

fLE**X**i**l**e



the Story of a joint



I'm a joint and I'm called **flexible**. Flexible means moveable. Everybody has a number of joints which makes it possible for you to move. For example – if you didn't have a knee joint, you wouldn't be able to bend or stretch. So you see joints are pretty important.



~~flexible~~
flexible

Sometimes I'm not really flexible, because I have arthritis. There's less movement at the front and back of my joints – that's why my friends call me **LEXI**.

But now it's your turn to introduce yourself.

My name is.....

and I'm years old.

And this is what I look like:



Please draw a picture of yourself or stick in your photo.

Now you know that I have arthritis. But some children don't really know what that means. That's why I'd like to tell you about it.



Arthritis isn't only an old person's illness, it can affect children, too. Even a kid your age can have arthritis.

Arthritis is an illness of your joints. They get inflamed and sore. Many different joints can be affected by arthritis. Some children have arthritis in their knees, others have inflamed wrists and others have arthritis in their ankles.



Arthritis is an illness that just appears, but it doesn't go away as fast as a bad cold. Most children who suffer from this illness may have arthritis for years.



Let me tell you – there is a very smart name that explains this illness. It's called:

Juvenile Idiopathic Arthritis

↑
affects children

↑
there is no explanation what has caused it (even the doctors don't know)

↑
inflammation inside joints



Smart word, but difficult, right? You don't really have to memorize it.

There are different types of arthritis in childhood.
May I introduce three of them to you?



Often only a few joints are involved.
If there are less than five joints inflamed
at the beginning of the illness, you call
it **Oligoarthritis**.

Some children may have five or more
affected joints from the start of the illness.
These children have **Polyarthritis**.



Besides having swollen and painful joints, children may also have fever and a rash. Then the illness is called **Systemic Arthritis** or **Still's Disease**.



Which type of arthritis do you have?

Tick here!

- I have oligoarthritis.
 - I have polyarthritis.
 - I have systemic arthritis.
-



If you aren't sure, please ask your parents!

Can you imagine what an arthritic joint looks like and how it feels?



When I'm inflamed I will grow bigger and become swollen.
You can call this a **swelling**.



And sometimes I feel a lot hotter than
all the other joints around me.
We call this a **heat**.

I often can't bend or stretch as easily as before. That's why I'm not very **flexible**. My range of motion is reduced.



When I want to move it hurts a lot. Then I have **painful** joints.



Do you have painful joints, too? Tick here!

My joints are sometimes big and swollen.

Sometimes I have painful joints.

There is heat in my joints.

Sometimes my joints are not flexible. I feel like LEXI.

I don't have any problems with my joints.

yes - no

yes - no

yes - no

yes - no

○

Now you can imagine what an arthritic joint looks like.
In the box below you can draw one if you like.



It's true that I have juvenile arthritis, but I
would like to stay as flexible as possible.
I have some good suggestions how to do this.

Children with arthritis usually take their **medications** daily. They help a lot – because they do three things.

They fight against
my pain
my swelling and
my inflammation
and then I'm flexible again!



How does this work?

There is a certain system in our body which protects us against damages and dangers from the outside. You can compare it to a body police who keeps an eye on you.

And there is good medicine which helps your body police to fight the inflammation of your joints. Some medication helps quickly. Other medicine is strong and works very well. Some drugs may need more time to fight against the inflammation. But they all help the body police in finding and fighting the illness in your body.



May I introduce the different drugs to you?

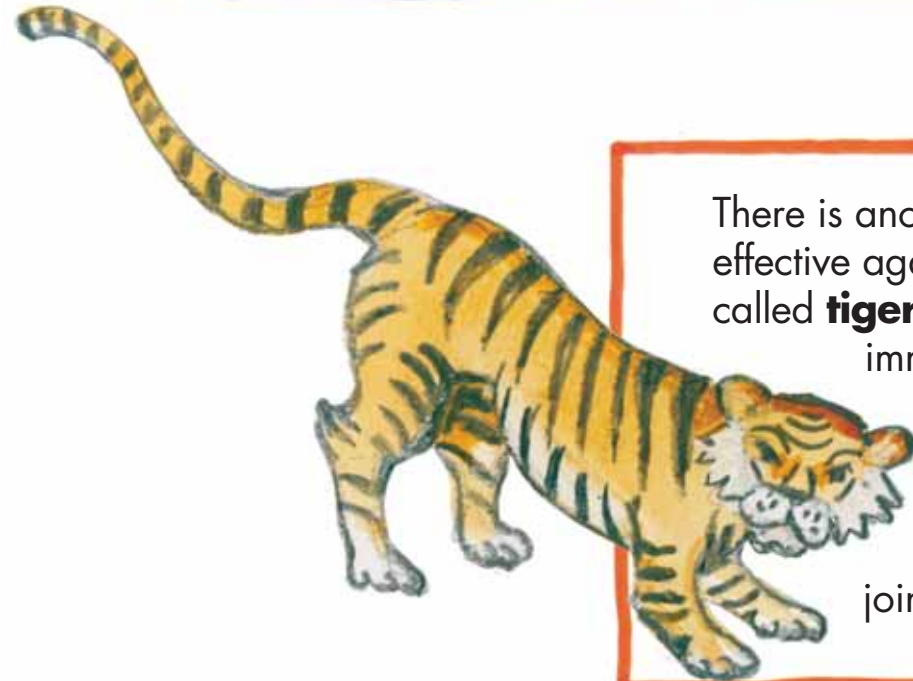
There is some medicine which helps fast, but is not very strong.

We call it **mouse medicine**.

It reduces your pain quickly, but only lasts for a few hours, then you have to take it again.

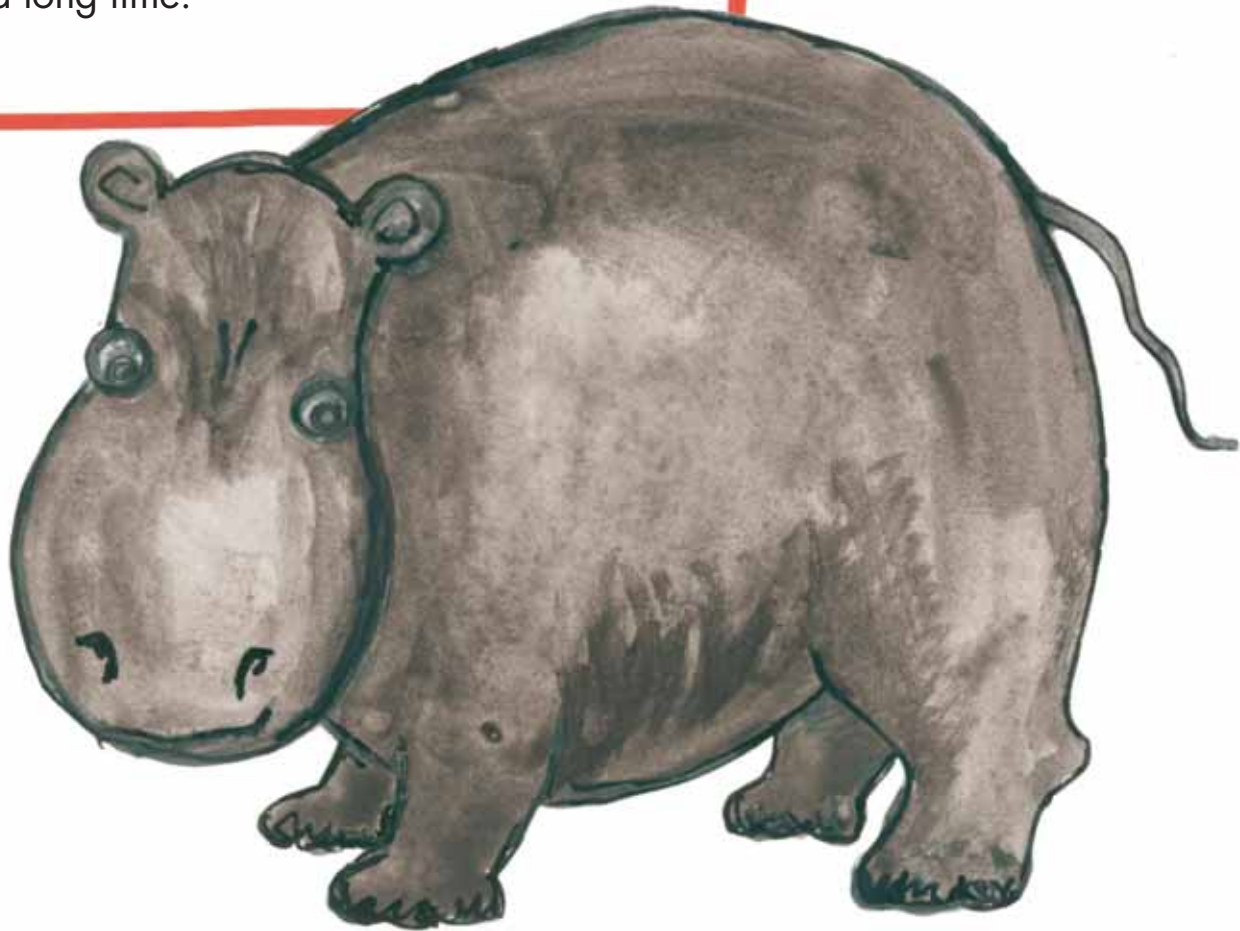


There is another drug which is strong and effective against the inflammation. This is called **tiger medicine** and helps immediately. When you need these drugs your doctor takes good care! The doctor prefers injecting this medicine into the inflamed joint to make it flexible again.

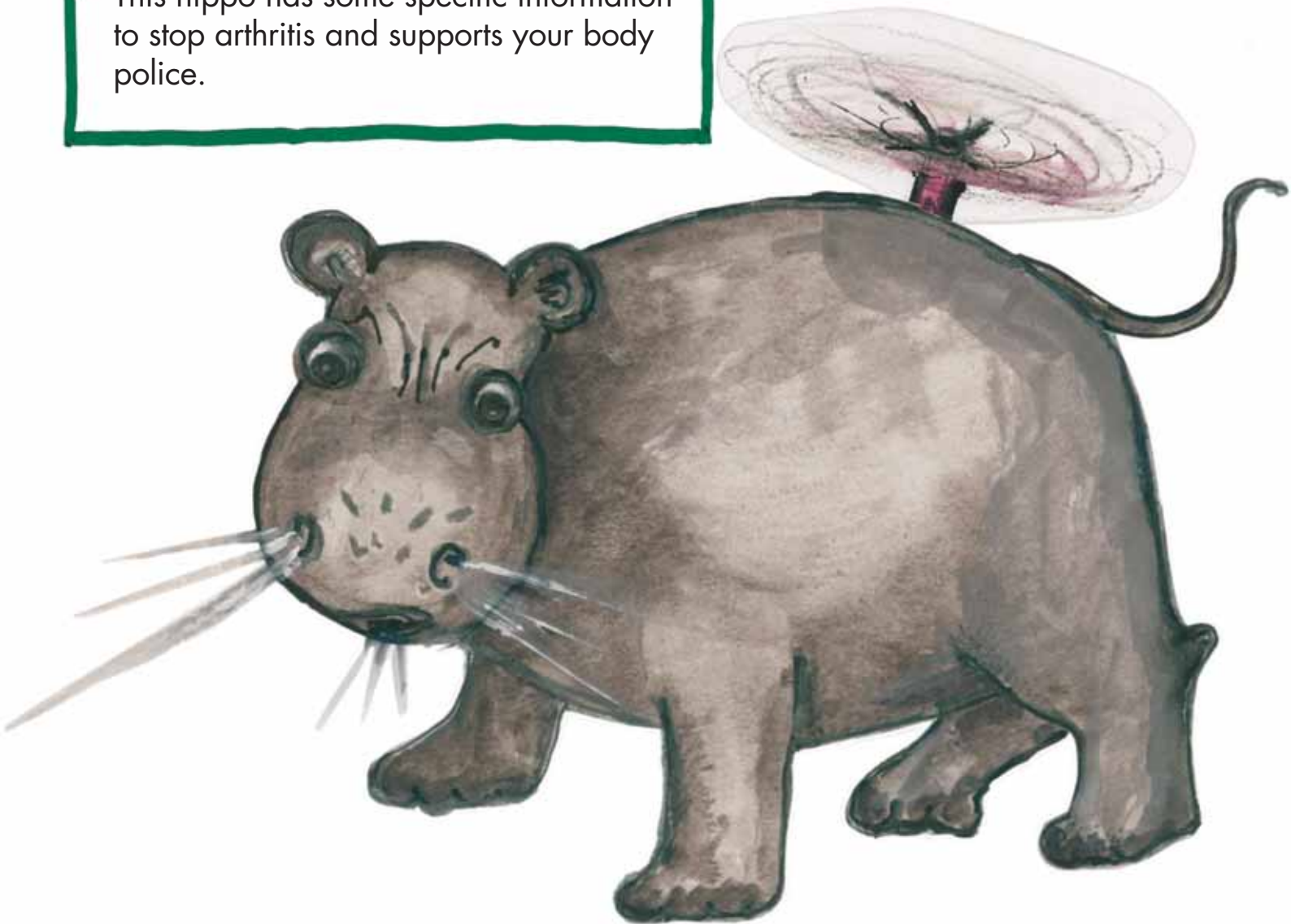


There is another medicine which helps a lot, but not immediately. We call it **hippo medicine.**





Hippo medicine may take a few weeks to have an effect, but then it will help very well to support your body police for a long time.



Last but not least there is a **turbo medicine** which is strong and very fast. It helps after a few injections. Perhaps you can imagine the picture of a hippo with a **turbo** on its back. This hippo has some specific information to stop arthritis and supports your body police.



Do you take medicine, too? Can you imagine which medicine belongs to which animal? Can you write down the name of your medicine and match it to the right animal?

	My medicine is called	I take it per day/per week/ every two weeks
mouse 		
tiger 		
hippo 		
turbo-hippo 		

I do **exercises** every day in order to keep flexible. My parents and physiotherapists help me. I like some of the exercises more, but others make me really tired. But when I do my exercises regularly, I'll become as flexible as before.



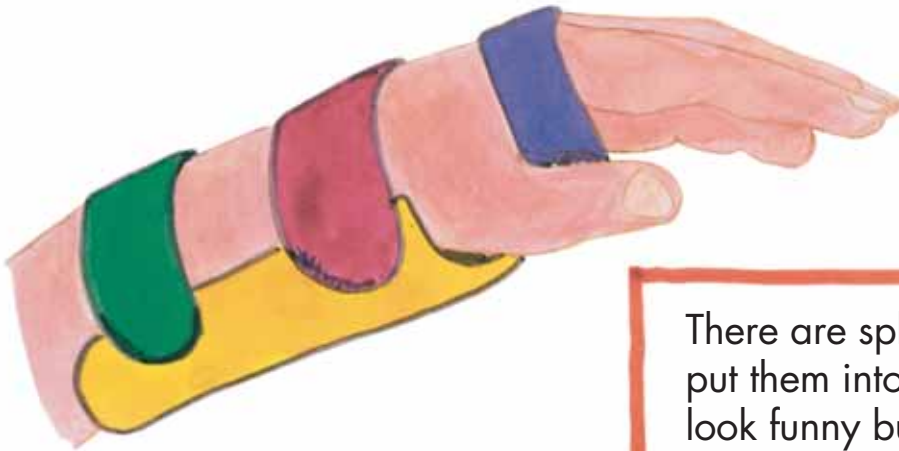
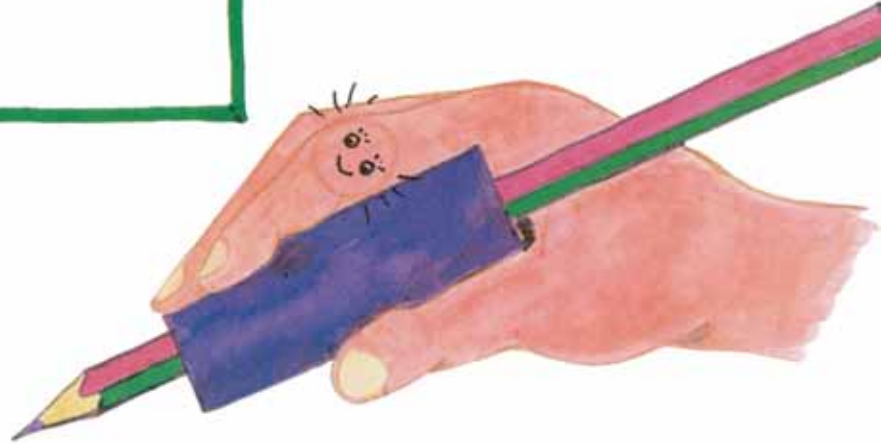
Children with active arthritis shouldn't do certain kinds of sports with their inflamed joints, but **physiotherapy** is possible. The best thing is to ask your doctor.



When your medicine helps and your arthritis has improved, you will be able to play and do sports with your friends again. Which activities do you like best? Here you can colour the picture of children doing sports.



During **occupational therapy** you learn how to use your joints correctly and how to put less strain on them. For example your finger joints don't have to strain so much if you use pencil-grips.



There are splints to support your joints and put them into the right position. Splints may look funny but they are actually comfortable and protect your joints. Here you can see a splint for your wrist.

ice



When I'm inflamed and feel hot,
I need to be cooled down by using
ice packs a few times a day.
Afterwards I feel a lot better, because the
swelling goes down and the inflammation
isn't that painful any more.

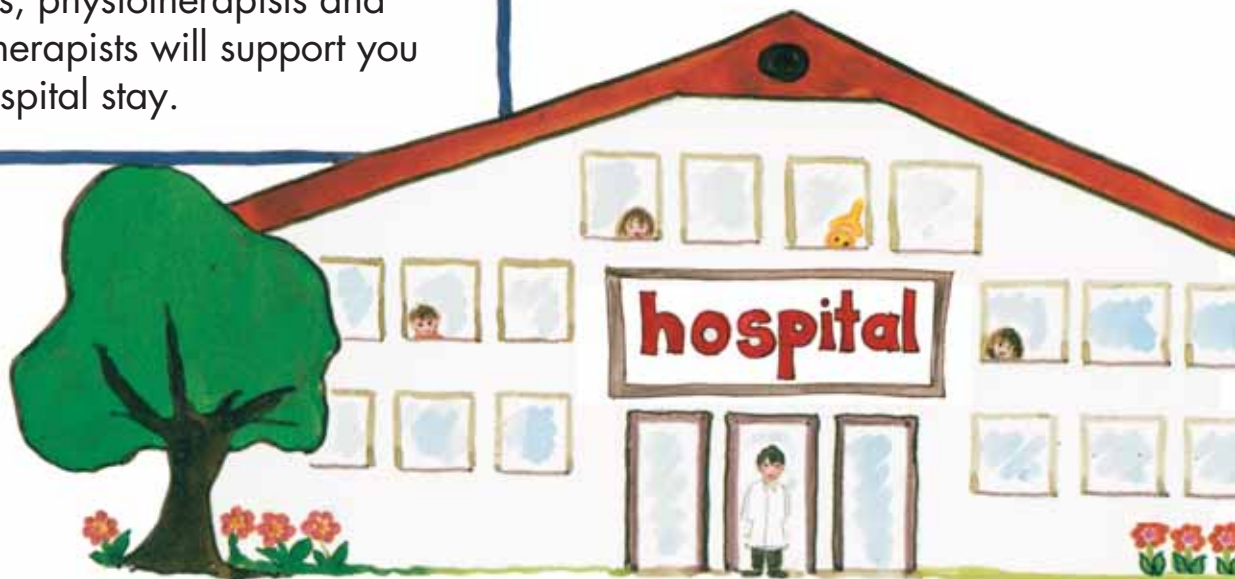


Children with arthritis have to see their **doctor** regularly for check ups. The doctor examines the joints carefully and finds out if the flexibility has improved. An **eye specialist** is important, too – he has a special light to check if an inflammation of the eyes has developed secretly.



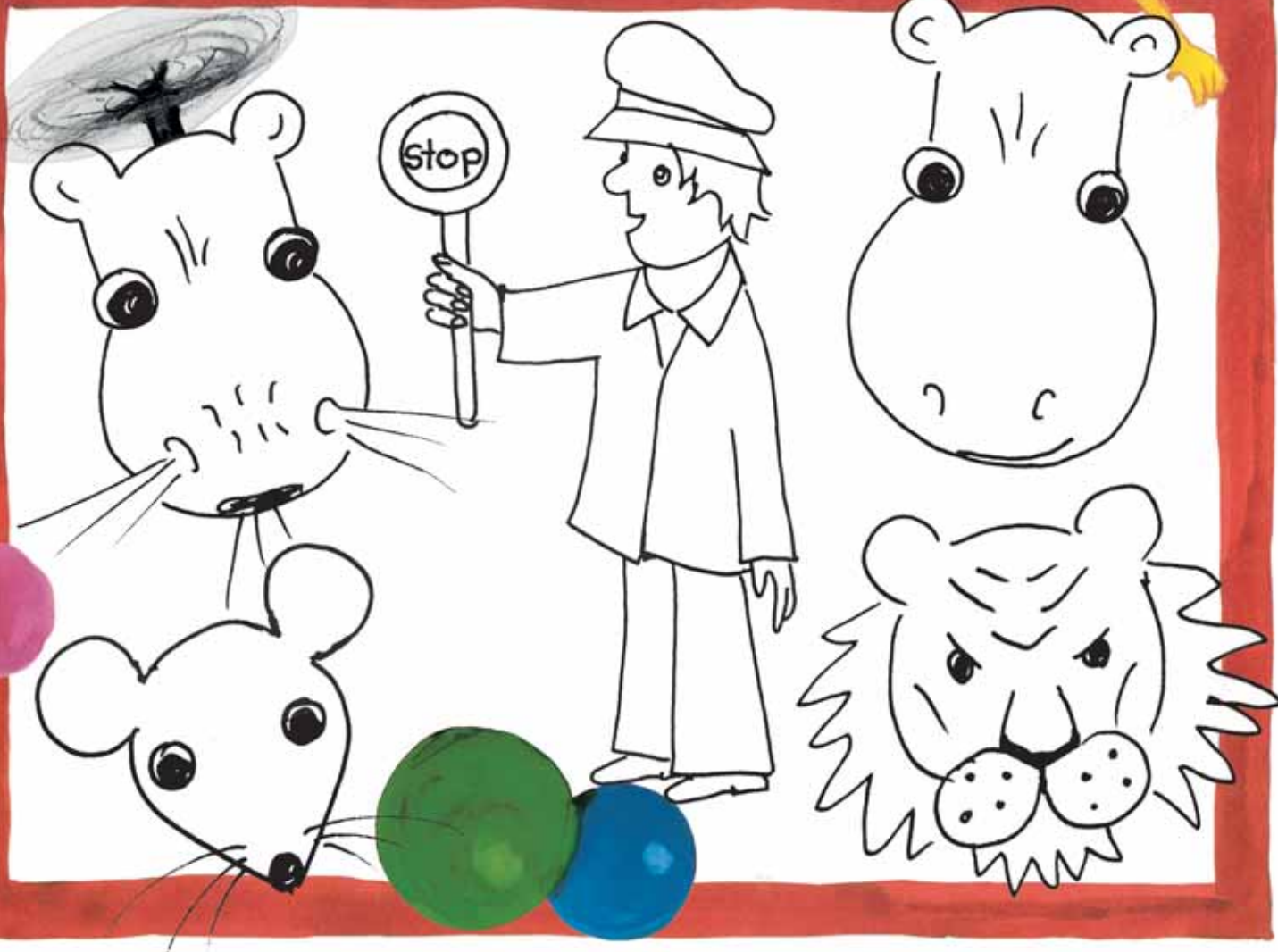
You will have a **blood test** at the doctor's. Your blood will be checked in a special lab and the doctor will know then if your medicine is appropriate and working well.

Sometimes children with active arthritis have to go to a **special hospital** where they are treated very carefully by doctors. Nurses, physiotherapists and occupational therapists will support you during your hospital stay.



While you are in hospital you will get to know many other children with arthritis, it's good to know you are not the only one. The doctors can help you to treat your illness, become active and return home when you are feeling better. To control your illness you need **outpatient visits** at your doctor regularly.

It can help you if your friends understand your illness and support you, especially when you are sick. Tell them that you will be flexible again soon and that they can't catch your illness. They can always visit you and play with you. Do you remember the animals? They show you how your medicine works. You can colour them here if you want.



fLEXible

by
Silvia Wiedebusch & Gerd Ganser

Text and psychological theory:

Prof. Dr. phil. Silvia Wiedebusch
University of Applied Sciences
– Developmental Psychology –
Caprivistr. 30a, 49076 Osnabrück,
Germany

Illustration/Layout:

Christiane Thome, Wiehl

Printed by:

Druckerei Preuß GmbH, Ratingen

Medical consultancy and realisation:

Dr. med. Gerd Ganser
Head, Rheumatic Clinic for Children and Adolescents,
Competence Center of Rheumatology for North West Germany
St. Josef Stift, Westtor 7, 48324 Sendenhorst

Edited and distributed by:

Bundesverband zur Förderung und Unterstützung rheumatologisch
erkrankter Kinder und deren Familien e.V.
Westtor 7, 48324 Sendenhorst
bank account: Bundesverband Kinderreuma e.V.
Sparkasse Münsterland Ost, BLZ 400 501 50, Konto 70 099 999
www.kinderrheuma.com, E-Mail: familienbuero@kinderrheuma.com

The booklet "fLEXible" aims to inform young children as well as their friends and families about juvenile arthritis and its treatment options. The goal is to live a "normal life" despite having a rheumatic disease beginning in childhood. This is also the main goal of joint editors the "German Association for Children with Rheumatic Diseases and their Families e.V." and St. Josef Stift in Sendenhorst, Germany.

The revised edition provides current knowledge about the disease and its treatment options for young children with the aim of integration and participation.

Many thanks to Abbott Company for promoting and supporting this booklet.





Children,
who look after
their arthritis, will
get better. So,
please take
good care and
follow the rules.
I want to be
flexible again.