

LUKI & the LIGHTS™

Education Packet



LUKi & the Lights story: Sascha Groen and Anjo Snijders
Educational Materials: Melinda S. Kavanaugh, PhD
Illustrations/artwork: Big Grin Productions

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Global Neuro YCare is the only global non-profit dedicated to children and youth living in families with Neurological support and disorders. Global Neuro YCare collaborates with organizations to create education, resources and supports, across language and culture



LUKi & the Lights to co-produced in partnership with the ALS Association. The mission of the ALS Association is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest. www.als.org

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Notes for Families

Acknowledging the intensity of the film, and suggestions for using these materials in watching the film with your child/youth

Finding support in your community

Given the global nature of ALS/MND, it can be difficult finding support. Links are included to assist in accessing support in the US and around the globe.

Guide for Care professionals.

This section includes guidance in using the materials, accessing the material, and accessing the film.

“Ask LUKi”

This section was created using LUKi’s voice, addressing common questions from children and adolescents about ALS/MND. Can be used by families and professionals.

Film questions.

These questions follow the film and are divided into sections, allowing you to answer after the film, or stop and start throughout.

Other LUKi & the Lights Items not included in this packet.

- LUKi & the Lights film
- The LUKi & the Lights Coloring Book

www.globalneuroycare.org

About LUKi & the Lights



In 2018, Anjo Snijders was diagnosed with ALS. He was 35 years old and had two small children. At the time, in the Netherlands, children's programming and education did not exist.

The back story of LUKi & the Lights

So, Anjo and his wife Sascha Groen, who were both teachers, set out to create something that they could use to help their own kids understand ALS, but that maybe could help other kids as well. Sascha first wrote the book, *Daddy Dragon can't be Cured*, about a dragon with ALS, which helped them both think about how to share the story of ALS.

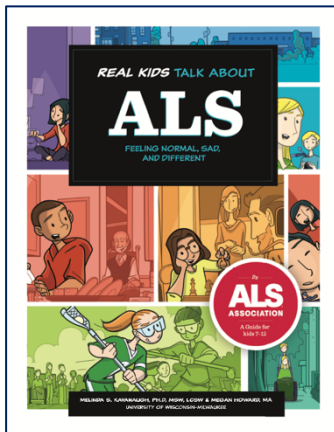


With Anjo having ALS and Sascha diagnosed with MS, they wanted to do more. After seeing an animated short film and writing their book, they came up with the idea of an animated short film, using a robot full of lights. Each bulb representing ALS progression – as they go out, ALS progresses. Sascha and Anjo knew this was a great way to share not only with their kids, but others around the world.

Getting support from the Dutch ALS community

In Late 2019, Sascha and Anjo reached out to their friend Janna, who had met Sascha as the daycare worker of her son, offered to help. Together, they officially started the LUKi project, and reached out to the ALS Netherlands, who became their first official partner in developing LUKi.

Children and youth expert in ALS/MND



Meanwhile, in the United States, Melinda S. Kavanaugh was conducting research and developing programs for children and youth in ALS - based on her research and practice as a neurology clinical social worker. For many years, Dr. Kavanaugh had collaborated with ALS Association, building children and youth research and education, writing several books for children and families in ALS, including a graphic novel using data from her ALS family study.

In January 2021, Conny van der Meijden from the ALS Netherlands association reached out to Dr. Kavanaugh, whom she had known for several years.

Conny asked if the Dutch ALS Association could translate the graphic novel to Dutch, but also wanted to connect Dr. Kavanaugh with Sascha, who had started building the story of LUKi. Sascha met with Dr. Kavanaugh, to share the story behind the film, and asked her to be the content expert, her expertise with children and families. A partnership was born. Meanwhile Sascha was looking for an animation studio to take on LUKi.

Creating the short, animated film

Sascha and Anjo searched for an animation studio that met their vision of what they wanted for LUKi, a short film without language, accessible to as many families as possible.



By working closely with content experts, the goal of the film was to not only provide educational value, but also medical accuracy.

They began working with Big Grin Productions (BGP) in early 2021, a studio with a simple mission of bringing big 'ol grins to people's faces by crafting heartfelt stories, memorable characters, and captivating entertainment.

Sascha discovered a personal connection with BGP when they learned that the producer, Adrian Ochoa, had lost his grandfather to ALS. Together with Toby

Cochran, the director and founder of BGP, they embraced the challenge of bringing LUKi's story to life. With a team of over 100 artists from around the world, several of whom had ALS in their families, they worked tirelessly to create the characters and universe of LUKi & the Lights. The whole team embraced the bold ambition of producing an Oscar-worthy short film.

Global Neuro YCare foundation



By late 2021, the story was complete, and the animation was in process. At the same time, Dr. Kavanaugh and a few colleagues were discussing the creation of a non-profit focused on creating educational materials and support, across language and culture for children and youth in Neurological disorders. No global entity like this existed, highlighting a gap in global programming, especially for families in ALS/MND.

Given Dr. Kavanaugh's involvement with the creation of the film, the foundation was ideally situated to be the home of LUKi, alongside other global youth programming. LUKi now had a home and a platform for global reach.

Funding the project

Sascha and Dr. Kavanaugh presented the film at the International Alliance of ALDS/MND Organizations, Allied Professionals Forum online in Dec 2021. This garnered lots of attention from folks around the world, including people who wanted to support the project. But it wasn't enough to fund the final film production.



In December 2022, the team met with the ALS Association, showed the animatic and an initial proof of concept of the short film, introduced the foundation, and Anjo shared his story. The ALS Association partnered with Global Neuro YCare, to fund the rest of the film, and work together to bring LUKi to the world.

The end, or rather just the beginning of the story

The animated short film, LUKi & the Lights is complete and making its way through film festivals around the world. People who know nothing about ALS are learning through LUKi's story, and that of his friends Theo and Neefa, who love and care for LUKi. Our goal is to get LUKi's story and that of ALS/MND, out to as many children and families as possible, both through the film itself and accompanying educational materials. All materials, and LUKi details can be found at:

www.globalneuroycare.org

Note for Parents

Why the LUKi & the Lights film?

We know that talking about ALS/MND, sharing a diagnosis, and discussing death and dying with your children and youth is not easy.

Guided by clinical practice and research with families, *LUKi & the Lights* was created to help families begin discussing ALS/MND with their children.

The film was created as an animation with no language to appeal to a wide audience, including children, allowing them to connect with LUKi and their friends is an honest, but fun way.

What the film entails

LUKi's story is told from their perspective of a robot depicting: 1) initial ALS/MND symptoms, 2) Doctor appointment where they receive their diagnosis, 3) anger at getting the diagnosis, 4) how they move forward as they progress, 5) friends helping take care of them, and 6) accepting and eventually dying.

Given the depiction of ALS/MND from initial symptoms through eventual death, the movie can be intense to watch. Acknowledging the potential intensity, we have created education materials to go along with the movie to help you facilitate the discussion with your child/youth.

Watching the film

Before you watch the film, all the materials addressed are available for download at www.globalneuroycare.com. We ask that you agree to read through them and keep a copy of them as you watch the film with your child/youth. These materials were created to support you, and we hope you find them useful.

The Full film will be available on the Global Neuro YCare website.

- a) Go to: <https://globalneuroycare.org/luki-and-the-lights>
- b) Click on LUKi and the Lights drop down menus
- c) Click on – “view full movie.”
- d) Check box to agree to sharing materials and provide contact information.
- e) Watch film!

Finding support in your community

Our goal with LUKi is to reach as many families as possible. After watching the film, you may have further questions for health care providers, or want to seek services in your area. Given the number of ALS/MND organizations around the world, it is impossible to list them all, but here are a few organizations who may be helpful.

Global support

The International Alliance of ALS/MND organizations keeps a listing of all organizations around the world who are part of the Alliance.

All organizations can be found here - <https://www.ALS/MND-mnd.org/find-ALS/MND-mnd-association/>

Children and youth

Global Neuro YCare foundation - created to address a gap in education and programming for children, youth, and families in ALS/MND – around the globe. To access materials, or to request translation of existing materials go to.”

www.globalneuroycare.org

US based ALS/MND clinical and supportive care

The ALS Association - A partner to the LUKi & The Lights film, the ALS Association offers clinical care, support for ALS for all family members, care services and programming. www.ALS/MND.org

Your ALS guide – listing of a broad range of clinics including MNDA, VA and ALS/MND- <https://www.yourALS/MNDguide.com/ALS/MND-clinics.html>

Using these materials: A Guide for Care Staff

The package is comprehensive but can be split into sections as noted. Feel free to share sections with families as needed.

- **Using pictures, art and logos**

- All the pictures and animations of LUKi, his friends, and the LUKi world, are proprietary. They may not be used in any other context than these materials.
- LUKi, his friends, logo, or any other aspects of LUKi may not be cut and pasted onto any other materials or work.

- **ALS or MND?**

Given the focus on Global connections, and to be as widely used as possible, we use ALS/MND throughout the book.

- **Accessing the materials:**

All LUKI materials are available for download on the Global Neuro YCare website: www.globalneuroycare.org

- **Accessing the Film**

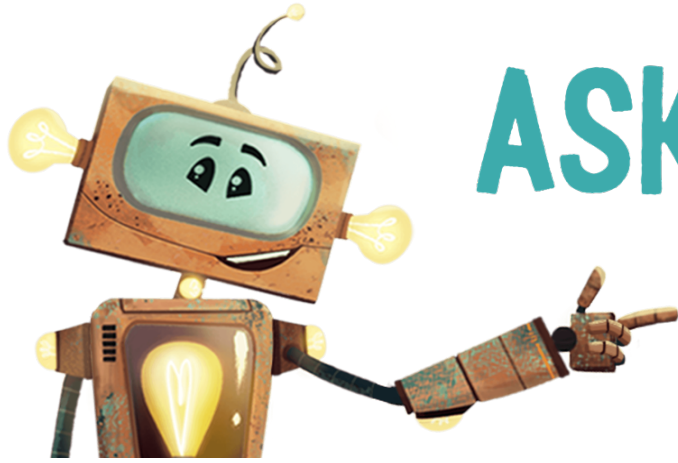
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- Check box to agree to sharing materials and provide contact information.
- Watch film!

- **Translating materials**

Global Neuro YCare is committed to provide accessible materials, including translated existing ones. Please contact us at

lukayouthfoundation@gmail.com to translate materials.



ASK LUKI

**All about ALS/MND:
Young children**

**Hi! I'm LUKI. I am a robot full of lights.
I have ALS/MND, just like your family member. Do you have
questions about ALS/MND? If you do, let me try to answer some
of the questions kids have asked me!
I also asked my favorite human, Anjo Snijders to help. He had
ALS/MND too!**

**Why do you
have
ALS/MND?**

It may be hard to hear, but I don't know. But we do know that lots of doctors around the world are trying very hard to figure that out. But for now, it is something I have so we need to figure out how to do what I used to do, just different!

**Why do your
hands get
so weak?**

You know how when you plug something into the wall, the electricity goes, and it turns on? Well, think about my hands being plugged in but the electricity just does not go to them. The muscles can't work because the wiring is off.

**Can I catch it
from you?**

No, you can't catch it like you would "catch" a cold. Isn't that awesome?

Can you get better?

Right now, no I can't. I know that is hard, but what I can do is find new ways to do things and hope that one day the doctors will make sure people like me can get treatment.

Why can't you walk?

The muscles in my legs are not getting the right signals from the brain to tell me to walk. Like the lamp plugged in to the wall, the electricity has to travel to the lamp. But in people with ALS/MND, the electricity, or the signal does not get to the muscles, so we can't move.

Why don't your eyes get ALS/MND?

For some reasons the muscles and the nerves in the eyes are just not as affected like the much bigger muscles in your arms or legs. This is good, so I can keep my eyes on you!

How does it feel to have ALS/MND?

Because my muscles get weaker, things feel heavy. And some things I used to do are now hard or impossible to lift. Not being able to do things myself also makes me feel frustrated and sad sometimes. So, it is good when I get to talk about it!

Does ALS/MND hurt?

Not really, but sometimes I feel a little achy because I can't move my muscles around as easily. That is why it is so nice when someone helps me move my arms and legs to keep them going. Or have a wheelchair race with 😊

**Can you get
old with
ALS/MND?**

Yes, many people get old, but it is tough to answer because it depends on the type of ALS/MND you have. So, some people grow old, and some people do not. Which is hard to hear, I know.

**Are there
medicines you
can take?**

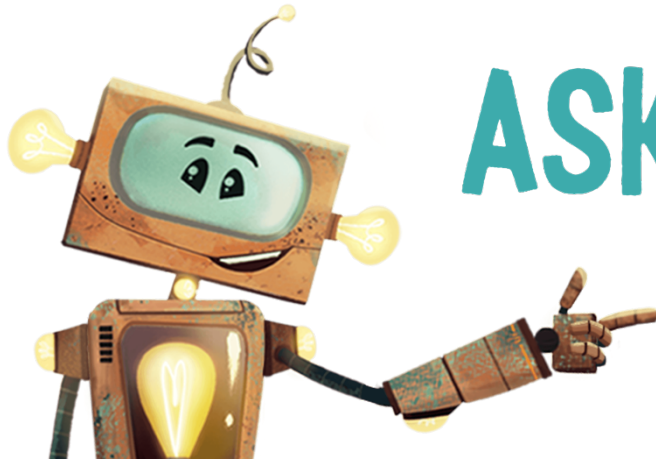
That is hard, because there are still so many things that the doctors don't know about ALS/MND. There are some medications that can help slow down a bit for some people, but the doctors are working hard to find even more for everyone!

**But HOW do you
know you have
ALS/MND?**

The best way is to see a doctor. They will do lots of tests, looking at your muscles, your arms, legs, chest, they will look at you're breathing and swallowing - like the doctor with his big eye! Then they will let you know if you have ALS/MND.

**I bet you have more questions. I know I did when I
first found out I had ALS/MND.
Just like you asked me, you can ask your mom or dad,
or your grandparents.
There are lots of resources for kids like you – check
out.**

www.globalneuroycare.org



ASK LUKI

ALL about ALS/MND: Adolescents

Asking family and friends about ALS/MND can be tough. It is easy to just not ask, look online or just ignore it. But, because so much online isn't true, I thought I would answer some basic questions, maybe help you feel a little better and more informed. I asked my friend Anjo Snijders to help – he had ALS/MND/MND and was a great resource for families like yours.

How do you get ALS/MND?

Well, you can't catch it. And there are still lots of questions unanswered, but what we do know is that the junction of the nerves dies. And when that happens, the nerve is not getting to the muscle, which makes it not be able to contract. These specialize nerves are called motor neurons. When they die off, you get the basis of ALS/MND or Motor Neuron Disease.

It is only by a doctor's diagnosis, but not just any doctor. It needs to be done by a specialist who knows ALS/MND – usually a Neurologist. Some of the ways ALS/MND looks, can be like other disorders. So, it can often take a few visits to be sure.

How do you find out you have ALS/MND?

Why are the symptoms so different in different people?

Some of that has to do with where the motor neuron death started, and it also has to do with who you were before you got ALS/MND. Were you more athletic, exposed to environmental toxin, is this the hereditary form? There is no standard course of how it will progress, but we do know that different types tend to move a bit quicker than others.

Can anyone get ALS/MND?

Yes, from what we know, anyone can get ALS/MND. Although it tends to happen slightly more often in men. But anyone can get it. But there are again many doctors working around the world trying to figure out why certain people (athletes and military) get it more often than others.

How many people have ALS/MND, worldwide?

We know that more than 200,000 people have MND/ALS/MND. But that may not be completely accurate as many places do not have doctors with expertise to diagnose, nor do many places and countries have good access to healthcare. So, the real number is likely higher.

What is the difference between ALS/MND, PLS, PSMA and MND?

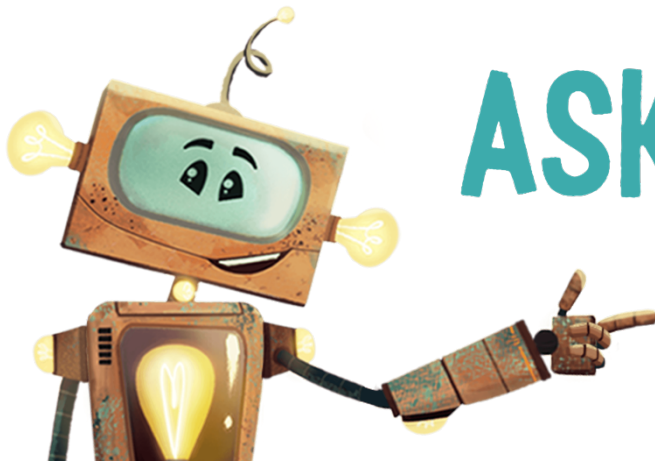
Motor Neuron Disease (MND) is the name given to a group of diseases in which the nerve cells (neurons) that control muscles undergo degeneration and die. Amyotrophic Lateral Sclerosis (ALS/MND), Progressive Muscular Atrophy (PMA), Progressive Bulbar PALS (PBP) and Primary Lateral Sclerosis (PLS) are all subtypes of motor neuron disease.

How can families like mine, deal with ALS/MND?

Well, first just ask. **It is always OK to ask your family member how they are doing and if they need anything.** The most important thing we or any family can do is talk about ALS/MND, even if it seems hard or makes you emotional. If we talk about it, we can support each other and know what the other needs. You can also help by telling other people about ALS/MND or by participating or creating a fundraiser so that more people can hear about and understand ALS/MND.

We know this is only a few questions and you probably have more. To find more resources, including books, and support programs for children and youth in families with ALS/MND:

www.globalneuroycare.org



ASK LUKi

**Film Q&A for families
and professionals**

- The below questions were developed to follow along with the film, thus the expectation is to use them after watching the film.
- The questions are divided by sections in the film. That way, the film can be stopped to ask the questions of the youth in the room, or they can be asked after viewing the film.
- The questions are suggestions and starting points for discussion. We encourage open discussion, allowing for additional questions of the child/youth.
- Make sure to access the LUKi & the Lights coloring book found at: www.globalneuroycare.org

Early symptoms of ALS/MND

In the film, the first change happens when LUKi is playing soccer. His hand stops working. Use that as a talking point for the below questions.

Identifying with LUKi

- What does it feel like to play soccer with your friends?
- Have you ever been hurt in a game, or not been able to play like LUKi?

Noticing the change in LUKi

- What changed in LUKi?
- Did something happen on him first?

Connecting to the person in their family with ALS/MND

- Have you seen something change in your (person with ALS/MND)?
- What changed first for them?
- Thinking about LUKi's lights, where on the person you know with ALS/MND might their lights be changing or going out?
- What kinds of things are different in your person with ALS/MND, like when LUKi couldn't use the clock?

Getting a diagnosis

For most people with ALS/MND, getting the diagnosis is often confusing with little information. The film shows the wait, the fears, what little information they received and the importance of bringing someone with you when a diagnosis is given.

Showing the process of getting a diagnosis

- LUKi went through lots of tests for ALS/MND. How do you think you would feel?
- Theo came with LUKi to support them. Have you been to clinic with your family member with ALS/MND? If you have, what was that like? (who they saw, talked to etc.)
- The doctor showed LUKi and his friends all about ALS/MND. What do you think he was saying?
- What questions would you have for the doctor?

Showing the emotion

- LUKi got really upset about having ALS/MND. How did that make you feel watching it?

Connecting with own feelings

- Have you ever gotten really upset about ALS/MND? Diagnosis in (your person with ALS/MND)?
- What happened after that? Did you talk to someone?
- What would you say to other kids like yourself, in managing your feelings about the ALS/MND diagnosis?

Making a “new normal” with ALS/MND

This section in the film shows how LUKi turned their anger and sadness in to a positive – making a chair, racing Theo and joining in life actives, just with help.

Turning bad news to something positive

- LUKi was still very upset about ALS/MND making it hard to get around. But he made his own chair.
- What did you think about LUKi’s wheelchair?
- What kind of chair would you make?

Normalizing to their own family

- Does someone in your family use a power chair?
- What cool things does their chair do?
- Have you ever tried it out to see what it feels like?

LUKi and Caregiving

LUKi's friends take care of them, in several ways including bathing, feeding and transferring. These are all things we know children and youth do to help their family member with ALS/MND. This is a great time to normalize ways they help and share their experiences.

Sharing the caregiving experience

- LUKi has ALS/MND and needs help to take care of himself.
- Do you help to take care of (person with ALS/MND)?
- What kinds of things do you do to help take care of someone?

Personalizing the feeling of helping in care

- Their friends were sad about LUKi, but wanted to help because they love LUKi.
- Do you ever feel that way helping someone?
- Who do you talk to about how you feel?

Assisting with devices for care

- LUKi needed to use something to help him breathe.
- Does (person with ALS/MND) use something like that?
- Maybe they need the help of other machines. What other machines does your person with ALS/MND use?

LUKi and End of Life

Talking about death and dying is difficult but not always for the children and youth who want to know and have lots of questions. This section of the film may be the most emotional, so is a great time to stop, discuss, then go forward if the child is getting upset.

Identifying death and the experience of death

LUKi dies in the end, which is very sad. His friends are with him and show him they love him, but they are sad. It is ok to be sad and wonder what happens.

- Have you ever asked (person with ALS/MND) about when they die?
- What kinds of things do you wonder about when someone dies?

Remembering the person who died

Their friends think about all the things they did with LUKi, having fun with him, helping him, laughing with him.

- What things would you like to remember about your (Person with ALS/MND)?
- Who can you talk to about how you may feel when your person with ALS/MND dies?
- How can you create something to remember them? Can you draw or make pictures, or write something?