

## **CHILD OR TEENAGER WITH EPILEPSY? NEW FAMILY SUPPORT PACKAGE LAUNCHED**

### **Conference, handbook and plans for seizure diaries 'boost for young people' with epilepsy**

A support package for parents of children and teenagers living or newly diagnosed with epilepsy - and the young people themselves - was launched today.

The plans, developed by epilepsy charity The National Centre for Young People with Epilepsy (NCYPE) as part of its Childhood Epilepsy Information Service, include:

- a specially tailored parent's handbook, to provide mums and dads with information and support after first diagnosis
- an interactive event for families living with childhood or teenage epilepsy to be held in London on Saturday 17 October 2009
- plans for funky children's and teenage seizure diaries to make it easier for them to record their feelings and day to day life as well as their seizures.

The NCYPE's Childhood Epilepsy Information Service Manager, Gill Gallagher, said:

"Parents - and children and young people themselves - often face a lack of information and support when diagnosed with epilepsy.

"This new and vibrant handbook is the result of feedback from parents and professionals – we hope it will make real difference and give a boost to families living with epilepsy.

"Together with the conference in October and the seizure diaries we plan to launch later in the year, we want to help parents and children make contact with others in the same position and get the support and information they need.

"Epilepsy isn't who you are, it's what you have, and with the right support, people with epilepsy and their families can live life to the full."

The vibrant, clearly written 96 page looseleaf A5 parent's handbook is designed to help parents find their way through the maze of information and services.

A step-by-step approach means that parents and older children can dip in and out of the handbook, so that the whole family can start to understand epilepsy and how to get the most of out of life once someone is diagnosed.

The handbook, available free to parents, includes:

- a simple guide to epilepsy and its diagnosis and treatment
- tips for dealing with school
- holidays and travel
- living with epilepsy and the emotional issues
- epilepsy and teenagers
- a guide to useful websites, forums, books and DVDs
- sample seizure and health record charts

Parents of children with epilepsy tested out the handbook and it received an overwhelming 'thumbs up'.

Caroline, whose 9 year old daughter was diagnosed with epilepsy at age 7 said: "I feel that you are putting the real live parent in focus, there are so many different aspects to managing this condition and I feel all of them are covered here. There is something new that jumps out at me each time I look.

She adds "I like the fact that the sections give the information in a way that suits the time poor parent!"

The handbook, along with details of the conference and the seizure diaries, is available from the NCYPE's Childhood Epilepsy Information Service on [enquiry@ncype.org.uk](mailto:enquiry@ncype.org.uk) or telephone 01342 831342. Sample pages can be viewed at [www.ncype.org.uk/epilepsy](http://www.ncype.org.uk/epilepsy).

The Childhood Epilepsy Information Service also runs a confidential helpline for parents, professionals and young people themselves – telephone 01342 831342 Mon-Fri 9am-1pm or email [enquiry@ncype.org.uk](mailto:enquiry@ncype.org.uk). Information about training courses is at [www.ncype.org.uk/epilepsy](http://www.ncype.org.uk/epilepsy) or on 01342 832243 x296.