

# NEW THINGS AT MAX'S HOUSE

**A Story About Huntington's Disease**

By Ailie Finlay, Grant Walker and Kirsten Walker



Scottish Huntington's Association Youth Service has developed this booklet to support you in talking with children about Huntington's disease. Max's story is designed to be read out loud and introduces the name 'Huntington's disease', along with some of the changes caused by the mood, mind and movement symptoms. We hope it will offer the opportunity for you and the children to talk about what is happening.

We would encourage you to use the booklet frequently; it isn't intended to be a one-off conversation. You can read it over several nights, or you can come back to different pages and characters. Try to keep the conversation about Huntington's disease natural and continuous. Allow your child to ask questions, pause and interrupt the story, and to go back to different pages.

We have included some 'Questions to ask' boxes which may help you chat in more depth about Huntington's disease with your child. We encourage you to personalise these questions so they relate to your family circumstances (for example, your extended family). You may also want to chat about some of the changes happening in your family.

We hope you enjoy reading about Max and his family.



# NEW THINGS AT MAX'S HOUSE

## A Story About Huntington's Disease

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I'm Max. Can you spot me on my bike?

Our house is the last one in the street. I live there with my mum, my dad and our cat.

My dad has Huntington's disease. We call it HD. HD is changing my dad's brain.

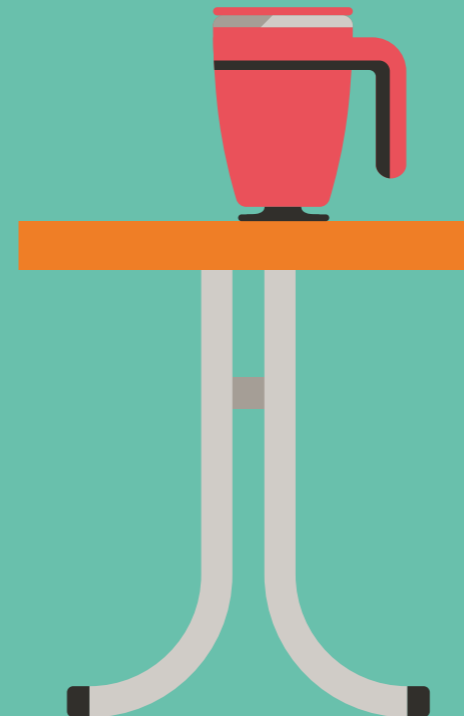
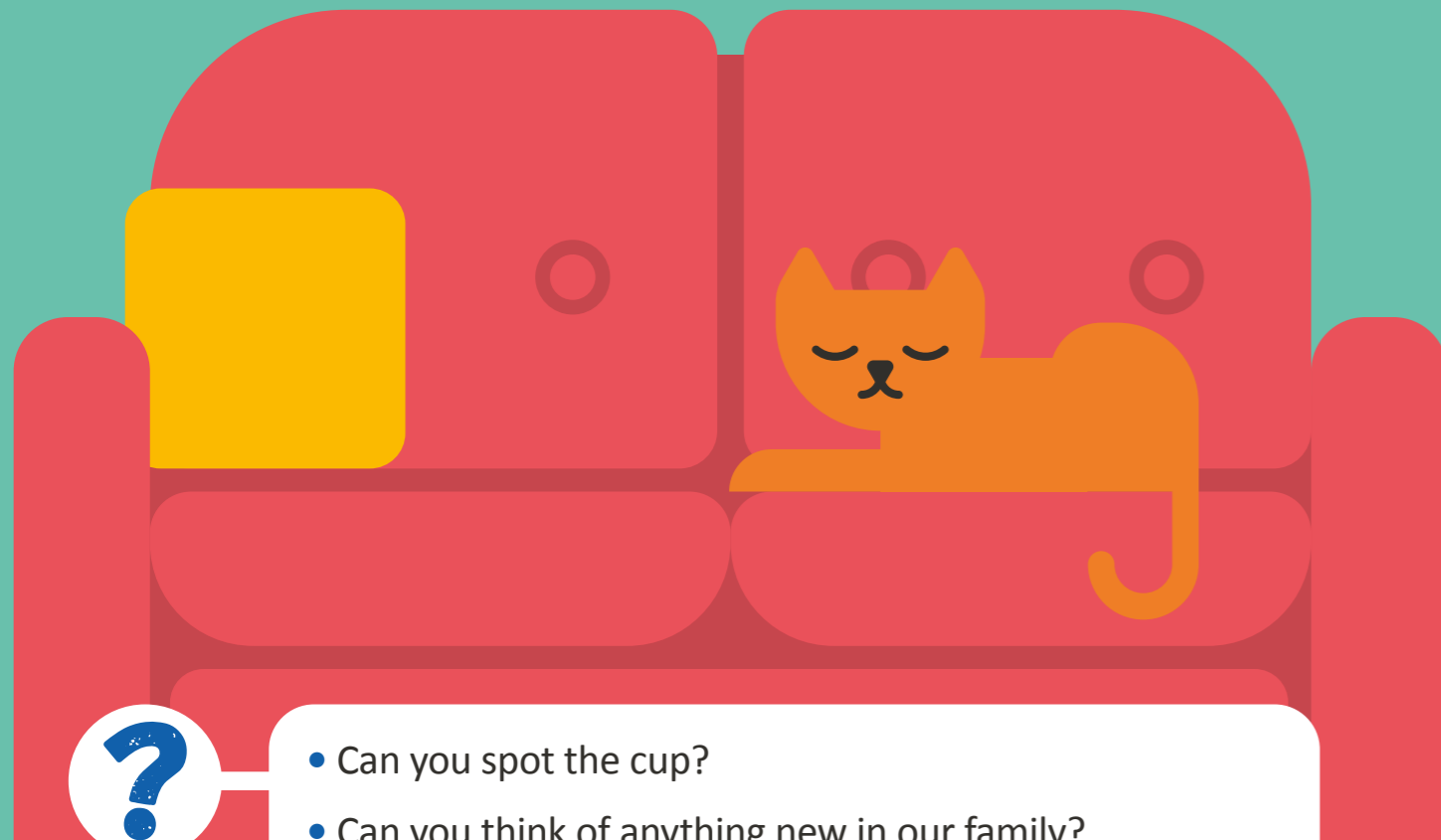
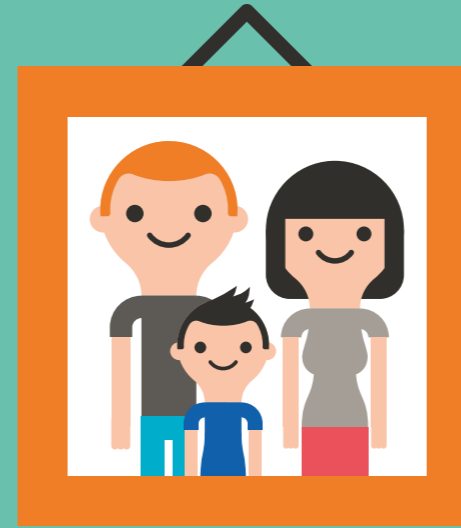


- Does anyone in our family have Huntington's disease?
- What do you know about Huntington's disease?
- What do we call Huntington's disease in our house?

My dad has a new cup. It is big and red and doesn't tip over easily.

Huntington's disease has changed the way my dad moves. Sometimes Dad drops things or knocks them over because his brain isn't working properly. And his legs and arms move when he doesn't want them to.

It's good that his new cup doesn't tip over easily.



- Can you spot the cup?
- Can you think of anything new in our family?
- Have you noticed anything about Mum/Dad/Grandparent?

## WEDNESDAY

Doctors 10am

Shopping

Bank 2pm

Wheelchair Assessment

Mum working 8-12

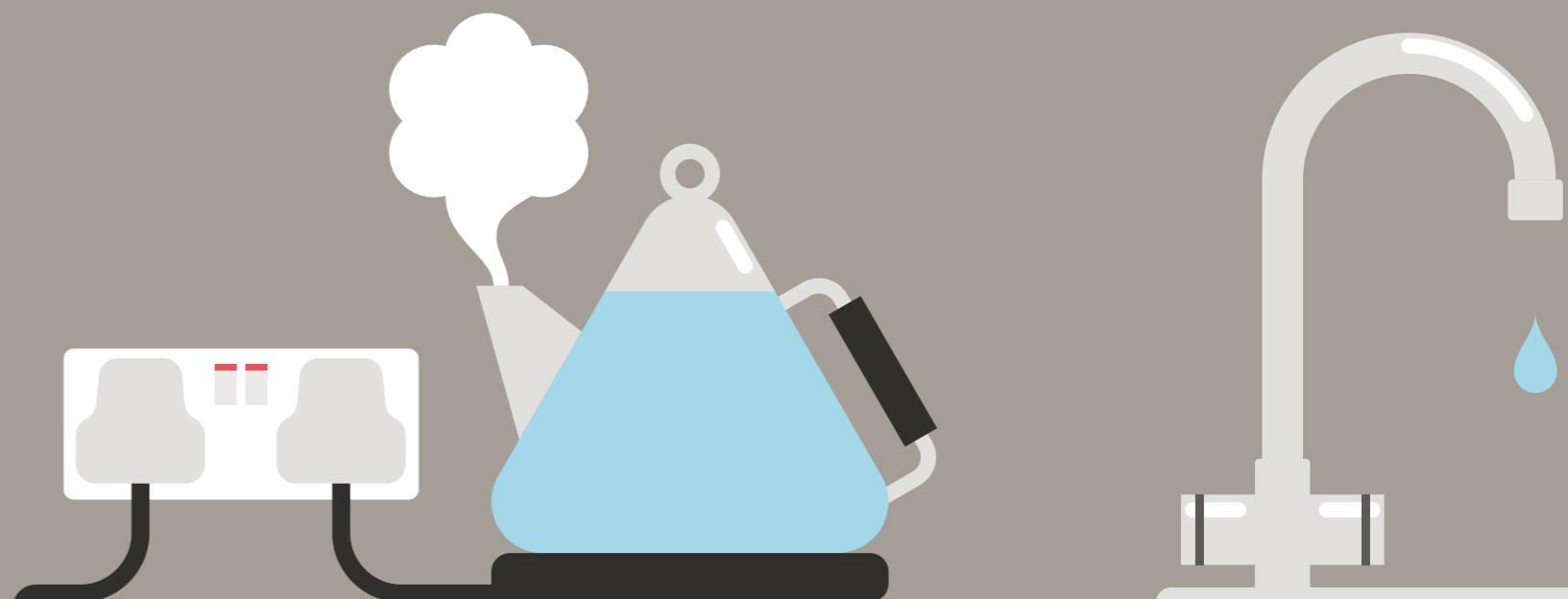
MAX'S  
BIRTHDAY!

MAX

My dad has a new blackboard as well. It is a little one that sticks to the fridge.

We write things on the blackboard to help Dad remember them. When it was my birthday I wrote 'Max's birthday!' in great big red letters!

Huntington's disease makes Dad forget things. The blackboard helps to remind him.



- Can you spot the blackboard?
- Is there anything new in our house that helps Mum/Dad/Grandparent?

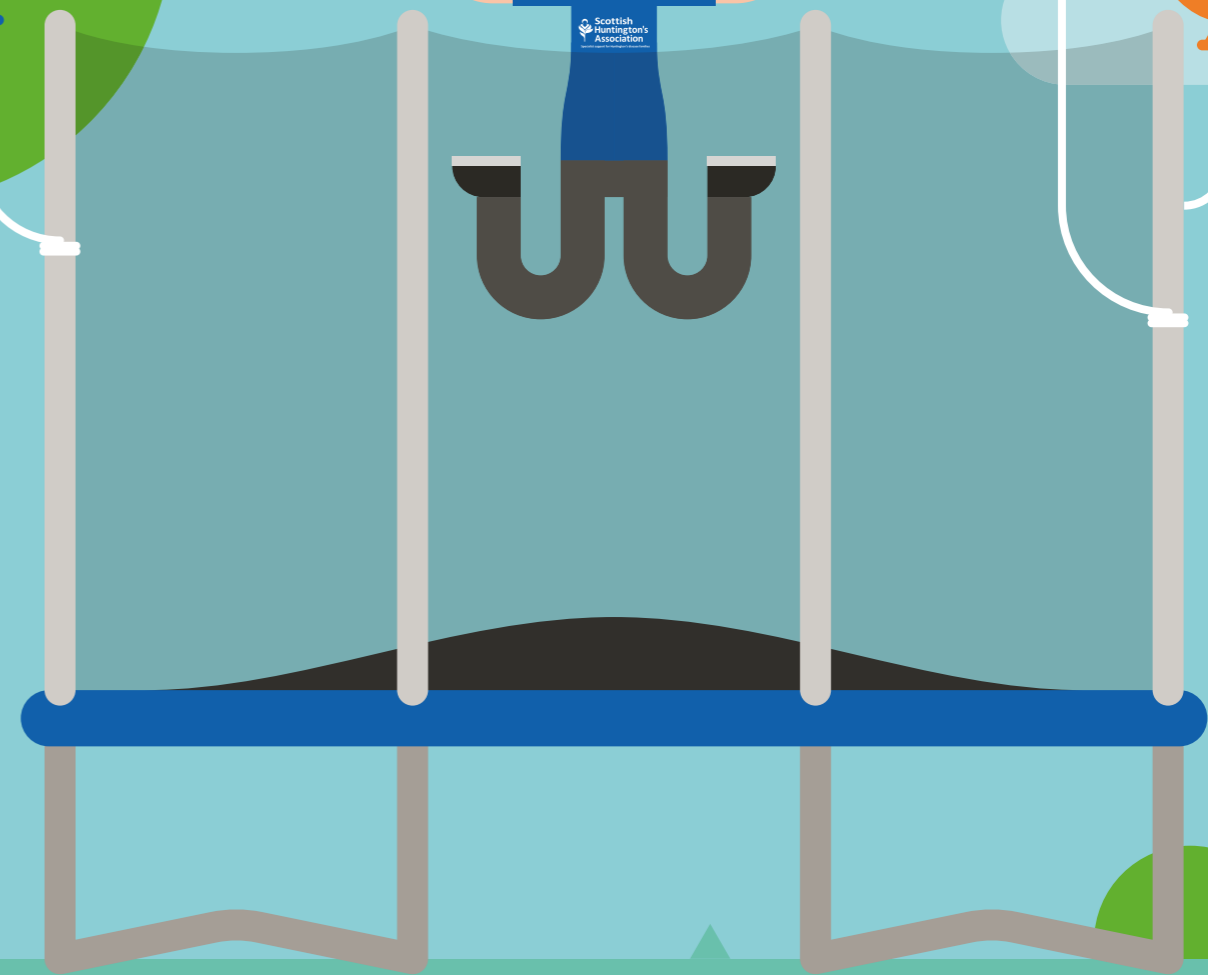
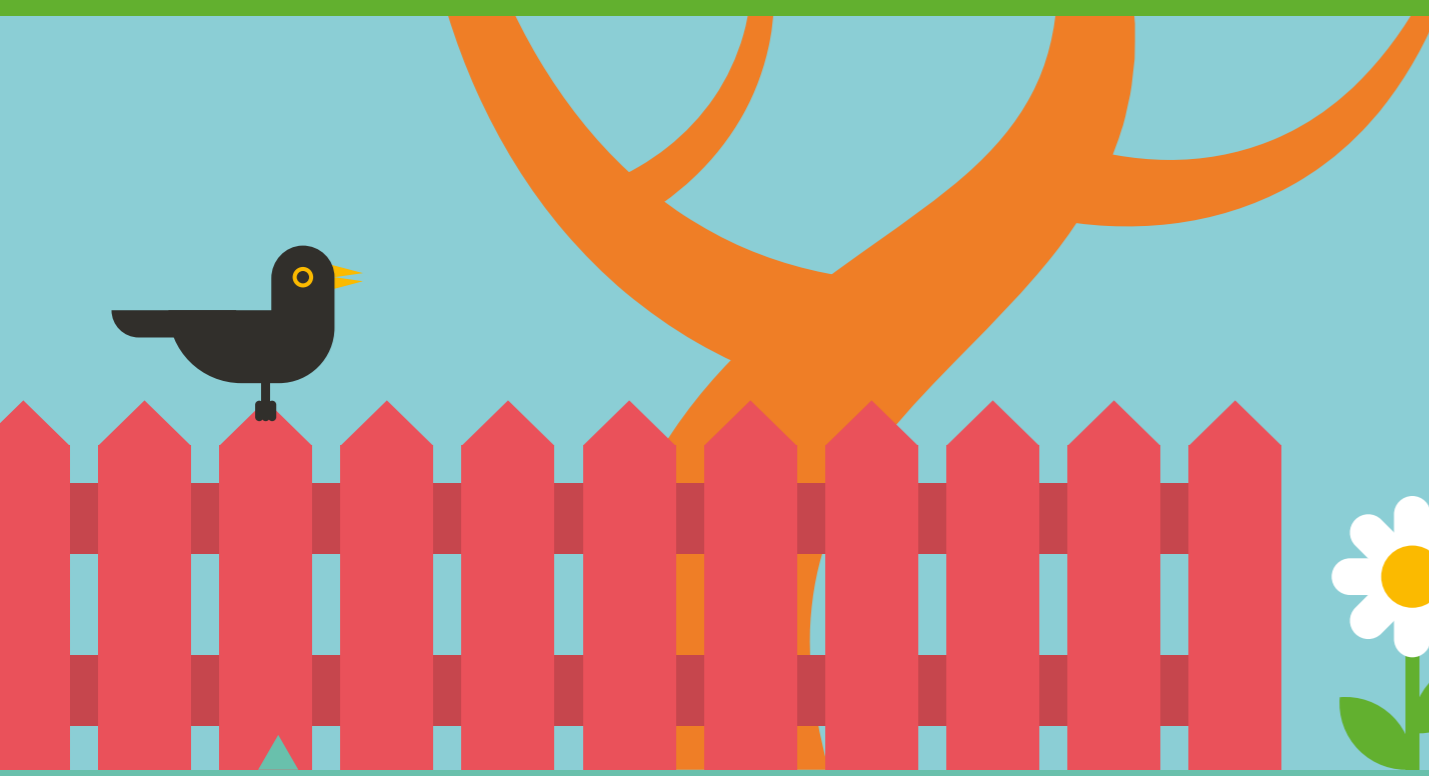
I have a new trampoline. I got it for my birthday. I like to jump very high. I like to jump when I am happy and I like to jump when I am sad.

Sometimes I feel sad if my dad gets cross. I know it's not his fault. HD can make him bad-tempered. I know it's not my fault either. Sometimes he gets cross even if I haven't done anything wrong.

If Dad is in a bad mood it's best if I just leave him alone. I go in the garden and jump on my trampoline. Then I feel better.



- What do you like to do when you are sad or upset?
- Who do you think you could go and talk with when you are sad or upset?



My grandad has a new biscuit tin. He keeps my Jammie Dodgers in it.

I go for my tea at my grandad's when Mum is working, and we always have Jammie Dodgers afterwards!



My gran has Huntington's disease too. Grandad mashes up all her food because she can't chew so well. She can't eat Jammie Dodgers any more, but she still loves the custard grandad gives her.

Grandad says he knows a lot about HD and I can ask him anything I want.

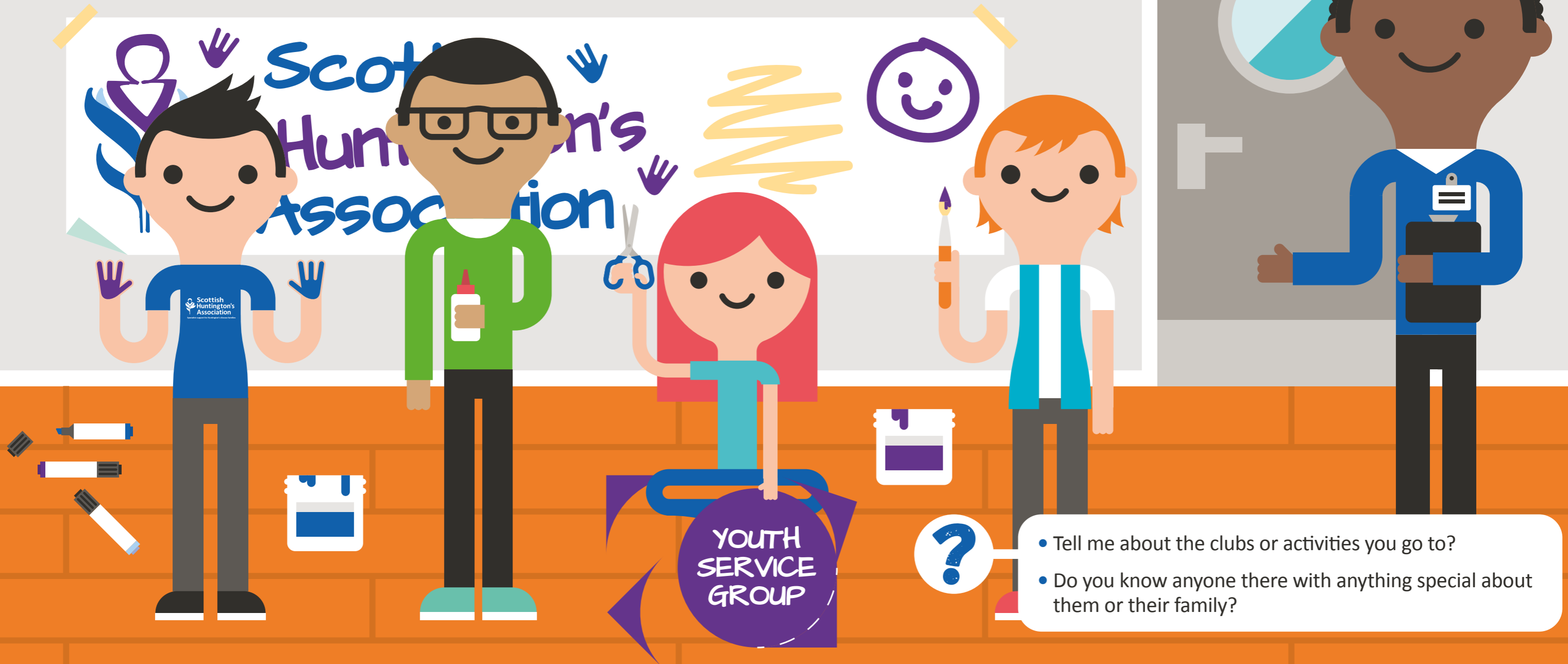


• Is there anything you'd like to ask *me* about HD?

I have a new group I go to. It's the Scottish Huntington's Association Youth Service group.

The group is on in the school holidays. I started going after my birthday. Everyone in the group has somebody with Huntington's disease in their family. We learn about HD and do fun activities.

I've made three new friends at the group: Jack and Evie and Ben.





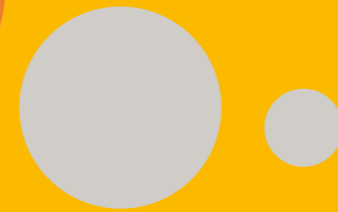


Jack told me that his uncle has Huntington's disease.

Jack's uncle has a special chair now. His legs and arms were moving so much that he couldn't sit in an ordinary chair any more.

This chair leans back and has a bit that lifts up your legs. The chair keeps people with HD safe and it's really comfy too.

Jack says that when he has a shot in the chair it feels like being a king on a throne!



- What do you think about the chair?
- Do you think it looks like a throne?
- Is there anything else that you think might help Jack's uncle?

Evie told me her mum has Huntington's disease.

Sometimes Evie's mum won't let her watch her favourite programmes on TV. Evie is sad about this.

I tell Evie about my trampoline and how it cheers me up when I feel sad.

Evie and I ask if our Scottish Huntington's Association Youth Service group can go to a trampoline centre so we can all bounce together! The answer is yes!



- What else could Evie do to feel better?
- Who would you like to tell about HD?





- What do you know about care homes?
- Do you know of anyone who lives in a care home?
- Do you know any magic tricks?

Ben told me that his grandad has HD.

Ben's grandad lives in a care home now. Sometimes he doesn't want to get up and stays in bed all day.

Ben doesn't like to see his grandad lying in bed so much, but he is glad that the carers in the home look after him so well.

Ben says some of the carers in the home are very funny. One of the carers taught him a magic trick! Ben showed me the magic trick. It's great to have new friends at the Scottish Huntington's Association Youth Service group!



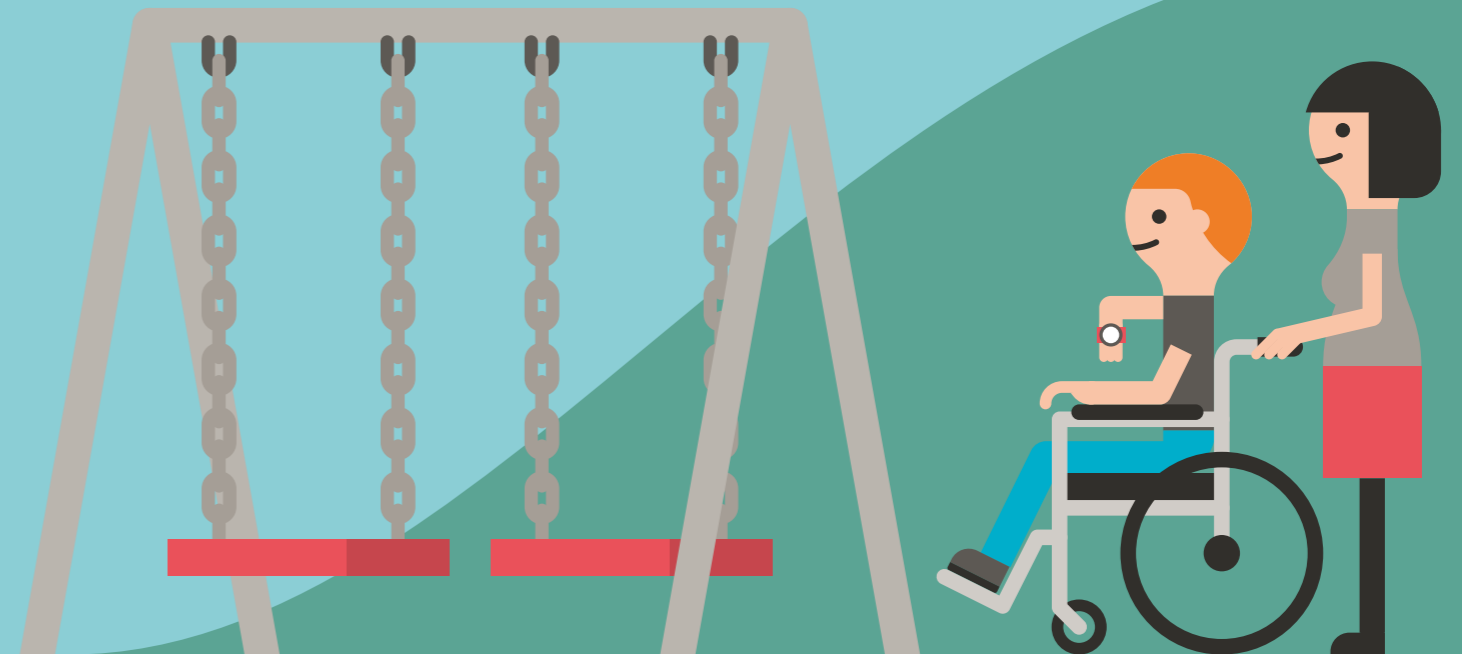
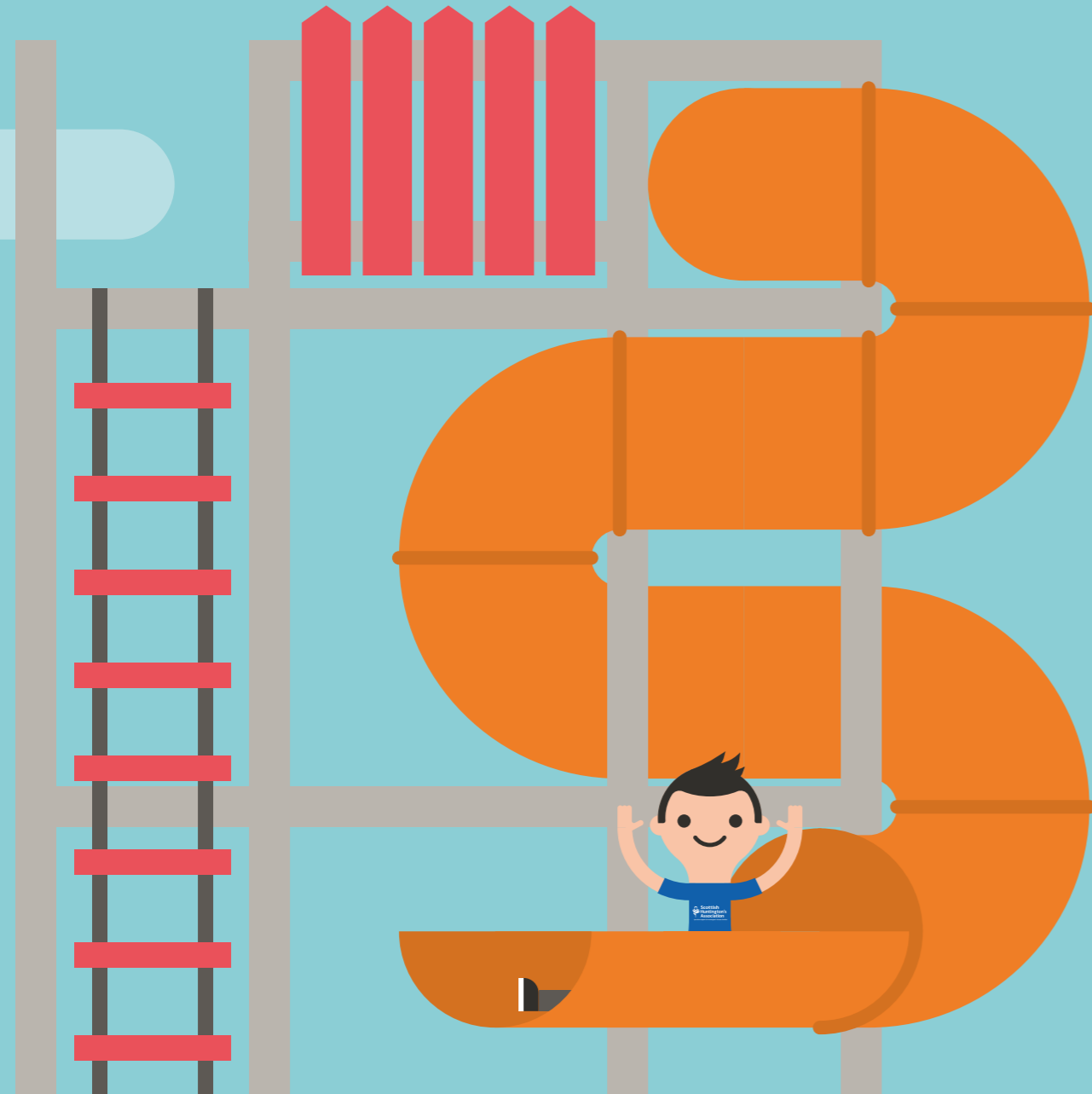
My dad and I have a new game. We play it at the park. Dad starts counting and I see how often I can run up and slide down the curly slide before he reaches thirty.

On the way home I help to push Dad's wheelchair up the hill. When we get to the top Dad always says he can see my muscles bulging!

My dad is the best person to go to the park with!



- What do you enjoy doing with Mum/Dad/Grandparent?
- Is there anything else you would like to do with them?



Use this space to draw or write things that are important to you and your family.



# SPOT THE DIFFERENCE



Can you spot the ten differences in the pictures?

Answers: Mug, Custard, Table, Chair, Playing Card, Family Photo, Remembering Birthday, TV Programme, Hand-Print, Trampoline

# WHAT DOES YOUR SCOTTISH HUNTINGTON'S ASSOCIATION YOUTH SERVICE OFFER?



Our Specialist Youth Advisors work across Scotland



Support for young people, parents and professionals



Support



Group sessions



Activity days



Residential breaks



5-day summer camp



Scottish Huntington's Association

Specialist support for Huntington's disease families

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