Aash

Aash is fictional but not unlike children we know who have SMA Type 2. He uses a Wizzybug to get around and does not have regular breathing support. This is what Aash and his parents might tell a school about him and how his SMA affects his health.

What's happening for me now?

- I go to my childminder for one day every week.
- She knows all about the help I need. It's just like being at home. My Mum and Dad have been talking to my childminder about how to get extra support and care when I start school.
- I can tell you more about the help I need but I'd like you to know more about me first.

Some of the people who are important to me

- My Mum and Dad, my big sister Baljeet and my little sister Meena
- My Grandmother, my Aunty, Uncle and Cousins
- Nathan, my physiotherapist

Things I like doing

- I use my Wizzybug to get around. I'm very good at driving it all by myself
- I am good at counting and colours and painting
- I know lots of words
- My voice is quite quiet, but I like singing
- I like playing with my farm animals and tractors.

Things I like doing when I have help

- Baking with my cousins is my favourite thing
- I'm good at choosing food when we go shopping
- Making castles in the sandpit
- Stretches and exercises with Nathan
- Doing jigsaw puzzles with my sister.

The help I get now

- I go to my childminder for one day every week. She knows all about the help I need and it's just like being at home. My Mum and Dad have been talking to my childminder and are finding out about getting an assessment for me to get extra support and care when I start school.

My movement and mobility

- With SMA, your muscles don't receive strong signals from the brain. This makes some muscles weaker and some movement more difficult.

Sitting

- At home and at my childminder's I have a special chair. It helps me sit as upright and comfortably as I can. It has a tray so that I can play or eat. It has straps to keep me upright and safe. I have to wear my spinal brace for most of the time when I'm sitting.

Standing

- Standing is really hard for me. I can't do it on my own. I have to use my standing frame. Nathan, my physiotherapist, says it's good for me to do some standing every day. Sometimes I paint while I'm standing. My parents and Nathan know how to help me stand. They can talk to you about when and how I can stand safely when I go to school.

Walking and mobility

- I can't walk so I really like using my Wizzybug to get around by myself. I don't like having to ask people for things all the time. My Wizzybug means I can get to places and things independently. I'm a really good driver because I have been using it since I was 2 years old.
- When I go to my cousins, my Aunty has to push me round in my supportive chair. There's really not enough space at her house to use my Wizzybug. But I don't like this as much. Sometimes I sit on the floor with lots of cushions to support me so that I can play with my cousins. I can do this for up to half an hour.

Transfers

- I need help to move to and from my seat to the floor or into my Wizzybug. I'm very light so everyone who helps me has been trained to lift me safely. I don't need a hoist to be moved now, but when I get heavier I will.

Other important things about my mobility

- If I sit for too long in the same position I can get very uncomfortable. Then I will need help to move. If you ask me I can tell you how I want to move or change position. I always need to have my spinal brace fitted properly and to be as straight as I can.
- When I get bigger, I will need a small powerchair to get around.
- Nathan and my Occupational Therapist (OT) helped my parents sort out the equipment I need at home and the training for my helpers. I hope they will be able to do this with school too.

My arms and hands

- ## Arm strength and reach

My arms are not very strong. I can't lift my hands above my head. I can only reach forward a little way. I can pick up light things if they are close enough and not too big – or too small! I can show you some of the farm animals and tractors I can play with myself. I like it when my cousins pick something up that I have dropped without me having to ask.

- ### Writing and drawing

I'm good at painting and I want to learn to write. I draw and paint my best when I'm sitting in my supportive chair and the paper and everything is ready on my tray. I like using felt tip pens best to draw. Mum and dad can show you the sort of pen gripper that helps me most.

- ### Fine motor skills

I like playing games like snakes and ladders with my cousins who help me. Like that I can play even if the pieces are too small for me to pick up. And I like doing jigsaw puzzles even though I can't always pick up the pieces or fix them together easily. Baljeet and me take it in turns to choose a piece and I tell her where to try it out.

- ### Other important things about my upper body strength

When I first went to my childminder, I was shy about asking for help. Now I know her better and I like that she doesn't do everything for me straightaway. She encourages me to ask her when I need help with something.

My bones and joints

SMA weakens the muscles which support the spine and other bones.

- ### My Spine

The weak muscles in my back mean that my spine has started to curve. So, most of the time when I'm sitting or standing, I have to wear my spinal brace to support me. It can get a bit hot and uncomfortable sometimes. My mum and dad and childminder know when it's ok to give me a bit of a rest from it.

- ### My legs, feet and ankles

Sometimes I have to wear AFOs (Ankle Foot Orthoses). These help to keep my feet and ankles in the right position when I'm sitting or standing. I can't put them on or take them off by myself. Mum, dad and my childminder have all been trained to help me.

- ### Stretching and flexing

Nathan has shown mum and dad and my childminder how to help me do stretches and flexes. I need to do them every day, to stop my joints from getting stiff. I don't mind doing them, especially if I can listen to a story at the same time.

- ### Other important things about my bones and joints

Nathan is the one who knows most about the physiotherapy and exercise I need and when.

Eating, drinking and nutrition

SMA can affect the muscles that are used for swallowing.

- ### Eating

Because my swallow muscles are weak, I need to have soft foods. It takes me longer to eat. My sisters always finish before me, but I don't mind.

- ### Drinking

I like to use my own cup with the handles. I can manage it by myself if it's half full or less. I can use a straw if I forget my cup but it's not as easy for me.

- ### Care and routine

I always have an adult watching me carefully whenever I eat or drink, even if it's only a snack. I need help cutting up my food, but I like someone to ask me if it's an ok size.

I like using my blue fork and spoon myself. If I get tired I sometimes need a bit of help with the last bits.

- ### Other important things about eating and drinking

My childminder and my Aunty always tell my mum what’s going to be for dinner. This is so that she can check I will be able to chew it enough. My favourite is pasta.

Other things during the day

- ### Getting changed

I like going outside in my Wizzybug when I can, but I can get cold. I need someone to help me put my coat, hat and gloves on and off and to get changed.

- ### Toilet time

I can tell you when I need the toilet. I can drive there in my Wizzybug. At home and at my childminder’s I have a special supportive toilet seat. I have to be lifted on and held on by someone who has been properly trained. They have to be careful because of my spine. I need a step to rest my feet on.

Sometimes it’s easier for me to pee into a bottle.

I need help with wiping and with washing my hands.

My childminder has a big bathroom with a changing table that folds down from the wall. We sometimes need to use it. When I get bigger and heavier I will have to use a hoist.

- ### Energy and fatigue

I get more tired in the afternoons and sometimes I need to have a rest. If I can lie down in a quiet place for an hour, that helps.

- ### Other important things during the day

I don’t usually have any problem with my breathing. But if I get a cold it can turn into a chest infection. So I have to be careful and I might need to stay home. Sometimes I will have to go to hospital or clinic for check-ups and appointments, but my mum and dad can tell you when they are.

My SMA treatment and medicines

I have a drug called Spinraza to treat my SMA. It is injected into my spinal fluid 3 times a year. A doctor at a specialist hospital does this. I might need a couple of days off school for this procedure.

- ### My medicines

I have one Vitamin D tablet every day with my lunch.

If I get a mild cold, I might need some Calpol while I am at school.

• Equipment I will need at school

Everyone who needs to help me will have training.

Equipment	How it helps me	Extra information
My blue fork and spoon	They are light and easy for me to grip. They help me stab and lift my food to my mouth.	I still need someone to help me cut my food and watch when I'm eating in case food goes down the wrong way.
Supportive chair	My chair can go up or down – so I can sit in it for carpet time on the lowest setting.	I can tell you the best angle for the tray when I'm doing different activities.
Toilet seat	The back and arms support me and help me feel safe.	I still need someone to lift me on and off and to make sure I don't slip.
Standing frame	It holds me in safely while I stand for up to half an hour every day.	Nathan can tell you about the sort of activities I can do when I'm standing.
Wizzybug	I love my Wizzybug, please allow me to use it whenever possible	If I use it outside, the ground has to be pretty flat and smooth

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