

Children, young people and adults may need access to tertiary services at certain times during their care and these services should be available to everyone who needs them through their specialist. However, the committee acknowledged that some groups may need extra tertiary support to manage their epilepsy, even if they are already receiving care from other specialists for another condition. The committee noted that people with a learning disability or mental health problem may struggle to access tertiary services and may need help to get appropriate referrals. They may also need additional support to attend appointments, such as having a family member or carer accompany them.

With the number of referrals increasing, the committee agreed that clearer and more specific criteria for referral would help to ensure that people who will benefit most from specialist services are prioritised. The proposed criteria aim to ensure that people with epilepsy that is difficult to diagnose or manage receive the specialist care and treatment they need, including consideration for clinical trials. The committee recommended, based on their knowledge and expertise, that people with epilepsy meeting these criteria should be seen within 4 weeks. The committee agreed that these are people with substantial health needs, so prompt referral could have a significant positive impact on their prognosis. This is in line with current clinical practice and consistent with the previous version of the guideline, so it is not expected to have an impact on resources. The committee agreed to retain and update the recommendation from the previous guideline because it was important to continue to guide clinicians to improve care and to reduce variation in service provision and outcomes between services.

The committee also discussed particular groups of children that should be prioritised for more urgent referral within 2 weeks. This was based on the committee's knowledge and experience, and on the probability that treatment from a tertiary paediatric epilepsy service would significantly benefit children meeting these criteria. They agreed that all children under 3 years should be referred to tertiary services without delay, because of the risk of developmental problems with some paediatric syndromes with onset before this age. Children with myoclonic seizures presenting aged up to 4 years should be referred because myoclonic seizures may start after 3 years and could indicate an underlying neurodegenerative disorder that may be treatable. Children with a unilateral structural lesion should be prioritised for immediate referral because this is likely to lead to difficulties in seizure management and surgery may need to be considered early. The presence of deterioration in the child's behaviour, speech or learning (such as loss of previously acquired developmental milestones), particularly in the absence of an established diagnosis, should also be a priority for prompt investigation in tertiary services.