

Being *me* with **HAE**

My guide to living with HAE



Biotherapies for Life™ **CSL Behring**

Introduction

This booklet is about HAE and you. We will talk about what HAE is and what it might mean for you at home and at school.

You will also meet Michael the nurse, who will talk about some activities you might like to try.



Home

What is HAE?

Not many people have HAE. It is a rare condition, affecting between one in every 10,000 and one in every 50,000 people in the UK.

This means that if you filled up all the seats in Wembley Stadium with people from the UK, as few as one or two people in the crowd could have HAE, and almost certainly no more than nine.



The H in HAE is for 'hereditary'. This means it is passed on from your mum or dad. Just like the colour of your eyes and hair.

Not everyone whose mum or dad has HAE will get it. This means that some children in a family may have HAE, but their brothers or sisters might not.



Who lives in your house?

Who has HAE in your house?

What is your favourite thing to do with your family?

What HAE means for you

Most children with HAE are able to do the same things as everyone else.

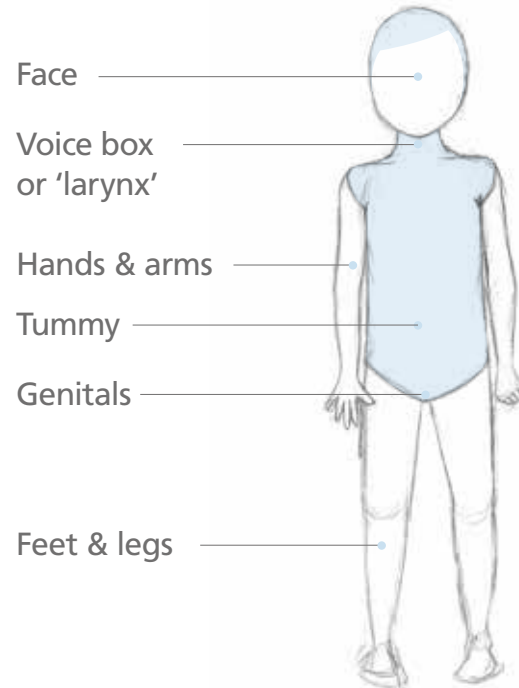
But it does mean you might have to watch out for 'swelling'. This is where a part of your body puffs up. You might hear your doctor or parents call this an 'attack'.

A swelling attack like this may be painful. Some people may still feel sore for a while after the attack too, even when the swelling has gone down.

Doctors do not always know why attacks happen. Some people have 'triggers' for their attacks. These are things that might make a swelling happen, like feeling worried about something or eating a certain type of food. Triggers can be different for everyone.

Where swelling happens

HAE does different things to different people. Here is a map of the body showing the places where swelling might happen.



You should tell an adult if you feel pain or tingling in any of these places. Watch out for any pains in your tummy. This might mean you have swelling inside your body that you cannot see.

When attacks might happen

Some people feel tingly or have pins and needles in the place where the swelling is going to happen. This could be in any part of their body.

There are other things that might happen just before a swelling.

- You might feel sick, or like you have a very bad cold very quickly
- You might feel grumpy or angry
- You might have a rash
- You might feel really tired

If any of these happen to you, speak to one of your parents or another adult right away.



Some people say that having a swelling is like having a water balloon under the skin.

How does it feel for you?

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What are your 'triggers'?



Think about the different times when you have had a swelling.

What were you doing before each swelling?

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Is there anything that has been the same each time?

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Maybe it has happened to you when you have felt poorly with something else?

Maybe it has happened to you when you have felt worried?

Maybe it has happened to you when you have felt excited?

Speak to your doctor or nurse about what makes you swell up.

If you think you are going to have a swelling for any reason, speak to one of your parents or another adult right away.

Staying healthy

Staying healthy is really important for all of us. You can do this by:

Eating healthy food

Lots of fruit and vegetables help you stay healthy.

Exercise

Exercise, like time on your bike or walking to school, can also help you stay healthy.

Drink lots of water

Water can really help you. Especially after you have had a swelling.

Medicines

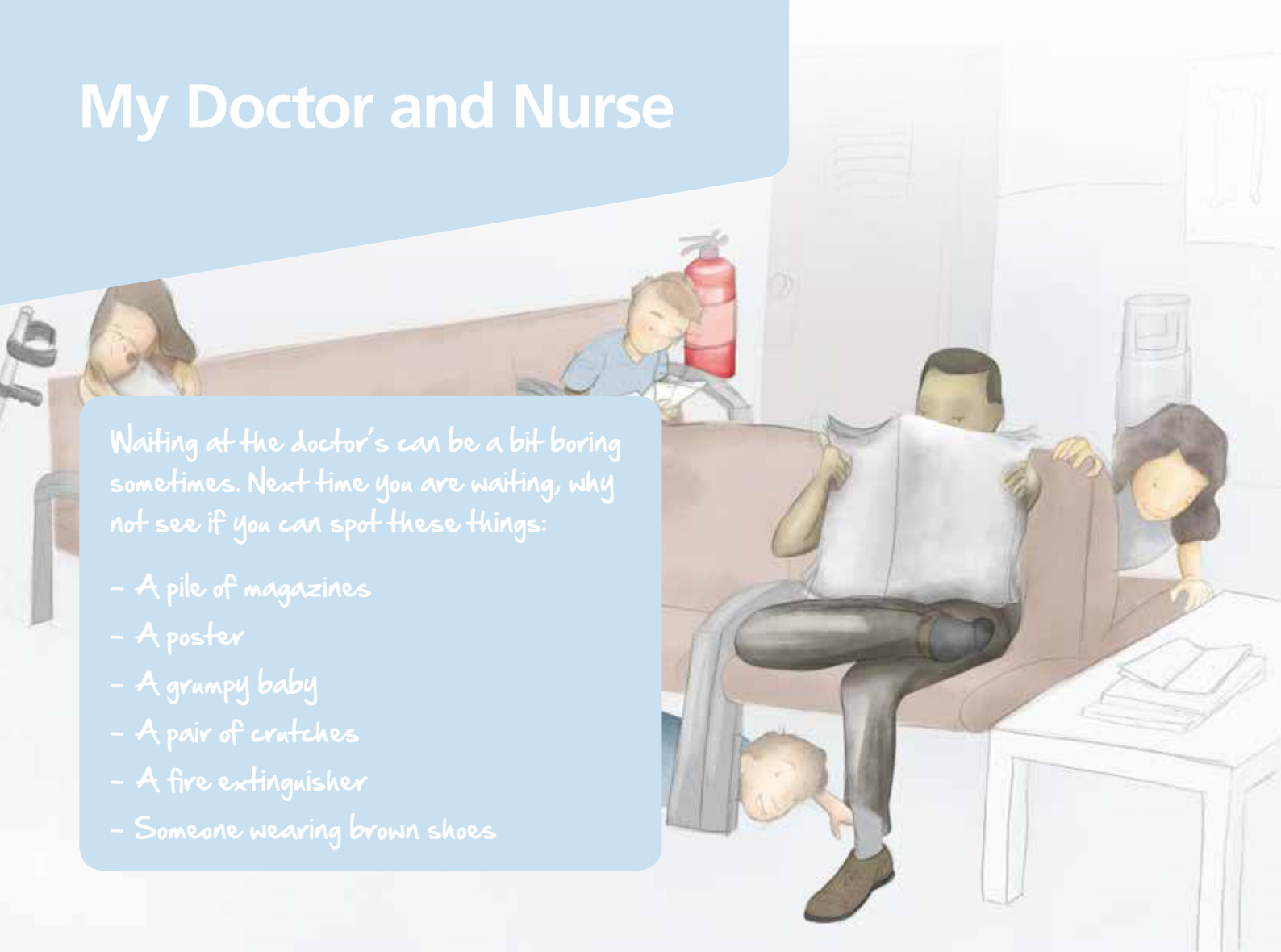
Medicines can help you with swelling. We will talk more about this later in this booklet.



My Doctor and Nurse

Waiting at the doctor's can be a bit boring sometimes. Next time you are waiting, why not see if you can spot these things:

- A pile of magazines
- A poster
- A grumpy baby
- A pair of crutches
- A fire extinguisher
- Someone wearing brown shoes



Seeing your doctor or nurse

You might see a doctor who knows about HAE, called an 'immunologist'. Or you might see a nurse who knows about HAE, called an 'immunology nurse'.

What is the name of your doctor or nurse?

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You might see your doctor or nurse a few times a year. It is their job to make sure that everything is okay with you. They can answer any questions you have.

What your doctor and nurse might talk about

Your doctor or nurse will talk to you and your parents. They will want to know about anything that has changed since the last time you saw them.

Do you remember reading about 'triggers'?

These are the things that might make you swell up. Your doctor or nurse may want to talk about what triggers you have.

They might have some ideas to help you manage your triggers.



My triggers

You can help your doctor or nurse by making a list of your triggers below. Talk with an adult about how you might be able to manage them.



Trigger	I can manage this by...
I sometimes have swellings when I feel very worried about something.	Taking some time out. Taking a deep breath. Doing something I find relaxing.

The “head, neck or tummy” rule

There are times when you need to see a doctor right away to help you. If you think you might be getting a swelling anywhere on your head, on your neck or in your tummy, you need to tell an adult right away. This is because they need to make the swelling go down quickly.

This includes: lips, throat, eyes, forehead, cheeks, lower tummy, upper tummy.

This type of swelling is an emergency. So if you think you are getting a swelling in these places, it is very important that you speak to an adult right away.

Your doctor will have decided what treatment you should get in an emergency. This is sometimes called an ‘emergency management plan’. Your mum or dad will know about your emergency management plan. They might give details of this to other adults that take care of you, like teachers, activity leaders or babysitters.

The plan tells doctors and other adults what to do in an emergency so they can look after you and make the swelling go down quickly.



Medicine

Your nurse or doctor might talk to you about medicine to help you.

You might already have had medicine to help your HAE. Different people need medicine for HAE at different times.

And you might have different medicine to other people in your family with HAE. Some people with HAE do not need medicine at all.

If you do need medicine, there are different times you may need it.

Going to the hospital for medicine

If you have an emergency type of swelling (remember the “head, neck or tummy” rule) you need to speak to an adult about going to hospital right away. It is very important that the swelling in these places goes down as soon as possible. You will need a medicine for this.

The medicine will be given by an injection, probably on your inside elbow or the back of your hand. There are more doctors and nurses at the hospital to help you get your medicine quickly. They will follow the instructions in your emergency management plan.



Medicine at other times

If you have a swelling in another place on your body, it is less important that it goes down fast. This means you may not have to go to hospital to get medicine. Instead, you might be given some medicine you can take at home. The doctors from the hospital will show an adult who takes care of you how to give you this medicine.

Some children take medicine every day that helps them to have less swelling. This medicine might be a tablet or an injection.

Some people do not like injections. But lots of children have them and get used to it after a little while.

Injections happen on the inside of the elbow or the hand.

These might seem funny places to put a medicine, but they help the medicine get to the right place in your body quickly.



Getting ready to see your doctor or nurse

Your doctor or nurse is there to help you. So if you are worried about something, you can tell them. They may have some ideas to help!

Your doctor and nurse can also answer questions you have.

Can you think of any questions you have?

For example:

- How do I know if I need to go to hospital?
- How often will I get a swelling?
- Can I play my favourite sport?



My School

You spend lots of time at school. Your school day does not need to be different from anyone else's. But it is important that your school knows about HAE and how to help you.

Who needs to know about HAE?

Your parents might have spoken to your teacher about HAE. This is so your teacher understands HAE and they can help you if you need them to.



Who else needs to know?

Think about the different people at school. Would it be good for them to know?

People I spend time with at school	They know about HAE
For example: - The school nurse - My after-school club leader	✓ ✓

Your friends at school

It might be helpful for some of your close friends to know about HAE. Think about which of your friends you would like to know.

You might want to show this book to them to help them understand HAE.

Talking to teachers

Your teachers should know about your 'triggers'. These are the things that can make you swell up.

They might be able to help you manage some of these triggers.

You might be at school when you feel you are about to have a swelling. Just like at home, it is important you tell an adult right away.

Your teachers should also know when you need medicine.

An emergency at school

Your school should know about your emergency management plan. This means they know just what to do if you need help.

Tell an adult right away if you feel you are about to have a swelling. They can tell your parents.

Having HAE is just part of being you.

Maybe some of your friends want to know about your HAE.

Try showing this book to them to explain HAE and what it means for you.



Parents' notes

This booklet was created for children who have been diagnosed with HAE. If you already have people in your family with HAE, you may know how it feels to have lots of questions about the condition.

Here, we have tried to answer some of those with some age-appropriate guidance, along with some activities.

We hope you find this booklet useful. You may wish to read it with your child and help out with some of the activities.

There are some other materials to help you as a parent, including:

- A template guide that your immunologist can complete, for you to provide to your child's school
- A template hospital emergency department letter (ED letter) that your immunologist can complete, for you to share with medical professionals in the case of a serious attack
- A symptoms tracker to record your child's symptoms – once completed, you can share this with your healthcare professionals

Speak to your child's immunology team about the additional resources available.

Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at:

www.mhra.gov.uk/yellowcard

By reporting side effects, you can help provide more information on the safety of this medicine.

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