



Editorial

Help youth with epilepsy to become competent and happy adults: Transition care

About 50% of children with epilepsy grow up to be adults with epilepsy. They fall into three broad groups: (1) those with early onset epilepsy that fails to remit. A large proportion have significant intellectual disability and there is strong evidence that adult neurologists are uncomfortable with patients with intellectual disability;¹ (2) otherwise normal children with Juvenile Myoclonic Epilepsy and related syndromes who may benefit from lifelong AED treatment and who have important lifestyle issues; and (3) normal patients with focal epilepsies that begin in adolescence and are likely to persist. Transition from nurturing, family-centered pediatric care to individually focused adult care may be difficult, although there is remarkably little objective literature to document the problems of youth with epilepsy as they make this move to adult care. Literature about transition for other chronic diseases in childhood indicates frightening outcomes if the process is poorly orchestrated. For example, in one center prior to a transition clinic, 6 of 9 children with kidney transplants lost their graft at the time of transfer, presumably from poor medication compliance. After a transition program was introduced there were no graft losses in 12 patients.² Extrapolating this experience to epilepsy would suggest that poor transition/transfer would lead to unsatisfactory seizure control, increased hospitalization, lack of access to newer therapies or epilepsy surgery and possibly higher rates of SUDEP. There is increasing evidence that the adult social outcome for children with epilepsy is often highly unsatisfactory even if the epilepsy has remitted, with high rates of academic failure, unemployment, social isolation, poverty and sexual misadventure.³

In this issue of *Seizure*, Iyer and Appleton report the results of a survey of 28 UK tertiary pediatric epilepsy centers about their process of transition.⁴ The survey had a 65% response rate, with 80% reporting some form of what they called a “transition program.” On closer inspection, 50% of these programs consisted of a single transition clinic visit with pediatric and adult specialists – all subsequent care was in the routine adult setting. Unfortunately it is not clear what preparation took place by patients, families and physicians for these brief transition clinic sojourns and what happened at the actual visits. How independent were the youth in the clinic? Overall, it seems that UK epilepsy centers have started in the right direction but the process of transition must begin in the pediatric world and a transition clinic needs to more than that just a handing over at a single visit (transfer) to the adult service. In addition, it is completely unclear what happens to children with epilepsy in the UK who are not followed in tertiary care pediatric centers.

Already in 1999, Appleton reported the Liverpool experience with a more comprehensive transition clinic that included several

visits before the youth moved on.⁵ This clinic was not just a passive exercise – in 10% of patients the diagnosis turned out not to be epilepsy and in 22% medication was changed. Smith reported a similar experience.⁶ There are other models for transition clinics including a very intriguing example in Alberta, Canada where the transition clinic is run almost entirely by the pediatric and adult epilepsy nurse specialists.^{7,8} None of these publications offer much data about outcome, although the Alberta publication includes a satisfaction survey.⁷

Also in this issue is a description of a special challenge – transitioning young adults on the ketogenic or Atkin’s diet.⁹ Although these dietary treatments have become mainstream in pediatric epilepsy care, they are nearly unknown in adult care. Kossoff et al. describe their experience at Johns Hopkins with 10 patients. Most were intellectually handicapped and dependent on others for dietary choices. Most transitioned to an Adult Epilepsy Diet Centre also at Hopkins, so they received ongoing sophisticated dietary care. Not surprisingly, this went well! The few who transitioned to more routine adult epilepsy care were likely to continue the diet without change from childhood or discontinue the diet – no one was available to offer dietary advice. We can all dream of an Adult Epilepsy Diet Centre but it will not be available in most places around the world.

We view the current paper of Iyer and Appleton as a call to arms for improving epilepsy transition and transfer services in the UK and around the world. But to do this, we think that the process needs to be comprehensive and, most of all, we need more data about the effectiveness of transition clinics for youth with epilepsy, both medical and social.^{10,11} These data will not come from randomized clinical trials but should at least be compellingly descriptive. The huge efforts made in pediatric care for children with epilepsy are perhaps fruitless if they do not lead to a satisfactory adult life. We view the current paper of Kossoff as a stimulus for more imaginative ongoing care for those who continue in adulthood to benefit from the ketogenic diet.

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