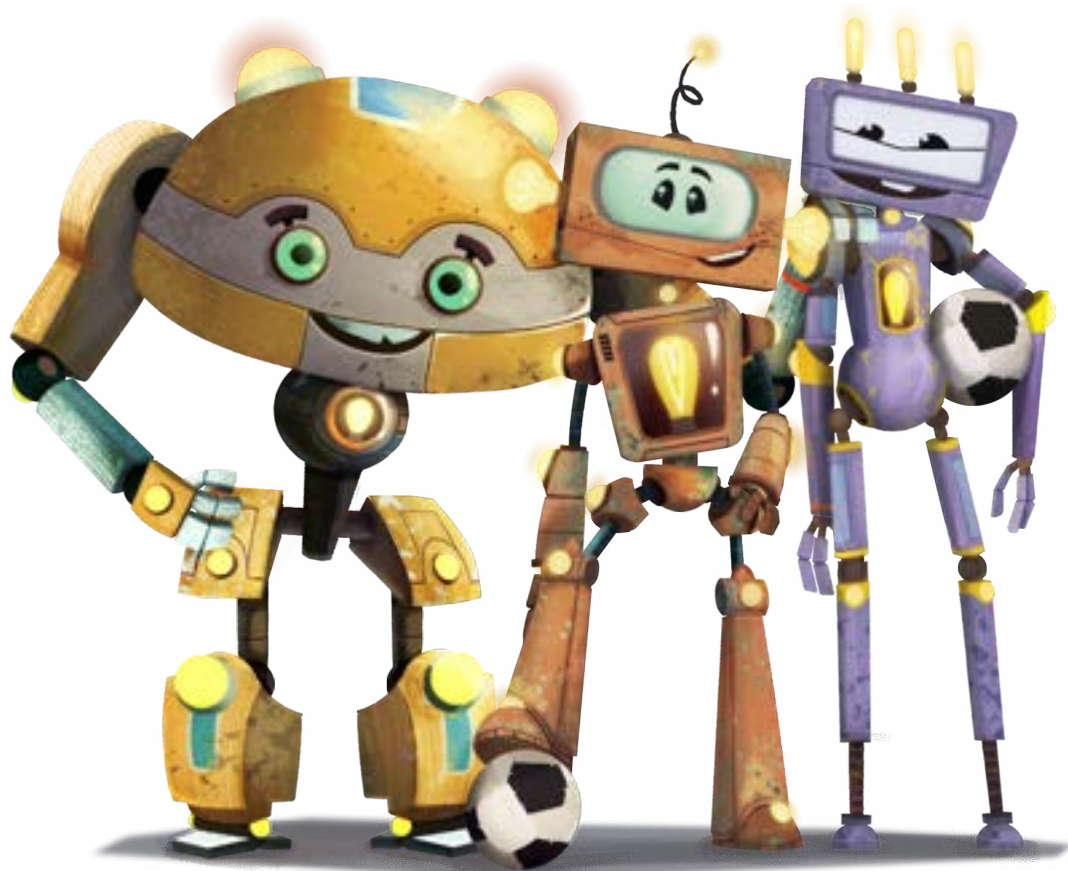


LUKI & the LIGHTSTM

Coloring and Activity Book



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About LUKi & the Lights

LUKi & the Lights was created by Sascha Groen and Anjo Snijders, to help explain ALS to their children – just like you!

We used LUKi's story to create a movie and this coloring book. You can watch the movie, then read and color this book to learn more about LUKi.

We hope you love getting to know LUKi as much as we do.

For more LUKi materials, activities and updates:

www.globalneuroycare.org

Coloring book: Sascha Groen and Melinda S. Kavanaugh, PhD

Art/illustrations: Big Grin Productions



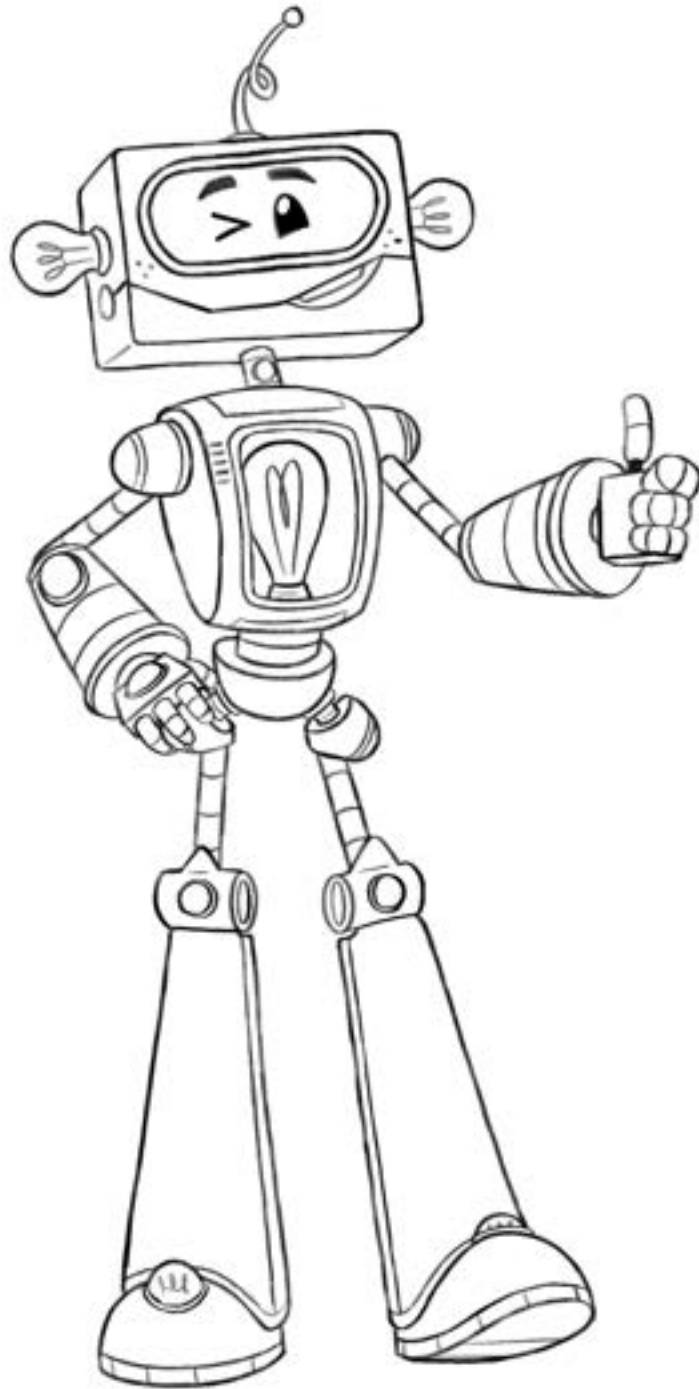
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Hi! I'm LUKi. I am a robot.



This is my story!



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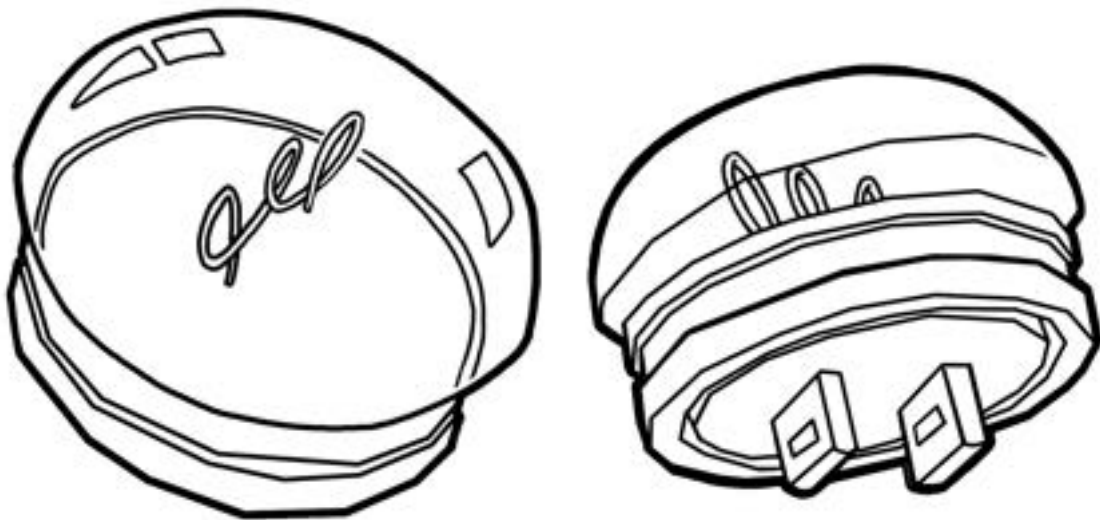


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As a robot, I have lots of wires in my body, like you have the nerves in your body.

My wires make my **lights work, like your nerves make your muscles work!**

I love my lights!



Can you find my lights in the rest of this book?



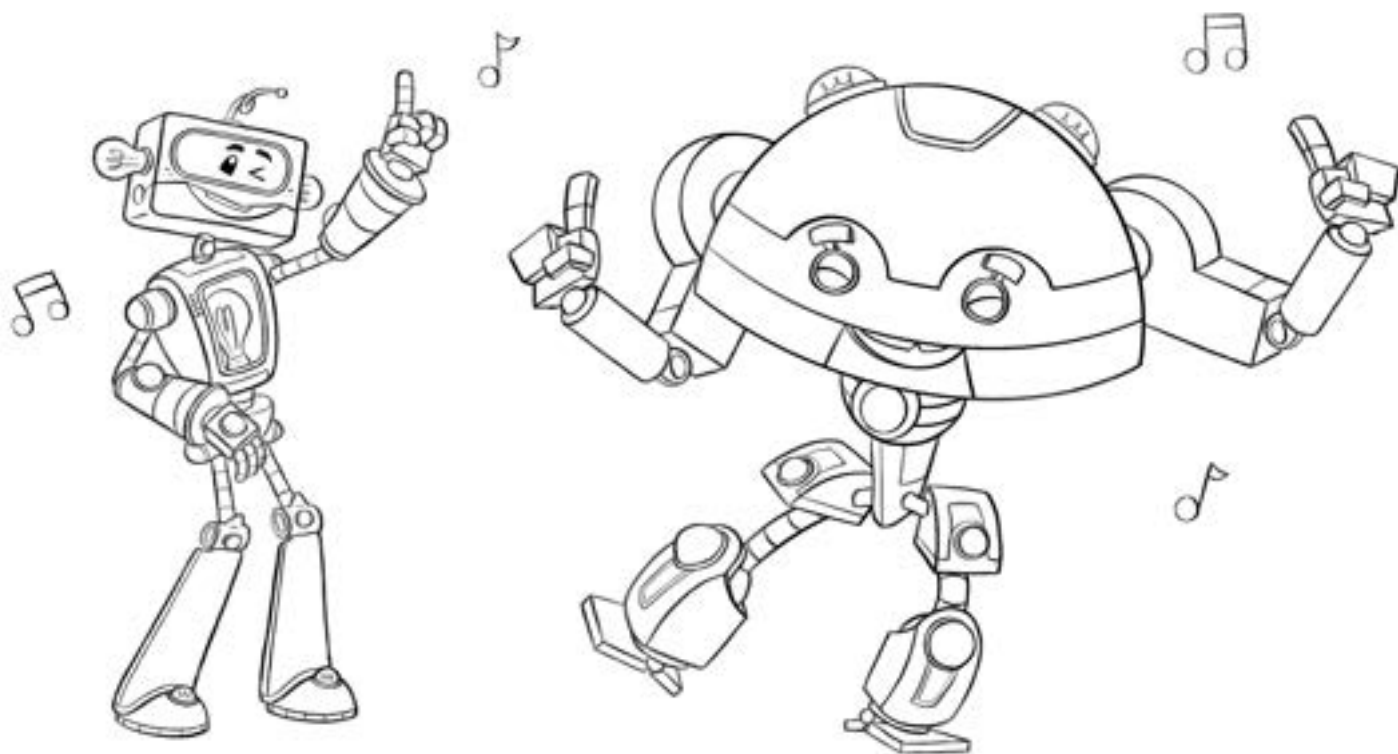
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**I have the best friends, Theo and Neefa.
They play with me, dance with me, laugh with me,
and make me smile.**



What do you do with your friends?



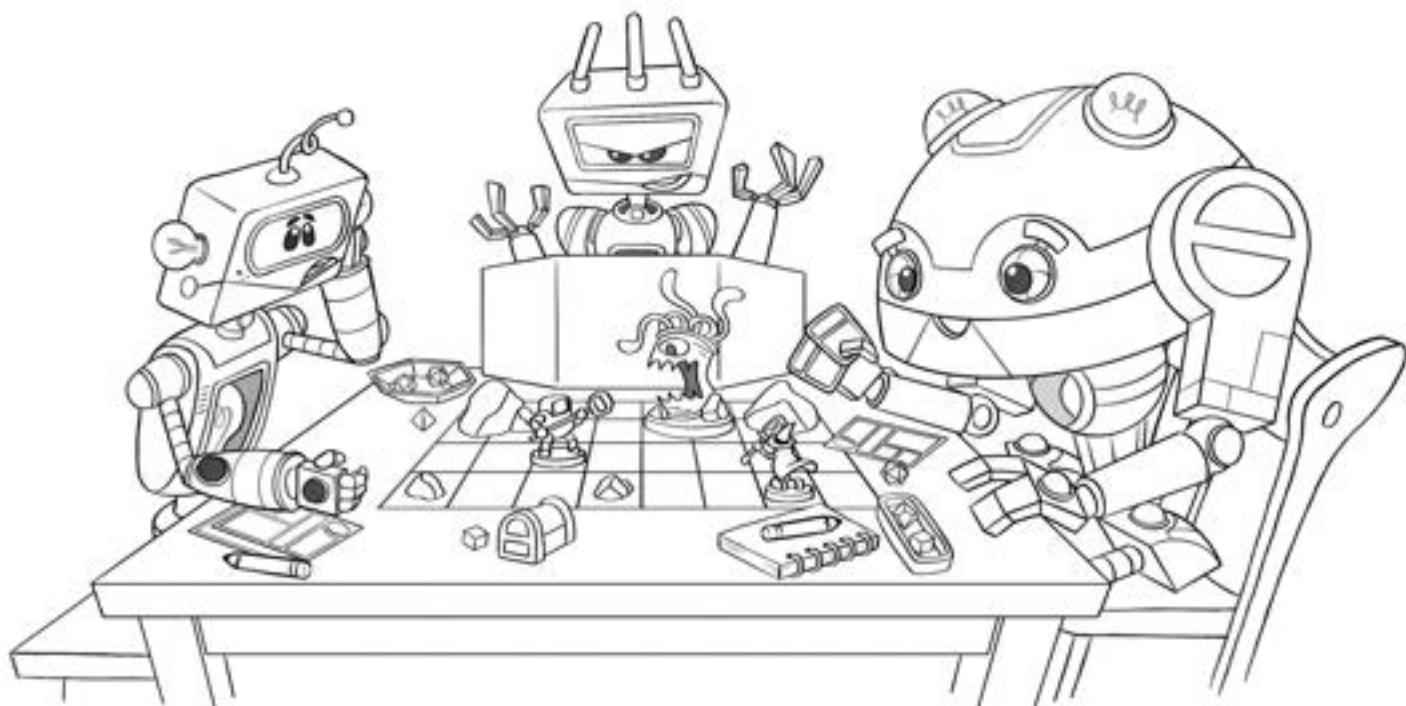
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I love to play Dungeons and Dragons with my friends, especially when we complete a campaign!



Do you play any games with friends or family?



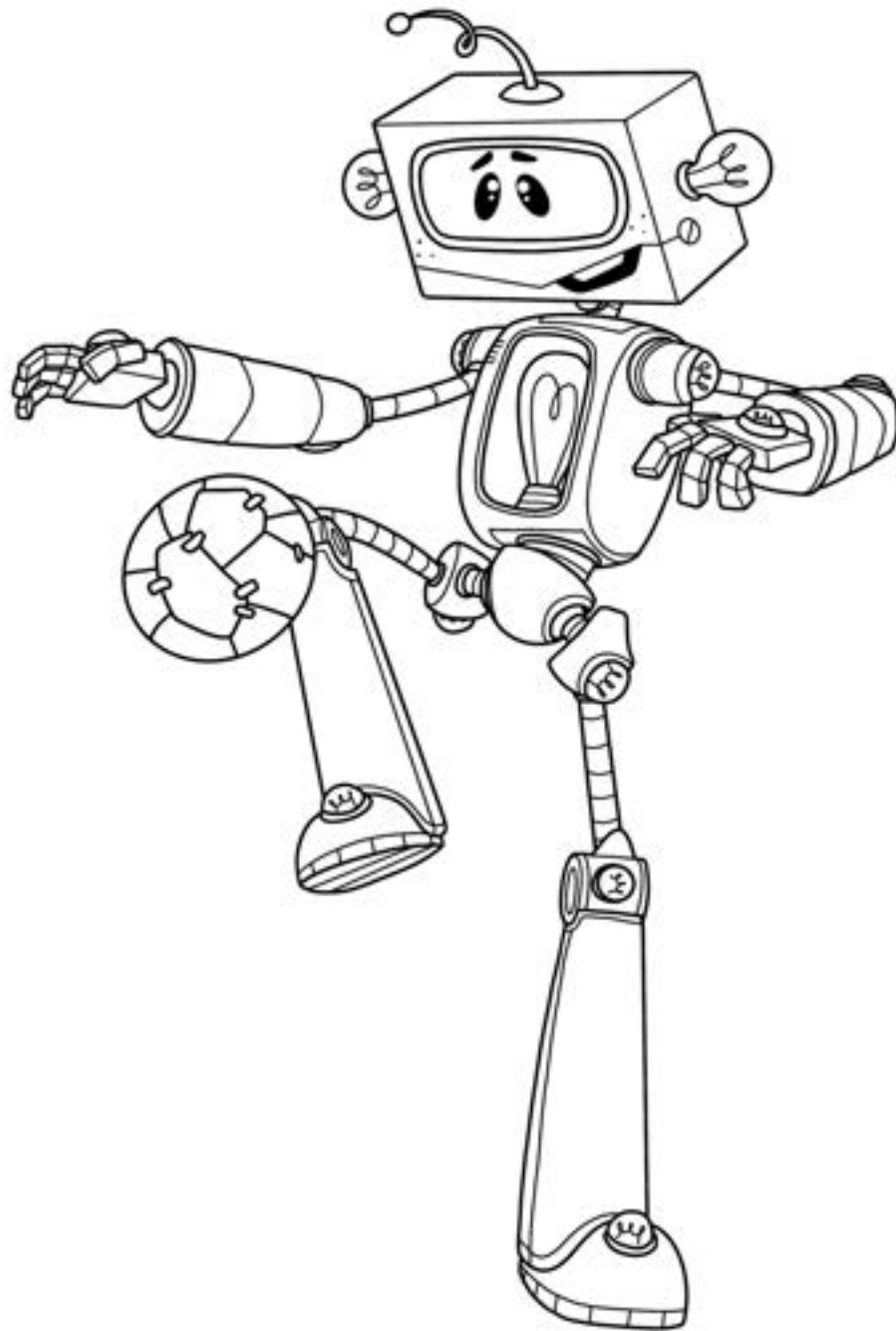
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My very favorite thing to do is play soccer!



What do you like to play?



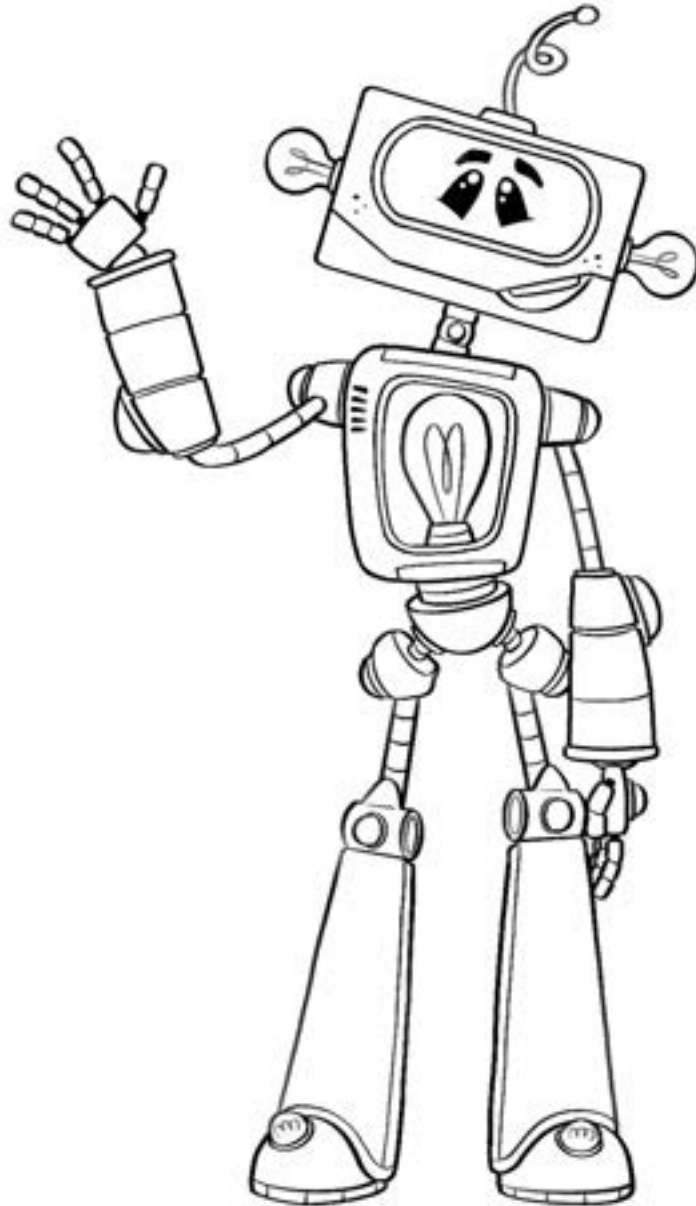
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One day, on my way to play soccer, something happened to one of my lights.



Can you show on me where it happened?



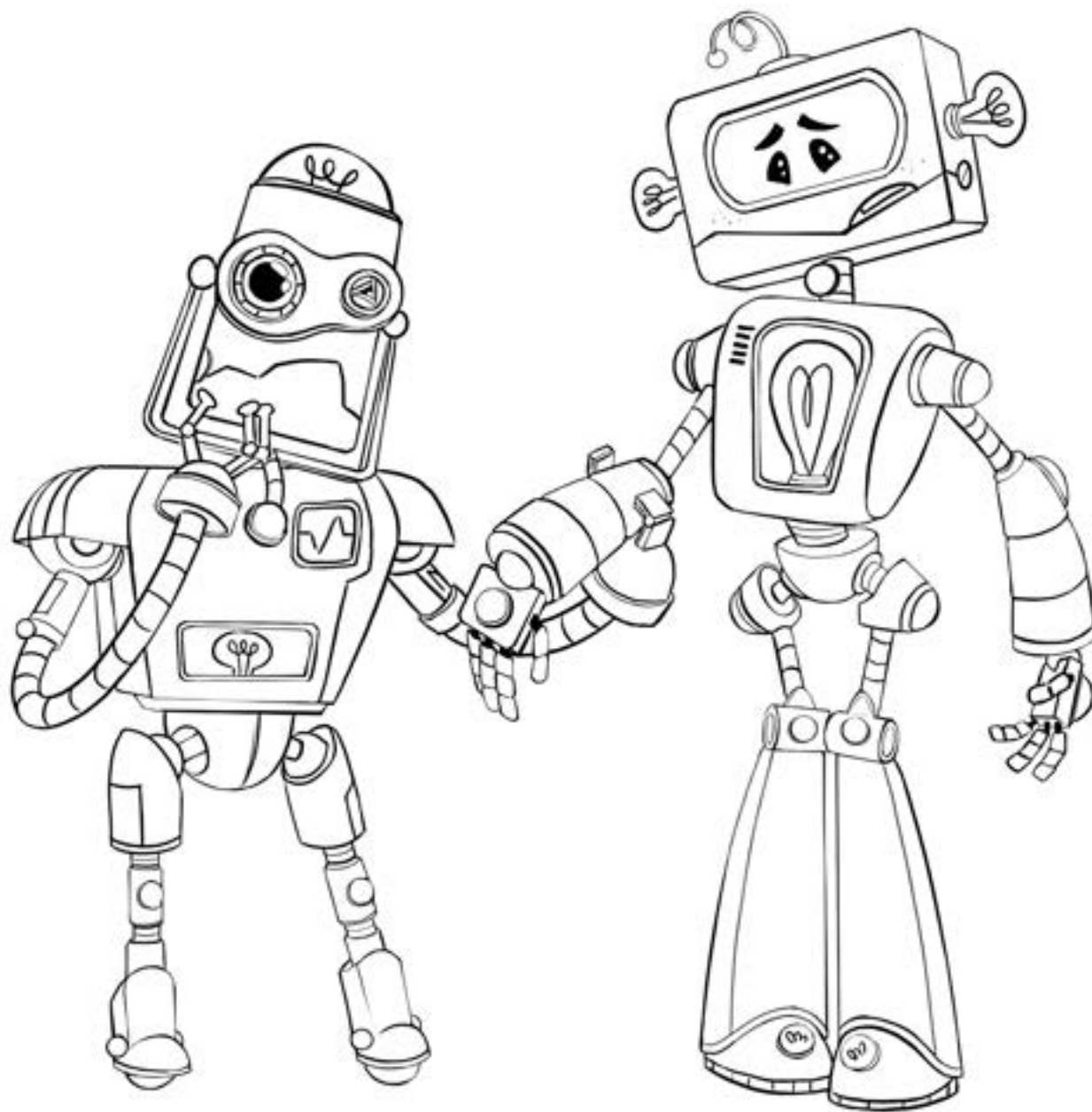
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I had a hard time telling my friends that something was changing, but they knew. They said we should go to the doctor.



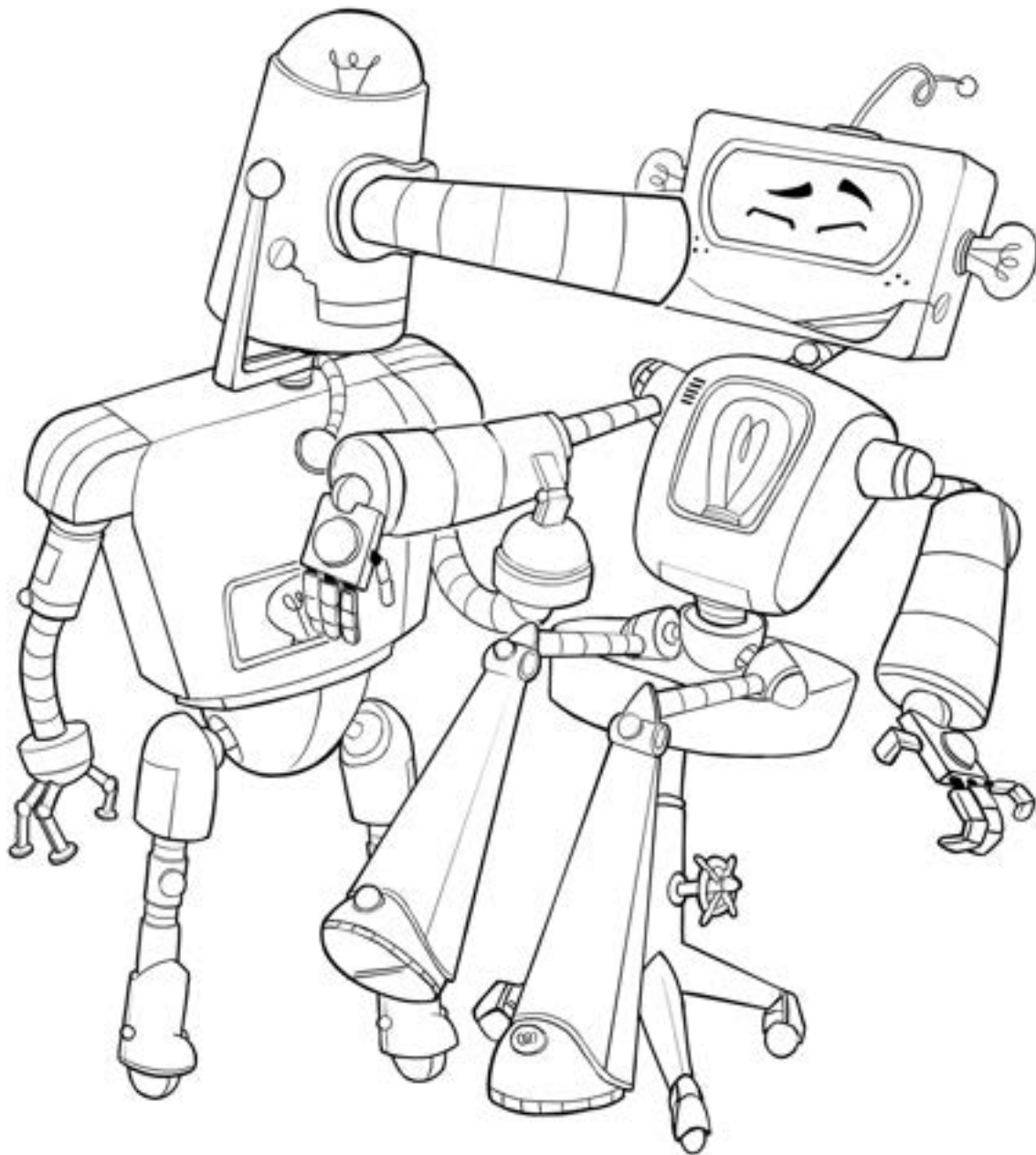
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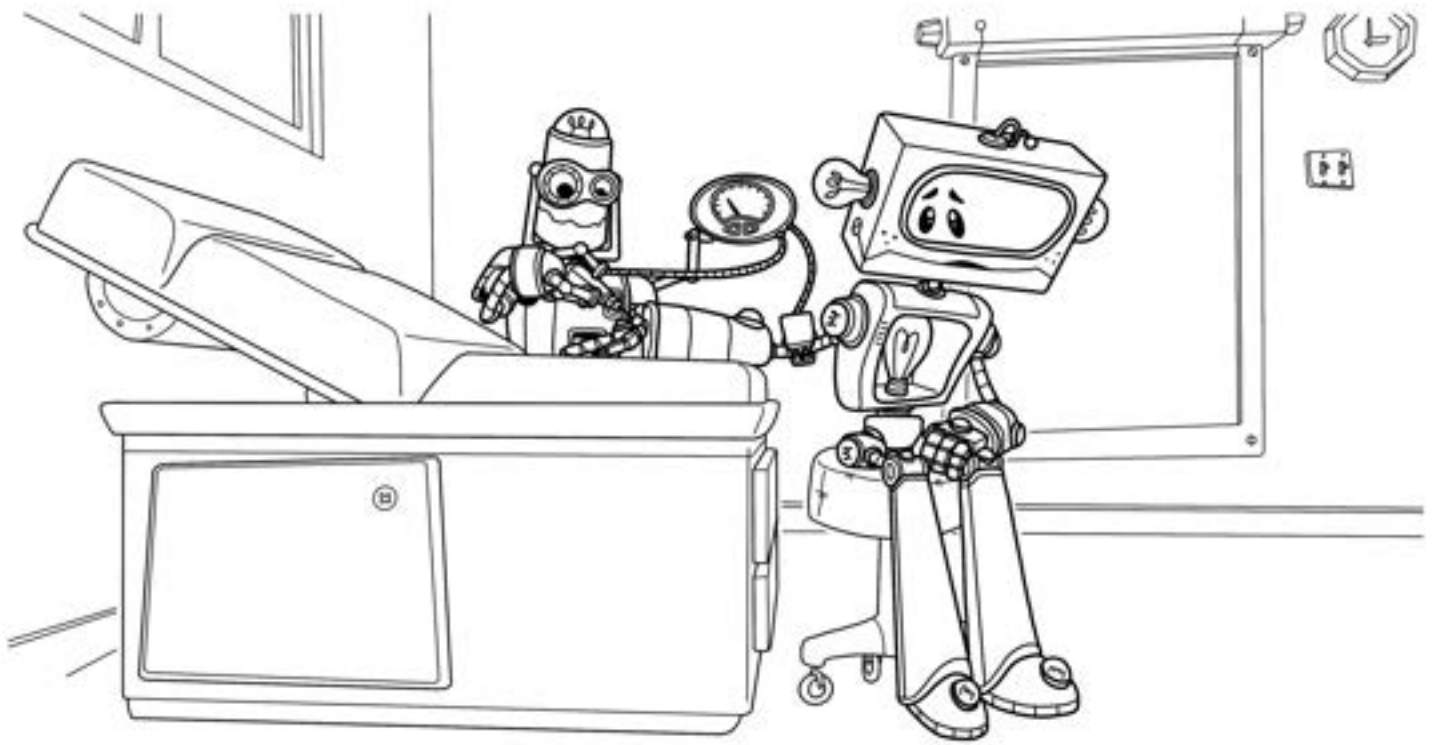
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Then he used his big eye on me, which was pretty funny.



**The doctor did some tests on my wires, since my
lights were going out.
I didn't understand what was happening.**



I tried to be brave, but I was scared.



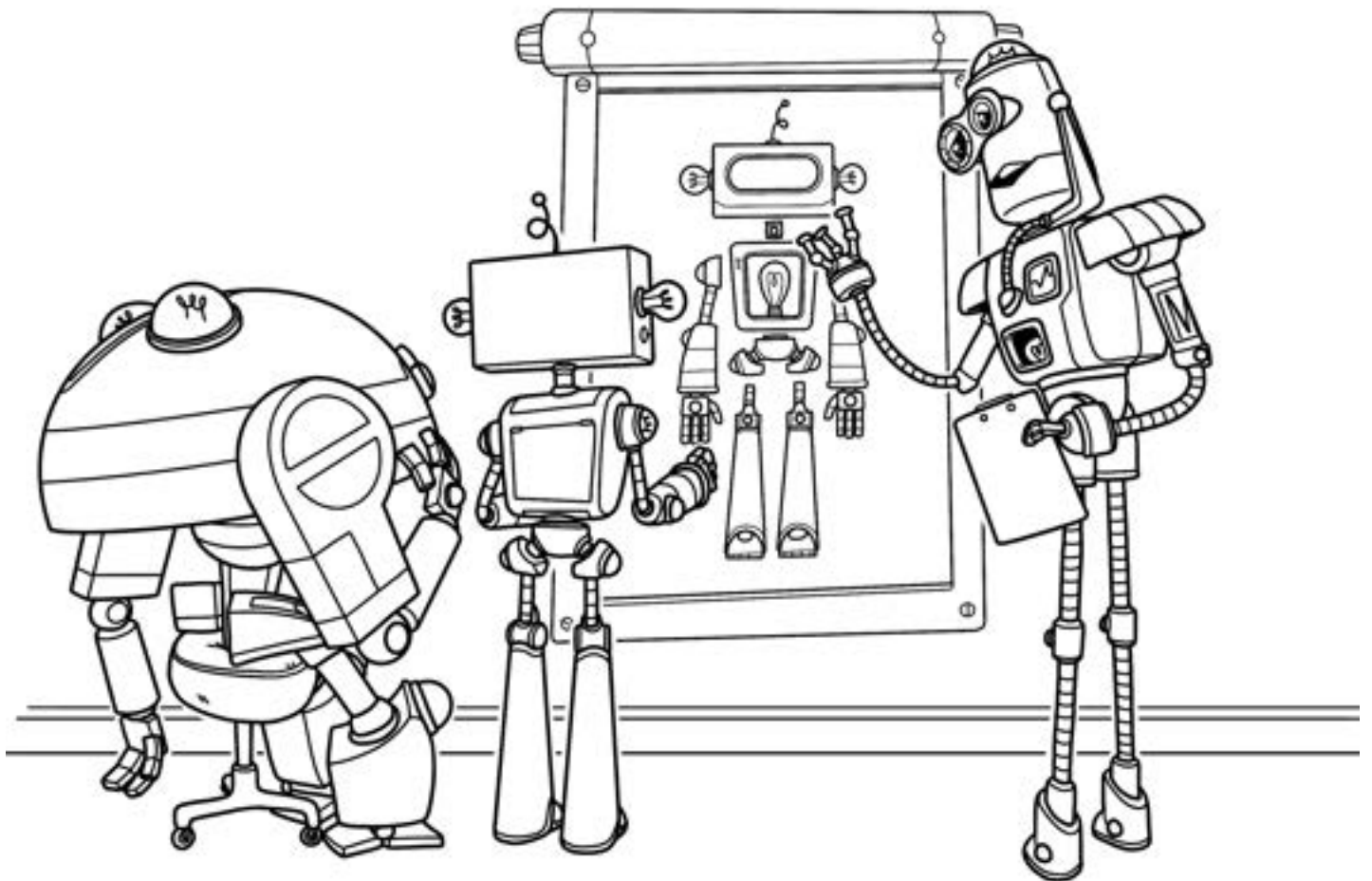
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**I am so glad I had my friends with me!
Especially when the doctor told me I had ALS.**



**This was hard to hear.
I was sad, angry and confused.**



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How did it make you feel watching me in the movie?

**I love to draw things when I am sad, and I don't
want to talk.**

Can you **draw or write how it feels to be sad about
something?**

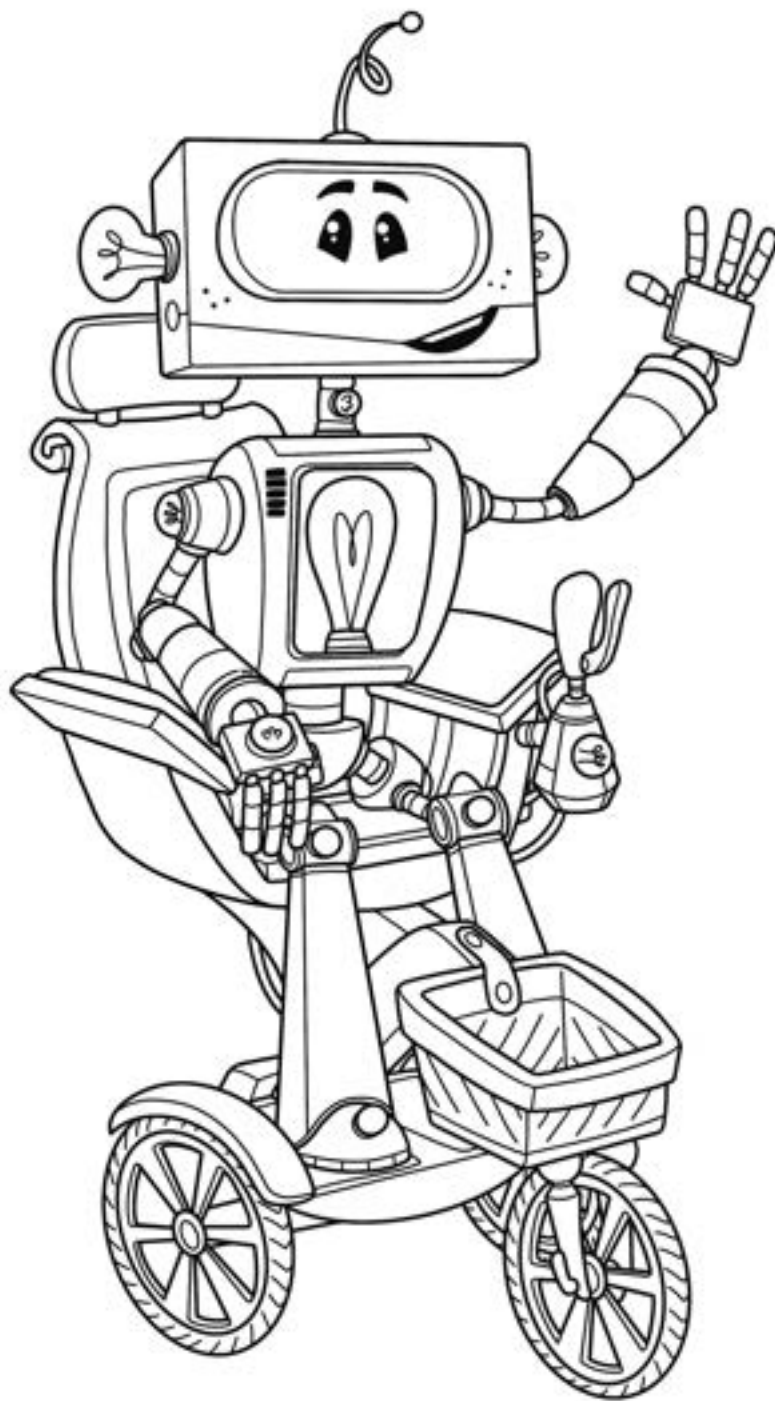


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My lights were going out, and it was getting hard to walk, so I decided to make my own chair!



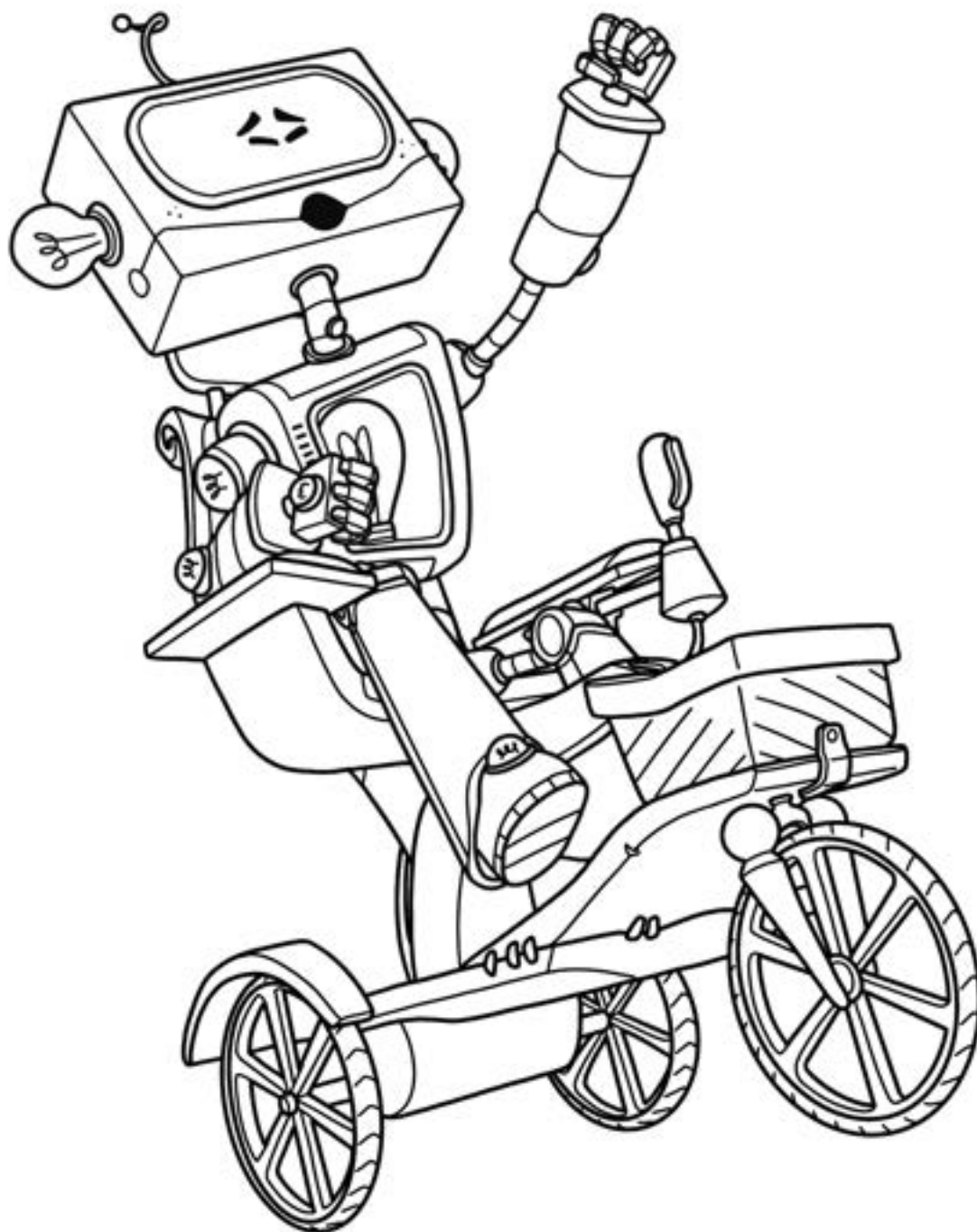
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Wooo hooo, I can really fly in this chair!



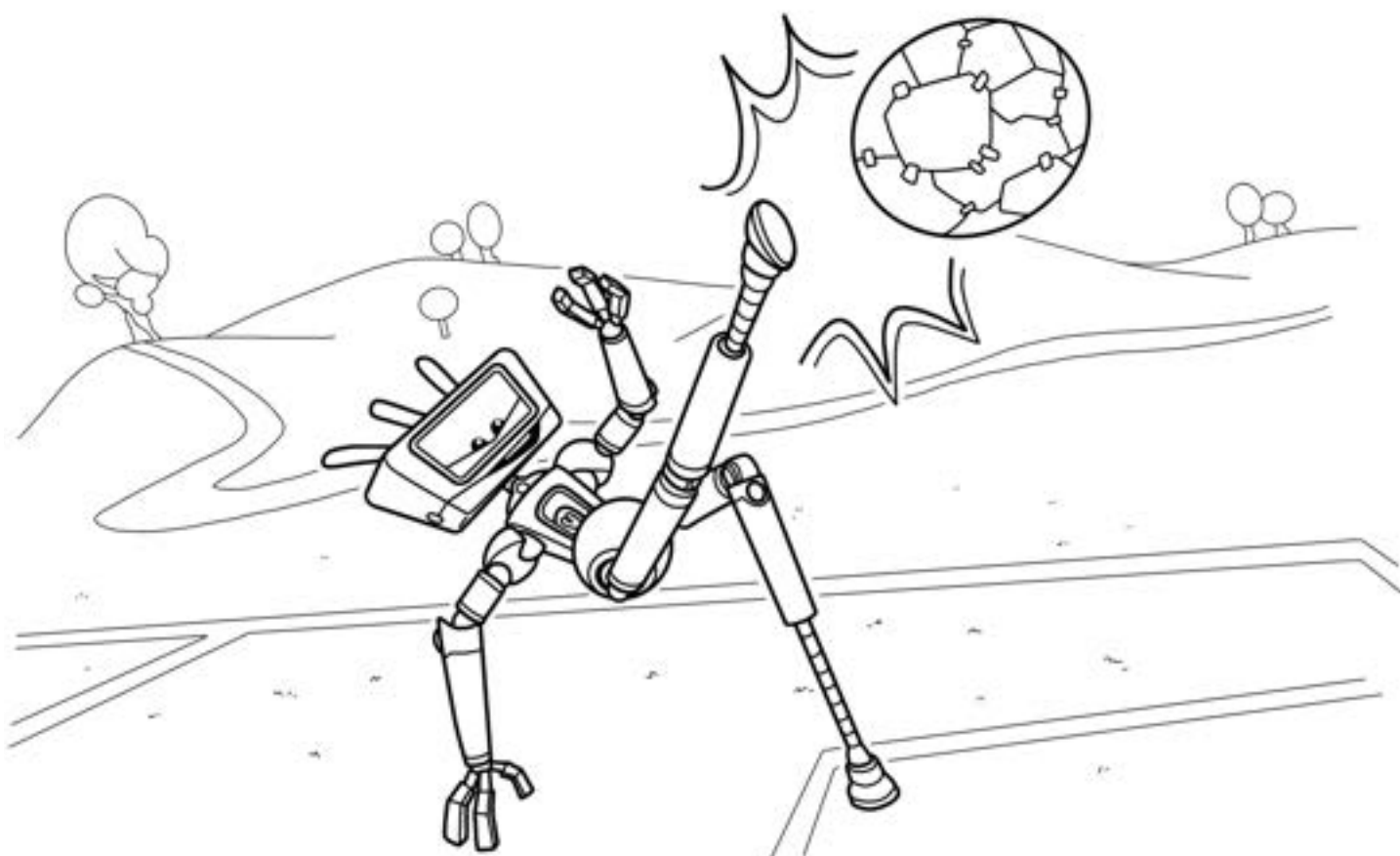
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**Things were changing, kinda fast.
My lights were going out, and I needed help with
lots of things.
But I didn't have to worry, because my friends were
there for me.**



Neefa is an awesome soccer player!



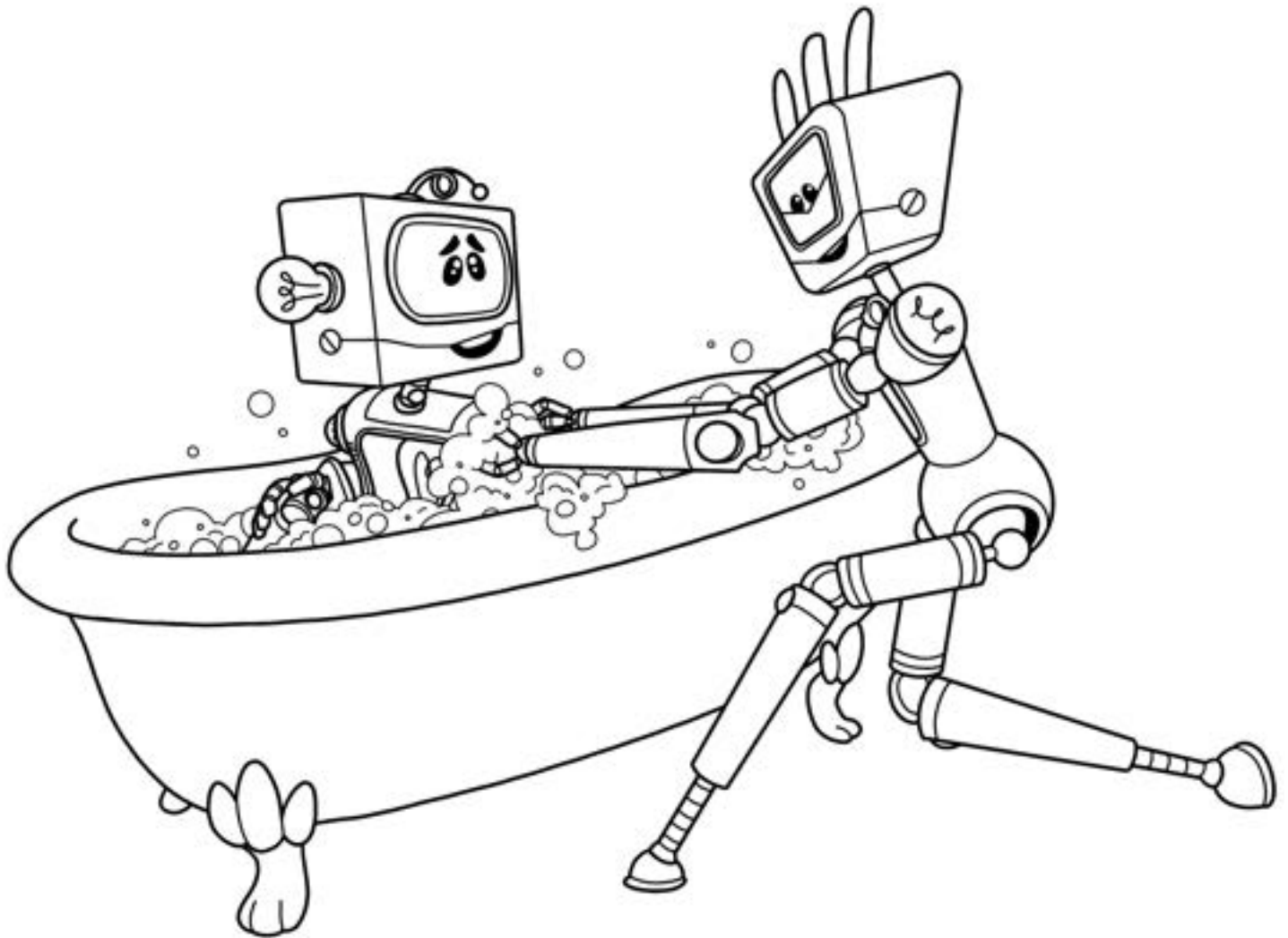
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She also takes care of me and makes sure I don't get rusty since I can't do everything to take care of myself anymore.



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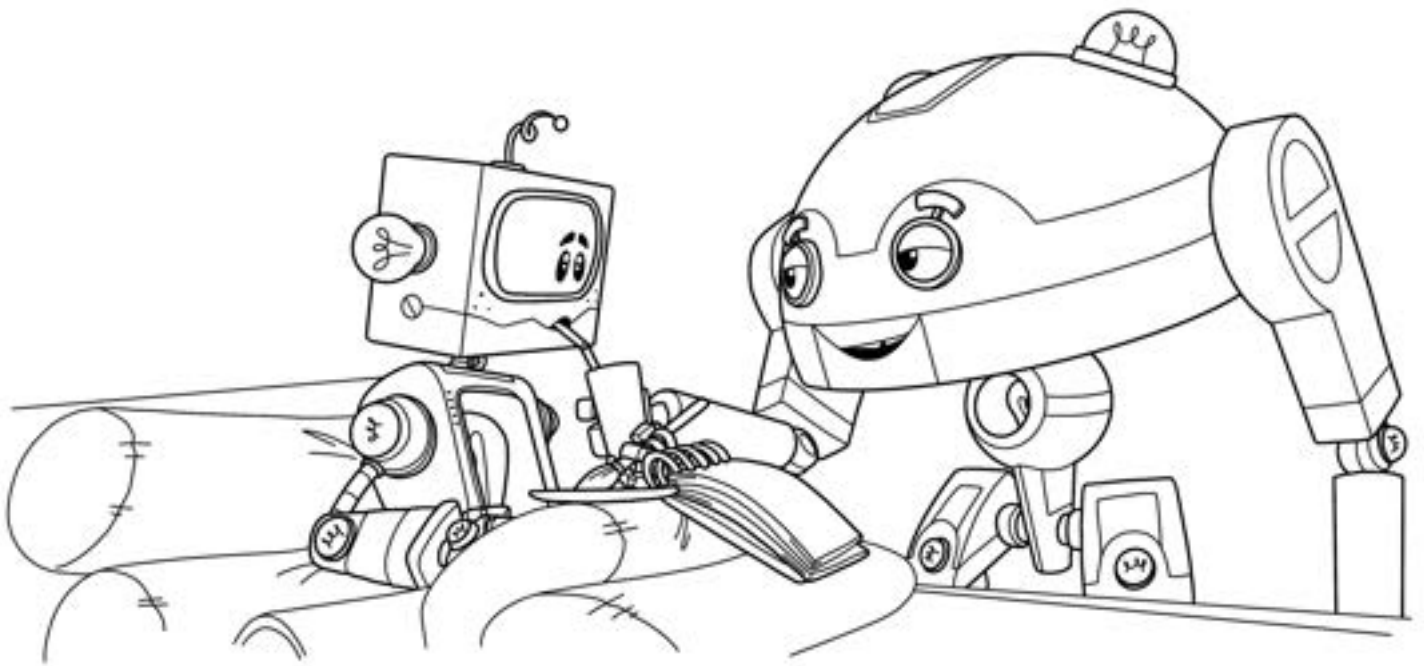
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Neefa isn't my only friend.

Since it has become harder and harder to use my hands and to swallow, Theo helps me use a special straw. Very cool!



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I am grateful my friends help me. I bet you help someone with ALS.

What things do you do to help someone with ALS?

I help my dad get dressed

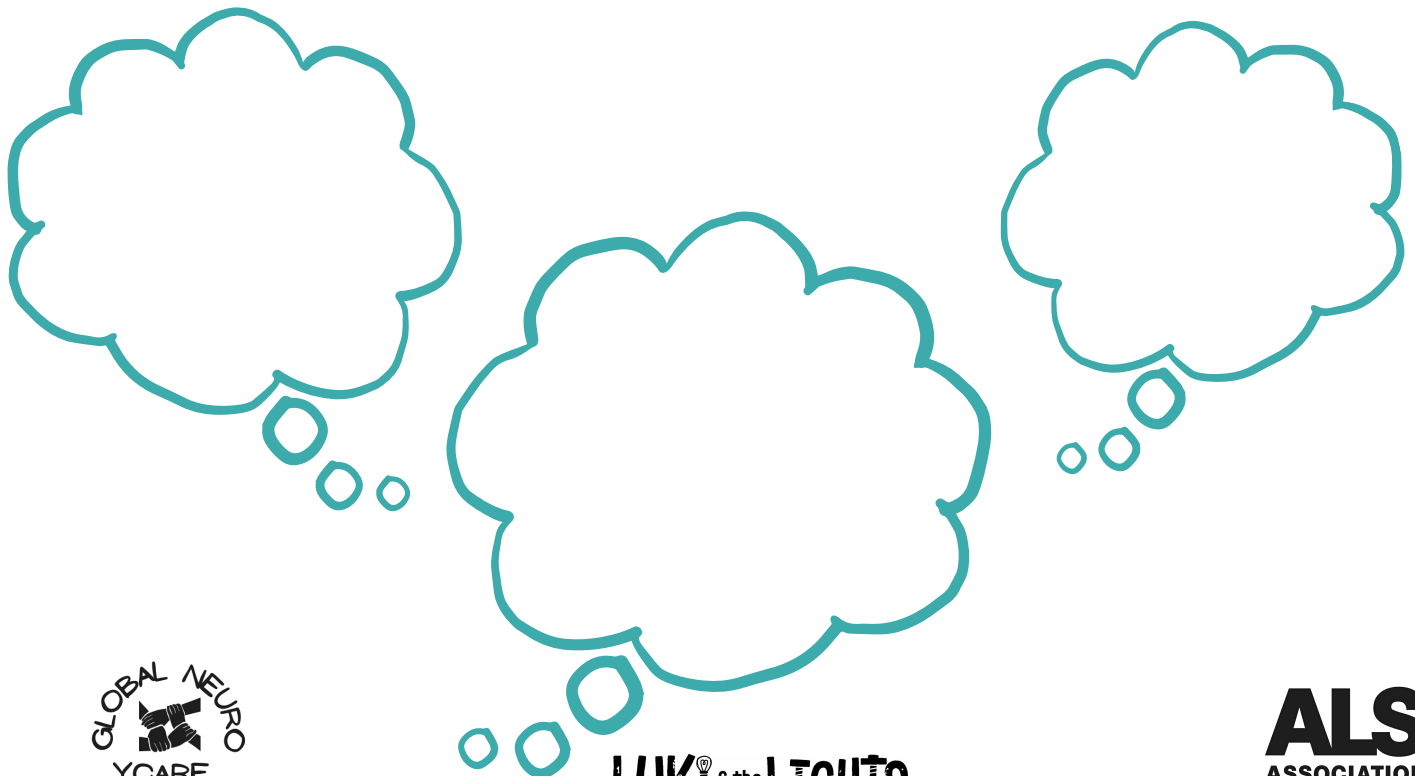
I help my gran use her communication device

I help my dad with his food.

I help my grandpa walk around.

I help my mom brush her teeth

What else do you do to help someone?

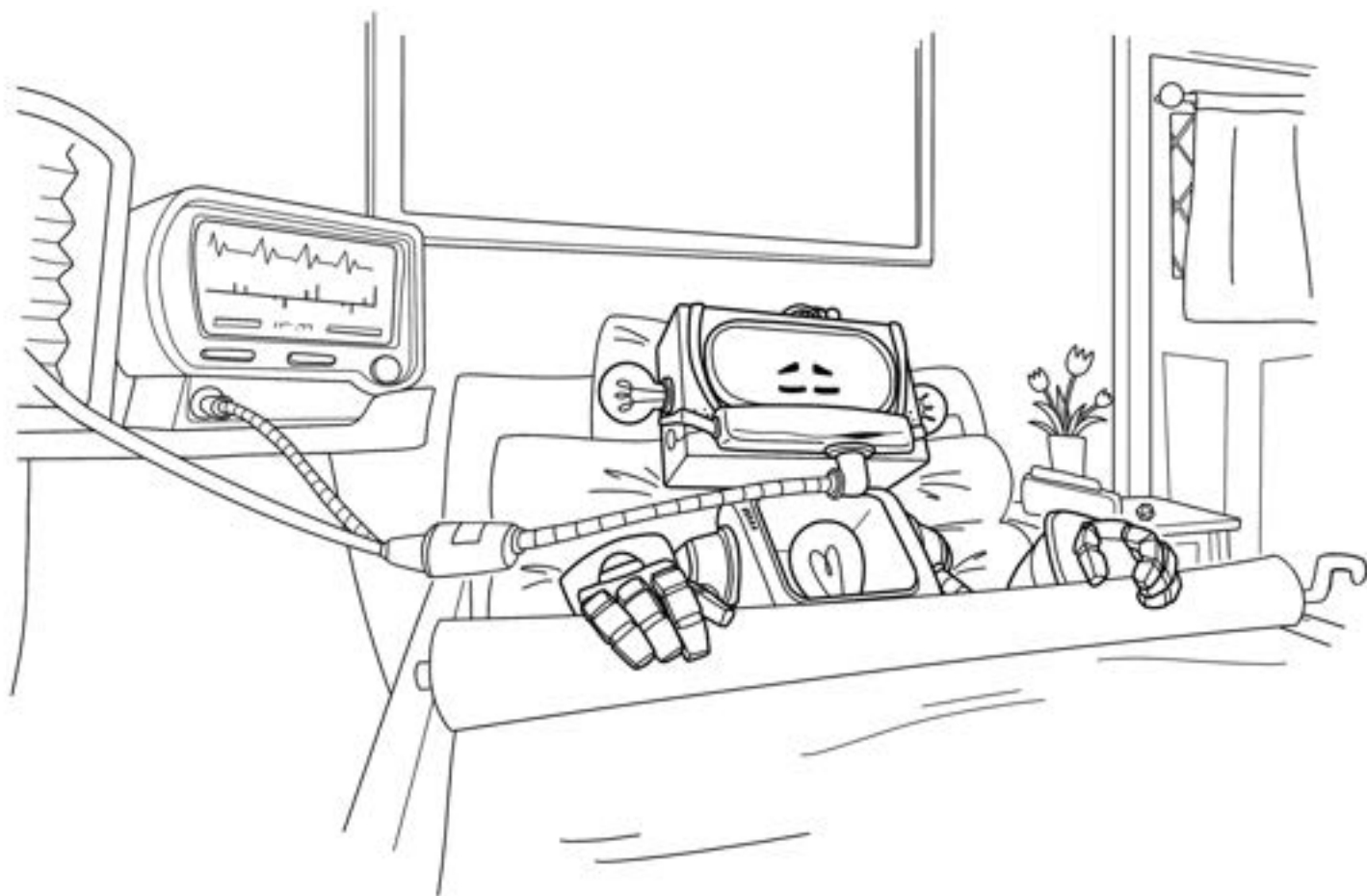


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One day, I just couldn't breathe on my own anymore. So, I got a machine that helps me breathe. It was pretty scary, but it made me feel better.



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Then one day, all my lights went out



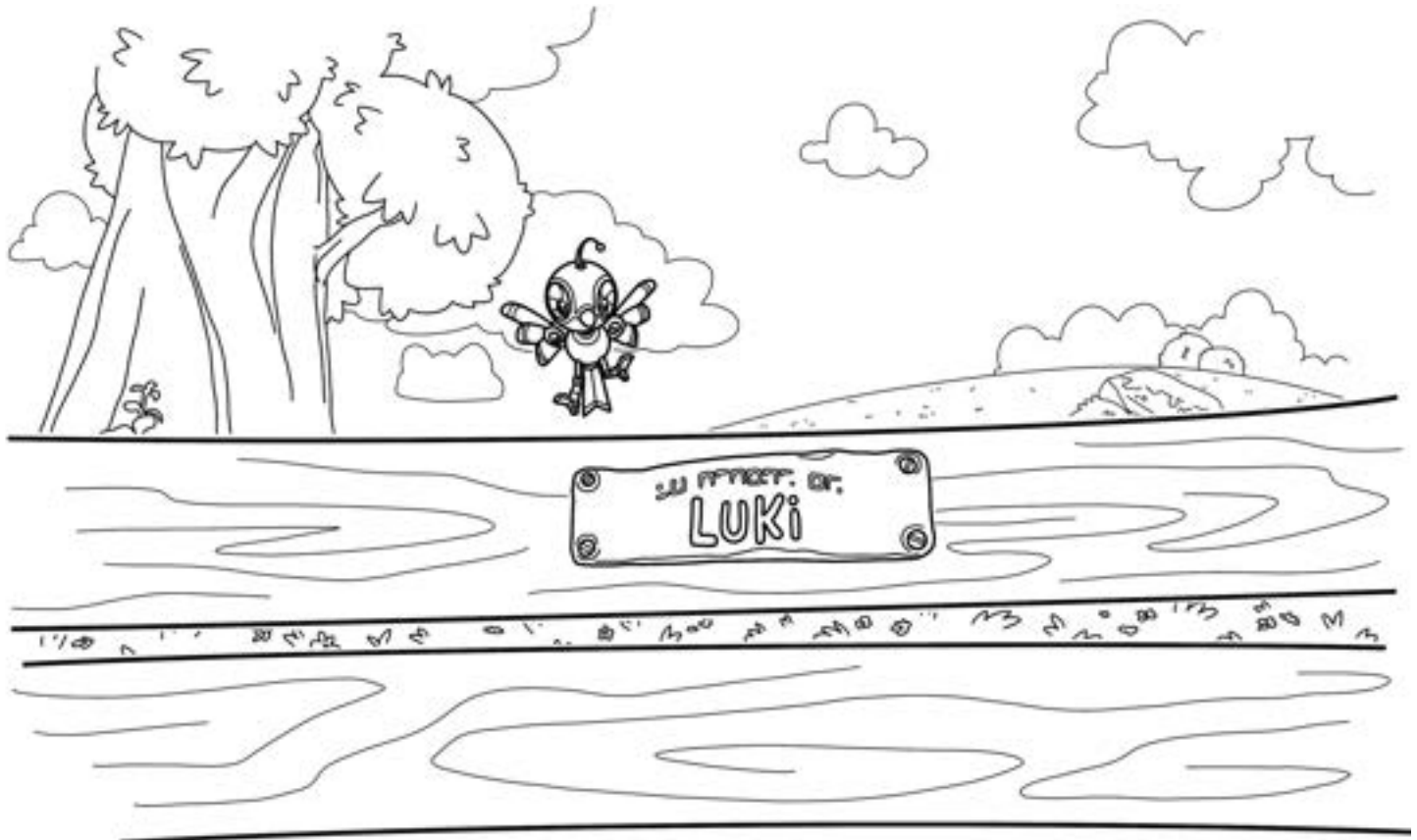
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My favorite place was the hill overlooking my soccer field. My friends made a bench with my name on it. That way they can always go there and remember me.



What things can you do to remember your person with ALS?



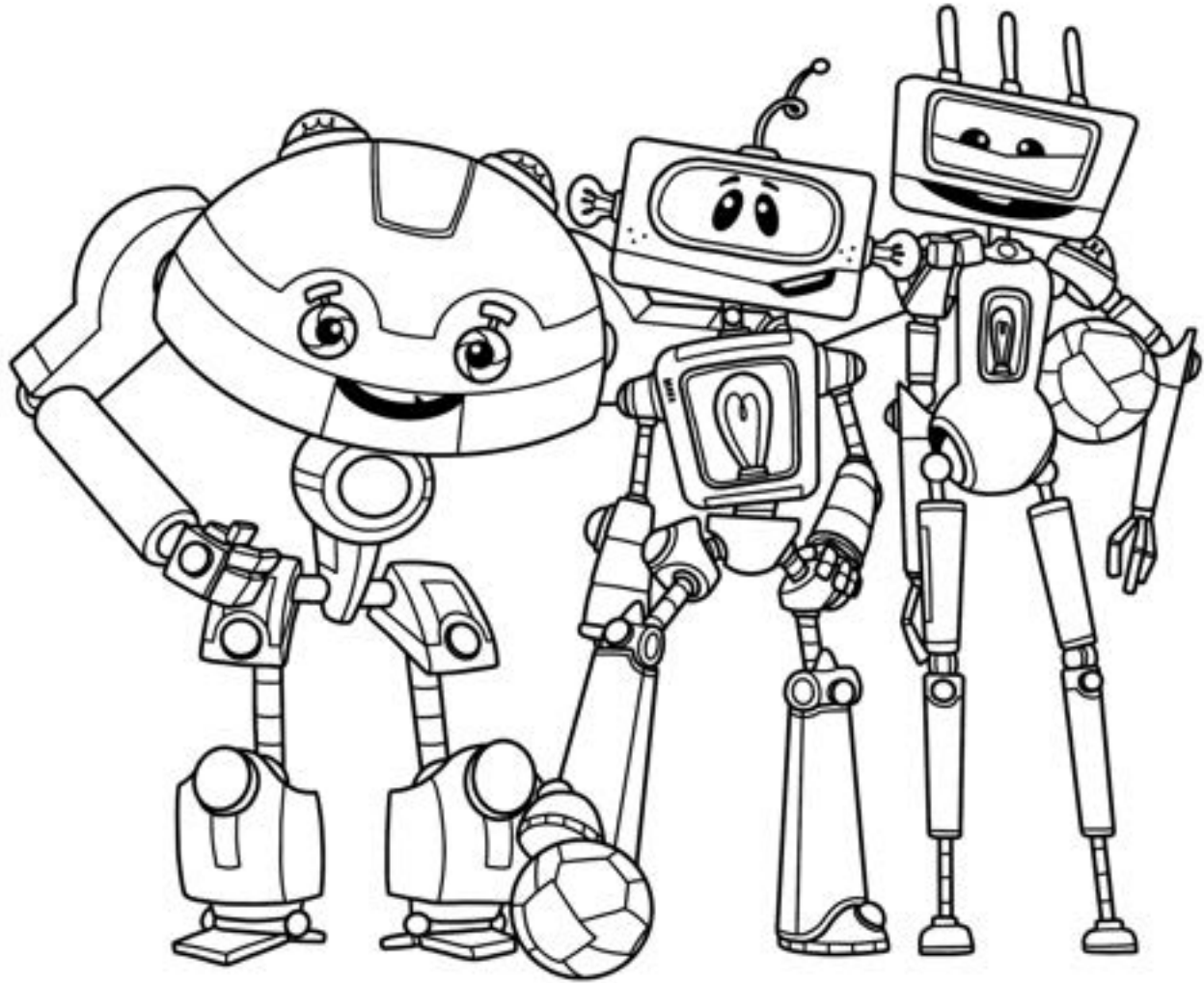
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**I told my friends about ALS, and they
helped me – a lot.**



**If you want to learn more about ALS, or meet
other kids like yourself, organizations are here
for you.**



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For more children and youth resources - books, videos and activities, or if you live outside the U.S. and need materials in different languages, visit:

www.globalneuroycare.org



The ALS Association

To get help with ALS, find a doctor, a support group, or other families living with ALS in the U.S., visit

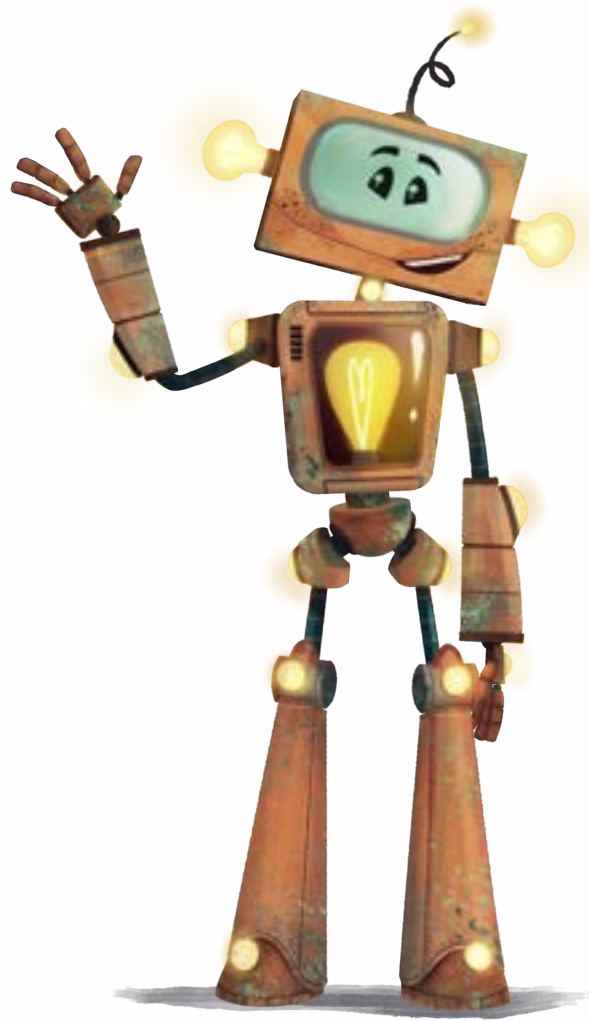
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