Teenagers with epilepsy

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Recent attention has focused on the importance, but inadequacy, of adolescent medicine, and the paucity of medical services for this specific population. Adolescence is, in itself, a difficult and traumatic time; when complicated by epilepsy it poses a great challenge not only to the young people themselves, but also to their carers and physicians. This paper provides a guide to the management of the teenager who has epilepsy.

Establishing a correct diagnosis
The adolescent period is an important time to review the diagnosis of both epilepsy (differentiating it from other paroxysmal but non-epileptic disorders/conditions) and the epilepsy syndrome, and to consider any underlying cause. Common misdiagnoses at this age include vasovagal attacks, migraine with aura (“classic” migraine), non-epileptic (pseudo-epileptic) attacks, and substance abuse (including recreational drugs). Cocaine, heroin, and 3–4 methylenedioxymethamphetamine (“ecstasy”) are known to cause convulsions; cannabis is less likely to have this effect. The false diagnosis rates of epilepsy and the epilepsy syndrome could be at least 10% and 6%, respectively. Juvenile myoclonic epilepsy is the most commonly recognised and misdiagnosed epilepsy syndrome; a history of myoclonic seizures, which are the defining seizure type in this syndrome, needs to be sought specifically because teenagers either fail to recognise them or consider that the early morning jerks are a normal part of waking up. Brain tumours and temporal lobe epilepsy (caused by hippocampal atrophy/ mesial temporal sclerosis) may present at this time. Finally, the onset of seizures in adolescence may, rarely, herald the onset of a neurodegenerative disorder including subacute sclerosing panencephalitis, Unverricht-Lundborg or Lafora body disease (both progressive myoclonic epilepsies), or juvenile Huntington’s disease.

Repeat electroencephalogram (EEG) monitoring and neuroimaging with magnetic resonance imaging may be indicated, particularly if seizures have an onset at this time, if seizures change in frequency or character, or if seizure control remains poor.

In girls, catamenial epilepsy may develop in adolescence and might manifest as either an increase in seizure frequency or, less commonly, as seizures that occur only at or around the time of menstruation.

Establishing the correct diagnoses of the seizure type(s), the epilepsy syndrome, additional neurological impairments, and any underlying cause is particularly crucial in the teenage years, in view of the imminent entry into adult life. Incorrect diagnoses, at any level of the diagnostic process, may have important and potentially serious implications for employment, driving, and psychosocial health.

The teenager with additional neurological impairments
Many teenagers with epilepsy dating from early childhood will have additional and occasionally major neurological impairments. These may include motor disorders (such as hemiplegia or quadriplegia), learning difficulties, and psychiatric/behavioural problems (such as autism and attention deficit disorder). These impairments are commonly associated with the more malignant epilepsies of childhood. Some patients will require lifelong care and support from many disciplines and others will be able to develop a degree of control over their lives, although with continuing support from their parents and carers.

Choosing the most appropriate antiepileptic drug
The correct identification of the seizure type(s) and epilepsy syndrome is important in helping to prescribe the most appropriate antiepileptic drug (AED), predicting the likely response (in terms of seizure control), and predicting the risk of seizure recurrence if the drug is discontinued. Carbamazepine and vigabatrin exacerbate myoclonic and typical absence seizures, including precipitating absence status, and should be avoided in syndromes characterised by these seizure types (for example, juvenile myoclonic epilepsy and childhood or juvenile onset absence epilepsy). Sodium valproate and lamotrigine have a relatively broad spectrum of action against most seizure types, although lamotrigine may not be as effective as sodium valproate in suppressing myoclonic seizures. Gabapentin and topiramate are of benefit in treating partial and secondarily generalised tonic clonic seizures, although their role in treating other seizure types and epilepsy syndromes is not yet clear. True catamenial epilepsy can be treated by a
number of regimens. For teenagers already taking an AED, a temporary increase in the
dose of this AED or the additional, intermittent
treatment with clobazam or acetazolamide for the
three days before menstruation, as well as through
out menstruation, may be useful; for teenagers who only experience seizures at
menstruation, intercurrent clobazam or acetazolamide, or perimenstrual progestogens, may
dbe prescribed.

The prescription of an AED must also take
account of the side effect profile, because of
both patient safety and compliance with medi-
cation. Although sodium valproate is effective
in most seizure types and epilepsy syndromes
of adolescence, it may be associated with a
number of side effects that limit its usefulness
and “acceptance” by this age group, particu-
larly girls. These include increased appetite
and weight gain, transient hair loss, menstrual
irregularities (including primary/secondary
amenorrhea and the polycystic ovary syn-
drome, which may, rarely, lead to infertility),16
and a distal tremor. The continued use of
sodium valproate in adolescent girls should be
considered on a risk to benefit basis.

The identification of a potentially surgically
treatable lesion is clearly important because
any surgery might result in a “cure” for the
teenager’s epilepsy and, as a consequence, it
might prevent or at least reduce the social,
educational, and behavioural sequelae of con-
tinuing seizures.

Specific issues
Teenagers with epilepsy are frequently caught
between paediatric and adult services with nei-
ther service being able to understand or satisfy
their specific needs and concerns.3

Pregnancy and contraception are important
issues—for both sexes. In certain situations,
particularly if the teenager is accompanied by
her boyfriend rather than her parents, it may be
prudent for clinic medical or nursing staff to
raise the issues of contraception and pregnancy
directly. The choice of contraceptive and,
in particular, the oral contraceptive should be
discussed, including the fact that some AEDs
may reduce its effectiveness, thereby necessi-
tating a higher strength of oestrogen to try to
“ensure” safe contraception.14 For young
women on enzyme inducing AEDs (car-
bamazepine, ethosuximide, phenytoin, and
topiramate) wishing to take a combined oral
contraceptive, the starting dose should be
50 µg of ethinyl oestradiol, but doses of 75 or
100 µg might be required if breakthrough
bleeding occurs. Preconception planning must
be emphasised, including optimising the
number, dosage, and blood levels of AED(s),
recommending daily folate supplementation,13
ensuring early antenatal booking, and monitor-
ing of the fetus throughout pregnancy, prefer-
ably in a fetal centre. Ideally, any change in
medication should be completed before con-
ception, with monotherapy as the objective.
Folic acid supplements (a minimum of 0.4 or a
maximum of 5 mg/day) should be taken by any
young woman with epilepsy who is sexually
active, irrespective of whether a pregnancy is
being considered, because at least 50% of
teenage pregnancies are unplanned. Although
folic acid supplementation has not been shown
to reduce the risk or incidence of neural tube
defects in children born to mothers who take
sodium valproate, it is reasonable to extra-
polate from data that have shown that folic acid
has a protective role in the prevention of neural
tube defects.15 16 There is an increased risk of
teratogenicity in women with epilepsy. The
aetiology is complex and encompasses demo-
graphic and genetic factors as well as environ-
mental factors, including AEDs and seizures.17
As yet, there is no conclusive evidence for a
difference in teratogenic risk between most of
the AEDs. Sodium valproate taken during the
first trimester is associated with a 1–3% risk of
neural tube defects, some 10–20 times higher
than the background incidence of 0.2–0.5%;
urogenital and cardiovascular malformations
may also occur.18 More minor defects, includ-
ing facial abnormalities and delayed develop-
ment, might also complicate the use of
valproate or phenytoin taken throughout preg-
nancy. Higher doses of valproate (> 1000 mg/
day) are thought to carry a higher risk, possibly
because of high peak concentrations.14 Car-
bamazepine may also be associated with neural
tube defects and microcephaly. The new,
established AEDs (gabapentin, lamotrigine,
and vigabatrin) appear to be safer but human
data are currently very limited.

Teenagers with epilepsy may apply for a
driving licence and drive providing that they
have not experienced a seizure of any type for
one year, or have had only nocturnal seizures
for three years.20 It is also important to remind
them that if they are already driving and an
AED is to be withdrawn, they should stop
driving at the time that the drug is withdrawn
and for a period of six months thereafter.

Alcohol is another important issue. Total
abstinence is unnecessary but more than two
units of alcohol a day is likely to increase the
risk of seizures in patients with epilepsy by a
number of mechanisms including a lowered
seizure threshold, an increased metabolism of
the AEDs or a disruption of “normal” sleep
patterns.21 22 Teenagers should also be in-
fomed that a relative lack of sleep, for whatever
reason, may also lower the threshold for further
seizures.

The choice of employment and the practi-
cialities of how to apply for jobs are frequently
of concern to the teenager with epilepsy. It is
important to stress that most careers or jobs are
available and can be undertaken by people with
epilepsy, but it is equally important to outline
those jobs that are not currently available—
specifically the armed and uniformed services
and drivers of public transport. This will
provide the teenager with accurate, realistic
information and prevent, or at least reduce, any
future disappointment. When applying for
jobs, a specific recommendation is to suggest
that the health section in the application form
is left blank, but that epilepsy must be
subsequently disclosed if the teenager is offered
the job. This approach is an attempt to prevent
the not uncommon discrimination against
people with epilepsy at the initial stages of job selection. Potential employers should also be provided with the name and address of the relevant hospital consultant.

The withdrawal of AEDs

The withdrawal of AEDs should always be considered in the teenager whose seizures appear to be well controlled. Although adolescent onset epilepsy appears to carry the highest risk of relapse, serious consideration should be given to discontinuing treatment in this age group, specifically to determine whether teenagers can stop taking treatment before they are living independently, driving, or working. Not all teenagers will need to remain on treatment for the rest of their life. It is important that the adolescent is given accurate information and facts about the risks of seizure relapse if the anticonvulsant is withdrawn. This again emphasises the need to have diagnosed the epilepsy syndrome accurately, because different syndromes may be associated with greatly different relapse rates—for example, juvenile myoclonic epilepsy is associated with a high relapse rate (70–75%), whereas the benign partial epilepsies in adolescence tend to have very low relapse rates after withdrawal of treatment. It must also be explained that any treatment should be withdrawn gradually, over at least six to eight weeks.24

The giving of information

Teenagers and their parents must be given adequate and accurate facts and information including the type of epilepsy syndrome, specific issues, and any AEDs that are prescribed. The rationale behind using an AED should be explained, in addition to the potential consequences if it is not taken regularly, or stopped suddenly, and any likely side effects, including possible interactions with the other drugs (specifically, the oral contraceptive, alcohol, and recreational drugs). Based on this information, the teenager and his/her parents should come to their own decision regarding whether treatment should be taken, and which drug should be used. Although it is often tempting to offer the teenager advice or specific “recommendations”, this may be perceived or misinterpreted as being directive or giving an order; advice or suggestions should therefore be offered only if specifically requested.

Doctors are often seen as figures of authority. In view of this and the fact that epilepsy is not just about having seizures or taking medication, other disciplines should be involved in talking to and “counselling” teenagers. Such disciplines could include psychology or nursing and specifically, nurse specialists. Nurse specialists have an important role in this area and may be considered by the teenager to be less authoritative and therefore more approachable; nurses are also more able to undertake home visits, the benefits of which are obvious.25

The process by which children take over responsibility for their medical care should ideally be begun well before the teenage years. They should always be included in the discussions and consulted in a way that is appropriate for their maturity. This approach should facilitate a more gradual passage from childhood into adolescence and, subsequently, into adulthood. All health professionals involved with teenagers must appreciate that adolescence is a time of self identification, a wish to become independent, and empowerment. Epilepsy can be a disempowering condition and can militate against achieving independence, with important social, educational, and behavioural/emotional consequences. These issues must be sensitively approached to allow the teenager to pass successfully from childhood into maturity and to enable the teenager to feel in “control” of their epilepsy as well as their life.

Whenever possible, verbal information should always be supported with written or audiovisual information. Teenagers should also be given the name, address, and telephone number of an appropriate voluntary epilepsy organisation so that they can make contact themselves, in their own time, and obtain the most relevant information for themselves.

The families and carers of the teenager

The families and carers of teenagers often need considerable understanding, support, and encouragement in allowing young people to develop their own personality and independence. Inevitably, there will be areas of conflict, with many parents tending to be overprotective and restrict their child’s demand for freedom. These concerns and the families’ needs must be sensitively approached to allow the teenager to take a sensible and realistic approach to the risks of everyday life.26

Follow up

Most teenagers or adolescents find it uncomfortable or inappropriate to continue attending a paediatric clinic. Teenagers who are likely to remain on antiepileptic medication for a number of years (irrespective of seizure control), should continue to have access to a specialist epilepsy service, although their day to day management should be undertaken by their general practitioner. This “specialist” service could be sited within a specific teenager/adolescent epilepsy clinic (supervised jointly by a paediatric and adult neurologist) or in an adult epilepsy clinic. The timing of referral to a teenager or adult epilepsy service will largely depend on the individual but should be considered from the age of 14 or 15 years. Importantly, a coordinated and multidisciplinary approach should be adopted, whichever clinic is felt to be most appropriate. For the teenager who is multiply disabled, it is important that the team includes individuals with the skills of developmental neuropsychiatry and of counselling people with learning difficulties. Failure to provide the teenager with continuing specialist epilepsy services may have potential medical and psychosocial consequences. Importantly, teenagers must always be given the opportunity to talk to the medical
or nursing staff alone, and without their parents.

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4 Smith PEM. The teenager with epilepsy. Lancet 1995;345:30.