

## **(6) Parents: Impact on family life**

### **Coping with your own emotions**

Depending on seizure control, a diagnosis of epilepsy can sometimes be life changing. Hopes and aspirations for your child's future may need to be adjusted, which can be difficult to accept. Many parents talk about feeling as if their world had been turned upside down. It is normal to feel a complex set of emotions such as disbelief, sadness, anger or even guilt when your child is diagnosed with epilepsy. Give yourself time to adjust, ask questions, and arm yourself with lots of information. Do not be afraid to get help for yourself from your own GP if you need it. Your child's epilepsy specialist nurse understands what you are going through and will also be able to provide support.

If you want to talk to someone about how you feel, our helpline 0808 800 2200 is here for you. Calls to our helpline are strictly confidential and you do not even have to give us your name.

### **Dealing with other people's reactions**

Before you talk to other people about your child's epilepsy, it is important you understand your own feelings. Not everybody needs to know that your child has epilepsy. You do not need to go into too much detail when explaining epilepsy to others. Depending on who you talk to, only give them the information they need or you want to give. Ask them to deal with the information in a sensitive way.

Most people will want to be supportive. Some may, however, be reluctant to talk about epilepsy because of their own personal experience or because of a perceived stigma still attached to epilepsy. By talking to others in an open, honest and informative way, you are also helping to slowly change attitudes towards epilepsy.

## Effect on siblings

Siblings may also feel confused, upset or angry, particularly if a lot of their parents' time and attention is initially taken up with going to medical appointments and looking after their brother or sister. Make a point of spending time with each of your children on their own giving them an opportunity to talk about how they feel and ask questions they may be too frightened or embarrassed to ask in front of everyone else.

Siblings often worry they will get epilepsy themselves or that their brother or sister will die. They may not want to be left alone with their brother or sister in case they have a seizure.

Creating a supportive family unit that discusses all major issues and jointly makes decisions will help to counter these fears. Children are very adaptable and can be a source of support as long as they feel they are part of the decisions that affect a family. They will usually be keen to learn some basic first aid to be able to help their brother or sister.

If your family needs further help, talk to your GP who can make referrals to family and other counselling services.

There is also help available from **Relationships Scotland** [www.relationships-scotland.org.uk](http://www.relationships-scotland.org.uk) offering counselling services for couples and families. For further information, visit their website or phone 0845 119 2020.

Specific support to siblings of disabled children and adults is available from the charity **Sibs** [www.sibs.org.uk](http://www.sibs.org.uk), 01535 645453. Their services also cover Scotland.

## Effect on your relationship with your partner

Looking after a child with epilepsy, particularly if the child also has other health conditions, can be time consuming, and physically and emotionally exhausting. This

kind of stress can sometimes impact on the relationship with a partner. If you want to talk to someone in confidence for further help and support, contact **Relationship Scotland** as above.