

ALEXANDER'S STORY



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Better Health for Our Community

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Foreword:

I began working with Alexander during 2007 in my role as a play therapist at Monash Medical Centre. My knowledge of kidney conditions and treatments at this time was very limited and I began to think about how daunting the process of dialysis must be for newly diagnosed renal patients and their families. As I was working closely with a child who was on haemodialysis I decided that I needed to extend my knowledge of peritoneal dialysis.

Alexander's Mum Sarem was very open to the idea of creating a book that could be useful to other families in a similar situation. Sarem was very knowledgeable about her son's condition and was enthusiastic about sharing her skills and experiences.

We envisage that this book will be a valuable teaching tool for children and families before they begin the actual treatment phase of their condition. This book has been written by a parent for other children and parents.

Sarem and I have learnt a lot in the past few months. We hope you do to.

Play Education and Arts Therapy Department
Monash Medical Centre Clayton

Acknowledgements:

Several people provided helpful assistance in making this book possible:

The front cover was drawn by Alexander, his sisters Somawe (14 years old) and Jennifer (10 years old) along with his brother Jemme (12 years old). Alexander's brother and sisters created illustrations about Alexander's experiences with kidney disease and his medical treatment in hospital and at home. They have done a fabulous job and we thank them for all their efforts.

Funding:

The Monash Kids Support Group

The Monash Kids Support Group was established in 1993 as a group of volunteers with the common interest in the needs of children at the Monash Medical Centre. Monash Kids have raised and donated \$10,000 towards this project in funding both the research and the publishing of this book.

We thank them for their ongoing support of the Play Education Department at Monash Medical Centre.

- The Peter Williams Trust
- The nursing staff in the paediatric renal unit at Monash Medical Centre, particularly Yogi, Gina, Meredith and Maria.
- Alexander and his Mum, Sarem, for their enthusiasm and willingness to share their story.

Thank you very much for your contributions.

About Alexander

This is Alexander. He is two-years-old. Alexander really loves 'The Wiggles' and one of his favourite things to do is laughing while watching 'The Wiggles' movies. In fact, Alexander is nearly always smiling, laughing and blowing kisses.



At home he is very happy when he is playing with his brother and sisters. Alexander has a pet dog and he enjoys feeding his fish. Look at all of Alexander's toys!



Alexander's Family

Alexander lives at home with his Mum Sarem and his Dad Thy. He has a brother Jemme who is 12 and two sisters. Jennifer is 10 and Somawe is 14.



Recently Alexander visited Gumbuya Park with his family. He thought the kangaroos were beautiful, but he wasn't really happy when riding in the racing car.



Alexander's Kidneys

I am Alexander's Mum, Sarem. Here I am at Monash Medical Centre with Alexander. When Alexander is in hospital he likes me to be near him.



When Alexander was born the doctors told me that he had enlarged kidneys and that they were not working properly. It was a sad time for our family, but we had to stay positive. Alexander has polycystic kidney disease.



Polycystic kidney disease is a kidney disorder passed down through families in which multiple cysts form on the kidneys, causing them to become enlarged.

Dialysis

Alexander began dialysis in hospital to do the job of his kidneys. This was done manually by his nurses.

When Alexander was 18 months old he had an operation to put a catheter in his tummy. It is like a soft plastic tube. The doctors leave the end of the tube hanging out. A catheter is needed so that Alexander's dialysis can be done at home.



The whole catheter.



This part of the catheter sticks out of the tummy.



This part is inside the tummy.



Alexander feels comfortable with the catheter in his tummy. He also has a peg in his tummy where he can be given extra food as well as medicine if he needs it. This helps him to feel much better. Alexander also had an operation to take one of his kidneys out so that there was room for the catheter.

Caring for the catheter

It is important to keep the area clean around where the catheter comes out. As soon as Alexander gets out of his bath I need to change the dressings straight away to stop germs getting in.



Alexander likes to hold the swabs and dressings when I do this. He is a good helper.

Sometimes Alexander develops an infection and he needs to stay in hospital to be given medicine through his catheter. Antibiotics treat the infection.



Infection is the most likely complication of peritoneal dialysis. Peritonitis needs to be treated straight away with antibiotics.

Peritoneal Dialysis

Alexander's dialysis is called Peritoneal Dialysis. He has this at night time while he is asleep. The nurses taught me how to do this so I could do it at home for Alexander. Over a few weeks, I learnt how to use the dialysis machine as well as the many other things I needed to know about dialysis.



The dialysis machine

If your kidneys cannot remove waste substances from your blood, you will need dialysis. Children with sick kidneys have treatment to make them feel better. During peritoneal dialysis a blood cleaning liquid is pumped into your tummy to get rid of all the waste products.

There are two different types of dialysis. One is called peritoneal dialysis and the other is called haemodialysis. Your doctors and nurses will help you and your family decide which type to use.

Diet and Meals

Alexander is fed a special formula through his peg tube in his tummy. This helps him to grow.

Medications

Four major areas of concern are blood pressure, diet, anaemia, (low red blood cell count) and growth. The child may need to take several medications (both orally and by injections) and be on a modified diet.

Blood Pressure Tablets (may include one or two of the following)

Atenolol
Nifedipine
Amlodipine
Irbersartan
Enalapril
Ramipril

Phosphate Binders to prevent renal bone disease (may include one of the following)

Calsup
Titalac
Tums

Multivitamins are used as a supplement for vitamins lost in dialysis.

Erythropoietin Injections to promote red cell production and prevent anaemia. May be given weekly, fortnightly, once every three weeks or monthly.

Human Growth Hormone Injections to improve growth.

Vitamin Suppliments

Play time

Alexander likes to play in the playroom at the hospital. Here he is pretending to be the doctor and he knows just what to do with the stethoscope. First he checks the doll then he checks me.



Maybe Alexander will be a doctor or nurse one day!



What are kidneys?



The main job of the kidneys is to remove waste from the blood and return the cleaned blood back to the body.

Kidneys are a special filter system for your body.



They are located near the middle of your back, just below the rib cage.



Your kidneys are bean-shaped organs, each about the size of your fist. There are normally two kidneys in your body.

Useful contacts

Play Education Department

Monash Medical Centre

246 Clayton Road

Clayton Victoria 3168

Phone: Head of Department 9594 4171

Staff Office 9594 6951

Paediatric Renal Unit

Monash Medical Centre

246 Clayton Road

Clayton Victoria 3168

Phone: 9594 4235

Kidney Health Australia

Phone: 1800 682 531

Website: www.kidney.org.au

- You can download a range of information brochures and fact sheets
- Look for the KIDney kids section



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accountability, respect, excellence