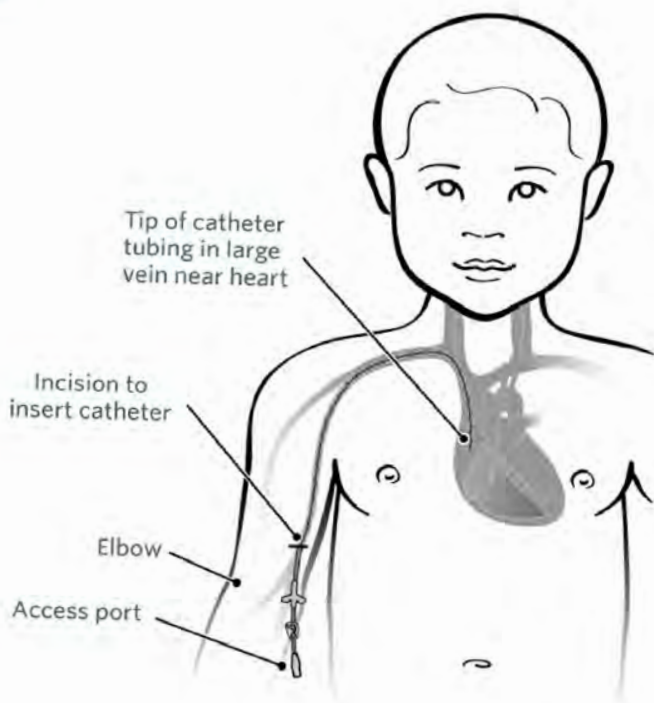
A PICC line is a long, soft tube that is inserted into a vein in the arm that carries blood into the heart. It is used because it is a quick and easy way to get medicine, like antibiotics, in to the body.

You can do most normal activities with a PICC line, like going to school, but might not be able to play sports like football or rough playing, which might cause damage to the PICC line.

Quick Tip:
Wash your hands
regularly to keep
germs at bay!



PICC Line



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Going to School with a PICC line

David's
PICC line

Did you know that our Education Officer Natalie can come and speak to your class about CF?

Natalie recently went to David's school and talked to all his classmates about CF and why he had a PICC line. David tells us all about himself and what it's like having a PICC line:

My name is David and I'm 6 years old and in year 1 at Weld Square Primary School. I have a little brother Oliver who's 5 and is in kindy.

I like to play with my friends. I especially like running and playing "it". I also like to play soccer because I really like running back and stopping the goals.

I had to get my PICC line because I couldn't get rid of my cough myself and needed extra antibiotics to help me.



Is this your first PICC line? How did you feel about getting it put in?

No. I felt freaked out because I was afraid I would wake up during the doctors putting the PICC line in my arm.

Do you have to be careful with your PICC line?

Yes, because it could fall out.

What did your friends at school think about your PICC line?

Um I didn't really ask them, but when I showed them they were amazed.

Was it good having CFWA come and speak to your class about your PICC line?

Yes, because they helped explain to everyone what a PICC line is in a different way to our teacher so other people may understand it better now.

What would you say to other kids with CF who might need to get a PICC line?

Try and be brave, try not to be scared. A PICC line is hard work but it is needed to keep your lungs healthy.



Get your School
to do a ...

Crazy Hair Day!

Feel like you want to raise awareness about CF and raise some money for CFWA?

You can help by encouraging your school to host a Crazy Hair Day! For a gold coin donation, your classmates and teachers can join in the fun and wear their craziest hair at school- think gel, teasing, spiking, colouring and styling your hair in a crazy way!



1.

Ask your parents about hosting a Crazy Hair Day at your school. You can then speak to your teacher to get the school on board.

2.

Your school can register online at www.crazyhairday.com.au and we will send them all the details.

3.

We can provide your school with a Crazy Hair Day Digital Starter Pack, posters, a certificate and more to help your Crazy Hair Day be a success.



Check out www.crazyhair.com.au to get started and download the fun free activity sheets!

2017 Sibling & Offspring Camp!

The Sibling and Offspring Camp is a two-day camp for kids between 8 and 16 years old, with a sibling (brother or sister) or parent with CF.

Each year we have a great time and get to do heaps of awesome activities that we wouldn't normally be able to experience like high ropes courses, flying fox, abseiling, swimming and more! You get the chance to make friends with other kids who know what it's like to have someone with CF in their family.



What we did on the camp:

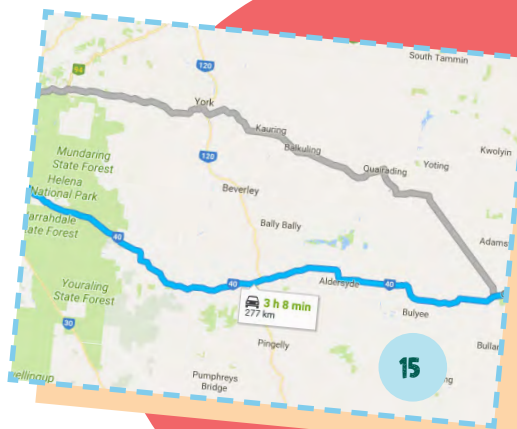
This year's camp was held at **Woodman Point Recreational Camp** which is right on the beach near Fremantle. We did activities like flying fox, vertical challenge, rock climbing, kite making, beach games, raft building and even a bus trip into Fremantle where we turned into detectives and cracked the code at The Escape Hunt followed by fish and chips at Cicerellos.



2018 camp in Kulin!

We can't wait for next year when it's going to be a 2-night camp! We'll be heading to **Kulin** which is in the Wheatbelt, about 3 hours south east of Perth. We will be able to do heaps of new and exciting activities! Camp Kulin has awesome custom built activities, including the gaga dodge ball pit, giant human foosball, a sensory walk and low ropes elements. Camp Kulin also uses local facilities including Kulin Aquatic Centre and Waterslide which has the biggest waterslide in Regional Australia!

You can check out Camp Kulin on their website www.campkulin.com.au



ZOE

Can you tell us a little bit about yourself?

I am 9 years old and I like running, swimming and dancing such as ballet, acrobats, jazz and tap. I like to collect figurines (Shopkins and Beanie Boos.)

This was your first camp. Were you nervous? How did you overcome your nerves?

Yes, I was nervous. I overcame my fear by talking, making new friends and having lots of fun.

What was your favourite activity you did on camp?

My favourite activity was the 100m long 9m high flying fox.

Did you find the camp helpful?

Yes, I found it very helpful, listening to other peoples' stories was good. I made lots of new friends.

What would you say to someone thinking about coming to their first camp but might be feeling nervous?

Don't be nervous you will have fun, make new friends and talk to lots of people.

What is it like having a parent who has CF?

Sometimes it isn't fun, like when Dad has to go to hospital. Dad taking lots of medication is a bit different but it keeps him strong and healthy. I like to help him get his medications ready. Then he is able to do good things with me like playing games and swimming when it's hot. We like to stay fit together.

Do you have any tips for other kids who have a family member with CF?

Be very supportive. Give lots of kisses and hugs.





**HAPPY
CAMPERS**

ZAC

Can you tell us a little bit about yourself?

I have autism and I was born on the 27th of October, I love Star Wars, Lego, Xbox One and WW1.

**This was your first camp. Were you nervous?
How did you overcome your nerves?**

I was nervous about going to camp but I made sure to pack my favorite book and my pillow and that made me feel happy. I was scared of the zip line but I gave it a go. The second time I was happy and had fun.

What was your favourite activity you did on camp?

The zip line. I also liked the rock wall.

**Did you find the camp helpful? would you like to
come back next year?**

YES PLEASE DEFINITELY.

**What would you say to someone thinking about coming to
their first camp but might be feeling nervous?**

I was nervous, but after meeting the other children and the camp leaders I felt great. There were lots of fun activities that made it easy to meet people.

What is it like having a sibling who has CF?

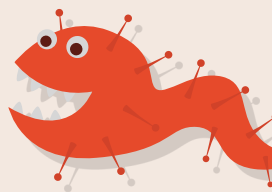
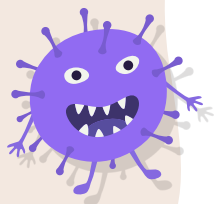
It is sometimes sad, like when Josephine goes into hospital, especially when it's on my birthday. I have to go stay at my aunties when she goes to hospital and it is very crowded, but I have fun there so it is ok. Jo has to have lots of medicines and physio and it takes a long time. Mum is always busy helping her and that makes me a little sad too.

Do you have any tips for other kids who have a family member with CF?

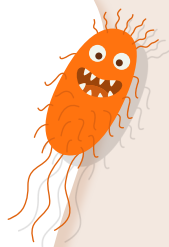
Try your best to be kind and helpful. Have fun even when things are difficult. The hospital has fun places you can visit, like Megazone, which is a great place. Be helpful; it's good when you understand what your sibling is needing or doing. I like helping Jo get her medicine and keep her physio stuff together (even though she loses it a lot). I like to keep an eye out for smokers so Jo knows that she can avoid them and I know it helps her stay healthy.



What is Cross-infection?



Did you know that people with CF shouldn't come too close to each other? This is because of something called cross-infection, or put simply, sharing germs.

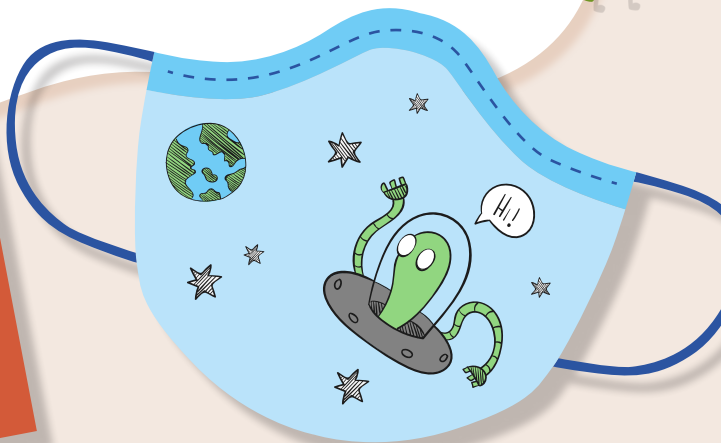


Some people with CF carry germs in their lungs. These germs are usually picked up from the environment, but can also be passed on between people with CF.

The germs can make you sicker, so to protect yourself it is important not to be around others with CF. If you are in a situation where you might be near other people with CF, it is important to keep your distance, wear a face mask and wash your hands regularly.



Quick tip:
You can even decorate your mask to make it fun. Some people like to draw on theirs and use stickers to make it their own. You can get creative with yours too!



How To Deal With Anxiety



Adapted from the Hey Sigmund article www.heyigmund.com/anxiety-in-kids/

What is Anxiety?

Have you heard of anxiety? Maybe you have felt anxious before. Maybe you have but didn't know what it was, or that the feeling even had a name.

Anxiety is a feeling that has sometimes been described as a knot or butterflies in your stomach, that panicked feeling that comes when you miss a stair, or that feeling you get when you're almost asleep and you feel like you're falling.

Anxiety is normal and everyone experiences anxiety at some time in their life – before a medical procedure, when meeting new people or starting at a new school. But sometimes it happens for no reason at all – and that's normal too.

Why Do We Get Anxiety?

It happens because there's a part of your brain that thinks there's something it needs to protect you from. The part of the brain is called the amygdala. It switches on when it thinks you're in danger, so really, it's like your own fierce warrior, there to protect you. Its job is to get you ready to run away from the danger or fight it. People call this 'fight or flight'.

If your amygdala thinks there's trouble, it will immediately give your body what it needs to be strong, fast and powerful. It will flood your body with oxygen, hormones and adrenaline that your body can use as fuel to power your muscles to run away or fight. It does this without even thinking. This happens so quickly and so automatically. The amygdala doesn't take time to check anything out. It's a doer not a thinker – all action and not a lot of thought.

If there is something dangerous – a dog you need to run away from, a fall you need to steady yourself from – then the amygdala is brilliant. Sometimes though, the amygdala thinks there's a threat and fuels you up even though there's actually nothing dangerous there at all.

If you don't need to run away or fight for your life, there's nothing to burn all that fuel – the oxygen, hormones and adrenalin – that the amygdala has flooded you with. It builds up and that's the reason you feel like you do when you have anxiety.

When this happens:

- Your breathing changes from normal slow deep breaths to fast little breaths. You might feel puffed or a bit breathless. You also might feel the blood rush to your face and your face become warm.
- You might feel dizzy or a bit confused.
- Your heart beats faster to get the oxygen around the body. Your heart can feel like it's racing and you might feel sick.
- Fuel gets sent to your arms (in case they need to fight) and your legs (in case they need to run). Your arms and legs might tense up or your muscles might feel tight.
- Your body starts sweating to cool itself down.
- You might feel like you have butterflies in your tummy. You might also feel sick, as though you're going to vomit, and your mouth might feel a bit dry. You might lose your appetite for a while.

What to Do:

1. Give Your Anxiety a Name

Now that you understand that your anxiety feelings come from the 'heroic warrior' part of your brain, let's give it a name. Pick a name and picture it in your mind. For example, we called ours 'Zep'.

2. Tell It You're the Boss

The problem with anxiety is that Zep is calling all the shots, but we know that you're really the boss. Zep actually thinks it's protecting you, so what you need to do is let it know that you've got this and that it can relax. When you get those anxious feelings, that means Zep is taking over and getting ready to keep you safe. It doesn't think about it at all – it just jumps in and goes for it. What you need to do is to let it know that you're okay.

The most powerful thing you can do to make yourself the boss of your brain again is breathe. Part of the reason you feel as you do is because your breathing has gone from strong and slow and deep to quick and shallow. That type of breathing changes the balance of oxygen and carbon dioxide in your body. Once your breathing is under control, Zep will stop thinking he has to protect you

and he'll settle back down. Then, really quickly after that, you'll stop feeling the way you do.

3. Breathe

Breathe deeply and slowly. Hold your breath just for a second between breathing in and breathing out. Make sure the breath is going right down into your belly – not just into your chest. You can tell because your belly will be moving. Do this about 5 to 10 times.

Practice before bed every day. Remember that Zep, the warrior part of your brain, has been protecting you for your entire life so it might take a little bit of practice to convince Zep to relax. But keep practicing and you'll be really good at it in no time. You and that warrior part of your brain will be buddies – but with you in control.

4. Practice Mindfulness

Mindfulness helps you to have control over your brain so you can stop it from worrying about things it doesn't need to. The brain is like a muscle and the more you exercise it the stronger it gets.

It sounds easy enough but minds quite like to wander, so staying in the moment can take some practice.

- Close your eyes and notice your breathing. How does the air feel as you draw it inside you? Notice the sensation of the air, or your belly rising and falling. Notice your heart beating. If your mind starts to wander, come back to this.
- Now, what can you hear? What can you feel outside of you and inside your body? If your mind starts to wander, focus on your breathing again.

5. Talk to Someone

If you feel anxious sometimes, or a lot, it can be helpful to talk to someone. Tell your parents, a teacher or an adult you trust.

Check out the free meditation and mindfulness apps on the following page. Always ask your parents before downloading any apps.



Mindfulness Apps



1. Stop, Breathe & Think

Stop, Breathe & Think is a meditation app designed specifically for tweens and teens. It gets you to 'check-in' with how you're feeling and then guides you through a meditation based on this information.

<https://itunes.apple.com/au/app/stop-breathe-thinkid778848692?mt=8>



2. Headspace

Enjoy fun, engaging activities that teach you the basics of mindfulness. With this app you'll practice breathing exercises, visualizations and even try some focus-based meditation. There are three age groups: 5 and under, 6-8 and 9-12 year olds.

There are 5 themes to this app:

- Calm
- Focus
- Kindness
- Sleep
- Wake up

<https://itunes.apple.com/au/app/headspace-guided-meditation/id493145008?mt=8>



3. Settle Your Glitter

Settle Your Glitter takes the form of a snow globe image on the screen. This app will walk you through identifying your emotions, rating how strongly you are experiencing them and then using the glitter ball to settle. Shake your device, (like shaking a snow globe) and then do a slow and deep breathing exercise as modelled by a cute puffer fish. The breathing exercise 'settles the glitter' and helps restore balance.

<https://itunes.apple.com/au/app/settle-your-glitter/id962467492?mt=8>



4. Smiling Mind

This is a mindfulness meditation app that helps you deal with pressure, stress and challenges of daily life. There are age specific programs for 7-9, 10-12, 13-15 and 16-18 year olds

<https://itunes.apple.com/au/app/smiling-mind/id560442518?mt=8>



5. Mindfulness for Children

This app includes both breathing and visualization exercises. You can learn breathing exercises that you can use at school, during sports, or anytime you are feeling anxious or overwhelmed.

<https://itunes.apple.com/au/app/mindfulness-for-children-free-meditation-for-kids/id1124028741?mt=8>

Handprint Christmas tree card

Idea from www.blitsy.com

What you will need:

- 🎁 An adult to help with cutting and gluing
- 🎁 Pencil
- 🎁 Scissors
- 🎁 Glue stick
- 🎁 Glue dots or glue gun
- 🎁 Hard paper to use as the card
- 🎁 Rhinestone decorations (or other accessories)
- 🎁 Green card
- 🎁 Brown card
- 🎁 Yellow card



1. Using a pencil, trace around your hand onto the green card and then cut it out. This will be the 'Christmas tree'.
2. Using the brown card, cut out a small rectangle to use as the 'tree trunk'.
3. Now grab your paper that you're using as the card and fold it in half.
4. On the front page of the card, glue the 'tree trunk' piece towards the bottom and then glue the handprint 'Christmas tree' on top.
5. For ornaments you will need to use either glue dots or a glue gun. You could use anything you already have at home to decorate your tree, such as pipecleaner (as tinsel), pom poms or any other crafty items you might have.
6. Cut out a star shape using the yellow card and stick it to the top of your tree.
7. Personalise the inside of your card with a Christmas message.

NOTE: Ask an adult to help with the cutting and if using a glue gun.



How to make a

Smoothie Bowl



Smoothie bowls are what they sound like, but they're better. You can create pretty much any combo of flavours that you want and then top it with your favourite fruits and other crunchy things like cereal and nuts. They are a great way to have a high calorie, healthy meal or snack.

There are so many variations you can use so there's sure to be a combination to suit you. Here's how to make your own smoothie bowl:

1. Start with 1 cup of any frozen fruit and a banana. Some popular fruits to use are:

- Mango
- Strawberry
- Pineapple
- Mixed berries
- Peach

You can also add about 1/2 cup stemmed and chopped leafy vegetables like kale or spinach.

2. Add about **1/2 cup liquid**. You can play around, but any of these work great:

- Plain milk
- Almond milk
- Soy milk
- Yoghurt
- Orange juice
- Pomegranate juice
- Coconut water
- Carrot juice

3. Add a tablespoon of nut butter and/or sweetener and adjust to taste.

- Peanut butter
- Honey
- Maple syrup
- Almond butter
- Agave

4. Blend all ingredients in a blender until you have a smooth consistency and then pour into a bowl

5. Then you can top your bowl with pretty much anything, like:

- Nuts
- Seeds
- Cereals
- Fruit
- Chocolate nibs



Chocolatey Peanut Butter & Banana

Here's an example recipe:

Ingredients

- 1 cup almond milk
- 1 large banana
- 1 cup ice
- 2 Tbsp. peanut butter
- 1 Tbsp. unsweetened cocoa powder
- 1/4 tsp pure vanilla extract
- 1 Tbsp. maple syrup
- 2 Tbsp. cocoa nibs
- 2 Tbsp. granola
- 2 Tbsp. chopped peanuts

Preparation

- Blend the almond milk, 1/2 the banana, ice, peanut butter, cocoa powder, vanilla extract, and maple syrup until smooth. Transfer to a bowl and top with the cocoa nibs, granola, chopped peanuts, and remaining 1/2 banana.

Sourced from Buzz Feed
(Recipe by Lindsay Hunt)
https://www.buzzfeed.com/lindsayhunt/smoothie-bowls?utm_term=.f12PbnSkj#lJgmrvPZ

CSR 2



Game: CSR Racing 2

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

CSR Racing 2 is the next game to follow the number 1 drag racing series. With high quality graphics and an entertaining story, it is an enjoyable game for killing time. The story follows you through different drag racing events, including crew battles, where you move up by racing different people in the crew.

The story is very good and I have only scratched the surface of the game. There are other drag racing races, like ladder, which you move up by winning races and earn bigger prizes. The game does not give you super-fast cars to start off with, you slowly move up and upgrade your car when you get beaten. This gives you bigger satisfaction when you get the faster cars later in the game. Only down side is if you don't have good internet it might take a while to download, but it is definitely worth it.

Review by Blake

This game is available to download on iTunes for free.

Puzzles & Stuff

Jokes to have up
your sleeve...

Jokes from www.kidspot.com.au

Q: What do you call a boomerang
that doesn't come back?

A: A stick!

Q: What do you get when you
cross a Labrador and a magician?

A: labracadabrador!

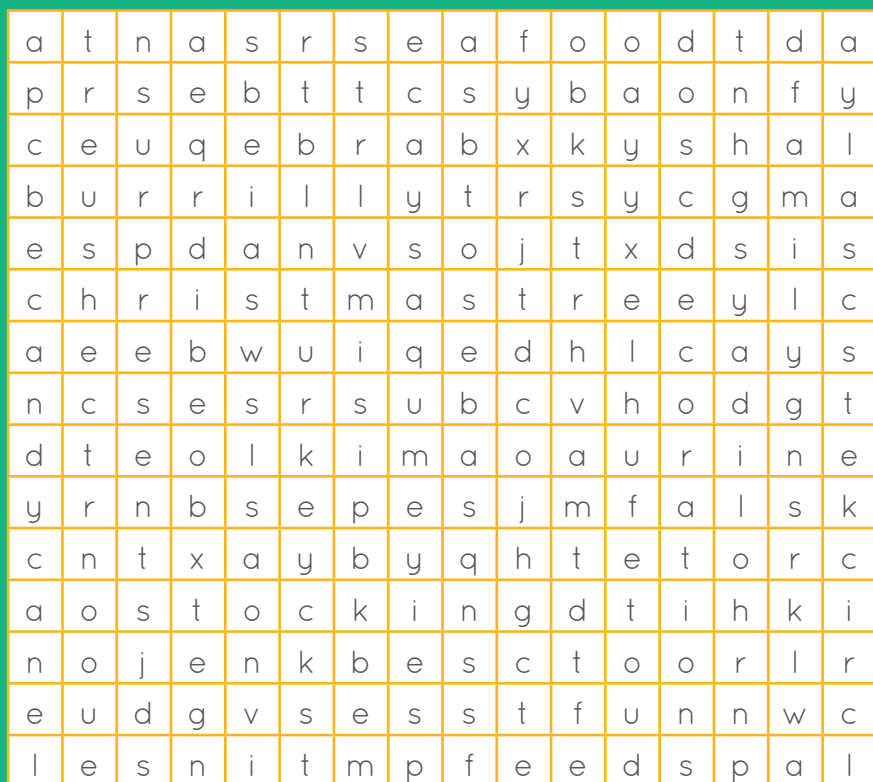
Q: What do you
call cheese that
isn't yours?

A: Nacho cheese!

Knock, knock
Who's there?
Interrupting cow.
Interrupting co....
MOO!!!

Word Search

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


☐ Barbeque

☐ Decorations

☐ Seafood

☐ Beach

☐ Family

☐ Stocking

☐ Candy Cane

☐ Holidays

☐ Tinsel

☐ Christmas tree

☐ Presents

☐ Toys

☐ Cricket

☐ Santa

☐ Turkey

