Evelyn

Evelyn is fictional but not unlike children we know who have SMA Type 1. She has more complex health needs, including the need for regular breathing support. This is what Evelyn and her parents might tell a school about her and how her SMA affects her health.

What's happening for me now?

I go to specialist nursery 3 days a week – I love going. I have extra support, so when I'm there, I always have one of my helpers with me and join in with everything. Mum and Dad and the people who know me well are updating my support plan so I will get the same sort of extra help when I start mainstream school.

I can tell you more about the help I need when I'm at nursery, but I'd like you to know more about me first.

Some of the people who are important to me

- My Mum and Dad, and my big brother Wil who plays with me.
- My support team who help me at home and nursery.
- My Granny and Grandad.
- My dog Rusty – he thinks he is a person!

Things I like doing myself:

- I love playing games on my tablet and watching YouTube videos.
- I use my Wizzybug to get around. I'm very good at driving it all by myself.
- I am good at counting and can already count to 10.
- Drawing pictures and some letters.

- I love talking and I know lots of words, but people sometimes find it hard to understand me. Once people know me they get better at understanding what I am saying.
- I like people to talk to me not my helper.
- I am good at remembering stories and telling them back.
- I love anything to do with dinosaurs.
- Music with a good beat.
- Choosing things on my iPad.
- Cracking eggs!

Things I like doing when I have help

- Cooking
- Building with Lego
- Swimming
- Physio exercises
- Playing with a soft ball

Other important things to know about me

- When I am at nursery, I like to be treated just like the other children are treated when they do things well or do things that aren't safe or sensible.
- I like people asking me and my helper how things can be changed a little bit to make sure I am included.
- I get scared when there is a thunderstorm
- I'm really looking forward to starting school next year – joining in, learning and playing with everyone else and making new friends.

The help I get now

I go to specialist nursery 3 days a week – I love going. I have extra support, so when I am there, I always have one of my helpers with me. I join in with everything. Mum and

Dad and the people who know me well are updating my support plan. This is so that I get the same sort of extra help when I start mainstream school.

All my family and helpers at home and nursery know what to do when I need extra help. I call them my support team. I nearly always have one of them with me. They have all been trained how to use any machines I need and how to move me safely if I need lifting. Any new people on my team get trained too. I always have one of them with me. Mum and Dad, my support team, my doctors and nursery all agree I will need help like this when I am at school.

I would like to tell you more about the help I have now and why. Then you can talk to Mum and Dad about how this could work at your school.

My movement and mobility

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

- **Sitting**

If I am on the floor, I can stay sitting without help if I have good support for my back.

At nursery I like to sit in the same sort of chair as the other children. But I need someone watching me closely and sometimes holding me steady. I do have a special chair with an adjustable table for playing. It has straps to keep me upright and safe. I have to wear my spinal brace when I'm sitting up.

- **Standing**

Standing is really hard for me. I can stand up for up to 5 minutes if I have something suitable to hold on to. But I must not be left to stand by myself. I must wear my spinal brace when I am standing. My helpers all know how to help me stand safely. I practise standing in my physio sessions.

- ### Walking and mobility

I can't walk but I can get around really well in my Wizzybug. I have been using it since just before I was 2 years old. I am very good at driving it and very careful when other people are around. If it's really not possible for me to use my Wizzybug, I can be pushed around in my supportive chair. But I much prefer being independent using my Wizzybug.

Nursery has been really good at letting me do that. At nursery the other children know I don't like them to touch my Wizzybug.

- ### Transfers

When I need to move between seats, if I have help, I can stand. I am still quite light so at the moment I can be lifted into different seats or on to the floor. I don't need a hoist to be moved now, but when I get heavier I will.

- ### Other important things about my mobility

My helpers always ask me if I am comfortable. This is especially when I have just transferred to a new seat or piece of equipment. I always need my bum right at the back of the seat and my spinal brace fitted correctly.

When I get bigger, I will need a small powerchair to get around.

My Occupational Therapist (OT) helped the nursery sort out the equipment I needed there. I hope they will be able to do this with school too.

My arms and hands

- ### Arm strength and reach

I can lift my hands above my head and reach out. I can lift light things. Nursery always makes sure they give me toys that are a good weight and size for me. Then I can manage them on my own. I really like that as I can feel really upset if I can't manage something.

I can support my weight with my hands in a ‘crawling’ position for a short time, but because my neck muscles are very weak, I find it really hard to hold my head up. Mum says it’s because my brain is so big and heavy!

- ### Writing and drawing

I can grip a thick crayon or paintbrush really well. I find it harder to hold a pencil because it needs more pressure, and my arm and hand muscles aren’t very strong. A pencil grip can help. We experiment a lot at home and nursery to see what works best.

I love drawing and painting and find this easiest when I am sitting in my supportive chair with the straps done up and the tray tilted.

- ### Fine motor skills

It’s difficult for me to pick up small things like Lego pieces or to join them together. I know exactly what I want to do with them and can tell my helper what pieces to choose and what help I want.

I can do most craft activities, but I may need help with some of the fiddlier things.

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

I can catch a very light soft ball, but I’m not strong enough to throw it very far. I like joining in with other children. Nursery has been really good at finding ways to make sure I can join in with any games.

My bones and joints

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

- ### My spine

I have a slight curve in my spine because of my weak muscles. This is why I wear a spinal brace. It helps me stay supported when I am sitting or standing. Sometimes, I get pain in my back so my helper takes my brace off. I mustn’t sit upright without it for very long. If I can't be sitting up, I like to lie on a beanbag or roll around on the floor if possible. After a short break of up to an hour I am usually fine to have my brace back on and sit again.

My legs, feet and ankles

I wear AFOs (Ankle Foot Orthoses) to keep my feet and ankles in the right position. Usually that's OK but it's fine for my helper to take them off if I say they are uncomfortable.

Stretching and flexing

My joints are fairly flexible, but I can't easily move them by myself. To make sure my arm, leg, hip and ankle joints don't get stiff I need my helper to stretch them out at some point during the day. I have a daily stretching and flexing programme to follow. I usually do this at home, but it is okay to miss it very occasionally.

Other important things about my bones and joints

My physiotherapist comes into nursery for some sessions and to train my helpers. It would be good if that could happen at school sometimes.

Breathing

With SMA, breathing muscles can be weak.

Keeping my nose and mouth clear

At home we call it spit and snot!

I can't swallow well because of my weak swallow muscles. That means I can't swallow the secretions in my mouth. I can tell my helper if I need to spit them out. If there is a lot, I might need my helper to use my suction machine to get them out. Sometimes I like to help do this.

Occasionally I need my helper to use a suction down my nose with a long suction tube. If I need that regularly then my helper rings home.

- **Coughing**

At home I have a cough assist machine which helps me make a big cough. We use it in the morning and at night. Sometimes I need it during the day if I have a cold.

- **Help to take bigger breaths**

I have a mask that sits over my nose to help my breathing. It is attached to a non-invasive ventilator (called a BiPAP) machine. I use this overnight and if I get tired during the day. I bring this to nursery just in case I feel I need it.

When I am on my BiPAP, to stop the air escaping out of my mouth I sometimes like a dummy as this helps. Nursery told the other children why in case they thought I was being a baby.

- **Other important things about my breathing**

If I have a bad cold I will always stay at home.

Eating, drinking and nutrition

SMA can affect the muscles that are used for swallowing.

- **Eating**

Because my swallow muscles are weak, I get all my food through a tube into my stomach (called a PEG). My helper sorts this out for me using a feed pump. We are going to start trying to give me some pureed food to try to swallow, but we will only do that at home.

- **Drinking**

My helper gives me water through my PEG and manages everything to do with any machines I use.

- ### Care and routine

I have my food at lunchtime at the same time as other children. My helper is always with me when my food pump is running. I don't have to be sitting right up, but I shouldn't be lying completely flat. It usualy takes about half an hour. I like to watch a tablet or read a book while it's going as it feels like quite a long time. I don't mind watching other children having their food, but I usually prefer to be in a quiet space to have mine.

- ### Other important things about eating and drinking

It's safer not to give me anything to swallow outside of home. That includes drinks. If there is a special day, like Christmas dinner day, I would probably like to have my food sitting with all the other children. It's always best to ask me where I prefer to be and how I am doing when I am having my food.

Communication

SMA can affect the muscles needed for speech.

- ### Speaking

My SMA means my face muscles aren't very strong. That and my secretions mean my speech isn't very clear or very loud. But I love talking and knows lots of words. As people get to know me, they begin to understand me more.

I always want people to talk to me directly, not to my helper. But if they don't understand I don't mind them asking my helper what I have been saying. Nursery has been very good at making sure I have opportunities to talk with other children and to 'show and tell' in a bigger group. I have really enjoyed that, and it's made me feel more confident.

Listening

I like listening to stories. I am usually good at following instructions. Sometimes if I stop listening it could be because I feel anxious. A bit of quiet encouragement usually sorts that.

Communication support and technology

I am really good on my iPad. It might be a good way to record my work when I get to school.

Other things during the day

Getting changed

I need a helper to take my coat on and off and to get changed. But I need to stretch up to do as much as I can myself.

Toilet time

With all the extra things I have to manage, starting to use the toilet has had to wait until now. So, I still use nappies. I have to be changed carefully because of my spine. There needs to be a safe space for me to be changed. That means safe for me and my helper, so they don't get a bad back. At nursery, my OT helped find a changing table where the height can go up and down.

I am beginning to ask to use the toilet and expect I will do that more when I get to school. I would want to drive myself there. It will need to be an accessible one and there would need to be a supportive toilet seat. I can stand with support and then be lifted onto the toilet by my helper. They have to wipe me and wash my hands.

When I get bigger and heavier I will have to have a hoist.

Energy and fatigue

I don't get tired at nursery which has surprised Mum and Dad. If I do get tired and need a rest, I will say.

- ### Other important things during the day

I have to sometimes miss nursery because I have to go to the hospital quite a lot for check-ups and treatment.

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 am at school with a mild cold, I might need some Calpol to keep the symptoms at bay.

Equipment I will need at school

Equipment	How it helps me	Extra information
Food Pump	I have all my food through the pump. The milk is prescribed by my doctor.	
Cough Assist	The cough assist gives me a big breath through the mask. It then pulls the air out of my lungs, bringing any secretions with it. My carer then suctions it out.	You can only help do this if you have been trained by respiratory physiotherapists at my specialist hospital.
Bi-PAP Ventilator	My Bi-PAP machine supports my breaths. I control when I breathe and the machine 'tops up' each breath, further expanding my lungs.	The mask sits on my nose.
Supportive chair	My chair can go up or down. So, I can sit in it for carpet time on the lowest setting.	
Wizzybug	I love my Wizzybug, please allow me to use it whenever possible.	If I don't follow instructions, please warn me. If I still don't listen, turn it off! It can be controlled by an adult!

Version 2 June 2025

SMA UK Information Production Team