

## ***CARERS FACT SHEET 12***

### **Caring for a child with a disability**

Being the parent of a child with special needs can be very difficult and it is important that you take time to find support for yourself and the rest of your family.

In some areas, there are face-to-face schemes, which pair you with someone who has had similar experiences to yours, whom you can talk to and ask for advice. You can obtain details of these from your local Carers Support Worker or Health and Community Care office.

You are the best person to know what your child needs. You should keep in contact with any specialist health services in your area, which can help if their health needs change.

The important thing to remember is that you are not on your own – many people have been through the same emotions as you, and there are many support groups offering both practical and emotional help.

Obtain a copy of Pinpoint (available free by calling 0800 028 0888), which lists all local services, ranging from sporting facilities to take-a-break schemes, and includes details of national organisations you may be interested in.

Before asking for help it is important you think about what your child needs, what you need and what other members of your family need. You may find it useful to consider points listed in the Carers Assessment Guide (available from Carers Together) to help you work this out.

Your doctor can advise you about the portage system, where a trained specialist can work with you on educational issues to improve your child's skills.

Your doctor can also advise on specialist support services available to you if you are caring for a child with a terminal illness. This is a very demanding role, and you must always remember that your needs are important too.

Carers Together is there during normal working hours whenever you need to talk and the Carers Active Listening Line is there for you out of hours. You don't need to be having a crisis to call, as the staff will always be happy just to listen to you for as long as you need.

The Children Act 1989, the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 give the Health and Community Care Department specific duties towards disabled children and their families. A disabled child must have access to the same facilities as those available to other children.

Local authorities are required to provide services that minimise the effect of disabilities and give disabled children the opportunity to lead 'normal' lives. The Health and Community Care Department provides many services to children with special needs through local Family Resource Centres. You can obtain details from your local Health and Community Care office.

Instead of providing you with services directly, the local authority is able to give you an agreed sum of money so that you can buy the services you need to support your child and your family yourself.

This scheme (known as Direct Payments) gives you greater choice and freedom in arranging the help you need. You can find out more about this scheme from Carers Together and from your local Health and Community Care Department.

The Education Department produces a series of booklets about the help available in schools.

When your child is 14, the Education Department must inform the Health and Community Care Department, who will send a social worker to discuss with you the extra help you will need when your child leaves school.

This is your chance to request an assessment of your child's changing needs as they become an adult, and a carer's assessment for yourself – even if you have had one before.

Remember that, as your child grows up, their needs will change, and this will affect your ability to care for them, so make the most of the chance to talk about the future.

Because of the Carers and Disabled Children Act 2000, your child could now receive Direct Payments themselves once they are 16. These may make the transition into adulthood easier – contact Carers Together or your local Health and Community Care office for details.