

00:00:00:00 00:00:00:08  
Carl MBI

00:00:14:16 00:00:16:17  
Hi, my name's Carl.

00:00:16:21 00:00:21:09  
I'm in Year One  
and I've got haemophilia.

00:00:21:13 00:00:28:11  
When I wake up  
Mum comes in.

00:00:28:15 00:00:33:00  
Then I get up and say  
good morning to everybody.

00:00:33:04 00:00:36:04  
Then I have my breakfast.

00:00:37:07 00:00:40:15  
Once the kids are busy  
with their breakfast -

00:00:40:19 00:00:45:10  
- I begin to mix the medicine so that  
when Carl has finished eating -

00:00:45:14 00:00:47:17  
- his medicine is ready.

00:00:47:21 00:00:52:06  
Mum gives me my medicine  
through a port.

00:00:52:10 00:00:56:02  
Vigga, do you  
want to help today?

00:00:56:06 00:00:57:22  
Yes, Vigga in the morning.

00:00:58:01 00:01:02:05  
She used to be jealous of  
Carl's medicine.

00:01:02:09 00:01:05:00  
But now she's found  
a role for herself -

00:01:05:04 00:01:08:20  
- in that special space  
Carl and I had to ourselves.

00:01:18:14 00:01:23:06  
He spent most of  
his first 18 months in hospital.

00:01:23:10 00:01:27:20  
As a baby he used to bump his head  
on the floor and get huge lumps.

00:01:27:24 00:01:32:21  
We kept going into hospital  
to see if there'd been another bleed.

00:01:33:00 00:01:37:18  
As a toddler he kept falling over  
and had lots of injuries.

00:01:37:22 00:01:41:04  
So again we were constantly  
going into hospital.

00:01:42:11 00:01:45:10  
Then it's time for school.

00:01:47:03 00:01:50:01  
The biggest challenge  
is the time it takes.

00:01:50:05 00:01:54:09  
You have to be ready  
if school phones -

00:01:54:13 00:01:58:09  
- to ask us to come over  
because he's had a tumble.

00:02:01:08 00:02:05:09  
Who was on the go-karts with you?  
Were you having a race?

00:02:05:13 00:02:09:09  
- I was on my own.  
- Why did you crash?

00:02:09:13 00:02:11:16  
I tipped over on a corner.

00:02:11:20 00:02:14:22  
- Because you were going too fast?  
- Yes.

00:02:15:20 00:02:21:20  
My little boy has haemophilia A and  
he's complaining about a new pain.

00:02:21:24 00:02:24:16  
So I had to go to hospital.

00:02:26:11 00:02:30:20  
The best person at  
telling I've got a bleed is me.

00:02:30:24 00:02:36:14  
We tell him "You know your body best.  
If you say hospital, that's where we go".

00:02:36:18 00:02:41:11  
He's good at taking  
responsibility for his body.

00:02:42:01 00:02:46:15  
It doesn't hurt when you bend it  
but when it straightens again.

00:02:50:19 00:02:53:13  
In hospital they scan me.

00:02:53:17 00:02:59:18  
The scan shows what my body looks  
like. Fluid shows up as pitch black.

00:02:59:22 00:03:01:18  
And it means there's a bleed.

00:03:01:22 00:03:06:13  
The more hospital visits, the more  
it affects the whole family.

00:03:06:17 00:03:12:10  
It affects me and my time and Carl  
and the way he sees himself.

00:03:12:14 00:03:16:19  
Is it hard to have haemophilia  
or is it cool?

00:03:18:06 00:03:23:02  
Seven-year-olds also begin to think  
about things in a different way.

00:03:23:06 00:03:27:14  
At some point he won't want me along  
when he goes into hospital.

00:03:27:18 00:03:32:24  
That will be another normal step  
in him gaining his independence.

00:03:34:01 00:03:37:20  
"Villads wanted a look, too."

00:03:37:24 00:03:40:19  
To me it also means a lot  
that Carl and Vigga -

00:03:40:23 00:03:42:19  
- have a special relationship -

00:03:42:23 00:03:47:24  
- when they grow up and

me and Allan are no longer around.

00:03:48:03 00:03:52:11

So it's extra important for them  
to care for one another.

00:03:55:06 00:03:57:11

Night night, darling, sleep tight!