

GETTING THE RIGHT SUPPORT AND EDUCATION IN NORTHERN IRELAND, SCOTLAND AND WALES FOR YOUR CHILD WHO HAS SMA

A GUIDE FOR FAMILIES



**Spinal
Muscular
Atrophy uk**

SUPPORTING • INFORMING • ADVOCATING

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CHAPTER 1:

WHERE DO WE FIND INFORMATION ABOUT PRIMARY EDUCATION OPTIONS AND HOW SCHOOLS PROVIDE ADDITIONAL SUPPORT?

Northern Ireland

Contact – Charity for Families with Disabled Children, provides detailed information on their website and also have an advice line: tinyurl.com/486cxjfk

SENAC: give information and advice about getting help and support for children with special educational needs SENAC: senac.co.uk

Scotland

Contact – Charity for Families with Disabled Children provides detailed information on their website and also have an advice line: tinyurl.com/43fysmbf

Enquire is the Scottish advice service for additional support for learning: enquire.org.uk

Wales

Contact – Charity for Families with Disabled Children provides detailed information on their website and also have an advice line: tinyurl.com/2k9ppxex

SNAP Cymru provides information, advice and support to parents, children and young people (0-25), who have, or may have, special educational needs or disabilities: www.snapcymru.org



CHAPTER 2:

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 do your country's inspection bodies say about schools in your area? (Education Scotland; Estyn Wales; Education & Training Inspectorate Northern Ireland)
- 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?

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- 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 other key staff 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 3:

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, policies for supporting disabled children 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 (such as specialist seating, a height adjustable table, a hoist and slings, computer equipment) that your child needs? Ask the staff member who leads on support for disabled children 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 reception teacher and any other key staff.”

CHAPTER 4:

HOW DO WE MAKE A DECISION?

Useful to remember:

All children and young people with additional educational needs 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.

*"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 staff member who leads on support for disabled children / 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 5:

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)

Local Authority 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)

