



Amputees
Federation
of New Zealand
Incorporated

Little Jellybean

By Margot
and Anton Wuts





A Letter to You, The Parents

It is an overwhelming concept, tainted with a shadow of terror; the thought of amputation. The loss of a limb, a piece of body. How can that not be horrific?

As with all decisions we make when deliberating the future well-being of our children in a holistic and enduring way, we need to create a black and white picture which really will be the yes or no. Of course it is more likely that the need to make a decision has been taken out of your hands and what you are facing may be a difficult (but not impossible) journey of preparation, during which you must take every opportunity to observe and think critically about how you want this process to go, not just for the child in question, but for every member of the family.

Ask every question that comes into your head and never under-estimate the knowledge there is to be found and the power you have as a parent, grown from the deep understanding and regard for your child.

One of the best ways to prepare is to talk to your child and always be watchful of how they are responding to the different terms you use. They may wish you to change Rose's name to their own or only listen to the first/last pages of this book. It is important to allow yourself to be led by the child. There are so many ways of approaching different situations. Of course we are all doing the best we can and this is a trauma everyone is going through so it is important to remember to be gentle and kind to yourself. There is no book to tell you how this should be done and mistakes will be made along the way, but to get through this time with something to recover with, there has to be kindness. To each other and to yourself.

One of the biggest surprises for me was also the biggest lesson and I continue to learn from it. This was all about my fear, the fear of how I would cope with my child waking up and finding that a part of her, a part that featured so hugely in her life, was simply not there anymore. I was completely unprepared for how she reacted to this. She lifted the blanket and had a look while I held my breath, then she gave a huge gasp and turned to me with such an expression of wonder and delight and said "Mum! I've got no feet!" It was as though she had just received the best Christmas present ever! I was completely stunned and realised with so much relief that she wasn't afraid, she was relieved! I hadn't lived her first four years. I couldn't possibly know how it was going to feel for her, I was imagining how it would feel for me and we have such a different history.

This is one of the reasons I cannot stress enough how important it is to observe the child. Nothing else will be as crucial to your approach because only through observation can you become really in tune with the child's individual reaction and response.


I hope there are many lovely story-telling times with this book and I really hope that this letter has been of some benefit. This time will pass, that is something you can be sure of and the lessons learnt from it will stand you in good stead.

Write down your experience so that you can read it later and marvel at yourself and the strength you didn't think you had.

*Good luck to all,
Margot*

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There is a Mum, who is soft, curly and sings all the time. There is a Dad who reads stories, laughs a lot and bakes delicious biscuits. There is a big sister called Violet who climbs trees and knits. There is a little brother called Louis who is a stomping, shouting pirate ...

... and there is a little girl in the middle called Rose, who is a funny, face-pulling trickster !





Every night, after dinner, the music
starts and everyone dances ...

'Round and 'round they dance, running
and jumping and twirling around Rose,
who dances on her knees ...



Sometimes when Rose is twirling
and whirling, she falls over
and sometimes it hurts to dance ...

Rose has a foot that is different;
it is not a dancing foot
and looks a bit like a jellybean
(or a hockey stick or
an umbrella handle !) ...



Rose's foot has meant that Rose has
been in hospital a lot.

It's a BIG serious place with lots of
important people doing lots of
important work ...

When Rose was in the hospital,
Mum and Dad and Violet and Louis
all stood around Rose's bed
while the important people touched
Rose's foot and drew
funny-looking arrows on it.
They were deciding what to do
to make it better.



At the hospital there are doctors and
nurses and they are fixers.
They fix all sorts of things
on all sorts of people;
for Rose they are foot fixers !

... and they tried to fix Rose's foot,
but the foot still won't dance
and it still looked like a jellybean
(or a hockey stick,
or an umbrella handle !) ...



**Rose's Mum and Dad sat together
and wondered.**

**"This foot is just no good !
If only we could
swap it for a new one".**



Mum and Dad decided to have a chat with the important people about this.

“Is it a good idea?”

“Can it really be?”

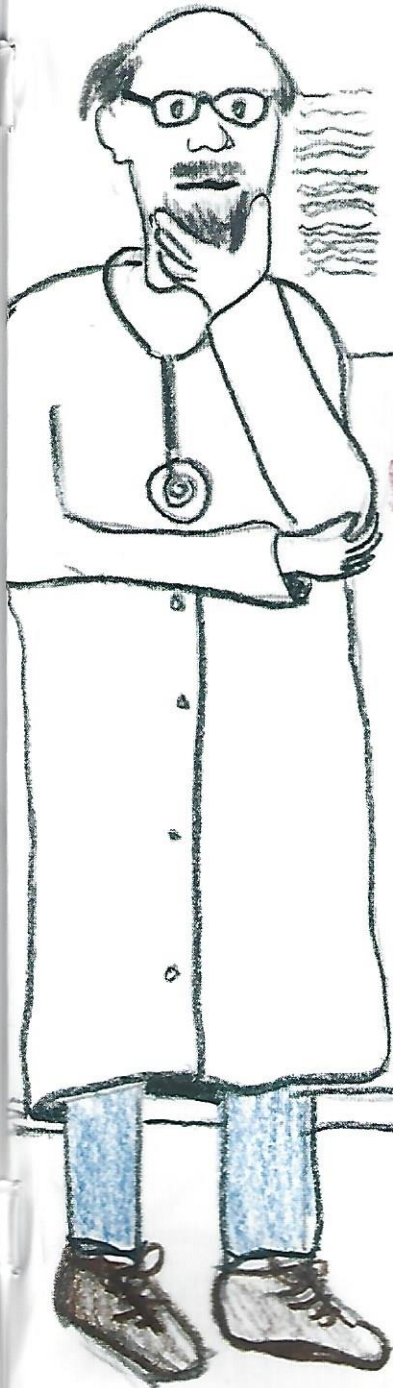
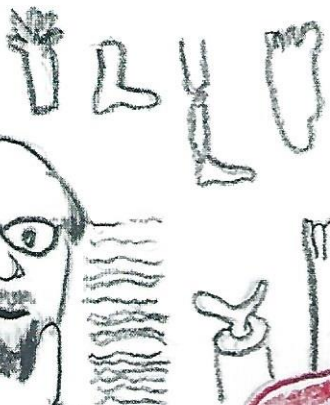
“YES!” they said, “It can !”

“We can take away the foot that doesn’t work and make a new one that you can take on and off like a shoe !”

“That sounds FANTASTIC !”
said Rose’s Mum and Dad:

“Lets do it !”

PROSTHESES



**Rose was a bit worried about how
this would happen ...**

... and so was Violet.

**Mum and Dad knew all about it though,
and made them feel better
with lots of talking and cuddles,
kisses and stories,
and lots of laughter !**



The big day came and Rose had some
medicine that helped her
go into a deep sleep.

When she woke,
her leg was very heavy.

She pulled the blankets up and saw
that her leg was wrapped up
in a thick, hard, white cast
and at the bottom it was round !

NOT like a jellybean
(or a hockey stick,
or an umbrella handle at all !!)



Rose's Mum and Dad,
and Violet and Louis,
looked after Rose's leg
for many weeks.

They kept it warm and dry and safe.

They read stories to Rose
and sang songs
and made Rose laugh.



When Rose's leg was ready, her Mum
took her on a plane to a big, windy
city where the houses were very
close together and it
smelt like the sea.

A special place where there were
people who made legs and arms
and hands, and even feet !

They made Rose a new foot
she could pull on
and take off like a boot ...



When Mum and Rose came home,
Dad and Violet and Louis
were ALL so happy !

Rose climbed out of the car and
walked up to the big white house,
she came through the gate and
walked around and around
the garden.

Her two feet made her proud:
her old sensible foot knew the way,
and her brave new foot
would soon learn ...



That night, after dinner,
when the music came on,
everyone danced and danced !

There was twirling and whirling
and skipping and stomping
(so much dancing that Louis fell over !)

But Rose did not,
because Rose had dancing in her head,
dancing in her arms
and dancing right down to her feet !



Margot and Anton Wuts are parents to three children.
They live in Haumoana, Hawke's Bay, New Zealand.

Their daughter Trixie was diagnosed with Distal Arthrogryposis in utero, and from birth suffered through many procedures to try and correct the deformities in both of her feet.

With no resolution in sight, and other parts of her body being adversely affected by the lack of improvement, they asked for amputation to be considered.

The medical professionals involved in Trixie's case agreed that it would be the best chance of her having an active and hopefully pain-free life.

After much preparation, surgery, debridement and recovery, Trixie now leads a full and active life. She is very happy with her new feet and most wonderfully, pain free !





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