

National Institute for Health and Clinical Excellence

Epilepsy (update)

Stakeholder Comments – Draft scope

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Stakeholder organisation:		Association of Child Psychotherapists 120 West Heath Road, London NW3 7TU Tel: 020 8458 1609 Fax: 020 8458 1482 Email: acp@dial.pipex.com
Name of commentator:		Beverley Tydeman, Chair
Comment No.	Section number <small>Indicate number or 'general' if your comment relates to the whole document</small>	Comments Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
1	General	The ACP welcomes the guidelines' focus on the clinical needs of children and young people with epilepsy. As child and adolescent psychotherapists working in paediatric settings, we fully acknowledge the centrality of medical treatment. However, we are disappointed that the draft scope of the review, in solely considering pharmacology, excludes psychosocial issues.
2	General	The current guidelines (October 2004) indicate that access to "counselling" should be available. We consider that this aspect of care, particularly in relation to children and young people, requires greater emphasis and detail. With regard to children, Kim (1991), quoted by Otero and Hodes (2000) (see references below) found that childhood epilepsy involves increased risk of psychiatric disorder and school and family problems. We would suggest that this indicates a need for psychotherapeutic intervention with children and their families at an emotional level with the intention of mitigating the psychological sequelae.

3	General	<p>From clinical experience, we would argue that epilepsy in children often leads to considerable anxieties in parents faced with dilemmas regarding the wish to protect the child from risk as against allowing the child to lead a normal life – an issue faced by the parents of disabled children more generally. These complex difficulties may be compounded in the parents by feelings of shame and guilt. Without sensitive, clinically-informed support and treatment, these natural emotions can set in train cumulative distortions of family relationships with deleterious effects for marital and sibling relationships.</p>
4	General	<p>Otero and Hodes (2000), in a study of 21 families with a child who had epilepsy, found that “good treatment compliance was found to be associated with less maternal hostility and criticism”. They note that “significantly more of the group who had a good level of compliance had recovered from epilepsy at follow-up”.</p>
5	General	<p>The review of research for the 2004 guidelines cites Wilde (1996) (see references below), in a study of the effects of epilepsy on adolescence, in which the issue of stigma was a significant factor. Whilst the majority of these patients had adjusted to their medical circumstances, a minority did not seem to have done so. It is such patients who are most in need of psychological treatments and support.</p>
6	General	<p>A clinical case provides an example of the difficulties which can arise and the role of psychological services in addressing them. A sixteen-year-old young man, without siblings, in a single parent family, was seen in a mental health paediatric liaison service because his nocturnal epileptic symptoms had caused such anxiety to his mother and himself that it had necessitated him sleeping in his mother’s bed. This arrangement had led to emotional difficulties. A brief intervention by two child and adolescent psychotherapists in the paediatric liaison service allowed the young man and his mother to share their concerns about his auditory hallucinations and their joint sense of the fragility of his mental and physical health. The intervention resulted in a referral to their local Child and Adolescent Mental Health Service (CAMHS) for individual therapy for the son and parenting support for the mother.</p>
7	General	<p>Conclusions A range of psychological interventions is required for children with epilepsy and their families. Some interventions are needed at a cognitive level (such as Cognitive Behavioural Therapy, or CBT) but others employing psychodynamic psychotherapeutic techniques, carried out by suitably trained and qualified clinicians, are essential to address the effects of the deep seated anxieties of children and young people with epilepsy and their parents and families.</p>

8	General	<p>References</p> <p>Kim WJ (1991) Psychiatric aspects of epileptic children and adolescents. <i>Journal of the American Academy of Child and Adolescent Psychiatry</i> 30: 874-86</p> <p>Otero S. and Hodes M. (2000) Maternal expressed emotion and treatment compliance of children with epilepsy. <i>Developmental Medicine and Child Neurology</i>, 42: 604-608</p> <p>Wilde M, Haslam C,(1996) Living with epilepsy: a qualitative study investigating the experience of young people attending out-patients clinics in Leicester. <i>Seizure</i> 5:63-72.</p>
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Closing date: 5pm on 2 March 2009

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