



my  
Mommy  
has MS

Written by  
Elizabeth and Deborah Kellett

Design & Illustrations by Michael Speke



Multiple Sclerosis  
Society of Canada

my  
Mommy  
has MS

This book was written by  
Elizabeth Kellet, with the  
help of her mommy,  
Deborah



**Multiple Sclerosis  
Society of Canada**

250 Bloor St. E., Suite 1000  
Toronto, ON M4W 3P9

1-800-268-7582  
[www.mssociety.ca](http://www.mssociety.ca)

Hi, my name is  
Elizabeth.

I'm four  
years old.



This is my  
brother  
William.  
He's two.

This is my  
daddy

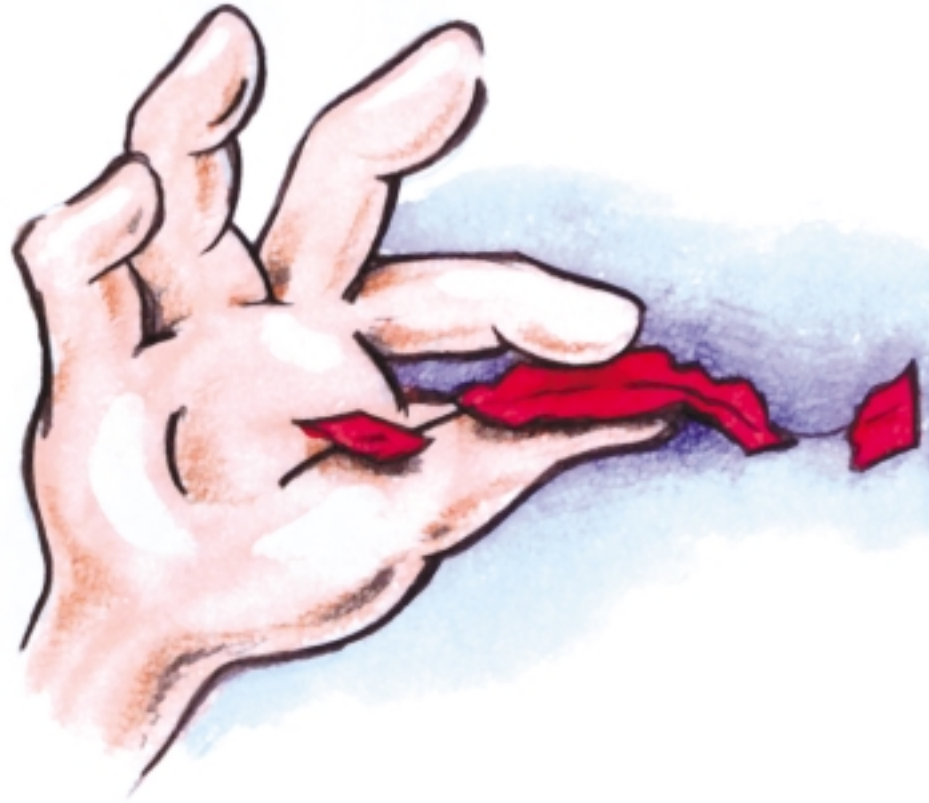
and this is  
my mommy.



Mommy  
has multiple  
sclerosis,

but I  
just  
call  
it  
MS.

Mommy told me that MS is a disease that affects her nervous system. That's the part of her body that sends the messages that tell her hands and feet and other parts of her body what to do.



Mommy says that some of the covering around her nerves is destroyed because she has MS. Then the nerves can't send the messages properly.

The covering has a special name. It's called *my-e-lin* sheath.  
Mommy showed me two twist ties.



One had all the paper on it and the other one had some of the paper missing so that the wire showed. The good nerves are like the first twist tie and the bad ones are like the one that is *missing* the paper.

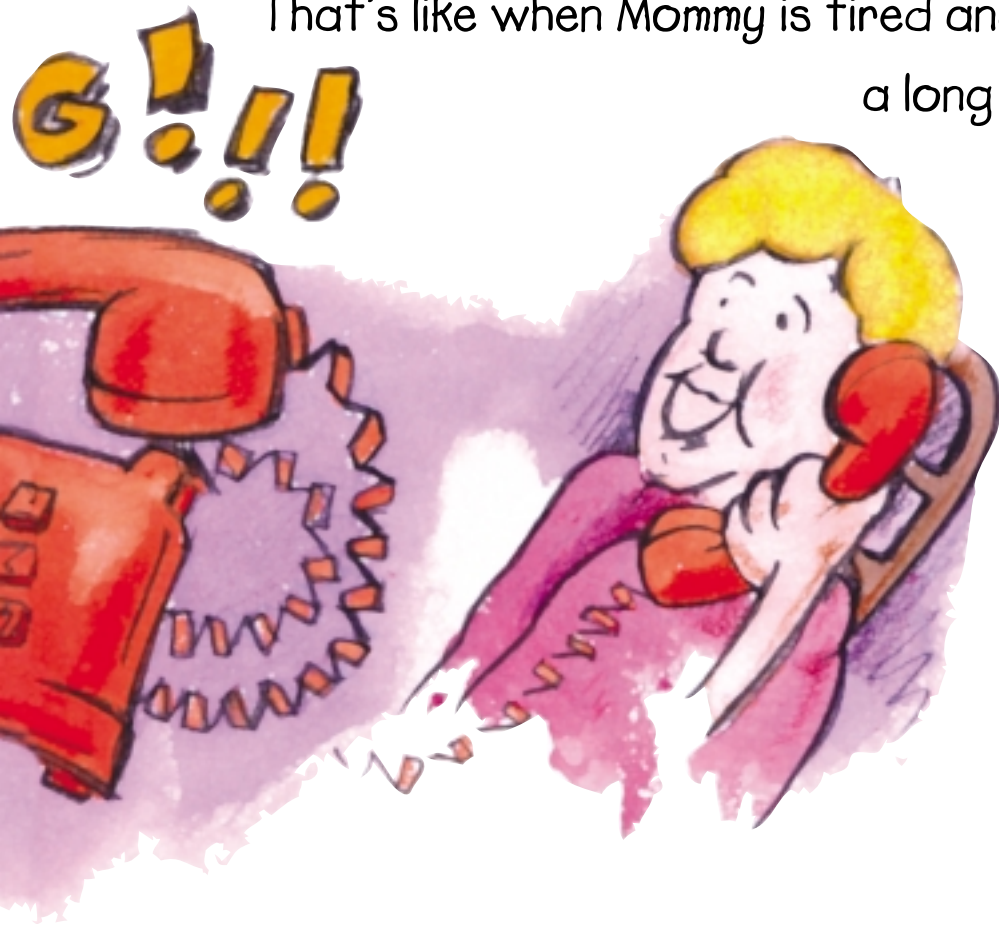
Mommy says that her brain and spinal cord are the parts of her nervous system that are affected. A brain is like a computer that sends messages to the body telling it what to do. Because some of Mommy's nerves don't work properly, some messages take longer to get there or they get mixed up or are lost completely.

Mommy says, for her, it's kind of like calling grandpa on the phone. Sometimes he answers the phone right away. That's like when Mommy is feeling fine and the messages are getting through.



Sometimes the phone rings for a while before he answers.

That's like when Mommy is tired and the messages take a long time to get through.



Sometimes there is no answer.

That's like when Mommy can't feel an ant crawling up her leg and I have to tell her it's there.

And sometimes we get a wrong number and that's like when I put a cold drink box against Mommy's leg and she yells and says it burns her.

Mommy has lots of different symptoms. She feels very tired most of the time. She needs to take an afternoon nap almost every day. Mommy's leg gets very tired too.



Sometimes her bladder is bothered and she has to keep going to the bathroom. On days like that we don't go out very much. When Mommy's leg is very tired, she says it feels like someone has tied a big bag of sand to her foot and she has to drag it along with her.

Lots of times, she has “pins and needles” feelings in her arms and legs. She says it’s like when you sit on your leg the wrong way and your foot “goes to sleep.” The funny feeling that you get when you move your leg is what it feels like, but it doesn’t go away when Mommy moves.

On those days, she uses her cane. I thought only old people use canes but Mommy said lots of people do and it is her friend because it helps her go places.





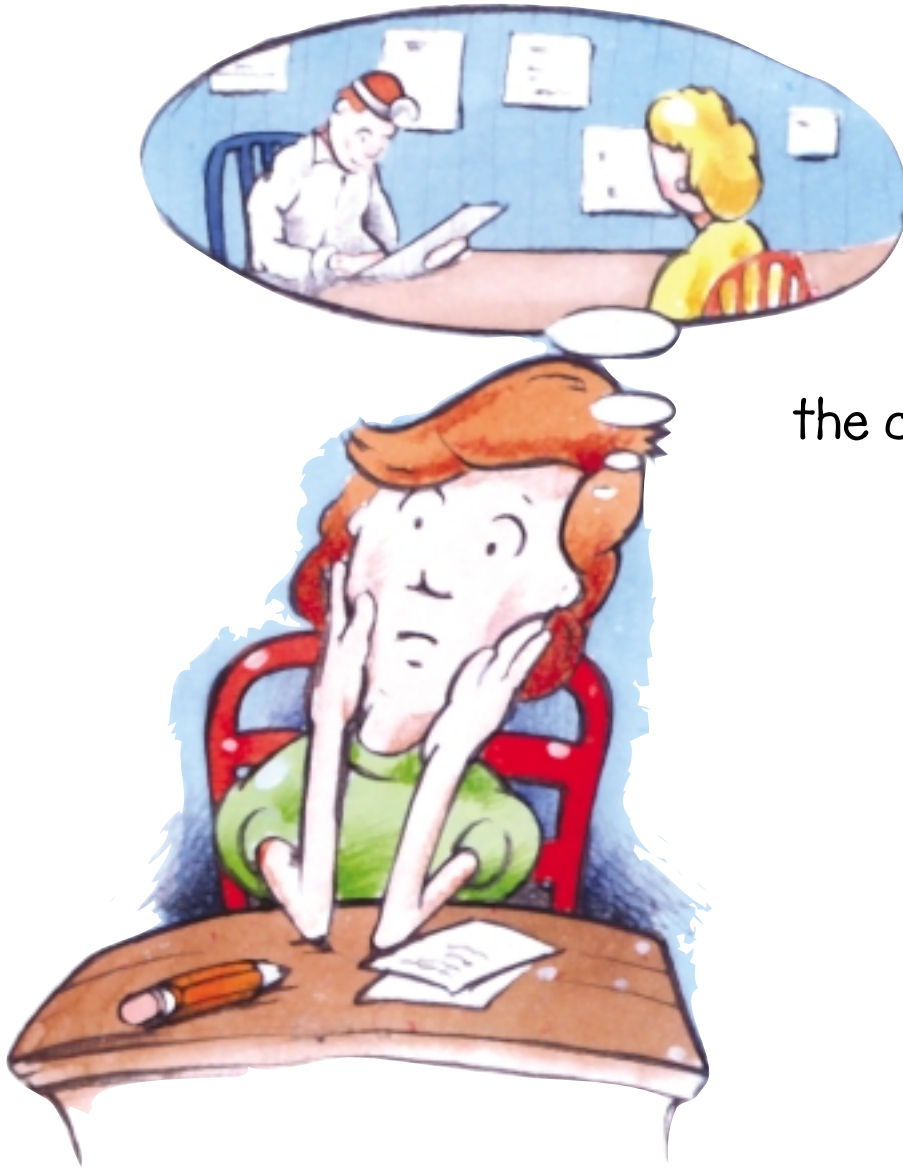
Sometimes Mommy is really tired at night  
and she goes to bed before William and I do.  
On those nights, Daddy gets us ready for bed.

Then William and I crawl into bed with  
Mommy and she reads us a bedtime story in her bed.

I like that.

Sometimes I feel sort of sad that Mommy has MS. I miss her when she

has to go to the doctor a lot and I miss her when she's sleeping in the afternoons. I also miss her when I'm at school.



Sometimes I say to Mommy, "Why can't  
you do things the way you used to?  
I don't like it when you sleep. I don't like  
going to the babysitter's."





I asked Mommy,  
“Will your MS  
ever  
go away?  
Are you ever  
going to get  
better?”

She said that there are some medicines that some people can take that slow down the MS but there is no cure. She says, hopefully some day the doctors will know what causes MS so they can make it better; but for now, she will have days when she is fine and days when she is very tired.



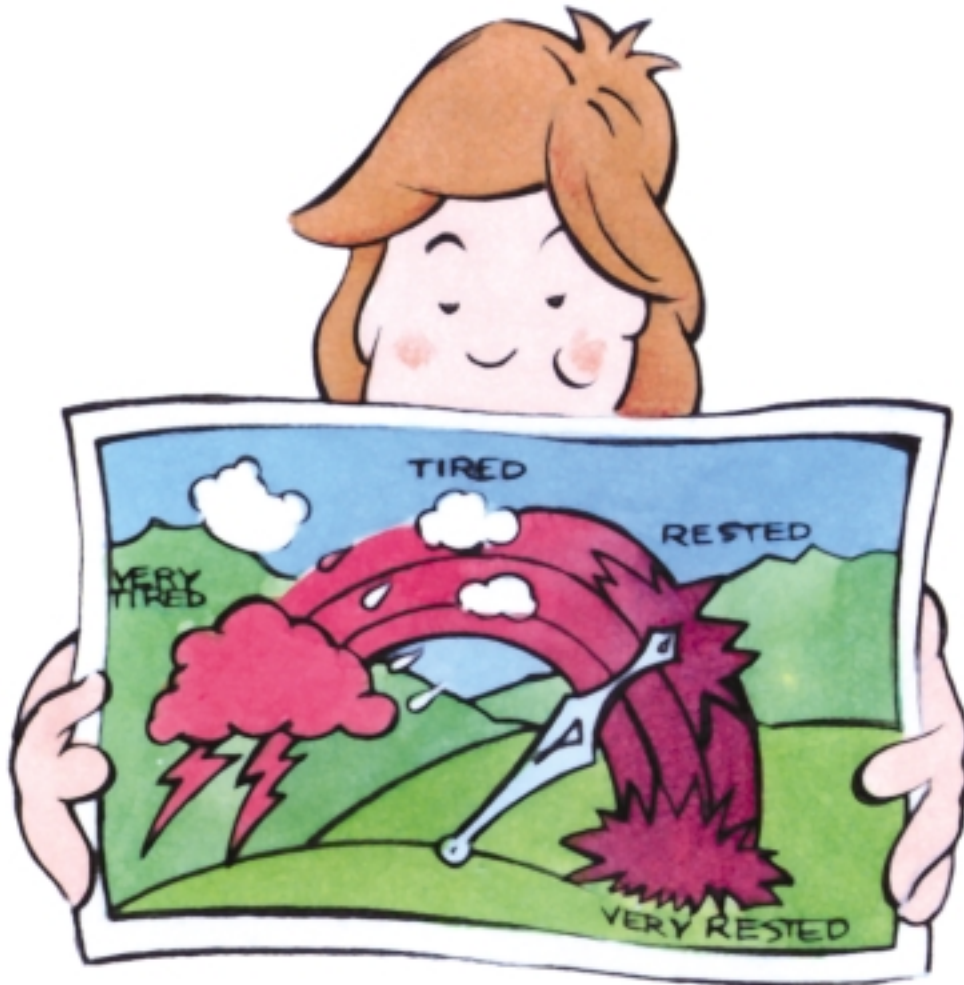
One day I was worried and I asked Mommy if I would get MS. She said that I probably wouldn't; that it isn't hereditary, whatever that means. She also said it isn't contagious. I think that means I can't catch it like I sometimes catch a cold... or like when I got chickenpox.

One afternoon when Mommy was having her nap,  
Daddy and I made a special Rainbow.

This is our Rainbow.



We use it to explain how Mommy is feeling.



The Red in the Rainbow means she is tired and is losing her patience. This happens when her MS is bothering her the most. At these times, Mommy needs my brother and me to be on our best behaviour.

The Purple of the Rainbow means that Mommy is very rested and very calm. This is when she has the most energy to play with us.

One day Mommy carried me up the stairs and I was so surprised. I said "You still have MS but you can do it, just barely, can't you?"

Mommy can hold my hand, and she can help me with my breakfast.

When I am sick, Mommy looks after me and lets me sleep and cuddle in her bed with her.

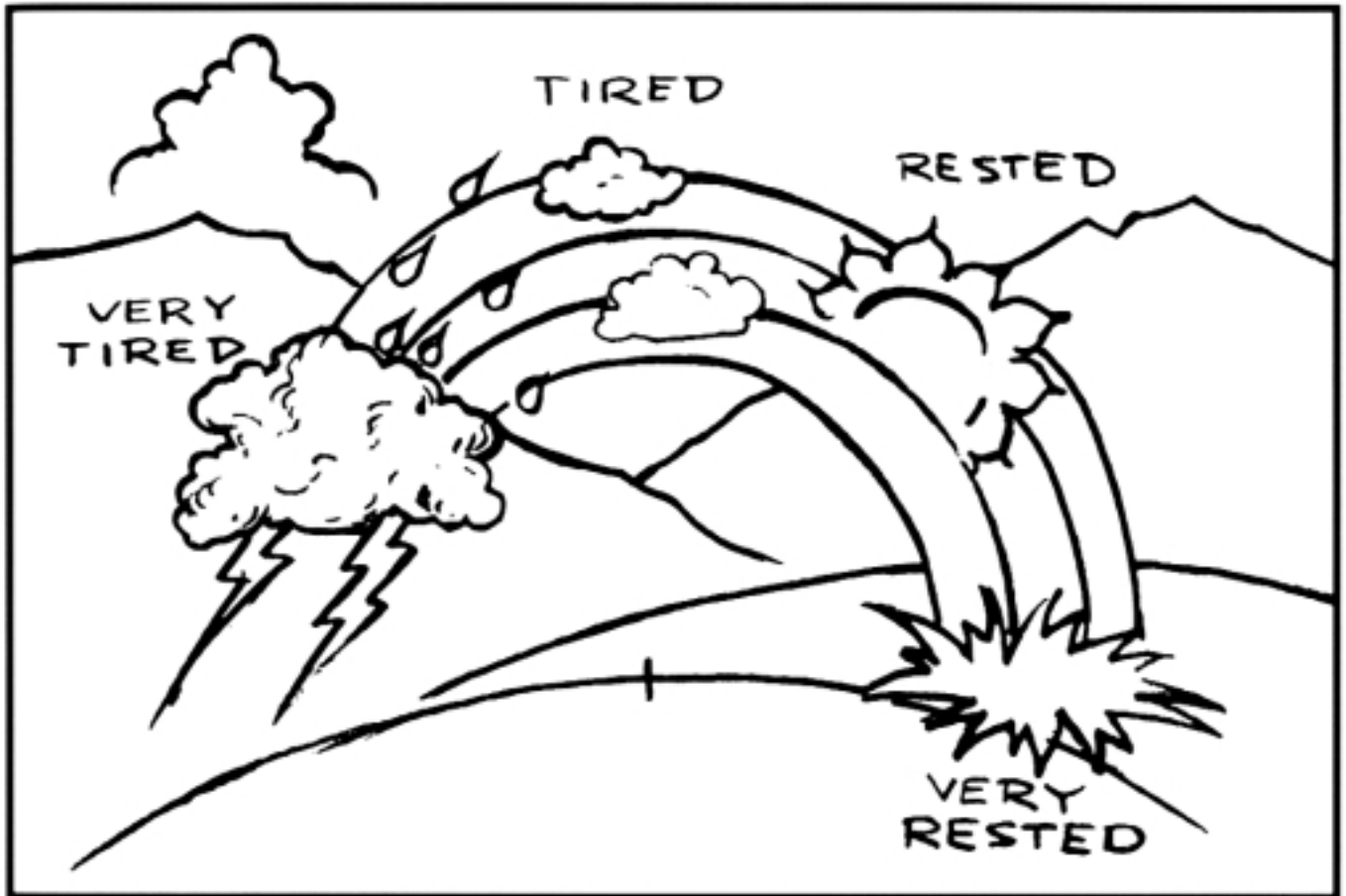
She can take care of me!



And I know that no matter what kind of day Mommy is having, she loves me and William and that's really the important part.

MS can't  
change  
that!





You can make a Rainbow too! Get someone to help find scissors, crayons, and a paper fastener. Then carefully pull the large drawing out of the book, cut out the parts, colour them, and put them together. You may want to get an adult to help you.

Have fun!

Liz



See Ya!!



**Multiple Sclerosis  
Society of Canada**

### **Atlantic Division**

71 Ilsley Avenue, Unit 12  
Dartmouth, Nova Scotia  
B3B 1L5  
(902) 468-8230

### **Quebec Division**

666 Sherbrooke Street West  
Suite 1500  
Montréal, Québec  
H3A 1E7  
(514) 849-7591

### **Ontario Division**

250 Bloor Street East  
Suite 1000  
Toronto, Ontario  
M4W 3P9  
(416) 922-6065

### **Manitoba Division**

141 Bannatyne Avenue  
Suite 400  
Winnipeg, Manitoba  
R3B 0R3  
(204) 943-9595

### **Saskatchewan Division**

150 Albert Street  
Regina, Saskatchewan  
S4R 2N2  
(306) 522-5600

### **Alberta Division**

10104-79th Street  
Edmonton, Alberta  
T6A 3G3  
(780) 463-1190

### **British Columbia Division**

1130 West Pender Street  
16th Floor  
Vancouver, British Columbia  
V6E 4A4  
(604) 689-3144

### **National Office**

250 Bloor Street East  
Suite 1000  
Toronto, Ontario  
M4W 3P9  
(416) 922-6065

Call toll-free in Canada: **1-800-268-7582**

Email: [info@mssociety.ca](mailto:info@mssociety.ca) Web site: [www.mssociety.ca](http://www.mssociety.ca)

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