

Why the EACD cannot be a source of help for individuals:

People with disabilities such as cerebral palsy or autism may look in vain on this website for advice about treatment and management of the problems that present for their children. There is a simple reason for this. At the moment many of the conditions we are concerned with have no known 'cure'. It is difficult for people with these conditions and their families is to recognise this fact.

In many chronic conditions though there are ways in which a child with a neurodevelopmental disorder can be helped. The problem is that there are many people who have ideas about how this should be done and sometimes lack any basic knowledge of the problem but nevertheless come up with a 'cure'. In medicine today we try and practice only 'evidence based' medicine. That is to say that we use treatments which have been proven to be effective. For example new drugs may be subject to a "double-blind trial" when half the participants who are on the trial are given a similar looking tablet (placebo) which does not contain the effective agent given to the other participants. The researchers looked for a statistically significant difference between the two groups. Sometimes the study may show that people in both groups get better and there is no difference between them. One has then to conclude that the so-called effective agent is not in fact effective but receiving special 'attention' has caused the improvement.

Similar approaches are used when we try to develop effective means of helping people with chronic neurodevelopmental disorders and not expose them to the expense of paying for a supposed treatment which does not work. Sometimes the people who develop a treatment may feel certain it does work. Some people will get better "naturally". The problem for a scientist involved in the field is what should be done about these supposed 'cures'. The difficulty is if they are pronounced to be invalid the originators of the cure, perhaps genuinely convinced they have something new to offer, will object. Sadly numbers of doctors and others have been sued for making these criticisms and have had to spend a lot of money defending themselves. Unfortunately, there is really no solution to gaining the knowledge which will allow such decisions to be made except by studying and continually reading the scientific

literature in the field while remaining open to new ideas from outside, often from so-called alternative medicine.

The EACD runs meetings and workshops where such problems are discussed and has an official journal – *Developmental Medicine and Child Neurology* – which publishes much material about the treatment of neurodevelopmental disorders. Details of our meetings with topics covered are up on the EACD website and those papers are often then published in scientific journals. All this may sound a little dull and frustrating if you are looking for help with a child with a movement disorder, behaviour problems or learning problems. We try our best to educate and inform health professionals about treatments but we don't think it is useful to put up 'cures' on our website.

Notes for EACD website