

Who's who – key professionals you may meet

As a family you will come into contact with a large number of professionals who will be involved in your child's care journey, from health, social care, education and from the statutory and voluntary sector. Their common goal is to provide a service to your child and family that best meets your needs. This directory gives a brief description of what each one does.

Healthcare professionals – community based

Chaplaincy: Chaplaincy services are available in the community as well as in the hospital.

Children's hospices: Provide needs-led support and friendship to all family members including brothers and sisters. This may include short-term breaks (respite care), outreach services and visits to you at home as well as emotional and bereavement support.

Children's palliative care service: You may have a team in your area that provides multi-disciplinary care for children with life-limiting illnesses from the time of diagnosis. This type of service is not available in all areas.

Community children's nurses: Provide nursing and supportive care at home and often act as your child's key worker. They will liaise with other agencies. Some will provide short breaks in your home.

Community paediatrician: A senior children's doctor, usually a consultant working in the community. They work closely with the other doctors and specialists involved with your child, ensuring that your family's needs are managed and supported at a local level.

Dentist: Your child will be entitled to free dental care on the NHS.

Dietician: Will advise you on your child's dietary intake. If your child has difficulty with eating and drinking they can advise on supplements and special nutritious foods.

District nurses: May provide nursing care at home to your child, although they usually nurse adults. They can help with nursing supplies that your child requires.

Family doctor (GP): Provides medical and supportive care. They are able to refer your child to other services that may be needed, and they will also write prescriptions for medications. A list of family doctors will be available from your local primary care trust or from the NHS website.

Health visitors: Provide health education and health promotion advice. They can also provide supportive care to you and your family. Some areas have specialist health visitors who have particular experience and expertise supporting families with very young children with an identified condition or disability, or who need extra help.

Occupational therapists: Work with children using play and other activities to maximise their abilities in all aspects of daily living, including education. They will help and advise you on managing everyday life for your child. They will assess your child for any equipment required such as wheelchairs, bathing aids and adaptations to your child's environment.

Pharmacist (local chemist): Able to supply most of the drugs your child will require. Many families find it helpful to use the same pharmacist who will then become familiar with your child's medication. Many provide a home delivery service, especially for large bulky items.

Physiotherapists: Help and support your child if he or she has difficulties with mobility, movement or breathing, caused by illness or surgery. They will assess your child's needs and abilities, set achievable goals and help you to carry out a physical management programme for your child. They can also provide advice on equipment that may be needed.

School nurse: Every school will have a named school nurse. They provide health promotion and education to school aged children. If your child attends a special school the school may have its own nurse. These nurses are able to give medication and nursing care to your child whilst at school.

Speech and language therapists: They will assess your child's communication ability and advise you on how to offer support. They can also help and advise if your child has difficulty with swallowing.

Healthcare professionals: hospital based

Clinical nurse specialist: These nurses work closely with the specialist paediatrician in providing nursing care and support to your child and family. They are usually based within a hospital, but provide outreach services in your own home. They will have expertise in the type of condition your child has. They work closely with the other community health care professionals.

Consultant paediatrician (local general hospital): This doctor at your local hospital will be a children's doctor but may not have expert knowledge about your child's condition.

Consultant paediatrician (specialist hospital): This will be a children's doctor with an expert knowledge of the type of condition your child has. Depending on to the rarity of your child's condition this specialist may be based a long way from where you live.

Both of these doctors will work very closely with your family doctor and community paediatrician to provide medical services for your child.

Therapists: You may also meet speech and language therapists, physiotherapists and occupational therapists in the hospital. They work closely with their community-based colleagues.

Other services

Adult palliative care service: Most areas of the UK have an adult palliative care service. They can provide advice and support to you and the multi disciplinary team working with you. Your child may transfer to their care when he or she reaches adulthood.

Benefits advisor or welfare rights advisor: Welfare rights advisors work in welfare rights units, Citizens Advice Bureaux and independent advice centres. They can help you claim Disabled Living Allowance (DLA) and other benefits to which you may be entitled.

Child and adolescent mental health team: This team provides psychological and psychiatric services for children and their families. The team includes psychiatrists, psychologists, nurse specialists and social workers. Services for children with learning disabilities are often part of this service.

Independent Parental Supporter (IPS): An Independent Parental Supporter is someone trained by the Parent Partnership Service (PPS) to support parents and help them understand special educational needs and the SEN code of practice. Your local Parent Partnership Service should be able to put you in touch with one, if your local education authority (LEA) is considering issuing a statement of special educational needs. They help by providing information and sometimes by coming with you to meetings.

Key worker/ lead professional/ link worker/ care co-ordinator: A key worker, sometimes known as a lead professional, link worker or care co-ordinator, maintains regular contact with your family and takes responsibility for checking that you have all the information you need, that services are well co-ordinated and that information about your child is shared efficiently with everyone working with your family. Key worker services are not currently available in all areas.

Music therapist: A music therapist uses music and sound to help improve a child/young person's emotional wellbeing, relieve stress and improve confidence. They encourage patients to try different instruments and use their voices to explore sound and communicate through music, to help them express themselves, become aware of their feelings and interact with other people more confidently.

Nursery nurse: A nursery nurse is someone trained in, and able to support, the early stages of child development. They usually work in nurseries and schools. They are not medical nurses.

Parent support groups: These groups can provide invaluable support from other parents who have had similar experiences.

Play specialist: A play specialist helps children to make sense of difficult life experiences through the activity of play. Play is a child's natural way of communicating and with a play specialist they can explore various issues they might find difficult to express in other ways.

Portage home visitor/Portage worker: A portage home visitor, sometimes known as a portage worker, is someone who has received training from the National Portage Association to work with you and your child. Portage home visitors come from a wide range of professional backgrounds and may be teachers, speech and language therapists or occupational therapists, nursery nurses, health visitors, social workers or parents or volunteers with relevant experience.

Social services: Social services staff will carry out an assessment of your child's needs and you as parents are also entitled to a carer's assessment. The role of social services is to provide support for people to live as independently as possible – this may include care within the home, services that give you a break from caring and benefits advice.

Special educational needs co-ordinator (SENCO): A SENCO is a teacher in a school or early years setting who has responsibility for identifying children with special educational needs and making sure they receive appropriate support. This may involve working directly with the child, supporting mainstream staff in assessing a child's needs or a combination of both of these. SENCOs also work with external support services at Early Years Action or Early Years Action Plus.

Voluntary organisations: There are many types of voluntary organisations that provide a wide range of services and opportunities. These may include short breaks, bereavement support or holidays. Some also provide financial assistance in the form of care grants. Some are national organisations and some local, serving a specific community or condition. A member of your child's care team will be able to advise you on what is available for your family.