

LISA'S STORY



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Better Health for Our Community

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Foreword:

I began working with Lisa at the beginning of 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. I was also amazed at how much Lisa could tell me about the procedures of her dialysis treatment.

After collaborating with the staff in the paediatric renal unit I suggested to Lisa that we make a book together explaining all about haemodialysis. She was extremely enthusiastic and so began our journey together of teaching and learning.

We envisage that this book will be a valuable teaching tool for children before they begin the actual treatment phase of their condition. Lisa and I have learnt a lot in the past few months. We hope you do to.

Tracey Clinch
Play Therapist
Play Education and Arts Therapy Department
Monash Medical Centre
Clayton, Victoria

Acknowledgements:

Several people provided helpful assistance in making this book possible:

The cover artwork was created by Lisa. What a great job she did!

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 Monash Medical Centre. Monash Kids has raised and donated \$10,000.00 towards this project in funding both the research for 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.
- Lisa and her Mum, Ley Fong, for all of their knowledge and enthusiasm
- Emmerson School for their co-operation

Thank you very much for your contributions.

About Me

My name is Lisa and I am 12-years-old. I go to Emmerson School and I am in Miss Searle's class. Kathryn and Jasmin are my friends.



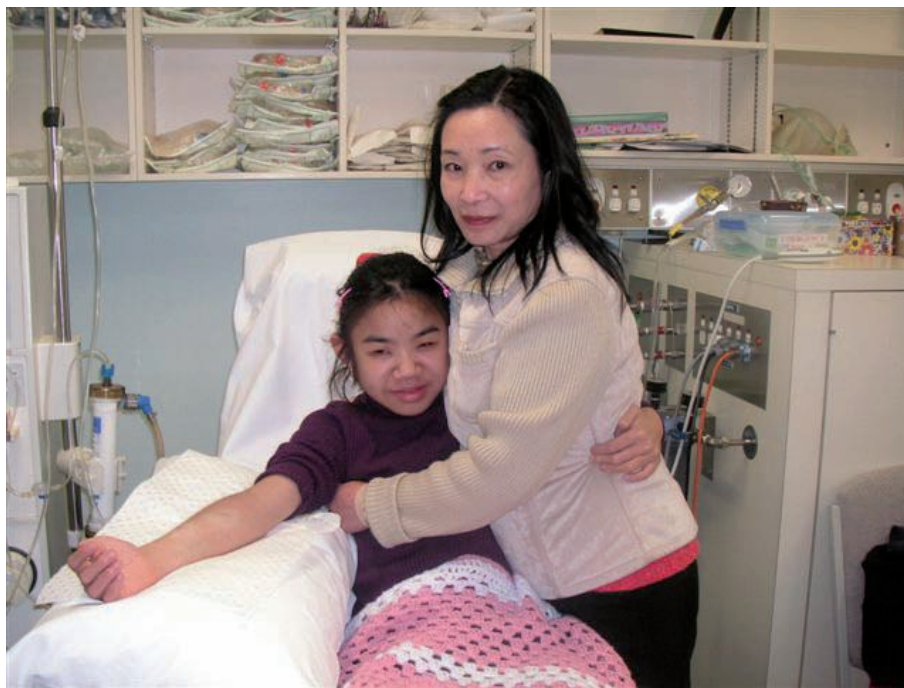
At school I like learning about planets. Usually we do the seasons – Summer, Autumn, Winter and Spring. I catch the bus to school.



My Family

I live with my brother Kevin, Mum and Dad. I like spending time with my family.

At home I clean up my bedroom all the time.



My Mum comes to the hospital with me when I have dialysis. I love giving her cuddles.

Going to hospital

I come to Monash Medical Centre on Monday's, Wednesday's and Friday's for dialysis. My Mum drives me in her car. Sometimes I have to leave school to come to the hospital. Sometimes it is school holidays so I come from home.



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.

The Dialysis room



When I am doing dialysis I like to watch 'Sponge Bob' on television. I have a pink and white blanket to keep me warm. Sometimes I read my books from school.

During dialysis I make things with Anne. Tracey comes every Friday. They are the play therapists at the hospital. We do painting and colour mixing. We play "Connect Four" and I win!



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.

Haemodialysis

My dialysis is called **haemodialysis**.

Dialysis takes three hours. The nurse puts two needles in my arm. I have a fistula in my arm that the needles go in. Mum cuddles me when the needles are being put in. I had an operation to make my fistula.



Before long-term dialysis can begin a fistula is created by connecting an artery and a vein, usually at your wrist. It can take up to three months before your fistula is ready to use. During this time you can go home and participate in normal daily activities.

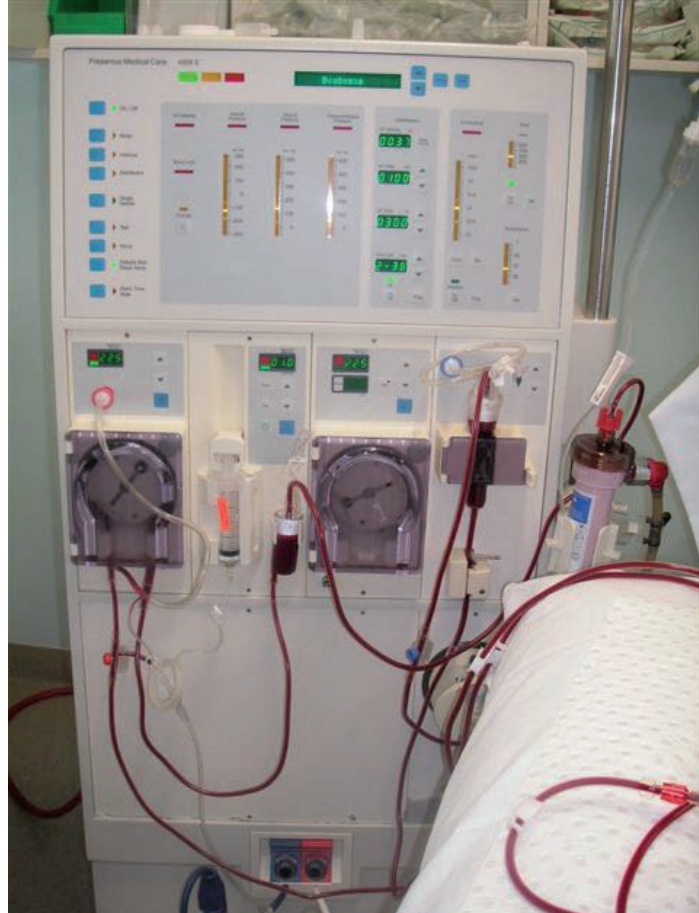
Two needles are inserted into the fistula – one to carry blood to the dialysis machine and the other to return the clean blood to the body.

The nurse then connects the tubes to the dialysis machine. The blue part connects to the top tube. This carries the venous blood. The red part connects to the bottom tube which carries the arterial blood.



The dialysis machine

Red blood goes around a maze of tubes. There are four clamps which need to be opened. The dialysis machine is busy washing my blood. There should be seven green lights on the machine. I count them. The machine makes a noise. I can hear the beeping. It is a loud noise.



The dialysis machine is like a big pump. It takes blood from your body and pumps it into a filter. The filter removes the waste and extra water from your blood. When the blood is clean, the machine pumps it back into your body.

Care during dialysis



Yogi is my nurse in the dialysis room. Some of the other people that help me are doctors and dieticians.

A dietician is an expert in food and nutrition.

During dialysis the nurse takes my blood pressure at least six times.



I need to keep my arm very still. It all feels quite right.

Your blood pressure is taken so that the nurse can monitor if the right amount of fluid is being taken out during dialysis. If your blood pressure is low it means that too much fluid is being taken out and it will need to be adjusted.

Diet and meals

I have morning-tea during dialysis. I have cookies and strawberry milk. During dialysis I also eat lunch. I like chicken and gravy and apple juice.



Good nutrition is important. A dietician will be able to provide you with advice and information. You will soon get to know which foods you will be able to eat more of and which ones to eat less of. Some foods will make you feel sick and tired so it is best to limit them.

My Mum picks me up when I have finished dialysis and we go home.

Medications

Every day I need to take tablets. One tablet I take three times a day when I have my meals and another one I take in the morning and at night. I swallow them with water. The tablets keep my bones strong and stop bone disease.

Medications for children on Dialysis

Four major areas of concern are blood pressure, diet, anaemia (low red blood cell count) and growth.

The Children may need to take several medications both orally and injections and be on a modified diet.

Medications

Blood pressure Tablets

(may include one or two of the following)

Atenolol

Nifedipine

Amlodipine

Irbersartan

Enalpril

Ramapril

Phosphate Binders

To prevent renal bone disease (may include one of the following)

Calsup

Titralac

Tums

Multivitamins

Used as a supplement for vitamins lost during dialysis.

Erythropoietin Injections

To promote red cell production and prevent anaemia. May be given weekly, fortnightly, once in three weeks or monthly.

Human Growth Hormone Injections

To improve growth.

Vitamin Supplements

Who can choose haemodialysis?

Haemodialysis is appropriate for younger children too!!



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