

Professionals Helping You?



newlife
foundation for disabled children

Action for disabled & terminally ill children in th UK

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What all people need is other people, family and professionals working together on the same side, in the best interests of your child. Professionals may do this through their training or experience, and you, through the special understanding and care you have for your child.

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Getting the most from your GP or Consultant Appointment

If you do not have a Family Doctor, it is worth doing some research. You may prefer to have a Doctor who has a particular interest in children. Local surgeries usually have a leaflet with some details of the Doctor's background, along with details of surgery hours, provision for calls out of normal surgery hours, etc. It may help to talk to surgery receptionists, the local chemist or other people who have children, to help you to make the most appropriate choice for your child's needs.

It is helpful to arrive in plenty of time for the appointment to give you time to gather your thoughts and go over the topics you would like to discuss. This is particularly important if the appointment is with a hospital Consultant because there may be long periods of time between appointments and there may be many things to discuss. If you have to cancel an appointment, try to do it with plenty of notice and make sure another appointment is made.

If the child's illness or condition is of long duration or ongoing, keep a diary of symptoms and/or treatments, with records of how the child is progressing, reactions to medication or problems with treatment.

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Try to find out if there is a family history of the condition (or any condition) prior to going for the appointment. Some things, which may not obviously be related, can give clues to a diagnosis.

Photographs of family members (including the parents) can sometimes also provide clues to a diagnosis. (These points are particularly useful for a genetics consultation).

Plan what points you would like to discuss, and any questions you would like to ask, and write them down – when the problem began, whether the symptoms have improved or got worse, any significant changes in the child's eating, sleeping pattern or behaviour.

If you have seen other Doctors, take their letters with you. Also, take any scan results that you may have, as they are often missing from the notes. Take along the names of other Doctors you have seen and the address of their hospital or surgery, as your present Consultant may need to write to them for results.

In case you have to wait, take along toys or games to keep the child occupied and calm.

If possible, make brief notes of the main points during the consultation or take another person with you so that they can make notes or so that they can confirm what was discussed at another time.

If the Doctor or Consultant uses medical terms you don't understand, ask for the meaning to be explained. If the child's condition is complicated, the Doctor or clinical Nurse may be able to write the main points down or provide you with written information.

If further tests or investigations are necessary, try to find out which hospital department will be carrying them out and, if possible, obtain a contact name and/or telephone number for that department.

Be direct in the questions you wish to ask but try to be friendly and firm, rather than aggressive. In this way, there is co-operation between the Doctor and the parents for the benefit of the child, rather than conflict.

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If you have read about alternative treatments or therapies, ask the Doctor's opinion. Some of these treatments may not have been fully tested or proved to be beneficial, and your Doctor may have some knowledge of these.

Make sure you understand what the child's medication is for and get full instructions about how and when it should be given. Ask about any possible side effects but if you are still unsure, ask your Pharmacist when you collect the prescription.

If you find that you have forgotten something you meant to discuss, ask yourself if it could wait until your next appointment. If it cannot wait, send a note or email to the Doctor (rather than telephoning) so that he or she can answer it more fully when time permits.

If you are unhappy or unsure about the Doctor's diagnosis or treatment, you could try to arrange for a second opinion. Don't be afraid to say how you feel.

P.A.L.S - Patients Advice and Liaison Services

The Patients Association is an organisation which represents patients' rights, influences health policy and campaigns for better patient care. The Patients Association can also offer further support. To contact your local P.A.L.S, telephone NHS Direct on 08456 084455 (10am-4.00pm, Mondays to Fridays) or ask for details at your GP surgery.

Who's Who

Below are a list of professionals you and your child are likely to have contact with. Although they have their own special roles to play in assisting you and your child, they can and often do liaise and work together to make sure all the services open to you are available.

AUDIOLOGIST - Carries out tests and assessments for children or adults, to determine if there is any hearing loss which requires a hearing aid or other treatment. Also provides advice on appropriate aids and equipment. Referral by GP or Consultant.

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ART AND DRAMA THERAPIST - Uses the techniques of art or drama to help people with complex problems to deal with traumatic events or to deal with difficult social situations. Contact via Social Services Department.

BEHAVIOURAL SUPPORT SERVICE - Advises schools on strategies for dealing with individuals or groups presenting with behavioural problems and assists the school to develop good behavioural policies. The aim is to prevent exclusion from school and, where possible, to re-integrate pupils who have been excluded. Contact via child's school.

CASEWORK OFFICER- Supervises the statutory assessment process, to make sure that time limits are observed and the appropriate advice is being sought. Contact via Local Education Department.

CHILD & FAMILY GUIDANCE TEAM - A team of professionals who can help parents to manage emotional, behavioural, social or educational problems. The team usually consists of a Clinical Psychologist, Social Worker, Community Nurse, Speech Therapist, Physiotherapist or Occupational Therapist.

Contact via GP or local Social Services Department.

CHILD AND ADOLESCENT MENTAL HEALTH NURSE - A registered mental health nurse who has received specialist training in child and adolescent mental health and is involved in the assessment and treatment of children with emotional and behavioural problems. Contact via GP, School Psychological Service or Social Services Department.

CHILD PSYCHOTHERAPIST - Offers social, psychological and/or medical treatment to children with complex needs. Contact via Social Services Department, GP or child's school.

CHIROPODIST or PODIATRIST - Provides specialised advice on foot care and treatment for foot problems. Will also advise on specialised footwear needs. Contact direct, via GP or through the Local Health Authority.

CLIC SEARGENT NURSE (Cancer and Leukaemia in Children) - Provides care for children with cancer, leukaemia or other chronic illnesses and support for the family. Contact via Consultant Paediatrician.

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CLINICAL PSYCHOLOGIST - Provides assessment, therapy and treatment for children under stress or who have behavioural or psychological problems. Assists parents to deal with problems such as aggression, antisocial behaviour, self-harm, etc. Contact direct or via GP, Paediatrician or Child Guidance Team.

CLINIC or COMMUNITY PAEDIATRICIAN - Provides assessment of developmental progress and general health needs of children in local clinics, mainstream schools and special schools and community contact through GP or Health Visitor, child development centre.

COMMUNITY CHILDREN'S NURSE is a specially qualified nurse who helps parents and carers provide treatment to children who are sick or disabled.

COMMUNITY NURSE - A nurse who has specialised training in caring for sick children from the ages of 0 to 19, at home and in other settings, to allow early discharge from hospital and or to prevent unnecessary admissions. Offers practical nursing care in partnership with children, parents and carers and provides support for family in liaison with the hospital, GP, Health Visitor and School Nurse. Contact via Hospital Consultant, Ward Sister, GP, School Paediatrician, Health Visitor, School Nurse or Social Worker.

COMMUNITY LEARNING DISABILITY NURSE - Offers specialist advice to people with a learning difficulty, their parents and carers, including help for parents to understand their child's disability. Advice on feeding, incontinence and diet, information on pre-school schemes (such as Portage), advice about medication, introduction to local services and management of behavioural problems. Also assists older people with a learning disability to live as independently as possible, to develop self-help skills, maintain good health, and to manage practical issues such as shopping, dealing with money and coping with emotional problems. Apply direct to Community Learning Disability Team.

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COMMUNITY LEARNING DISABILITY TEAM - A team of specialised professionals, which may include a Community Nurse, Social Worker, Clinical Psychologist, Consultant Paediatrician, Speech Therapist, Physiotherapist and Occupational Therapist. Offers support and guidance to people with learning difficulties and their families and/or carers and will help them to identify and contact relevant services. Apply direct.

COMMUNITY DENTAL OFFICER - Provides dental examination, treatment and advice to people with disabilities who have difficulty in accessing dental care through general dental services because of problems such as restricted mobility or behavioural problems. Apply direct.

COMMUNITY OR PAEDIATRICIAN - A doctor who has a special expertise in children's health, and/ or children with disabilities. A Consultant Community Paediatrician works in the community, rather than a hospital. Referral via GP.

CONNEXIONS SERVICE - Provides guidance and support to young people through their teenage years and into adult life. Responsible for overseeing delivery of the Transition Plan for those pupils with statements, over the age of 9 years. The personal advisor attends the Year 9 annual review and subsequent annual reviews. They help to plan key stage 4 and post-16 options taking into account the wishes and feelings of the young person concerned. Contact via child's school.

CONSULTANT PSYCHIATRIST - A doctor who has been trained to help people who are experiencing emotional problems or severe behavioural disturbances. Contact direct or via GP or Health Visitor.

DAY CARE OFFICER - Offers advice on finding childminders who have particular skills in working with children with special needs, helps to find child care for working parents or those needing respite care and advises on playgroups, nurseries or play schemes. Contact via Social Services Department.

DIETICIAN - A dietitian works as part of the multidisciplinary team and provides nutritional assessment, treatment and education for children with disabilities and their families and carers.

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DISABLED PERSON'S SOCIAL WORKER - Works with young people and adults with disabilities to enable them to have the best possible quality of life. Advises on living independently, training for work or gaining employment and provides general support on all aspects of dealing with everyday life. Contact via Social Services Department.

DISABLEMENT RESETTLEMENT OFFICER - Offers help and advice on job opportunities, training for employment, specialised schemes for people with disabilities. Provides information on sheltered employment and the Disabled Person's Employment Register. Based at the local Job Centre or Employment Service. Contact direct.

EDUCATIONAL PSYCHOLOGIST - Provides help for children of school age who have difficulties in learning, physical disability or emotional/ behavioural problems. Advises and assists teachers in the psychological aspects of child development and how they might deal with behavioural difficulties. Also provides guidance for parents or carers and will assist with the formal assessment of a child's special educational needs if this needs to be carried out. Contact via the child's school or Local Education Department.

EDUCATION OFFICER FOR STATEMENTING - Responsible for setting up the statutory assessment process of the Code of Practice, gathering information and writing a draft statement, in collaboration with parents and teachers. Contact via the child's school or Local Education Department.

EDUCATION WELFARE OFFICER - Provides independent educational counselling for children of school age and their families and helps parents to meet the statutory obligations in relation to attendance at school. By maintaining contact between home, especially where attendance at school is sporadic. Contact via the child's school.

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GENERAL PRACTITIONER - A GP is usually a first point of contact for anybody who wants to discuss their health. A GP can help families with disabled children talk about health problems, prescribe medicine where appropriate and make referrals where necessary. Referrals are where a doctor contacts another specialist and requests an appointment for their patient.

GENETIC COUNSELLOR - A professional who has studied the ways in which diseases or disorders can be passed on from parents to children. May be able to provide more information about causes of a child's disorder or syndrome. Contact via GP or Consultant Paediatrician.

HEALTH VISITOR - A State Registered Nurse who works with families and has a special responsibility to children under 5. Makes home visits and assists parents to cope with normal crises of life. May be able to detect early signs of ill health, abnormal development or social stress. Undertakes developmental assessments of children and gives support to the family. Contact via GP or local Community Health Clinic.

HEARING IMPAIRMENT TEACHER - A teacher with specialised qualifications in teaching children with a hearing impairment. Will also offer advice on aids and equipment and provide support for the child in accessing the curriculum and using a hearing aid. Contact via Local Education Department.

HOME TUITION AND HOSPITAL SCHOOLS - Special schools, maintained by LEAs within general or specialised hospitals, providing short or long-term education for children in hospital. Contact via Local Education Department

HOME TUITION SERVICE - Provision of part-time education for children who are not receiving education in school, from teachers who visit the child's home for between 5-10 hours per week. Contact via Local Education Department.

KEYWORKER - A Keyworker acts as a lead professional in co-ordinating support and service for children and young people with disabilities and / or special educational needs.

MACMILLAN PAEDIATRIC NURSES - Provide support for children with cancer and their parents at home and in hospital.

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NEUROLOGIST - A physician who specialises in disorders affecting the brain and other parts of the nervous system. Contact via GP or Hospital Consultant.

OCCUPATIONAL THERAPIST - Offers services at home, schools, and hospitals to children with disabilities. Advises on equipment aids and adaptations. Offers support to parents in the management of disability, such as the use of wheelchairs and electronic equipment and assists children in a programme of activities to improve everyday ability to perform tasks in play, schoolwork and self-care. Contact via hospital or Social Services Department.

ORTHOTIST - Advises, measures and takes casts to provide braces or appliances to be fitted externally to the body, e.g. leg splints. Contact via child's Consultant.

PALLIATIVE CARE TEAM - The children's palliative care team works to care and support children with life-limiting illnesses and their families. The team consists of a consultant community paediatrician, clinical child psychologist, dedicated social worker, sick children's district nurse, health visitor, school nurse and a senior member of staff from the children's ward. Other professionals can be included onto this team where appropriate, such as a hospice consultant or pain specialist.

PARENT PARTNERSHIP DEVELOPMENT WORKER - Provides independent advice and support to parents and carers of children with special needs, so that they are able to make informed choices about their child's education. Also sets up courses for parents in association with local colleges. Contact via Local Education Department.

PHYSIOTHERAPIST - Assesses child's movement abilities and plans a treatment programme suited to his/her needs. Explains treatment techniques and advises how to carry them out, to continue the treatment at home. Will demonstrate how to carry, handle and assist the child, to stimulate good controlled movement and will advise on equipment such as chairs, wheelchairs and pushchairs. May also recommend hydrotherapy treatment (play and exercise in water). Referral via GP, Consultant or hospital.

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PLAY SPECIALIST - A play specialist prepares and desensitises children who require medical treatment, distraction through a procedure or to help the child understand what they have experienced.

PORTAGE SERVICE - Teams trained to enable parents to teach their own child. Provide a planned approach to give home-based pre-school education for children with developmental delay, disability or other special educational needs. Contact via Health Visitor or National Portage Association.

PRIMARY HEALTHCARE TEAM - Groups of professionals delivering health services in the community. The team includes administrative staff such as receptionists and practice managers and clinical staff such as GPs, nurses, physiotherapists and counsellors.

RESPITE CARER - A person who provides a break to those families who have sick or disabled children and who care for them around the clock.

SCHOOL DOCTOR - A doctor who has had additional training in childhood development and the problems of children with disabilities. Makes regular visits to schools and will look into any medical problems a child may have. Contact via child's school.

SCHOOL NURSE - A School Nurse works in partnership with the school to create an environment that promotes healthy living as well as responding to the needs of individual children.

SPECIAL EDUCATIONAL NEEDS (SEN) PANEL - A team of officers and teachers who meet together to assist the decision-making process concerning formal assessments and the final statement provision. The SEN team will discuss with parents any changes to the draft and if possible take the parents' wishes into consideration. Contact via child's school

SPECIAL EDUCATIONAL NEEDS (SEN) TRIBUNAL - A decision making body, made up of a lawyer and members from the education profession, to arbitrate between

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parents and their local education authority when a dispute has arisen regarding their child's statement of special educational needs. The service offers independent facilities to resolve disagreements but has no role in the decision-making process. Contact via local Education Authority.

SOCIAL WORKER - Professionally trained to help families to cope with times of stress and conflict. Will offer support to parents of children with special needs, information about local services and parent support groups. Contact via Social Services Department.

SPECIAL EDUCATIONAL NEEDS CO-ORDINATOR (SENCO) - Collaborates with heads of departments of faculties to determine the strategic development of special educational need policy of the school. Seeks effective ways of overcoming barriers to learning and sustain effective action through the analysis and assessment of a pupil's needs, monitoring the teaching and standards of pupils' achievements and setting targets for improvement.

Contact via the child's school.

SPEECH & LANGUAGE THERAPIST - Trained to assess and treat a wide range of communication problems, such as stammering, cleft palate, voice problems, delayed or disorders of language development and those caused by head injury, degenerative disease, learning disability or physical disability. Contact via GP, school or clinic, health centre, hospitals or special school.

VISUAL IMPAIRMENT TEACHER - A teacher who is specially trained in the education of visually impaired children from birth to 18 years. Will also advise on appropriate aids and equipment for children with little or no sight. Contact via Local Education Department.



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