

## The contributing kids.

Jessica is a sixteen-year-old girl. She is currently in Year 10. Her kidney condition is called Medullary Cystic Disease. This is a genetic condition that was only diagnosed early last year, after a period of ill health prompted testing. Jessica has an identical

twin sister with the same condition. When Jessica was diagnosed she commenced peritoneal dialysis.

In November 2002 Jessica received a kidney from her mother. Her sister will probably receive a kidney from her father within the next year.



Adam is a sixteen-year-old boy and is currently in year 11. His kidney failure is a result of a disease called IgA nephropathy. This is an autoimmune disease where high levels of antibodies cause damage to the kidney tissue. He commenced haemodialysis in March 2003. His mother has donated a kidney to him and both are doing well.



Proudly supported by an education grant from



## The Kid's Companion On Kidneys.



Adam and Jessica  
tell it how it is as a kid living  
with kidney disease.

## Foreword:

Chronic Kidney disease in children is uncommon. However, the challenges facing children and young people who have kidney disease and their families are many and varied. Meeting these challenges can be made more difficult when someone who was in good health suddenly becomes sick.

This book explains about the kidney and how it works and the treatments available as kidney disease progresses. Insights are also provided on initially coming to grips with the facts about kidney disease. The hope is that children, young people, their family and community will have an easier introduction and understanding of chronic kidney disease, and the treatments available through reading this book.

Dr. Colin Jones,  
Director of Nephrology, Royal Children's Hospital,  
Melbourne.  
Associate Professor, University of Melbourne.

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# Kids and kidney failure.



Hi, I'm Jess. I'm 16 years old and in Year 10. I love dancing; jazz and contemporary dance are my favourites. I'm also a member of the Venturer Scouts. I get to go walking, hiking, rock climbing and canoeing with my group. It's excellent. I guess you could say I'm the active type!

G'day, my name is Adam and I'm also 16 years old. I'm in Year 11 at school. I'm really into music. I play the bass guitar and the drums, and I am in a band with some mates from school. We practice loads at my parents' place. I also like going fishing with my dad. I don't really like eating fish much but it's fun trying to catch them!

We are just like other boys and girls, but we also have **chronic kidney failure**. We're probably a bit older than you, but we think our stories will help you understand what it's like to be a kid living with kidney failure.

## Amazing kidney facts.



There are normally two kidneys in the body. They look like kidney beans. To get an idea of the size of your kidneys, make a fist. That's how small the kidneys are.

To find out where your kidneys are, put your hands on your hips. Now move your hands up until you can feel your ribs and put your thumbs on your back.

The spots where your thumbs are pressing are where your kidneys are.



5.

The kidneys do lots of jobs to help the body work. One of the most important is cleaning up the blood.

The kidneys are full of tiny filters. As blood passes through the filters they grab any waste stuff and extra water that the body doesn't want and turn it into urine. When people pass urine this gets rid of the waste that the kidneys cleaned out of the blood!

But that's not all the kidneys do. Here are some of the other jobs:

1. Kidneys tell the **bone marrow** (the soft bit in the middle of bones) to make **red blood cells**.

2. Kidneys make sure the blood has the right amount of **minerals** like calcium and phosphate in it.

3. Kidneys keep the blood free of wastes so that **growth hormone** can work properly.

4. Kidneys regulate the pressure of the blood flowing around the body.



6.

# What happens when your kidneys don't do their job?

Chronic kidney failure is an illness that makes the **kidneys** – an important part of the body – stop working. Doctors often call this illness **renal** failure. It means the same thing. Doctors use the word renal to describe everything to do with the kidneys.

Doctors use lots of other big words. To help you understand what these big words mean we have explained them at the back of this book. When you see a word that stands out **like this**, look in the part at the back of the book for big words to see what it means.



I didn't really know anything about my kidneys before I got sick. I didn't even know where they were! It was a bit scary when the doctors first told me I had kidney problems.

I had heaps of thoughts going through my mind. My mum and I wrote down lots of questions and asked the doctors and nurses. That really helped us figure out what was going on. It's good to ask questions. You could too!

The doctors told me that it wasn't my fault my kidneys stopped working. It never is anyone's fault. Sometimes kidneys just stop working!

I felt sick for quite a while before the doctors figured out there was something wrong with my kidneys. I used to get very dizzy, I wasn't hungry but I was tired. This was because the waste stuff that my kidneys normally get rid off was building up in my blood. Doctors call this **uraemia** (say **yur-ee-me-ah**).

I also found it really hard to concentrate at school. I'd sleep all hours of the day and be in bed most of the weekend. It stopped me from doing the things I liked. I couldn't see my friends and I missed lots of school.

I was tired because my body wasn't getting the oxygen it needs. This was because my kidneys couldn't tell the bone marrow to make enough red blood cells to carry the oxygen.

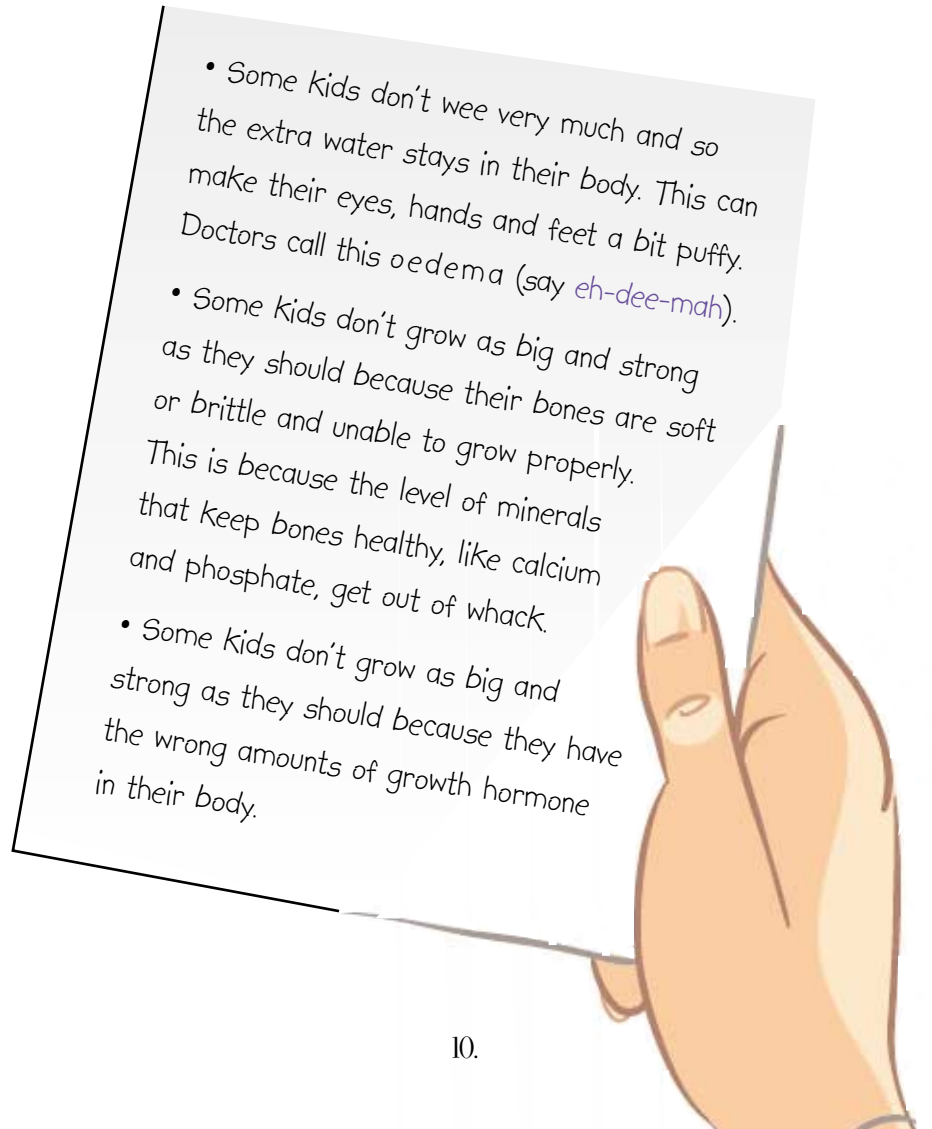
Doctors call this **anaemia** (say **a-nee-mee-uh**).

**anaemia**



There are other problems kids can get when their kidneys stop working. Look, I've made a list of some of them.

- Some kids don't wee very much and so the extra water stays in their body. This can make their eyes, hands and feet a bit puffy. Doctors call this oedema (say **eh-dee-mah**).
- Some kids don't grow as big and strong as they should because their bones are soft or brittle and unable to grow properly. This is because the level of minerals that keep bones healthy, like calcium and phosphate, get out of whack.
- Some kids don't grow as big and strong as they should because they have the wrong amounts of growth hormone in their body.



## Making you feel better.

Kids with sick kidneys have treatment to make them feel better. One type is called dialysis (say **dye-al-uh-sis**). Dialysis does the job the kidneys would do if they weren't sick. Dialysis gets rid of the waste stuff and extra water in the blood that the body doesn't want. It isn't a cure and so once people go on dialysis they have to keep having it regularly.

There are two different kinds of dialysis. One is called peritoneal dialysis (say **per-it-toe-nee-al dye-al-uh-sis**) and the other is called haemodialysis (say **hee-moe-dye-al-uh-sis**). A doctor or nurse helps people decide which type to use.

# dialysis



## Peritoneal dialysis.

After the doctors found out I had kidney problems they put me on peritoneal dialysis, or PD as I call it. PD is usually done at home, which I liked because it meant I could be at home with my mum, dad and sisters.

Before I started PD I had to have a soft, bendy plastic tube put in my tummy. It takes doctors about 30 minutes to put the tube in. You don't feel anything because you are fast asleep. They leave the end of the tube sticking out a little bit, which is a bit weird. It was also a bit sore at first.

To begin with I didn't want to look at the tube. I kept asking my mum and dad if it was still there! My mum and dad were cool though. They cheered me up and helped me to look after my tube. It's really important to keep the skin where the tube comes out clean so we bathed it every night. After a couple of months I didn't really notice that the tube was there. One of my friends even gave my tube a name – she called it Rodge! No one can see your tube, because your clothes hide it. My mum also made me a special belt to tuck the tube into to make sure it stayed hidden!

## The cyler machine.

Most kids have PD at night-time. That way they can sleep while the treatment is working. There are a couple of things you need for PD. One is a blood-cleaning liquid. The other is a machine called a cyler that works like a pump.

The blood-cleaning liquid is put into your tummy through your tube. The cyler machine stays on all night and helps to get the liquid in and out of your tummy through your tube. When the liquid is in your tummy, it grabs all the waste stuff and extra water. When the liquid comes out of your tummy it gets rid of all of the waste stuff.

Some kids have PD every single night, while others have it several times a week. Grown-ups usually help kids with their PD.



Dilly and me!

At first the noise of the cyler machine kept me awake at night. But I got used to it. Then, when I had friends to stay over, the noise would keep them awake but I'd be fast asleep! They got used to it as well though!

I didn't mind having the cyler machine in my bedroom. In fact I gave it a name – it was called Dilly! One of my friends even made a box for Dilly so I could take him to scout camps and to friends' places when I stayed over.

Most of the time I didn't mind having PD because it made me feel better. But sometimes it would hurt a bit. Other times I'd get a bit fed up with having to have it so often. I'd ask my mum and dad to make it all go away. Although they couldn't do that they helped cheer me up. They'd sit with me and talk to me to make me feel better. It's good to talk to people when you feel sad. They can make you laugh by telling you silly stories!



## Does PD change normal stuff?

Sometimes PD is a real drag because you have to do it so often. But I didn't let it stop me from doing the things I like. You shouldn't let it stop you either!

Tell yourself that it's just another part of normal stuff, just like cleaning your teeth or brushing your hair. You don't always want to do those things but you do!

Kids on PD can usually do most things. Never say you can't do something until you have checked whether there is a good reason why you can't.



I did my Venturer Scouts while I was on PD. I had to stay in a cabin instead of a tent because I needed electricity for Dilly.

But this just made me really popular with the other kids. They all used to come into my room because I had a heater and a TV!

I could do lots of the activities but not rock climbing, as the harness would hurt my tummy where the tube came out.

You're not allowed to go swimming when you first have your tube put in. But

most kids can swim a few months after as long as they use a special plastic cover to cover up their tube.

You can get the plastic cover from the hospital. It is better to swim in swimming pools but the sea because the sea is OK as well. You also have to clean your skin where the tube comes out after you've been for a swim.

## Haemodialysis.

I have a different sort of dialysis to Jess. It is called haemodialysis, or haemo. It also uses a machine but this one is called a dialysis machine. This machine is pretty big. It is normally kept in the hospital, although sometimes people have haemo at home.

I go to the hospital about three times a week to have my blood cleaned up by the machine.

The dialysis machine is really just a big pump. It takes blood from my body (just a little bit at a time) and pumps it to a filter. The filter gets rid of the waste stuff and extra water from my blood. When the blood is clean, the machine pumps it back into my body.

It doesn't feel funny having your blood going in and out of your body. You'd think you'd feel it but you don't!

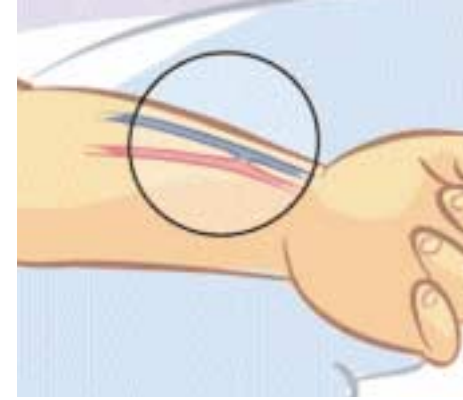


## Getting ready for haemo.

Doctors had to make a special place on my arm to hook me up to the dialysis machine. It's called a **fistula**. It was made about 6 to 8 weeks before my haemo started. Two tiny tubes, called **blood vessels**, in my arm under the skin were joined together. I was in and out of hospital on the same day!

I had to be careful with my arm after the fistula was made because it can easily get hurt. I also had to give up basketball; I couldn't risk my arm getting a knock. At first I was really protective of my arm. I didn't want to move it around but now I'm fine.

One of my mates accidentally put his hand on my arm where my fistula is. He jumped 10 metres and got as scared as! Then he said, "What's that?" and everyone in the class had to have a touch. It really freaked one kid out, which I thought was quite cool!



## Passing the time on haemo.

When it's time for my haemo the nurses put two needles in my fistula. You can have special cream put on your arm to make it numb so the dialysis needles don't hurt too much. Then I'm hooked up and ready to go!



It takes a few hours for a dialysis machine to clean your blood. While the treatment happens, you get to sit in a comfortable chair. I usually do some homework or listen to music to pass the time.

There are lots of other things you can do to stop yourself from getting bored. You could try watching TV, reading books,



eating your dinner, talking to your friends or playing computer games.

I'm sure there are lots of other things too. Have a think about what you would do!



## What's haemo like?

I feel a lot better because of haemo but it does take up a lot of time. There are times when I don't want to go to the hospital. But I know if I don't have my haemo I'll feel sick. I was sick every day before I started having it. Having haemo makes me feel well enough to do the things I want to, like hanging out with my mates!

I was nervous about haemo to begin with. The needles were scary and everyone seemed to rush around. But haemo is not as scary as I first thought! I understand what's going on now. It really helps when you know what's happening and why. I asked loads of questions. You should too. I found grown-ups are always happy to talk about things!

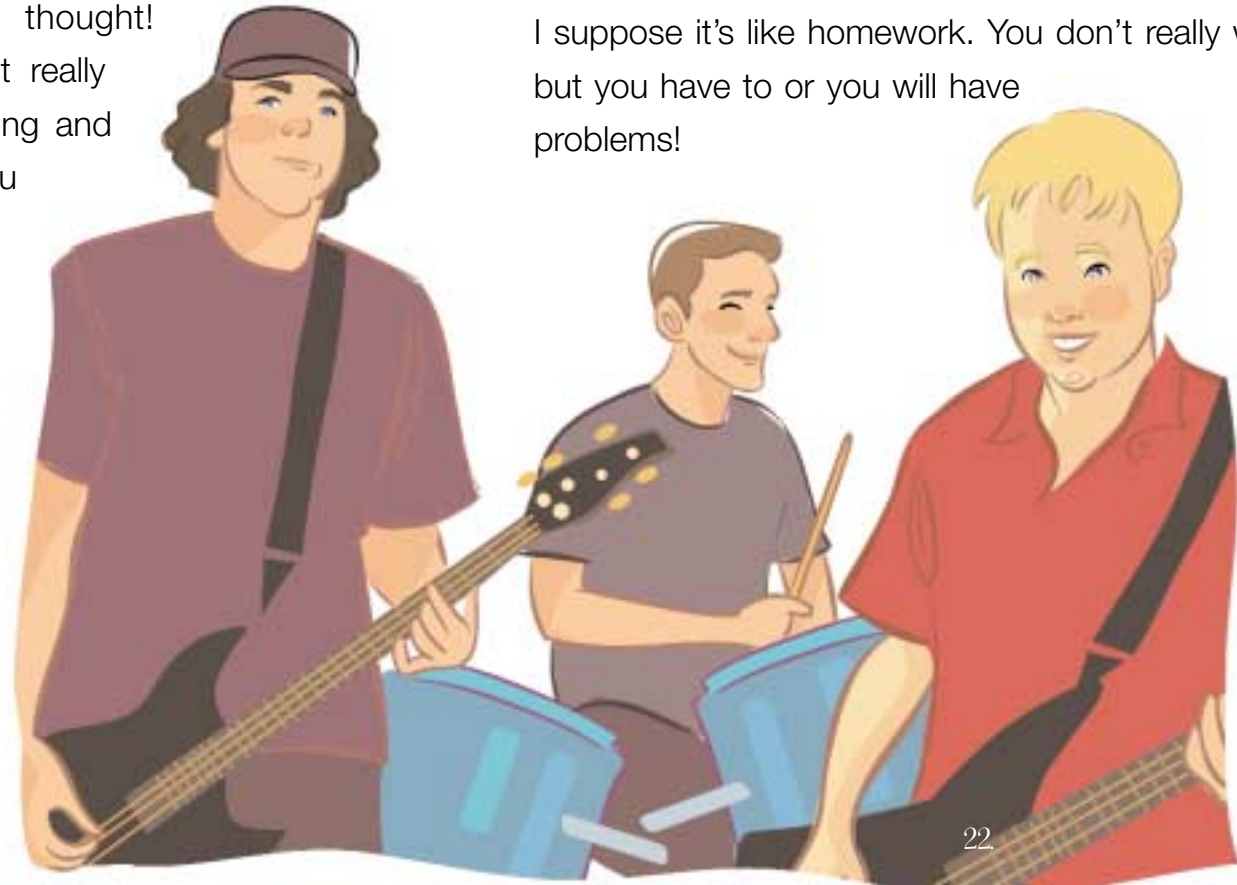
My mum and dad have been really cool too. They treat my haemo like a normal part of the week. We've got a timetable sorted out and we all stick to it.

I get tired on the days when I have haemo so I have a bit of rest on these days.

But I make sure I do as much as I can on the days when I don't have haemo. I see my mates, play my drums and go for walks. Kids on haemo can do most of the stuff other kids do.

I do miss a bit of school when I'm on haemo. But my teachers are cool! They help me catch up on stuff I've missed. I also get longer to do my homework!

Haemo can be a real drag but you learn to get on with it. Try thinking about haemo as another thing you just have to do. I suppose it's like homework. You don't really want to do it but you have to or you will have problems!



## Medicines.

Now I've made a plan that tells me when to take my medicines. I've never forgotten them again. You could make a plan too. There is a timetable you can use to help you in the insert section at the back of this book.

Use the timetable to write in the name of your medicines and the day and time you need to take them. You could also use stickers to remind you when to take your tablets! Why not stick it on the fridge door after you've filled it in.

You could set your watch alarm to remind you. You could also ask grown-ups like your mum, dad and teachers to help you remember. I've got little notes saying 'don't forget tablets' all over the house!



Having to take medicines all the time can be a real drag. Some of the anti-rejection medicines can do funny things to you. I got grumpy quite a bit when I took some medicines. I also ate more and had to get bigger clothes. I'm back to my normal size now though!

Some of the medicines can be a bit hard to take and some of the tablets are pretty big! This makes them hard to swallow. Some also taste a bit bad. Try taking them with milk rather than water. I found that this takes the bad taste away.

Remember, even if the medicines are a bit yucky sometimes, it's really important to keep taking them. You can always ask your doctor and nurses questions about your medicines.

Doctors check on you lots after you have your new kidney put in. But once they know it's settled in OK they don't see you as much. They trust you to take your medicines and look after your new kidney.

Sometimes kids find that their new kidney won't settle in. Even taking all the medicines doesn't help. In the end the new kidney stops working. These kids have to go back on dialysis. Then doctors start looking for another donor kidney for them.

## Lots of medicines!

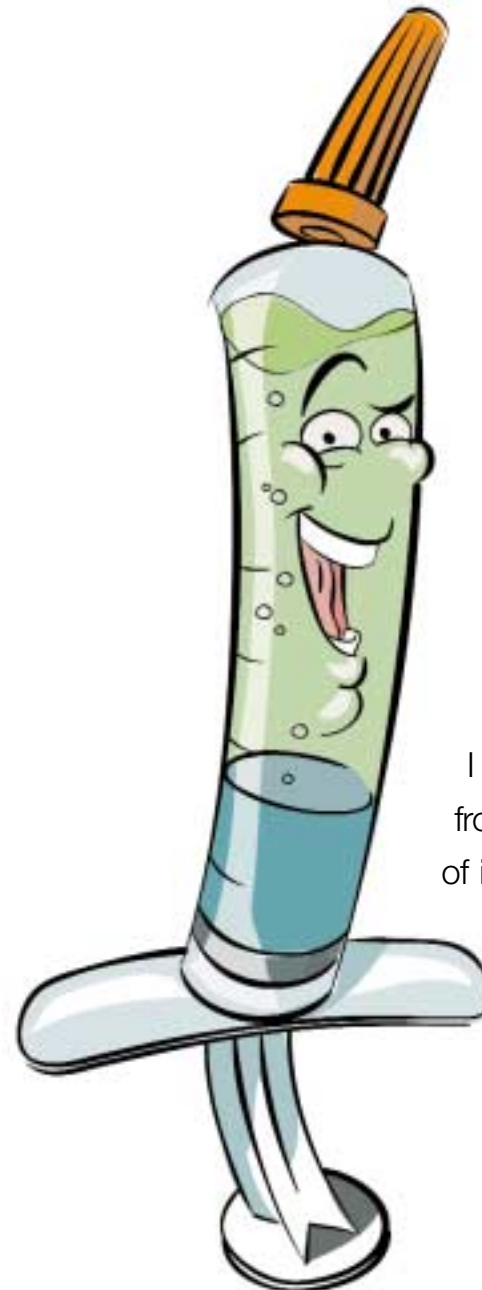
We have to take lots of medicines to make us better. They are very important. You will have to take lots too. It's very important to take them when the doctors tell you to.

Some of the medicines stop you from being tired all the time. They treat **anaemia**, which happens when you don't have enough red blood cells. Red blood cells carry oxygen to all the parts of your body.

When the kidneys are working properly they produce a hormone called **Erythropoietin** (say **ery-ethro-po-etan**). This hormone tells our body to make more red blood cells.

When the kidneys don't work properly they can't make Erythropoietin. So there is nothing to tell our body to make more red blood cells. This means that you need to inject a medication to replace this hormone. I have an injection when I have my haemo. When you take the injections you're not so tired and you can concentrate more at school.

Jess used to have the injection when she was on PD but she doesn't need it now she has a new kidney. Kids who aren't on



haemo have an injection just under the skin on their tummy or leg. Jess used to dread it when her parents came into her room to give her the injections. But it was over in a couple of seconds and it helped her feel much better. Some kids give themselves the injections but it's easier to get some help from a grown up.

I also take iron medicines to stop me from being tired. There are two types of iron medicine – iron tablets are one sort and an iron infusion is another. You have an iron infusion in the hospital.

# Looking after yourself.

## Drinking right.

I'm one of the kids with kidney failure who doesn't wee as much as normal. My body keeps too much fluid in it, so I have to watch how much I drink. This doesn't happen to all kids with kidney failure, only some. A doctor or nurse will tell you if you have to watch what you drink.

I can only drink a certain amount each day – less than 1 litre. Ask a grown-up to show you how much this is. I have a drink at breakfast time, another at lunchtime and the last one at night. It was really hard to stick to this at first. But now I've got used to it. I don't notice anymore when my mates at school have drinks and I can't have one.

Some people use smaller cups and take only little sips so it seems like they are drinking more! Others suck lollies to stop them wanting a drink. I get sick if I drink too much. I don't like being sick so I only drink what I'm supposed to.



## Eating right.

Dialysis is a good treatment. But it doesn't clean up the blood as well as your kidneys would do if they were doing their job. Because of this, you have to eat the right foods.

Grown-ups can help you figure out how to eat right. A person called a **dietitian** is really helpful. Kids see a dietitian about once a month or so.

G'day I'm Debbie and I'm a dietitian. I know all about food and what kids need to eat to be healthy. It is very important to eat right when you have kidney failure. Dietitians can help make eating fun even if you can't eat all of your favourite foods and have lots of cool tips as well.

When you have sick kidneys you end up with too much waste stuff in your blood. This gives you a bad taste in your mouth, makes you feel sick and tired and puts you off your food. By eating right you can cut down on the amount of waste stuff in your body.

A food plan helps kids eat lots of friendly foods and not too many unfriendly foods. It tells you what you can eat as snacks and gives you ideas for breakfast, lunch and dinner.

You should ask the dietitian at your hospital to help you work out a plan like this. It really helps! Take this book along with you when you see them.

## Friendly foods.

It is really important to eat a mixture of foods. You can eat lots of your favourite foods when you have kidney failure. But you mustn't eat too much of any one thing.

Below is a list of some of the foods you can eat. I call them friendly foods.

Some friendly foods

- Eggs
- Beef, chicken, lamb, pork, turkey, fish
- Bread
- Milk and ice-cream
- Popcorn
- Non-chocolate biscuits and cakes
- Most breakfast cereals
- Crackers, croissants and pastries
- Pasta and noodles
- Lemonade
- Sugar, chewing gum, jelly beans, marshmallows, mints, honey and jam
- Some fruit like apples, strawberries and grapes
- Some vegetables like broccoli, carrots and peas



**Hint:** There are lots of friendly foods. You should ask the dietitian at your hospital to tell you about more friendly foods.

## Unfriendly foods!

There are some foods that are a bit unfriendly to kids with kidney failure. You should try not to eat unfriendly foods. This is because these foods give you a bad taste in your mouth and make you feel sick and tired. Kids find it harder to stay healthy if they eat unfriendly foods.

Unfriendly foods hang out in groups. I've given each group a name so you can tell them apart. I'll tell you about each group one at a time!

### The potassium bunch.

The potassium foods that have a lot of potassium (a mineral) in them. These can be unfriendly foods for kids with sick kidneys. Having too much potassium in your blood can hurt your heart.

I've made a list of some of the foods that have lots of potassium in them:

- Potatoes, including chips and hot chips
- Bananas
- Orange juice
- Tomato sauce
- Baked beans
- Everything chocolate

**Hint:** Try eating things like unsalted popcorn or jelly beans instead of chocolate.





## The phosphate gang.

The phosphate gang are foods that have a lot of phosphate (a salt) in them. Foods that belong to the phosphate gang can be unfriendly foods. Having too much phosphate in your blood can hurt your bones.

I've made a list of some foods that belong to the phosphate gang:

- Peanut butter
- Dairy products like milk, ice-cream and cheese
- Bread
- Cola soft drinks
- Baked beans

You should try not to eat too many foods with phosphate in them. It can make you itchy if you have too much phosphate in your body!

**Hint:** To help foods taste good without salt, try putting lemon juice or vinegar on them.



Remember that you should not eat too many foods that have lots of salt in them. Salt makes the body hang on to too much water. It can also make people thirsty. This makes it hard for kids to control the amount of fluids they drink.

I've made a list of foods that have lots of salt in them:



- Bacon
- Sausages
- Pizza
- Hamburgers
- Potato chips
- Ham

You need to eat foods with protein in them to grow big and strong and have energy. But you mustn't eat too much protein. Dialysis can't

remove lots of protein from your blood. Too much protein can also give a new kidney (from a kidney transplant) too many jobs to do.

If you eat too much protein you may feel tired and sick, have a bad taste in your mouth and find it hard to concentrate on things.

I've made a list of foods that have lots of protein in them:

- Red meat
- Chicken
- Fish
- Eggs
- Dairy products like cheese and milk
- Peanuts





## Exercising Right.

I feel tired and don't always want to run around, but I still need to exercise. All kids should play sports and do other activities they like. Exercise is good for your muscles and bones. It also makes you feel happy. About 15 to 30 minutes of activities a day is the ideal amount. But even a little bit of exercise does you good.

Ask your doctor or nurse how much exercise and what type of activities you can do.

I like to walk to school and back with my mates. I also ride my bike sometimes on the weekend. Here are some other activity ideas that you might want to do:

- Swimming (kids on PD need to ask their doctor about this – have a look at the pink part of the book)
- Riding your bike
- Skating
- Dancing
- Ball games
- Bush walking

The best thing is to take as much exercise as **you** can. Make the most of when you have lots of energy. When you feel like running around, do it (unless your doctor has told you not to).

## Sun smart and tackling teeth.



To take really good care of yourself you also need to be sun smart. Too much sun is bad for your skin. All kids need to wear sunblock with SPF factor of 30 and remember to cover up with a hat, sunglasses and clothes. Staying out of the sun between 11am and 3pm EST is a good idea too!

If you've had a **kidney transplant** you need to be extra careful to avoid the sun. This is because some of the medicines some kids take make the skin even more sensitive to the sun.



You need to look after your teeth and gums to prevent cavities. Having fillings isn't much fun! It is important to brush and floss teeth twice a day and visit the dentist regularly.

You also need to get plenty of rest and sleep. If you take care of yourself you will have more energy, more fun and more chance of staying well.



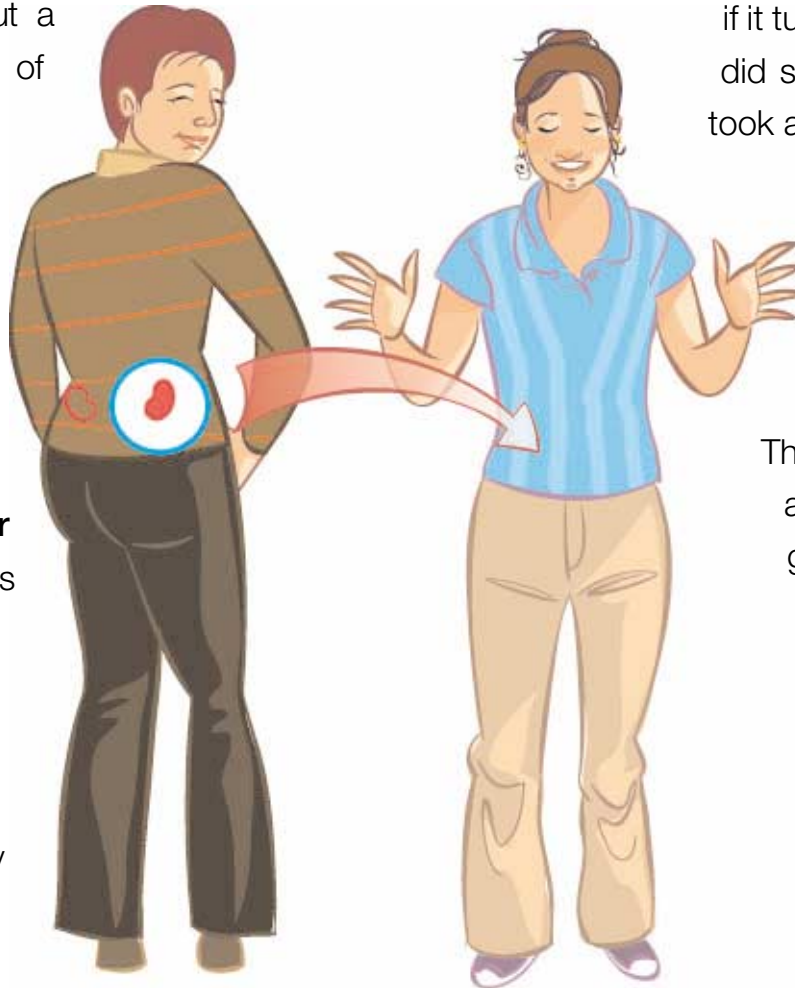
# Kidney transplant.

I'd been on dialysis for a little while and then the doctors and nurses started talking about a **kidney transplant**. This is another sort of treatment.

The doctors wanted to give me a healthy kidney from someone else, so that it could do the jobs my sick kidneys couldn't do. The doctors said I'd be able to stop dialysis if my kidney transplant went well.

Doctors call the healthy kidney a **donor** kidney. It can come from a person who has died. It can also come from someone who is alive, like your mum, dad, or another relative who is at least 18 years old.

Your body likes it better when the donor kidney is like your own! If the donor kidney is too different your body tries really hard to get rid of it. Doctors call this rejection.



You often have to wait a while to get a donor kidney. This is because it takes doctors a while to find a kidney that is a lot like your own kidneys.

My mum said I could have one of her kidneys if it turned out to be like mine. The doctors did some tests to find out if it was. They took a little bit of my blood and a little bit of my mum's blood. Then they mixed it up to see if my body would fight my mum's kidney too much. My mum's kidney turned out to be OK.

The doctors then did some more tests and gave me injections to stop me getting the flu and other bugs.

## Getting your new kidney.

You have to have a big operation to put the donor kidney in your body. My mum also had to have a big operation to take one of her kidneys out. We were both scared but we were excited as well. We were looking forward to me not having to have dialysis.

A doctor called a **surgeon** put my new kidney in me. He put it in at the front in the right side of my tummy. He left my other kidneys in my body because they weren't doing any harm! I was fast asleep when my new kidney was put in. I was a bit sore when I woke up but I soon felt better.

I've got a scar where my new kidney was put in. It's about 20 cm long. Have a look at how long this is on a ruler. It's not too bad! Besides, my T-shirt covers it up anyway. All my friends think my scar is cool! They're always asking to see it!



My transplant is going really well. I can eat more stuff now. But I still have to make sure I eat the right foods. I don't want to give my new kidney more jobs than it can do!

To keep my new kidney healthy I take lots of medicines. These stop my body from fighting with my new kidney. They are called anti-rejection medicines. If you think that's a mouthful wait until you hear what doctors call these medicines. They call them **immunosuppressants** (say **im-yoo-no-su-press-ants**)!

It's really important to keep taking these medicines. Take them when the doctors tell you, so you won't hurt your new kidney. If you don't take the medicines your new kidney won't live for very long.

I forgot to take my medicine once and I got really scared. I'd been on school holidays and then I forgot to take them on the first day back at school.

## Friends and school.

Having chronic kidney failure can be a real drag. But there are lots of things you can do to make sure it doesn't bother you too much.

For instance, when I first got sick I got fed up with all my friends asking me what was wrong with me. They all asked the same questions!

So I asked my nurse to come to my school and give my year a talk about the kidneys and treatment. Three kids fainted when the nurse showed them a bendy tube like the one I had in my tummy!

But then everyone thought it was cool!

My friends have all been really cool. They don't care that I have kidney problems. I'm just normal Jess to them. It's good to hang out with your friends. Friends are good at cheering you up if you feel a bit sad.



I go to school just like other kids. Sometimes I miss a bit of school. But my teachers are really cool. They give me extensions so I can get my work done. I never have to skip schoolwork – it's just that sometimes I have to do it a bit after my friends.

I also get extra tutoring now to help me catch up on any stuff I've missed. I don't mind my friends knowing. Some of them need extra tutoring as well! My teachers offered to change my exams around if I wanted but I didn't want to.

I got good marks too – all As and Bs!

Your teachers will know about your kidney problems and are always happy to talk to you if you're worried about anything. Teachers can be cool you know!

# The End.



# The big words explained.

**Anaemia (a-nee-mee-uh):** The name doctors use when someone doesn't have enough red blood cells. When people have anaemia, they can't get all the oxygen they need and this makes them feel tired all the time.

**Blood vessels:** Tiny tubes inside the body that carry blood all over the body.

**Bone marrow:** The soft bit in the middle of bones that can make a lot of different cells. Red blood cells are one type of cell made by bone marrow.

**Chronic kidney failure:** An illness that means a person's kidneys stop working forever.

**Dialysis (dye-al-uh-sis):** A treatment for people whose kidneys don't work properly. There are two types of dialysis: haemodialysis and peritoneal dialysis. They both do the jobs a healthy kidney would do.

**Dietitian:** A person who knows all about food. A dietitian helps people decide what foods they should eat to keep them healthy.

**Donor kidney:** A healthy kidney that someone gives to a person with sick kidneys.

**Erythropoietin: (ery-ethro-po-etan)** It works by telling the **bone marrow** to make more **red blood cells** and this gives people more energy.

**Fistula:** A special place on your arm that doctors make so that you can have haemo.

**Growth hormone:** A substance in the body that helps make kids grow big and strong.

**Immunosuppressants:** Strong medicines that people who have had a **kidney transplant** take to help stop their body fighting the **donor kidney**.

**Kidneys:** Organs that do lots of jobs in the body, including cleaning up the blood. The kidneys sit at the back of the body, one on either side of the backbone.

**Kidney transplant:** A type of treatment where you get a new kidney to do the jobs your sick kidneys can't do.

**Minerals:** Substances that are found in food and drinks, as well as other places, that give the body some of the things it needs to work. Minerals help keep things like teeth, bones and muscles healthy.

**Oedema (eh-dee-mah):** The name doctors use to describe it when there's too much water in your body. Oedema can make people's hands, feet and eyes a bit puffy.

**Red blood cells:** Red blood cells grab the oxygen people breathe in and carry it all over the body to the parts that need it.

**Renal:** The name doctors use to describe everything to do with the kidneys.

**Surgeon:** A type of doctor who does operations, including kidney transplants.

**Uraemia (yer-ee-me-ah):** The name doctors use to describe it when there's too much waste stuff in the blood. People with uraemia feel sick and tired, and don't feel like eating.

## Useful Contacts.

### Kidney Health Australia

Kidney Health Australia (formerly known as The Australian Kidney Foundation), is a not-for-profit organisation whose mission is to be the lead organisation promoting kidney and urinary tract health through research, advocacy, education and health service excellence.

The principal objectives of Kidney Health Australia are to provide a range of health programmes and resources designed to cater for the needs of patients with kidney problems and their families, general public, supporters and staff.

For more information about kidney and urinary health, contact your local branch of Kidney Health Australia.

### Kidney Health Australia

GPO Box 9993 in your capital city

Freecall: **1800 682 531**

website: **www.kidney.org.au** e-mail: **christine.frew@kidney.org.au**

### Renal Resource Contacts.

The National Renal Resource Centre is a community service of Northern Sydney Health, working in close partnership with Kidney Health Australia. It provides information, telephone counselling, resource material, seminars and peer support groups to patients with kidney problems, as well as family members and staff throughout Australia, to facilitate adjustment to living with kidney disease.

The Polycystic Kidney Disease Association is based at the Renal Resource Centre and provides information and counselling to families and individuals affected by this genetic condition.

### 'Duntrim',

Sydney Dialysis Centre, 37 Darling Point Road, Darling Point, NSW 2027.

Tel: **02 9362 3995**. Fax: **02 9362 4354**. Freecall: **1800 257 189**.

Email: **d.oshaughnessy@hcn.net.au**

# Paediatric renal units.

Please phone the switchboard number below and ask to speak with the renal unit nurse, social worker or dietitian.

## New South Wales.

**Children's Hospital at Westmead,**  
Cnr Hawkesbury Road and Hainsworth  
Street,  
Westmead, NSW 2145.  
Tel: **02 9845 0000.**

**Sydney Children's Hospital, Randwick,**  
Cnr High and Avoca Streets,  
Randwick, NSW 2031.  
Tel: **02 9382 1111.**

## Queensland.

**Royal Children's Hospital,**  
Herston Road,  
Herston,  
Brisbane, QLD 4006.  
Tel: **07 3636 3777.**

**Mater Children's Hospital,**  
Ward 8 East,  
Stanley Street,  
South Brisbane, QLD 4101.  
Tel: **07 3840 8111.**

## South Australia.

**Women and Children's Hospital,**  
72 King William Road,  
North Adelaide, SA 5006.  
Tel: **08 8161 7000.**

## Tasmania.

**Launceston General Hospital,**  
Charles Street,  
Launceston, TAS 7250.  
Tel: **03 6348 7111.**

(Please note that Tasmania does not have a renal unit specifically for paediatric patients. However, this unit does treat paediatric renal patients as well as adult renal patients.)

## Victoria.

**Monash Medical Centre,**  
264 Clayton Road,  
Clayton, VIC 3168.  
Tel: **03 9594 4497.**

**Royal Children's Hospital,**  
Ward 7W, Flemington Road,  
Parkville, VIC 3050.  
Tel: **03 9345 6635.**

## Western Australia.

**Princess Margaret Hospital  
for Children,**  
Roberts Road,  
Subiaco, WA 6008.  
Tel: **08 9340 8316.**

## Other Support Services.

### New South Wales.

**Renal Association of New South Wales,**  
PO Box 761, Brookvale, NSW 2100.  
Tel: **02 9531 2589.**

### Victoria.

**DATA (Dialysis and Transplant Association):**  
(An organisation for patient support and self-help.)  
14 Queen Street, Blackburn, VIC 3130.  
Tel: **03 9894 0377.**  
Fax: **03 9894 0266.**  
Email: [datavic@netspace.net.au](mailto:datavic@netspace.net.au)

### Western Australia.

**DART (Dialysis and Renal Transplant  
Association of WA Inc.),**  
C/- Australian Kidney Foundation West. Aust.  
3rd Floor, 68 St George's Terrace,  
Perth, WA 6000.  
Postal address: GPO Box 9993,  
Perth, WA 6848.  
Tel: **08 9322 1354.**  
Fax: **08 9481 3707.**  
Email: [akf@perth.kidney.org.au](mailto:akf@perth.kidney.org.au)

**TPG (Transplant Promotion Group  
of WA Inc.),**  
PO Box 932, West Perth, WA, 6872.