

Who's Who of Professionals

You can also read this guide on our website at smauk.org.uk/kivg where you can follow all the links we give to further information.

Who this is for

This guide is for adults, teenagers and parents of children who have SMA. It lists, in alphabetical order, the different professionals and teams you might meet over time. It gives a brief description of what they do. You will not necessarily need to see all of them.

Your Team

If you or your child has had a diagnosis of Spinal Muscular Atrophy (SMA), you / your child should receive care and support from a multidisciplinary healthcare team. Over time you are likely to come into contact with a number of different health, education and social care professionals. Who you actually see and what services can be provided will depend on your individual circumstances. If you have any queries about who you or your child should be seeing then please speak to your medical team.

Roles within a team may overlap. For example, a task or assessment may be performed by either a nurse, physio or doctor. Roles may also vary between centres; for example, a clinical nurse specialist in one centre may carry out different tasks to a nurse in another centre.

Children's Community Nurse

Children's community nurses provide specialist nursing care, advice and support for children living at home who have long-term conditions or life-limiting illnesses. They are part of children's community teams.

Children's Palliative Care Services

Palliative care is an active approach to care that supports physical, emotional and practical needs in order to achieve the best quality of life. This includes the provision of short breaks / respite care. Children's palliative care teams provide care for children with life-limiting conditions in hospitals, hospices and at home. Palliative care teams employ a number of different health and social care professionals, including specialist nurses, support workers and play therapists. (See also **Palliative Care Team** below.)

Clinical Academic

In some specialist medical centres linked with universities, doctors are employed by both the university and the National Health Service (NHS). This means they can see patients as part of their medical practice and also undertake scientific and medical research. You will always be asked for your permission to be part of any research they are doing.

Clinical Geneticist

Clinical geneticists are doctors with an additional qualification in genetics – which is the study of how characteristics are passed on from generation to generation by means of genes. If you have had a genetic test, a clinical geneticist will be able to discuss the results with you. They can help you to understand how the condition is passed on in your family. They can talk to you about the chances of future children or other family members having the condition, or their risk of carrying the affected gene. They can also discuss what steps you may wish to think about if considering a future pregnancy.

Clinical Trials Co-ordinator

Clinical trials test new treatments or ways of managing a condition. A clinical trials co-ordinator has the role of making sure the trials run smoothly. This person is often the first point of contact for people who want to find out more about a particular trial.

Consultant

A consultant is a senior doctor who has completed training in a specific area of medicine and is employed as a specialist in that area. You may see a number of different consultants covering different specialties, for example a neurologist, a consultant physiotherapist, a respiratory consultant. Who you see will depend on your or your child's needs.

Counsellor

A counsellor is someone who has been trained to listen to, talk with, and support people who are facing difficult times in their lives. This can cover a number of different areas, such as if a couple's relationship is not going well, help with adjusting to living with a disability, or how to deal with grief and bereavement after someone has died. Counsellors may specialise – for example there are relationship counsellors and bereavement counsellors.

Dietitian

A dietitian is an expert in human nutrition. They can advise on a suitable diet when a person has a medical condition or illness. If eating by mouth is not possible, they can advise on alternative options.

District Nurse

A district nurse visits people in their home to provide nursing care. They may also carry out assessments for nursing equipment, for example specialist mattresses and beds.

General Practitioner (GP)

General Practitioners are family doctors who deal with people's day-to-day medical care. They can refer their patients to clinics, hospitals and specialists. Most people go to their GP first when they have a health issue. For SMA-related issues, people will

usually see their consultant. However, it is the GP's responsibility to action any follow-up care, particularly with prescriptions and making sure these are kept up to date.

Genetic / Genomic Counsellor

Genetic / genomic counsellors are not counsellors who provide a listening and talking therapy for people affected by a particular issue such as grief, bereavement or depression. Instead they are trained to give advice and support to families on the issues surrounding having a genetic condition.

Genetic Nurse Specialist

A genetic nurse specialist is a nurse who also has training in genetics. They provide care to people who have been diagnosed with a genetic condition.

Geneticist

Geneticists have made studying genes their speciality. There are two main types of geneticist: scientists and doctors. You are less likely to meet the scientists, who are the people who test your DNA in the genetics lab. The geneticists you are more likely to come across are specialist doctors (clinical geneticists) who see people with a genetic condition. (See clinical geneticist.)

Health Visitor

Health visitors are nurses who also have training and experience in child health. They can help families to access the local services they need. They are usually based at GP surgeries and can provide information and advice on children's health until the age of five.

Junior Doctor

Junior doctors are qualified doctors who are working whilst also doing specialist postgraduate training.

Key Worker / Link Worker

The key / link worker's job is to make sure that all the professionals working with a person keep in regular contact. They make sure that everyone knows who is doing what, so that services and support run smoothly. They can also offer support with the

transition from children's to adult services. They are the main point of contact if you want to know what is happening or want to find out about how to get something done.

Neurologist / Paediatric Neurologist

A neurologist specialises in the diagnosis, treatment and management of the brain and nervous system disorders / neurological conditions. Because SMA affects the nerves, this may be the specialist that you or your child goes to for regular check-ups. Unlike a neurologist (who generally works with adults), a paediatric neurologist works specifically with children who have neurological conditions.

Neuromuscular Care Advisor (NMA) / Neuromuscular Liaison Nurse / Clinical Nurse Specialist

Neuromuscular care advisors, liaison nurses and clinical nurse specialists are attached to NHS neuromuscular clinics in many regions of the UK. They provide support and information to children and adults with neuromuscular conditions (such as SMA) as well as their families. They link up with other professionals and services so that people receive the local health and social support they need.

Occupational Therapist (OT) / Paediatric Occupational Therapist

An occupational therapist works with people who are having difficulty with day-to-day activities. They observe and assess how someone manages, usually in their own home. They can provide equipment such as specialist seating, bathing aids and wheelchairs to make things easier. They can also advise on what changes or adaptations can be made at home. Paediatric OTs work specifically with children.

Orthopaedic Consultant

Orthopaedic consultants are surgeons who specialise in conditions of the bone, joints and soft tissue. At check-ups they look out for any tightening of a person's muscles (contractures). They also look at what is happening with the spine to see if it is curving (scoliosis). The orthopaedic consultant will then advise on what is the best treatment or management for that person.

Orthotist

When someone has a condition that affects their bones, joints or muscles, they may need a fitting that will help them move more easily, stabilise and maintain their current situation (such as posture), or reduce pain. Examples are: supportive footwear, a leg splint or a spinal brace. These fittings are called orthopaedic devices or orthotics. Orthotists work out what fitting a person needs and the fitting is then custom-made especially for them.

Paediatrician / Community Paediatrician

A paediatrician is a doctor who specialises in children's medicine; they monitor the general health and development of children. Paediatricians can also refer children to a particular specialist when needed, for example a respiratory consultant if a child has difficulty with breathing. Community paediatricians are senior doctors who provide services to children in their local community. They work with a child's hospital consultant to provide care locally.

Palliative Care Team

Though palliative care is often associated with end-of-life care, unless needed it is not a focus for these services. They are there to help improve the quality of life of anyone facing a potentially life-threatening condition. This includes physical, emotional and spiritual care. They can also sometimes help with referrals to local hospices and places of support. (See also **Children's Palliative Care Services** above.)

Patient Registry Curator

A patient registry is a database of information about people with a particular condition. The curator is the person in charge of the information in the database. They are responsible for keeping the database up-to-date and for checking the information is accurate.

Physiotherapist / Paediatric Physiotherapist (Physio)

Physiotherapists help people to manage the day-to-day physical effects of their condition. They may be able to prescribe exercises or stretches that will help maintain or improve movement, perhaps reduce pain and generally keep the person as active

as possible. They can help prevent muscle shortening and tightening (contractures) through exercise or passive stretches and they can help to manage a curved spine (scoliosis). They can also advise on the best ways to sit and lie (positioning and seating). Physiotherapists may be at regular check-ups with the consultant, where they will look at what changes there have been since the last visit. Physiotherapists work in both hospital and community settings. Paediatric physiotherapists work specifically with children.

Play Therapist / Play Worker

Play therapists help children communicate their feelings, thoughts and behaviour through play, in order to help them make sense of difficult life experiences and psychological issues. Some play therapists specialise, for example in art or music therapy.

Portage Worker / Home Visitor

A portage worker / home visitor is an educational professional. They provide education and support at home for pre-school children with additional needs. This service is not available in all areas. You can check if there is a service in your area on the [National Portage Association Website](#) or ask your Local Authority.

Principal Investigator (PI)

A principal investigator is the lead doctor in a clinical trial.

Psychologist / Clinical Psychologist

Psychologists study people's behaviour – such as how they think, act, react and interact. Psychologists often specialise. You may meet: educational psychologists who help children with problems that impact on their learning and inclusion at school; occupational psychologists who assist with performance and job satisfaction in the workplace; and counselling / clinical psychologists who help with a wide range of emotional and mental health issues.

Research Nurse

A research nurse is a nurse who sees patients who are taking part in a clinical trial.

Respiratory Consultant

Respiratory consultants specialise in assessing breathing problems and how to manage them. If needed, they can arrange for people to have equipment to help with their breathing and organise a sleep study.

Respiratory Physiotherapist

This type of physiotherapist is different to the physio who prescribes exercises and stretches. A respiratory physio focuses on breathing, lung health and airway clearance. They can teach you techniques that would enable you to help clear secretions (or mucus) from the lungs to help reduce the risk of infection. There are a large range of techniques involved, some may involve using equipment, such as a suction machine or cough assist. The respiratory physiotherapist is normally based in a specialist centre. They will organise regular clinic reviews as well as work alongside the MDT. They will often set up a management programme to help clear secretions.

SENCO (Special Educational Needs Co-ordinator)

A SENCO is a teacher whose job it is to make sure a school knows about any children who have special educational needs and / or disabilities. It is their job to make sure that each child with special needs gets support to enable them to learn and join in with everything going on at the school.

Social Worker

A social worker works with individuals and families to enable them to resolve problems and enhance their wellbeing. They know what social care services there are to support an adult or a child and their family. It is their job to work out what social / community support is needed and see what is possible. They often help people to apply for benefits and services. Social workers usually work for a Local Authority (council) but they can also be employed by a hospital. They work closely with other health and social care professionals and are often part of a multi-disciplinary team.

Speech and Language Therapist (SALT)

Speech and language therapists work with children and adults who have speech and communication difficulties. They also work with children and adults who have eating, drinking and swallowing disorders. They help people to manage their condition.

Study Doctor

A study doctor is a doctor responsible for seeing patients as part of a clinical trial.

Support Groups

Support groups exist for many different conditions and also for common experiences such as single parenting. Support groups aim to complement the services provided by health and social care professionals by providing emotional support and guidance. There are many different types of support group. Some, like SMA UK are national organisations that provide support by phone, email and also face to face through home visits and events. Some are local community based groups and others are based on the internet and social media, providing support through forums and online groups. Your local library and GP surgery may advertise support groups and your social worker may also be able to advise you on appropriate groups. Many groups can be found through an online search.



Version 8

Author: SMA UK Information Production Team

Last review completed: June 2025

Next review due: June 2028

Links last checked: June 2025

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