

SHARING INFORMATION WITH SCHOOLS ABOUT A CHILD AND THEIR SMA

SOME EXAMPLES



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

These fictional examples show how information could be described for different children who have different levels of need.

'About Me' tells the school about the child more generally, including how their SMA impacts on them. When a child has more complex health needs, this is covered separately and in more detail by **'My Health Story'**:

Examples:

In green:

Liam has SMA Type 3. He is able to walk but gets tired and may need support. The impact of his SMA is explained within 'About Me':

- About Me

In blue:

Aash has SMA Type 2. He uses a Bugzi to get around and does not have regular breathing support needs:

- About Me
- My Health Story

In purple:

Evelyn has SMA Type 1. She has more complex health needs, including regular breathing support needs:

- About Me
- My Health Story

The Blank Templates booklet is for you to complete for your child, and to share with the school.

There is also information about SMA more generally in our sheet: **'5q SMA – Information for Schools'**, that may be helpful.

About Me

(Photo of Liam)

My Name : Liam

My Birthday : 15th May 2018

What's happening for me now:

I go to preschool 3 days a week – I love going.

I sometimes need a bit of extra support, but the teachers and helpers know all about me and how to make sure I can join in with everything and do as much as I can by myself.

Some of the people who are important to me:

My Mum and my big sister Maya who I live with

My Dad who I see sometimes at the weekend

My Granny, Grandad and Nana

Things I like doing:

Playing with my friend Luke

Looking at books and listening to stories

Swimming

Looking after our guinea pigs

Watching Strictly and dancing

Building things with Lego

Drawing pictures of my family

Making people laugh

I know some letters and can read some words

I can count a long way

My SMA:

I have Spinal Muscular Atrophy. You can read more about this in the **Information Sheet**.

My SMA means that:

My legs can get tired which can make running around and keeping up with games hard work.

Sometimes when I start getting tired, I fall over because my legs aren't very strong and then I need help to get up.

I like to sit on the floor with the other children, but I do need someone to help me get up. If I'm sitting on a chair, one with arms is best for me. At preschool I have a frame around the toilet to help me stand up.

I take a medicine at home every day to treat my SMA and have to do physiotherapy exercises at home every day as well.

I don't mind other children knowing about my SMA – my mum and dad can tell you more about what we usually say about it.

Other important things to know about me:

I don't like dogs as one bit me once!

I want to join in with everything at school and do as much as I can by myself.

I'm really looking forward to starting school next year - joining in, learning and playing with everyone else and making new friends.

About Me

(Photo of Aash)

My Name : Aash

My Birthday : 20th June 2019

What's happening for me 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.

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 like looking at books and hearing stories

I use my Bugzi 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

Why I need extra help:

I have Spinal Muscular Atrophy – or SMA for short. You can read more about this in the **Information Sheet**.

With the right support and equipment, I can join in and learn and play with everyone else. There's more about this and the help I need to manage my SMA in My Health Story.

Other important things to know about me:

I like to do as many things as I can for myself, so I use my Bugzi to get around and I'm a very good driver!

I like joining in and doing the same things as my sisters and my cousins. My mum and dad can tell you more about how they help everyone make sure I can join in.

I am quite shy and a bit anxious, but I really want to start school soon. I'm looking forward to making friends and learning and playing with lots more children.

(Photo of Aash)

My Health Story

My Name : Aash

My Birthday : 20th June 2019

I have Spinal Muscular Atrophy - or SMA for short. You can read more about this in the **Information Sheet**, but that's just general. My Health Story tells you how SMA affects me. With the right support and equipment, I can join in and learn and play with everyone else.

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.

I'd like to tell you more about the help I have now and why so 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:

At home and at my childminder's I have a special chair to help 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, and I can't do it on my own. I have to use my standing frame and 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 and can talk to you about when and how I can stand safely when I go to school.

Walking and mobility:

I really like using my Bugzi to get around by myself because I can't walk. I don't like having to ask people for things all the time and Bugzi means I can get to places and things independently. I'm a really good driver because I've 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 as there's really not enough space to use my Bugzi, 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.

My movement and mobility – continued:

Transfers:

I need help to move to and from my seat to the floor or my Bugzi. I'm very light so everyone who helps me has been trained to lift me safely 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:

If I sit for too long in the same position I can get very uncomfortable – then I'll 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 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 and I can only reach forward a little way. I can pick up light things if they're 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. If I drop something, I like it when my cousins pick it up for me 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's ready for me on my tray. I like using felt tip pens best to draw, and 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, 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, but now I know her better and I like that she doesn't do everything for me straightaway but 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 and 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, but my mum and dad and childminder know when it's ok to give me a bit of a rest.

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 so my mum and dad and childminder have all been trained to help me.

Stretching and flexing:

Nathan has shown my mum and dad and my childminder how to help me do the stretches and flexes I need to do 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 and 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 but 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 so that she can check I'll be able to chew it enough. My favourite is pasta.

Other things during the day:

Getting changed:

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

Toilet time:

I can tell you when I need the toilet and drive there in my Bugzi. At home and at my childminder's I have a special supportive toilet seat which I have to be lifted onto 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 and sometimes it's easiest 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 in case we need to use that. 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 lay 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.

Medication:

Treatment for my SMA:

I have a drug called Spinraza which goes 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:

Medication	Frequency	Extra information
Vitamin D	1 Every day	With my lunch

Other important medication things:

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

Equipment I will need at school:

Everyone who needs to help me will have training.

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

About Me

(Photo of Evelyn)

My Name : Evelyn

My Birthday : 10th April 2018

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 Will 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

Why I need extra help:

I have Spinal Muscular Atrophy – or SMA for short. You can read more about this in the **Information Sheet**.

With the right support and equipment, I can join in and learn and play with everyone else. There's more about this and the help I need to manage my SMA in My Health Story.

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.

(Photo of Evelyn)

My Health Story

My Name : Evelyn

My Birthday : 10th April 2018

I have Spinal Muscular Atrophy - or SMA for short. You can read more about this in the **Information Sheet**, but that's just general. My Health Story tells you how SMA affects me. With the right support and equipment, I can join in and learn and play with everyone else.

The help I get 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 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 and 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'd like to tell you more about the help I have now and why so 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've been using it since just before I was 2 years old and 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.

My movement and mobility – continued:

Transfers:

When I need to move between seats, if I have help, I can stand. I'm 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'm comfortable, 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 and 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 so that 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 and nursery have 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 to help 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'm 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 but it is okay to miss it very occasionally. I usually do this at home.

Other important things about my bones and joints:

My physiotherapist comes into nursery for some sessions and to train my helpers so 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:

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 usually 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, which 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'm 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 then 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, and 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 which 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 – 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 so 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 who has 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.

Medication:

Treatment for my SMA:

I have a drug called Spinraza which goes 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:

Medication	Frequency	Extra information
Vitamin D	One every day	At lunchtime with my feed

Other important medication things:

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:

Everyone who needs to help me will have training.

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