

GETTING THE RIGHT SUPPORT AND EDUCATION IN ENGLAND FOR YOUR CHILD WHO HAS SMA

A GUIDE FOR FAMILIES



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

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CHAPTER 1:

WHEN DOES OUR CHILD HAVE TO GO TO SCHOOL?

Most children start school full-time in the September after their fourth birthday. They join the 'reception year' and turn 5 during their first school year (September to August). Learning in reception year is mainly through games and play.

You need to apply for a place for your child in the school year before they turn 5. Your Local Council (also known as your Local Authority) should send you information about how to do this, along with details of all the local primary schools in your area.

There is quite a lot to think about, so you may want to start looking at options before this.

If you think your child will not be ready to start school at the usual time, they can start later – as long as they are in full-time education by the time they reach '**compulsory school age**'.

Compulsory school age is on whichever of these dates comes first after their fifth birthday:

- 31st December
- 31st March
- 31st August

If your child's fifth birthday is on one of those dates, then they reach compulsory school age on that date.

They can start:

- Part time
- Part-way through the year
- In the next school year, in the September after they turn 5

For more information see:

www.gov.uk/schools-admissions/school-starting-age

www.gov.uk/national-curriculum

CHAPTER 2:

WHAT CHOICES DO WE HAVE?

State-Funded Schools

All children in England between the ages of 5 and 16 years are entitled to a free place at a state school. These are funded by their local authority (LA) or local council, or directly from the government.

- **Mainstream Schools**

These provide education for pupils of a wide range of abilities. They may be community schools, foundation schools and voluntary schools, or academies and free schools.

A very small number have a specialist "unit" which may provide extra support for children with physical disabilities.

- **Special schools**

These provide education only for pupils with Special Educational Needs (SEN); this can include physical disability.



OTHER OPTIONS

Independent (or Private) schools

These charge fees and are not Government funded.

Some have places specifically for children who have SEN. Some offer schemes to help pay all or part of the fees.

- **If they are a 'Section 41' Independent Special School**, they have been approved by the Secretary of State as school which a parent or young person can request to be named in an EHCP (Education, Health & Care Plan) – see page 7.

Education Other Than At School (EOTAS)

This is where the local authority provides home tutoring.

Home Education

Sometimes called 'home schooling', this is when parents / carers teach their child at home, either full or part-time.

For more information: www.gov.uk/types-of-school



CHAPTER 3:

HOW DO SCHOOLS PROVIDE ADDITIONAL SUPPORT?

All children need help and support to learn. When teachers plan their lessons, they adapt and include activities and different ways of learning. They aim for every child to progress and achieve as much as they can.

Special Educational Needs and Disability (SEND)

A child is described as having SEND if they have difficulties or a disability that impacts on their learning, and / or their access to learning. This means they need support that is extra to, or different from, other children the same age.

The Special Educational Needs Coordinator (SENCo)

This teacher is responsible for assessing how much and what sort of extra support is needed by any child with SEND in their school. The SENCo then works with other teachers and liaises with parents to make sure the support is put in place and is working.

Who can have one?

Any child or young person with SEND has the right to extra support, whatever their educational setting.

Many, but not all, children who have SMA, need additional support to access learning opportunities. For example, if they need help communicating with other children, or support with physical or personal care such as eating, getting around school safely or getting to the toilet.

If you are not sure whether your child has SEND, and your child has not attended nursery or pre-school, talk to your child's GP or health visitor, or members of your child's specialist team.



How does an SEN Support Plan work?

An SEN Support Plan sets out what outcomes a child is expected to achieve, and what support is being put in place for this. The Plan should be based on an individual assessment of the child by the school's SENCo (**see page 4**). Parents should be fully involved in discussions.

Any child who can be supported by an SEN Support Plan has a legal right to attend a mainstream school – if this is what the family wants. Most children with SEN go to mainstream school.

The school should regularly check how well the Plan is working and make changes if necessary. They should meet with the parents at least three times a year to review progress and what the next targets will be.

This should be in addition to the usual parents' evening meetings. The child's views should be included in both the discussions and Plan. The school should provide a progress report at least once a year.

If needed, the school can ask specialist support services (such as educational psychology or speech and language therapy) to carry out assessments and provide further advice and support. There may be a waiting list.

Schools may, or may not, be able to seek extra SEN funding from their local authority.

Independent schools, where parents pay fees, are not legally required to identify SEN or provide SEN support in the same way as a state-funded school.

Who can have one?

A child whose health, education or social care needs cannot be met by the resources that a typical mainstream school (or nursery) would be able to provide through an SEN Plan.

Many, but not all, children who have SMA, need a lot of support at home and when out and about. They may need therapies from external specialists, or specialist equipment beyond what a mainstream school can provide. They may need an EHCP to support this.

If you think your child is going to need a lot of support at school to ensure they can access learning opportunities and at the same time ensure they are safe and healthy, talk to your child's early years worker (e.g. portage / nursery SENCo, if they have one), GP or health visitor, or members of your child's specialist team.

How does a child get one?

Parents / carers and / or the child's education provider can make a written application to their local authority for an EHCP assessment. This can be at any stage during a child's education, including when they are at preschool or nursery.

What happens next with an EHCP?

If the local authority agrees to assess a child, information is gathered from the people who know and support them. This is summarised in the assessment which will say if the local authority will issue an EHCP.

If the local authority has agreed, an EHCP is drafted. If they do not agree, parents can appeal.

This information sheet published by the charity Contact tells you more:

tinyurl.com/3utxjfj7

It is important to be as prepared as possible before requesting an EHCP assessment. See page 20 for organisations that provide support and advice about the sort of evidence of additional needs that is helpful, and what to do when.

It should not take more than around 5 months (20 weeks) from assessment to the date the EHCP is issued.

What sort of school can a child with an EHCP go to?

Children who have an EHCP may go to a state-funded mainstream school or special school, an independent school, or be home-schooled.

Suitable schools are considered as part of the process. Parents / carers may say what option they prefer when the plan is being drafted. The final decision about which school will depend on the child's needs, parents'/carers' preferences and the school's admissions criteria.

If the local authority agree to an EHCP for a child, the school is named on the final plan.

How is an EHCP paid for?

An EHCP may or may not be linked with extra funding, depending on the local authority.

This must be agreed between the parents / carers and the health professionals that support any child who has health needs. When a child starts school, this should also include the school nurse or whoever has responsibility for first aid and health.

Whether or not they have an EHCP, many children who have SMA will have health needs that need careful management and monitoring. This may be from early on or develop later.

Your child's school will need to know about the current and possible future impact your child's SMA may have – especially what the signs are that your child needs urgent medical attention and what to do in case of any emergency.

The plan may include, for example:

- who will give any medication
- what to do in an emergency
- any other special arrangements such as:
 - the need for your child to use an accessible toilet
 - assistance with any suctioning or non-invasive ventilation.

It is important that the IHP is shared with, and understood by, all staff and that you make the school aware of any **Emergency Healthcare Plan (EHP)** your child has. An Emergency Healthcare Plan is a written plan of action that any medical team can follow should a child become unwell. If you would like to read more about this, please see the **'Regular and Emergency Care'** tab on this page of our website: smauk.org.uk/1ews



Continuing Care (CC)

Continuing Care is a way of funding healthcare packages for babies, children and young people (from birth to 18 years old) with complex healthcare needs whose needs cannot be met by existing mainstream or specialist health services. This is free and not means tested. Some children who have SMA may already receive this support at home.

There will be a review to discuss whether this support can continue at school. If it is agreed, usually, the nurses who provide this care would come from the same agency the family are already working with. This will mean that either the child's current nurses would cover the extra hours, or others would be recruited by the same agency.

Personal Emergency Evacuation Plan (PEEP)

There must be an individual PEEP in place for every pupil who has mobility difficulties. It must describe their needs and how they will be kept safe and evacuated from any building where they will be – for example, if there was a fire in school.

Reasonable Adjustments

If you choose a state-funded school and your child is allocated a place, by law the school will need to make "reasonable adjustments" for your child, including to the building.

"Reasonable" can be interpreted differently. There is no straightforward definition for what this includes, and each school varies.

A young boy with blonde hair, wearing a black baseball cap and a grey t-shirt, is smiling. He has red and white Spider-Man face paint on his face. The background is a blurred outdoor setting with green foliage. There are decorative geometric shapes in blue and pink on the left and right sides of the page.

“

“It is important to ask how willing the school seem to make necessary adaptations. If they seem negative, how important is it to you that your child goes to this school? Will you continue to have battles?”

CHAPTER 4:

WHAT ELSE MUST A SCHOOL DO TO SUPPORT ADDITIONAL NEEDS?

You may want to ask the school to see any of the following reports, policies or plans (or they may be on the school's website):

All children in England between the ages of 5 and 16 years are entitled to a free place at a state school. These are funded by their local authority (LA) or local council, or directly from the government.

Special Educational Needs (SEN) Information Report

All schools must have one of these. It explains things such as:

- The kinds of SEN the school is able to support
- How children's needs are identified and assessed
- What support is offered
- How the curriculum is adapted

Special Educational Needs (SEN) Policy

Every school should also have a policy which says how it supports disabled pupils to be included in school activities. Examples of what this must include are:

- The expertise and training of school staff and how other specialist expertise will be available.
- The support the school provides for improving emotional and social development and what it does to prevent bullying.
- How children with SEN are supported to access activities in the school that are available to pupils without SEN.

Accessibility Plan

This includes information about what the school is doing to make both the environment and the curriculum more accessible for disabled pupils, such as installing lifts or ramps. It may be included within the SEN Information Report.

Medical Needs Policy

All state-funded schools must make arrangements to support children who have medical needs – and say what these are.

Behaviour Policy

All state-maintained schools must publish this on the school's website. It covers how the school encourages good behaviour and what happens if school rules are broken. It must also cover what the school does to prevent bullying.

Academies and Independent Schools must also have a behaviour and anti-bullying policy. There is no legal duty for them to publish it on their school's website, though this is good practice.



CHAPTER 5:

HOW DO WE FIND OUT ABOUT SCHOOLS WHERE WE LIVE?

State-Funded Schools

www.gov.uk/apply-for-primary-school-place

Enter your postcode and you will be taken to your local authority's website. You can search here to see what options you have before you apply.

Independent schools

www.isc.co.uk

For more information, look at each school's website. Have a look at their policies and any admission criteria.

You may also want to look on your local authority's website to find out about your **SEND Local Offer**. This tells you what health, education and social care is available in your area for children and young people up to 25 years old who have a Special Educational Need or Disability (SEND).

To find your local authority's website, go to: www.gov.uk/find-local-council

OFSTED

reports.ofsted.gov.uk

OFSTED (The Office for Standards in Education, Children's Services and Skills) inspects all state-funded schools and about half of independent schools. Any report will be on the school's website.

Look at the date that OFSTED gave their last report and rating as this may be from several years ago. The school may have changed since then.

"Visiting schools and meeting staff can give you a 'feel' for a school that you cannot get in any other way. It's a good idea to start exploring options in plenty of time."

"It can be good to visit during school hours, when children are there and ask to speak to the SENCo."



CHAPTER 6:

WHAT DO PARENTS / CARERS SUGGEST WE START TO THINK ABOUT?

Parents / carers who helped us develop this pack came up with this 'checklist':

- Which schools are your children's friends / any siblings going to?
- Which schools link to any early years' settings your child is going to?
- What do local parents say about which schools are good?
- What does OFSTED (see previous page) say about schools in your area, including about their SEND provision?
- Have you a definite preference for mainstream school / mainstream with specialist physical disability provision (where they exist), or special school, or are you looking at all options?

Continues on next page

- How far away from home is OK? Thinking about:
 - your daily routine and commitments (e.g. other children, work?)
 - how long it takes to get your child up and ready
 - how tired they get
 - what travel time is reasonable to add on to their day
 - how they will get there
 - making friends with children who can come and play
- If you have to choose, is a headteacher and SENCo with experience of including disabled children, or a 'can do' attitude more important to you?
- If you get a commitment to making the building accessible, are you confident it will happen, or do you want the certainty of a school where the building is already accessible (e.g. for wheelchair access in toilets, changing areas and classrooms)?
- Is it going to be important for your child to have regular input from a physio, occupational therapist (OT), or speech and language therapist (SALT), and a school that will make this possible?
- If your child needs to use equipment or needs to be lifted, is it important that staff are already trained or that they have a commitment to appropriate training?



CHAPTER 7:

WHAT DO PARENTS / CARERS SUGGEST WE LOOK FOR WHEN WE VISIT SCHOOLS?

Parents / carers who helped us develop this pack came up with this 'checklist':

- Does the school already have (or has it had) children with similar access needs to your child?
- How good is physical access? e.g. for wheelchair access in toilets, changing areas and classrooms
- How many children would be in the reception class? How do new children get settled in?
- How much space is there in classrooms and out of doors?
- What happens at break and lunch times? How would they work for your child?
- How would your child access trips or outdoor visits?
- What is the school's attitude, SEN Policy and set up? How do they usually organise support so that your child would be fully included in all the classroom and other possible activities?
- How would the school go about organising and making room for any specialist equipment that your child needs – such as specialist seating, a height adjustable table, a hoist and slings, computer equipment? Ask the SENCo how access to equipment works and whether they will liaise with your child's physio or OT.
- What are the options for your child to get to school? If needed, would the local authority provide transport? What are the eligibility criteria and how would this work?
- What sort of outings, clubs or other activities like music and sports do they offer? Do they have experience of adapting them if needed?
- If your child needs support from a teaching assistant, how does this get set up and how will it work?

If you have already built your child's 'About Me' / 'My Health Story' (see 'Blank Templates to use and share with schools') this could help you to start a conversation about your child's needs, the support they will need and how this would work.



“Look out for open days when the school is ‘on show’ but it is also possible to request a quieter visit and, for example, ask to meet the SENCo and reception teacher.”

CHAPTER 8:

HOW DO WE MAKE A DECISION?

Useful to remember:

All children and young people with SEN are entitled to a mainstream education, if that is what they and their parents / carers want. However, this is not necessarily a right to a particular mainstream school.

For some children, mainstream school may not be the most suitable option and their needs may be better met by education at home or special school **(see page 3)**.

*"We went through all our questions and priorities, especially how welcoming the school was and how they reacted to our child's support needs. Most had no previous experience of SMA, but we looked for the ones who showed a willingness to learn." - **Parent***

*"Whatever it said about inclusivity, it was important for us how staff spoke to our child when we visited." - **Carer***

*"Many primary schools will have experience of working with children who have extra learning, or communication, needs. Physical disability is relatively "low incidence" but look out for a can-do, inclusive attitude from all staff."
- **Professional***

*"I looked at lots of primary schools and accessibility was very poor at most of them. For me, the attitude of staff is the MOST important thing, though. It didn't matter if they have previous experience with disabled pupils but they need to have a can-do attitude and not be afraid of them. They need to see the child as a human and not a problem! They need to be able to think outside the box and ensure inclusion." - **Parent***

Parents / carers who helped us develop this pack thought the answers to these questions were most important:

- Did we feel welcomed by the school?
- How did our child feel about the visit? What did they think?
- How did staff interact with our child? Do we think our child will be happy there?
- Did we see or meet any other children?
- What did we think of the SENCo / Headteacher?
 - Were they interested in us?
 - Did they listen?
 - Did we feel they are experienced or committed to meeting our child's needs?
- Do we feel the teachers and all staff will be inclusive and encourage our child to be as independent as possible?
- Would we feel able to talk to staff about any concerns or issues?
- What did we think of access and the general physical environment?
- Will the travel be OK?



CHAPTER 9:

WHO COULD WE CHAT TO ABOUT OUR OPTIONS?

Depending on their child's needs, parents / carers who helped us develop this pack told us who they talked to and who supported them and their children when preparing for and starting school.

Childminder

Communication and Assistive Technology team

Community Nurse

Community Physiotherapist

Consultant Neurologist

Continuing Healthcare Nurse

Dietician

Early Years Worker

Health Visitor

GP (General Practitioner)

LA Specialist or Advisory Teacher

Local Paediatrician

Neuromuscular Care Advisor

Occupational Therapist

"OneGene" Family Liaison Nurse

Other parents

Portage Worker

Respiratory Specialist

SMA UK's Support Team

Social Worker

Specialist Nurse

Specialist Physiotherapist

Speech and Language Therapist (SALT)



CHAPTER 10:

HOW DO WE APPLY FOR A SCHOOL PLACE?

My child has, or will have, an SEN Support Plan

My child does not have SEND.

State-Funded Schools

Children have a general right in law to a place in a mainstream state-funded school. This does not necessarily mean the right to a place at the specific school of your choice.

September – Local Authority Applications Open

This is for children who will start primary school in the following September.

You will need to fill in a single form and name the schools you would like your child to go to in order of preference.

How many schools you can name depends on your local authority (LA). You can apply for schools outside your own LA, but you still use your own LA's form.

If a school you are applying to has its own admissions criteria, you will need to check that your child meets these. You will need to submit any evidence needed when you apply to the LA.

15th January – Local Authority Applications Close

You will need to have applied by 15th January, even if you want your child to start later than the usual time.

Each school you list will let your LA know if they can offer your child a place.

Your LA will look at your preferences and what each school has offered. They will also look at the offers and preferences of all other families.

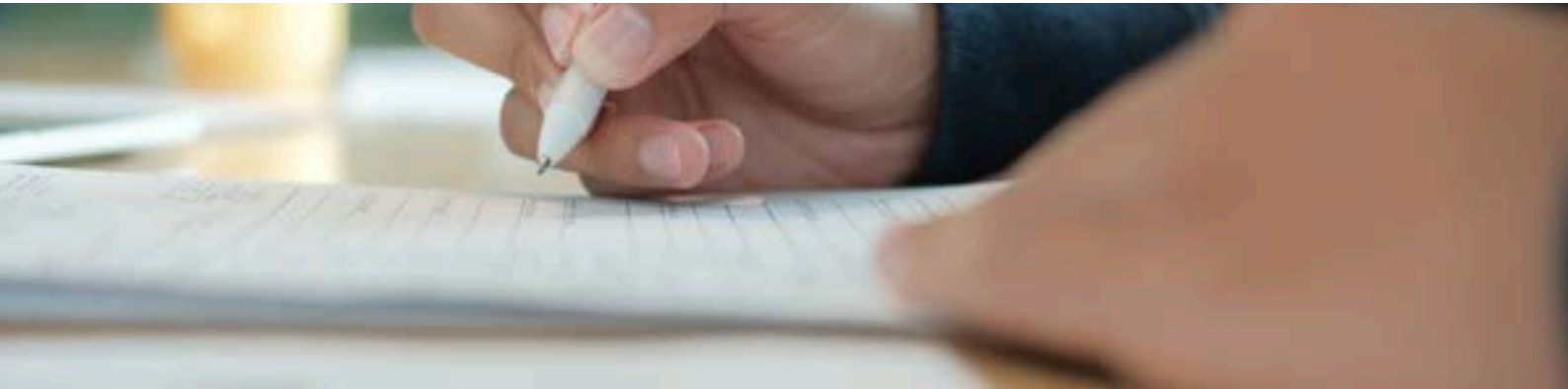
16th April – 'National Primary Offer Day'

You will hear from your LA.

Most families are happy with their offer, but if you are not then act quickly:

- Ask your LA about their appeals process.
- Accept the place while you appeal, so that you are not left without any place.
- You can refuse this place later, once the appeal or waiting lists have come through.
- Get specialist advice – **see page 20.**

You will need to contact the school directly. They will explain their admissions process and what happens next



My child is being assessed for an Education Health and Care Plan (EHCP)

Children have a general right in law to a place in a mainstream state-funded school. This does not necessarily mean the right to a place at the specific school of your choice which must also be agreed by your local authority (LA).

You will be able to state your preference for a school when the plan is being drafted or updated ([see page 6](#)).

A specific school will only be named on the final EHCP if it is agreed by your LA.

If you prefer a mainstream school, the LA can only name a special school against your wishes in very specific circumstances.

It is important to also apply for a school place through the usual application system ([see page 18](#)). This is in case an EHCP is not finally agreed for your child and instead your child will be supported by an SEN Support Plan ([see page 5](#)).

If your child is offered a place through the usual system and an EHCP is later agreed for a different school, your child will be able to move there.

If you need more information or advice, contact the organisations on [page 20](#).

My child already has an EHCP

Some children have EHCPs at nursery or preschool. You will take part in discussions about what is possible as part of the transition to school process.

A specific school should be named on the plan. Your local authority will explain how and when the application will happen, and when you should hear about a decision. The named school must admit your child.

CHAPTER 11:

FOR MORE INFORMATION AND ADVICE

Special Educational Needs & Disabilities Information, Advice & Support (SENDIAS) – sometimes also referred to as IAS

A free, impartial and confidential service, independent from local councils. It is for:

- parents or carers of a child or young person with SEN and / or a disability
- young people up to the age of 25 with SEN and / or a disability.

For your local service, visit: tinyurl.com/3su6nmaf

Contact

The charity for families with disabled children provides detailed information on their website and also has a helpline with advisors:

tinyurl.com/5fn3y5c7

IPSEA

A charity providing detailed information and advice on their website about any educational issue that is a result of a child's SEND. You can also book an individual appointment.

www.ipsea.org.uk

SOS!SEN

A charity with a free, independent and confidential helpline for parents and others looking for information and advice on SEND.

www.sossen.org.uk

Special Needs Jungle

A charity providing independent information, including downloadable flowcharts about the SEND system and EHCPs.

www.specialneedsjungle.com/flow-chart