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Epilepsy is a much stigmatised and misunderstood condition. Recent advances in our understanding of the condition and new treatments means that the opportunity is now at hand to start improving the healthcare for patients with the most common serious neurological condition.

General practitioners (GPs) can make a significant contribution to that improvement and, with the adoption of the GMS contract, which includes epilepsy as one of the Quality Markers, there is an additional incentive for GPs to take an active role in the treatment and long-term management of this condition.

I am delighted to see that Epilepsy Action has taken the initiative to support GPs in the delivery of this improved care with the production of this Epilepsy Information Booklet and the associated General Practice Epilepsy Toolkit.

It is not intended to transform the GP into an epilepsy specialist, but we want to make it possible to build on existing expertise to improve understanding of this long term condition and its impact on patients. The pack will support the GP in caring for their patients in ensuring early referral for newly identified patients to specialists for diagnosis and treatment initiation. It will also assist them in the ongoing monitoring and review of their patients and knowing when to refer for further specialist help as part of an improved system of shared-care. This is particularly important for high-risk patient subgroups, such as women of childbearing age, patients with learning disabilities and older people with epilepsy. Sections within the resource focus on the particular issues for these groups.

By utilising this toolkit and the additional information resources available from Epilepsy Action, GPs can make a real difference to the lives of their patients with epilepsy.

Professor David Chadwick MD, FRCP
Professor of Neurology, The University of Liverpool
Introduction

Epilepsy is the most common serious neurological condition, and after many years in the shadows the care and management of people with epilepsy has at last moved up the health agenda. The National Sentinel Clinical Audit into Epilepsy-Related Deaths highlighted some serious deficiencies, and at Epilepsy Action we are hopeful that the new focus on the condition will improve the lives of many people.

Epilepsy Action has worked for many years to support people with epilepsy by providing information and advice on our Freephone Helpline, an extensive range of literature, the most visited epilepsy website in the world outside the USA, www.epilepsy.org.uk and our Sapphire Nurse programme. Epilepsy Action have been campaigning for improved epilepsy health services, and is very encouraged by the inclusion of epilepsy as one of the disease areas in the GMS contract, as we feel that primary care has a key role to play in improving both the health and life of people with epilepsy.

As Dr Bill Hall, a GP from Settle whose help has been invaluable in producing this resource, says, “Epilepsy has been the Cinderella among long-term conditions in primary care. However with the advent of the Quality and Outcomes Framework in the GMS contract, practices are getting the encouragement and resources we need to improve services for a neglected group of patients. It’s not difficult to improve the care of our patients with epilepsy. This resource contains all the information you need to make a start and the rewards should be high. Each GP probably has one or two patients who could be helped to become seizure free. The quality markers for epilepsy are realistic and achievable with only a small amount of effort to set up the service.”

If we at Epilepsy Action can be of any more help please ring our Freephone Helpline on 0808 800 5050.

Simon Wigglesworth
Deputy Chief Executive
Epilepsy Action
Executive summary

This Epilepsy Resource Pack has been produced to assist implementation of publications, such as the National Institute for Clinical Excellence (NICE) guideline – *The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care*, the revised Scottish Intercollegiate Guidelines Network (SIGN) guideline – *Diagnosis and management of epilepsy in adults* (Guideline no. 70), the SIGN guideline on the *Diagnosis and management of epilepsies in children and young people* (Guideline no. 81), the GMS contract and the Department of Health Action Plan – *Improving services for people with epilepsy*. In particular, the NICE and SIGN guidelines place an emphasis on a structured management system in primary care, annual review, minimising side effects from epilepsy medications, addressing women-specific issues such as contraception and pregnancy, and improving quality of life.

This information booklet accompanies the Toolkit for Epilepsy, which is designed to help healthcare professionals in primary care review and ultimately improve services for patients with epilepsy. The toolkit is intended to provide the primary care team with the information and tools required to carry out:

- An audit of patients on the practice register who have active epilepsy
- Review of those patients with epilepsy
- Effective identification of those patients requiring referral to an epilepsy specialist
- Compilation of a practice report that can be used as evidence of the improved service provided.

Epilepsy is the most common serious neurological disorder seen in primary care, but with effective management up to 70 per cent of people with active epilepsy could become seizure free. However, drug management of epilepsy is currently considered to be inadequate in 20 per cent of adults and 45 per cent of children.

Sudden Unexpected Death in Epilepsy (SUDEP) is the main cause of seizure-related deaths. It is unclear what causes SUDEP, but the more frequent the seizures, the higher the risk. It is likely, therefore, that if more people with epilepsy had their treatment optimised to achieve consistently good control of their seizures, the incidence of SUDEP could be reduced.

When a new diagnosis of epilepsy is suspected in primary care, an urgent referral should be made to an epilepsy specialist. The primary care team can provide key information to aid the diagnosis, as the GP is often the first to suspect epilepsy and is in the best position to obtain a first-hand witness account and record the diagnostic features.
Anti-epileptic drug (AED) treatment should be initiated by an epilepsy specialist. However, the primary care team has an important role in reviewing patients who are taking AEDs, to ensure that:

- The patient's epilepsy is well controlled.
- Unnecessary side effects are not experienced.
- Referral for AED withdrawal is considered if appropriate.
- The patient is receiving the support and information they require regarding issues such as employment and driving.

The diagnosis of epilepsy and the use of AEDs in women of child-bearing age present particular challenges. Advice on contraception for young women with epilepsy should ideally be given before they become sexually active, in order to avoid unplanned pregnancies and the attendant risks of damage to the fetus. However some AEDs can reduce the effectiveness of the oral contraceptive pill. The NICE guideline therefore emphasises that the possibility of interaction with oral contraceptives should be discussed and an assessment made as to the risks and benefits of treatment with individual drugs.

Major and minor congenital malformations (teratogenicity) occur more commonly in infants exposed to AEDs during pregnancy than in those not exposed. There is evidence that suggests that the relative risk of congenital malformations may vary between different AEDs and for some AEDs the level of risk may be affected by the total daily dose. In addition, it has been consistently reported that women who take polytherapy are more at risk than those who take monotherapy.

Fundamental to the management of epilepsy is a structured system in which primary and secondary care share responsibility and communicate effectively. Each of the individuals within the primary care team has an essential role to play in coordinating the system of managed care for patients with epilepsy.

The first step towards a system of structured management in primary care is to develop a register of patients in the practice who have epilepsy and require treatment with AEDs. It is important to ensure that these patients then receive regular annual review. The aim of these reviews is to ensure that patients are being optimally managed and to identify those with issues that may require referral to an epilepsy specialist. The Toolkit for Epilepsy provided in this Epilepsy Resource Pack will enable your practice to do this effectively.
Background

Epilepsy is the most common serious neurological disorder seen in general practice. It commonly develops in childhood, with well over half of patients developing seizures before the age of 15 years. A second peak of new cases occurs in later life, with almost a quarter of people with newly diagnosed epilepsy being over 60 years old.

Studies have estimated that each year up to 80 people per 100,000 experience epilepsy for the first time and around 440,000 people have active epilepsy in the UK. Extrapolating from these figures, a general practitioner (GP) with 2,000 patients, will care for about 15 patients with active epilepsy and may see up to two new cases a year.

Epilepsy is commonly thought of as a single condition, but in fact there are many different types of epilepsy and over 40 different types of seizure. Unlike many other long-term conditions, most people with epilepsy lead normal lives most of the time. It has been said that a major part of living with epilepsy is 'feeling different'. The unpredictable nature of seizures is often coupled with a sense of overwhelming lack of control.

Unfortunately, epilepsy is still associated with a considerable degree of real and perceived stigma, and this can be one of the greatest difficulties a person with epilepsy will face. Seizure control allows them to take part in a full and active life in terms of relationships, social life and improved employment prospects.

People with epilepsy have a two to three times higher risk of premature death than the general population and most premature deaths are directly related to the epilepsy itself. Every year in the UK about 1,000 people die because of epilepsy, and most of these deaths are associated with seizures. The principal cause of seizure-related death is Sudden Unexpected Death in Epilepsy (SUDEP), accounting for an estimated 500 deaths each year.
**SUDEP defined**

Sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicologic or anatomic cause for death.¹⁹

It is not clear what causes SUDEP, but the most important risk factor is the frequency of seizures – the more frequent the seizures, the higher the risk.¹⁰ The National Clinical Audit of Epilepsy-Related Death revealed that 39 per cent of deaths in adults and 59 per cent of deaths in children were potentially or probably avoidable.⁹

SUDEP is not the only cause of death in people with epilepsy. Accidents resulting from seizures, of which drowning is a particular problem, account for between 3 per cent and 11 per cent of deaths.¹¹

Anti-epileptic drugs (AEDs) are not always chosen and used appropriately by clinicians. It is likely that if more patients with epilepsy received optimal anti-epileptic treatment and were able to achieve consistently good control of their seizures, the number of fatalities from epilepsy-related deaths could be reduced.²
Current guidance in epilepsy management

While many aspects of epilepsy management, such as diagnosis and initiation of treatment, should take place in secondary care, primary care still has a central role to play. GPs are usually the first point of contact for new cases of epilepsy and are well placed to coordinate the different aspects of healthcare provision. However, several published studies have highlighted shortfalls in epilepsy management in primary care. For example:

- An audit of the available primary care case notes of individuals who had died of SUDEP indicated that the review process in primary care was unstructured and lacking in detail.

- Secondary care notes available were also audited. In these patients, drug management of epilepsy was considered to be inadequate in 20 per cent of adults and 45 per cent of children.

- In a subset of patients who received all their care through the GP, there was documented evidence of only 33 per cent receiving a review in the year before their death.

- The advice and information provided to patients with epilepsy is often inadequate. Only a third to a half of women with epilepsy can recall being given advice about contraception and pregnancy by their GP.

This Epilepsy Resource Pack has been produced to assist implementation of recent publications, including

- The NICE guideline – The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care.
- The NICE technology appraisal guidance no. 76 – Newer drugs for epilepsy in adults and no. 79 – Newer drugs for epilepsy in children.
- The revised SIGN guideline – Diagnosis and management of epilepsy in adults.
- The SIGN guideline on the Diagnosis and management of epilepsies in children and young people.
- The GMS contract.
- The Department of Health Action Plan – Improving services for people with epilepsy.

The NICE guideline makes recommendations on important issues such as diagnosis and management of epilepsy, review and referral. In addition, it provides guidance on prolonged or repeated seizures in the community and treatment of status epilepticus, as well as guidance for groups of people with specific treatment needs such as women with epilepsy, people with learning
disabilities, young people and older people with epilepsy. The guidance on the use of the newer AEDs confirms their important role in the treatment of epilepsy.

The revised SIGN guideline replaces that published in 1997 and takes into account significant developments in the management of epilepsy, such as new therapy options and an increase in the number of specialist epilepsy nurses. A new section on women-specific issues such as pregnancy, contraception and hormone replacement therapy (HRT) has been added, and the guideline also makes a number of recommendations on how management should be structured within primary care. These include annual review, reducing medication side effects and referral to secondary care, and place an emphasis on improving quality of life.

A new SIGN guideline has been specifically produced to cover the diagnosis and management of epilepsy in children and young people from one month to 19 years of age. This guideline covers issues such as the management of teenagers with epilepsy, who have particular needs that may not be addressed by traditional paediatric and adult services. The importance of reviewing children and young people annually – even for those with well-controlled epilepsy – is emphasised.

Another significant incentive to improve the management of epilepsy in primary care is the publication of the GMS contract. This rewards practices for delivering higher quality care, and of particular importance are the targets of care in specific disease areas, including epilepsy. Points are awarded according to performance against quality indicators; extra funding is allocated on the basis of the number of points gained. More detailed information on how to fulfil the quality indicators for epilepsy can be found in the Toolkit for Epilepsy, associated with this booklet.

Although the allocation of points to epilepsy is low in comparison with some other disease areas, the targets are easily achievable and address significant unmet needs of patients with epilepsy. Also, a significant number of further points are available for holistic care, which scores at the threshold of the third lowest disease area. Therefore, the higher the score for epilepsy management under the contract, the higher the probable score under the holistic care award.

In addition to these recommendations, the National Service Framework (NSF) for Long-term Conditions, which has a particular focus on neurological conditions including epilepsy, was published in early 2005.
Epilepsy management and primary care

Primary care has a central role to play in the management of epilepsy. However, it is important to recognise that epilepsy is not a condition that should or could be managed solely in primary care. Improving the primary care management of epilepsy must therefore occur in conjunction with secondary and tertiary care services.

The Clinical Standards Advisory Group (CSAG) outlined two particular areas in which primary care can improve epilepsy services in relation to other disciplines:

- Better definition of role in relation to secondary care, depending on the status of the patient, i.e. whether they are newly diagnosed patients, patients with ongoing epilepsy or patients with controlled epilepsy (these are covered in the treatment section of this booklet).
- Better communication and information exchange between primary, secondary and tertiary care.

The NICE and SIGN guidelines also emphasise the importance of shared care in epilepsy management. Among other things they recommend that:

- All patients with epilepsy should be identified and basic demographic data recorded
- Annual review is desirable and could be facilitated and enhanced by specialist epilepsy nurses, linking primary care to secondary care (shared care)
- Once a provisional diagnosis has been made in new patients, appropriate information should be provided to the patient and referral made to a specialist centre
- Seizures should be monitored, with the aim of improving control by adjustment of medication or re-referral to hospital services.

This section outlines the role of healthcare professionals within their primary care team. It explains how services can be organised in relation to secondary care to provide patients with the best possible management of their epilepsy.
The role of the primary care team

Each of the individuals within the primary care team has an essential role to play in coordinating the system of managed care for patients with epilepsy.

Models of structured care suggested by CSAG recommend that epilepsy management in primary care is headed by a 'lead GP'. He or she works with suitable members of the primary care team who will liaise with secondary and social services. Useful contacts should ideally include the epilepsy specialist, an epilepsy specialist nurse, psychologist, social worker, community learning disability nurse and counsellor. He or she would also be responsible for organising review and recall systems, audit training and continuing education. However, much of this work can be taken on by the practice manager.

Epilepsy specialist nurses

Epilepsy specialist nurses work between secondary and primary care within many Primary Care Organisations (PCOs). These include nurses known as Sapphire Nurses, who are epilepsy specialist nurses, initially funded by Epilepsy Action. These nurses can provide more tailored advice and information about epilepsy for patients, and act as an interface between primary and secondary care. Research has demonstrated the potential benefits of epilepsy specialist nurses in reducing the length of hospital stay and increasing patient satisfaction. The role of the epilepsy specialist nurse follows the role of specialist nurses in other areas by providing:

- Support and information for the patient, their family or carers
- Up-to-date information and advice on epilepsy to the epilepsy team
- A contact point for GPs seeking advice
- A conduit for fast-track referral to secondary care
- Information about the strengths and weaknesses of the range of services in the local community (medical, statutory, voluntary), for GPs and hospital clinicians
- Training for primary care nurses and voluntary organisations

Epilepsy specialist nurses are considered to be such a valuable resource for primary care that the NICE and SIGN guidelines recommend that all epilepsy care teams should include an epilepsy specialist nurse.

GPs with a Special Interest

The newly developing role of GPs with a Special Interest (GPwSI) in epilepsy should also be a particularly beneficial development in improving care for people with epilepsy and improving communication between primary and secondary care. They can act as a source of information about local services, have up-to-date information on the condition and support practices to achieve the GMS quality indicators. They can also provide clinical leadership for developing epilepsy services and lead the development of shared care services.
**Audit and review**

Regular review of people with epilepsy can have a positive effect on seizure control, side effects experienced and psychosocial issues, and can reduce early mortality. However, most patients receive no ongoing review of their condition despite the national recommendations that all people with a diagnosis of epilepsy should receive an annual review. Having an accurate disease register and effective recall system can facilitate this annual review process. While regular review for the vast majority of patients is achievable, practices should be sensitive to the fact that some patients will make a conscious decision not to attend for review. However, it remains important to encourage these patients and to keep them informed about their epilepsy and how its management may be improved.

Patients who are not reviewed may have an incorrect diagnosis or be receiving suboptimal treatment resulting in:

- Continuing seizures
- Side effects from medication
- Poor adherence to prescribed medication
- Inappropriate medication
- Lack of awareness of specific issues
- Reduced employment opportunities
- Increased stigma.

In order to offer annual review to patients with epilepsy, the first essential step for any primary care team is to identify all its patients with epilepsy. This can be done by carrying out an audit of patients on the practice register who have active epilepsy requiring AEDs. This not only aids planning and provides valuable information about the type and size of the epilepsy burden in the local practice, but is also the first quality indicator of epilepsy care in the GMS contract.

The **Toolkit for Epilepsy**, which accompanies this booklet, provides instructions and resources to facilitate:

- Identification of all patients with epilepsy within the practice
- Systematic invitation of these patients for review
- Effective annual review of respondent patients.
**Working with secondary care**

Better communication between primary and secondary care is one of the most common suggestions made to improve epilepsy care. To operate efficiently, such a system requires effective communication between the GP and hospital clinicians.

Many communication problems derive from the diffuse nature of hospital care provision. GPs often do not know who to contact, and this is a particular problem with consultants covering several hospitals at once.

Suggested ways to improve communication include:

- Shared-care protocols
- An epilepsy specialist nurse, based within the epilepsy clinic at hospital level
- Patient-held co-operation cards including epilepsy records and seizure diaries
- Electronic patient/health records
- Provision of data sheets and information sheets to GPs
- Epilepsy clinics at a general practice level
- Seminars and training for GPs and practice nurses held at the hospital epilepsy clinic.

**Referral**

Once shared-care protocols have been established, members of the primary care team should be clear about to whom their patients with epilepsy should be referred. Ideally, patients should be referred to a specialised epilepsy service; however, if there is no such service in the area or access is limited, patients should be referred to a physician with a special interest in epilepsy.

Patients should be referred to a specialist for review of their epilepsy:

- After a first seizure. The NICE and SIGN guidelines recommend that services should be provided that enable patients with probable recent-onset seizures to be seen within two weeks of onset.
- If a brain tumour is suspected. Urgent referral, under the two-week standard, is recommended for people with new onset seizures characterized by one or more of the following: focal seizures, prolonged post-ictal deficit (longer than 1 hour), status epilepticus, associated inter-ictal deficit.
- To consider the risks and benefits of drug withdrawal. The consequences of poor advice at this stage can be profound.
- To manage specific problems or conditions such as drug side effects, psychiatric issues, pregnancy and related issues, social issues, genetic advice and mental deterioration.
- To monitor the underlying cause if it is potentially progressive.
If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, referral to tertiary services may be necessary.1

The purpose of any referral should be clearly understood by all concerned.11 There are several different types of specialist that might look after people with epilepsy in secondary care. These include general physicians, geriatricians, paediatricians, learning disability specialists, neurologists, psychiatrists and neuropsychiatrists. It is important to be aware that these doctors may or may not have a specialist interest and training in epilepsy.

Local referral guidelines may be available. The Toolkit for Epilepsy, that accompanies this booklet, provides:

- Guidance on when to refer.
- A standard referral letter that can be adapted.
A diagnosis of epilepsy can have important physical, psychosocial and economic implications for the patient, so it is important that the diagnosis is correct. Therefore, the diagnosis of epilepsy should be made by a neurologist or other epilepsy specialist. Primary care should make prompt referrals in suspected cases of epilepsy, and services should be provided in acute hospitals to enable patients with probable recent-onset seizures to be seen within two weeks of onset.

There is no one test that can diagnose epilepsy, although there are some that can be helpful. The most important information used in deciding if a person has epilepsy is the description of what they have experienced along with an eyewitness account of the event. The role of primary care can be key at this stage, as the GP is often the first to suspect epilepsy. They should attempt to:

- Obtain a first-hand witness account of the seizure
- Record the diagnostic features.

Information lost at this stage can profoundly affect the subsequent clinical course.

Diagnosis is carried out by a neurologist or other epilepsy specialist because there are many different seizure types and epilepsy syndromes, and classification of these is complex. The International League Against Epilepsy (ILAE) has published a proposed diagnostic scheme for people with epileptic seizures and with epilepsy. However, it is beyond the scope of this document to expand on this. For those who are interested, more information can be found on the ILAE website (http://www.ilae-epilepsy.org/Visitors/Centre/ctf/index.cfm).

An understanding of the classification of basic seizure types is useful in primary care. Therefore, you may want to refer to the ILAE system of classification to gain an understanding of epilepsy syndromes and seizure types. Table 1 outlines how the most common seizure types manifest themselves.
### Table 1: Seizure types chart

<table>
<thead>
<tr>
<th>Seizure type</th>
<th>Description</th>
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<tr>
<td><strong>Generalised seizures</strong></td>
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</table>
| **Tonic-clonic**              | • Loss of consciousness  
• Tonic phase: The muscles contract, the body stiffens. This is followed by the clonic phase  
• Clonic phase: Uncontrollable jerking of the body  
• The patient may let out a cry as air is forced out of the lungs and the lips may go blue due to lack of oxygen  
• When the patient comes round they cannot remember anything. They will need time to recover - from minutes to hours in some cases |
| **Absence seizure**           | • This is a momentary lapse in awareness  
• More common in children and teenagers  
• The patient may stop what they are doing, stare, blink or look vague for a few seconds before carrying on with what they were doing  
• It can go unnoticed and onlookers may think that the patient is just daydreaming |
| **Atonic seizures (drop attacks)** | • Spontaneous falls                                                                                                                                  |
| **Myoclonic seizures**        | • Cause brief, forceful jerks affecting arms, legs and sometimes the whole body                                                                                                                               |
| **Partial seizures**          |                                                                                                                                                                                                             |
| **Simple**                    | • No loss of awareness  
• Symptoms include one or more of the following: twitching, numbness, sweating, dizziness, nausea, disturbances to hearing, vision, smell or taste, strong sense of déjà vu  
• These symptoms last for several seconds and then go away  
• These seizures can often progress to other types of seizure |
| **Complex**                   | • Some loss of awareness  
• The patient may display automatisms, including: plucking at clothes, smacking lips, swallowing repeatedly or wandering around as if drunk  
• Other symptoms are similar to simple partial seizures |
Primary care has a key role in providing support and information to patients who have epilepsy. At the time of diagnosis, this information can help mitigate the impact epilepsy will have on many aspects of a person's life. A patient may have many different information needs at this stage, and the primary care team are well placed to inform patients about the support and information available to them (Table 2). The toolkit accompanying this booklet will help identify the information needs of the patient. This information can be obtained from Epilepsy Action, directly or via their website (http://www.epilepsy.org.uk/).

**Table 2: Information needs of newly-diagnosed patients, as identified by Epilepsy Action** (If you are not confident about providing this type of information, advice should be sought from secondary care, an epilepsy nurse specialist or the voluntary sector)

<table>
<thead>
<tr>
<th>ABOUT EPILEPSY</th>
<th>LIFESTYLE IMPLICATIONS</th>
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<tbody>
<tr>
<td>What epilepsy is</td>
<td>Employment</td>
</tr>
<tr>
<td>What happens in a seizure</td>
<td>Education</td>
</tr>
<tr>
<td>First aid in a seizure</td>
<td>Safety - home/outdoors/school/work</td>
</tr>
<tr>
<td>When to get medical help</td>
<td>Driving</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Sport</td>
</tr>
<tr>
<td>SUDEP</td>
<td>The pill/contraception</td>
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<table>
<thead>
<tr>
<th>PRECIPITATING FACTORS</th>
<th>ABOUT DRUGS</th>
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<tbody>
<tr>
<td>Stress</td>
<td>How they work</td>
</tr>
<tr>
<td>Lack of sleep</td>
<td>Importance of compliance</td>
</tr>
<tr>
<td>Boredom</td>
<td>Side effects</td>
</tr>
<tr>
<td>Alcohol</td>
<td>Free prescriptions</td>
</tr>
<tr>
<td>Missing tablets</td>
<td></td>
</tr>
<tr>
<td>Menstruation</td>
<td></td>
</tr>
<tr>
<td>Photosensitivity (television flicker)</td>
<td></td>
</tr>
<tr>
<td>Missed meals (hypoglycaemia)</td>
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</table>

Information should be provided in formats, languages and ways that are suited to the individuals requirements. Consideration should be given to developmental age, gender, culture and stage of life of the individual.

The involvement of an epilepsy nurse specialist, if available, is often useful, especially while the person is waiting to be seen by a specialist. For patients whose seizures are likely to recur before a hospital consultation, the GP should take advice from an epilepsy specialist about the most appropriate course of action; telephone access to expert advice should be made available.
**Treatment**

Although major treatment decisions, such as when to start treatment, withdraw treatment or switch treatments, should be made in secondary care, the monitoring of treatment is best performed in primary care. A structured management system should be established in primary care and, as for other long-term conditions, annual review is desirable.1–3

NICE and SIGN guidelines make recommendations about the involvement of primary care in the treatment of epilepsy. These responsibilities include:

- Prescribing continuing AED treatment in cases where management is straightforward and local circumstances and/or licensing allow1
- Monitoring seizures, aiming to improve control by adjustment of medication or re-referral to hospital services2
- Minimising side effects of medications and their interactions2
- Facilitating structured withdrawal from medication where appropriate, and if agreed by the hospital specialist and the patient.2

The role of primary care obviously varies according to the status of the patient and local protocols.

**Newly diagnosed patients**

The decision to start AED treatment should be made by the patient and an epilepsy specialist, in secondary care.1,2 The relative risks of recurrent seizures (including the important risk of SUDEP) are weighed against the potential side effects of taking long-term medication.2,3

If the patient and epilepsy specialist agree to start AED treatment, there is a wide choice of AEDs suitable for newly diagnosed patients. Those that are licensed as first-line agents for epilepsy monotherapy in adults are shown in Table 3.1

**Table 3: Licensed AED indications for patients over 12 years**29-34

<table>
<thead>
<tr>
<th>AED</th>
<th>PARTIAL SEIZURES (+ / - 2° generalisation)</th>
<th>1° GENERALISED TONIC-CLONIC SEIZURES</th>
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<tbody>
<tr>
<td>Carbamazepine29</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sodium valproate30</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Phenytoin31</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Lamotrigine32</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Oxcarbazepine33</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Topiramate34</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
If started on medication, patients are usually discharged back to the care of their GP when the condition becomes stable.\textsuperscript{12} It is then important that regular review is arranged, either with the GP or another suitably trained member of the primary care team, such as a specialist nurse, and that clear re-referral criteria are agreed.\textsuperscript{12}

Although the majority of people with newly diagnosed epilepsy respond well to AEDs, it is important to review their response to treatment as there is a risk of incorrect diagnosis of epilepsy, inappropriate choice of AED, failure to take the prescribed AED, underlying brain tumour and drug or alcohol abuse.\textsuperscript{2}

Major changes to drug treatment such as withdrawal or addition of drugs should be made within the shared-care treatment plan; therefore the patient will need to be re-referred to the epilepsy specialist to discuss changes in treatment.\textsuperscript{11}

Primary care also has a vital role in providing support and information to patients with newly diagnosed epilepsy. This is covered in the section on diagnosis.

**Patients with uncontrolled epilepsy**

All people with epilepsy should have a comprehensive care plan that is agreed between the individual, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle as well as medical issues.\textsuperscript{1}

All patients with epilepsy on a GP’s list should be offered an annual review, and the actions noted on the patient record.\textsuperscript{11} While implementing the management plan and reviewing the patient, GPs and other healthcare professionals in primary care should be aware of the most commonly prescribed AEDs (Table 3) and their possible side effects in patients.\textsuperscript{2}

**Side effects**

Some AED side effects are dose-related and predictable, and can be minimised by gradually increasing the dose up to the minimum effective dose.\textsuperscript{2} Straightforward adjustments to dosage or timing of doses can be made by the GP, but major changes such as withdrawal or addition of AEDs are best carried out within the shared-care treatment plan.\textsuperscript{11}

A number of side effects are associated with AEDs and can be a reason for patients stopping treatment.\textsuperscript{2} These side effects include weight gain, hair loss, ataxia, tremor, mood changes, depression, rash and cosmetic changes including acne, hirsutism and gum changes.\textsuperscript{2}

Patients should be warned of the potential side effects of their treatment and given clear instructions about what to do if side effects develop, particularly if they develop bruising, drowsiness with vomiting or rash, especially in the first few weeks of treatment.\textsuperscript{2}
During routine visits, the GP should monitor drug dosage and regimen, seizure frequency, adverse drug effects, adherence and other problems (medical or social). Repeat prescriptions for more than six months without seeing the patient should be avoided.

**Treatments for drug-resistant epilepsy**

Drug therapy is not effective in all patients, and other possibilities may be explored. Health professionals in primary care need to be aware of the availability of other treatments:

- Surgical treatments, including vagus nerve stimulation, are effective for the treatment of some patients with drug-resistant epilepsy, and should be considered as soon as it is established that the epilepsy is drug resistant as the benefits are greater in younger patients.  
- Psychological interventions can provide a useful adjunct to pharmacological treatment, especially when anxiety or stress are thought to precipitate seizures.  
- A wide variety of complementary therapies are increasingly popular with patients, including acupuncture, chiropractic, herbal medicine, osteopathy, homeopathy and yoga. There is, however, no evidence that these improve seizure control, and some may trigger seizures or interact with AEDs (e.g. St John’s Wort).  
- The ketogenic diet is a high-fat diet primarily prescribed to children with drug-resistant seizures. It can be effective in controlling seizures; however, it may be difficult for the patient to adhere to.

**Patient information**

Patients who have epilepsy have an ongoing need for information and support. There are a number of issues that may arise and these are outlined in Table 4. The primary care team is well placed to inform patients about the support and information available to them, especially from the voluntary sector. This information can be obtained from Epilepsy Action, directly or via their website (http://www.epilepsy.org.uk/).
Table 4: Information needs of patients with ongoing epilepsy, as identified by Epilepsy Action (If you are not confident about providing this type of information, advice should be sought from secondary care, an epilepsy nurse specialist or the voluntary sector)\(^{28}\)

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>COMING TO TERMS WITH DIFFICULT TO CONTROL EPILEPSY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment failure</td>
<td>Peer support</td>
</tr>
<tr>
<td>Treatment options (AED trials, vagus nerve stimulation, surgery, complementary treatment)</td>
<td>Counselling</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SAFETY</th>
<th>EMPLOYMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily living aids (alarms, safety devices)</td>
<td>Disability employment advisor (supported employment, health and safety at work)</td>
</tr>
<tr>
<td>Risk</td>
<td>Disability Discrimination Act</td>
</tr>
<tr>
<td>SUDEP</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIFESTYLE</th>
<th>FAMILY PLANNING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety in the home</td>
<td>Contraception</td>
</tr>
<tr>
<td>Day centres</td>
<td>Pregnancy</td>
</tr>
<tr>
<td>Memory aids</td>
<td>Caring for children</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SUPPORT SERVICES</th>
<th>OTHER HELPING AGENCIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social services</td>
<td>Statutory and voluntary services</td>
</tr>
<tr>
<td>Welfare benefits</td>
<td></td>
</tr>
<tr>
<td>Independent living/sheltered housing/residential</td>
<td></td>
</tr>
</tbody>
</table>
**Patients with controlled epilepsy**

The majority of adults with epilepsy have seizures that are completely controlled. Primary care should still ensure that a review is offered to these patients at least annually to document drug dosage, regimen and side effects.

**AED withdrawal**

**Withdrawal or addition of AEDs should be carried out under specialist guidance**

Patients who have been seizure-free for at least two years may be able to consider withdrawing AED treatment. However, there is an increased risk of seizures associated with withdrawal of treatment. The decision to continue or withdraw medication should be taken by the individual, their family and/or carers as appropriate, and the specialist, after a full discussion of the risks and benefits of withdrawal. At the end of the discussion, individuals and their family and/or carer as appropriate, should understand the individual's risk of seizure recurrence on and off treatment. This discussion should take into account details of the individual's epilepsy syndrome, prognosis and lifestyle. When AED treatment is being discontinued in an individual who has been seizure-free, it should be carried out slowly (at least two to three months) and one drug should be withdrawn at a time.

**First aid**

During a tonic-clonic seizure, bystanders should NOT:
- Move the patient unless he or she is in danger of further injury, e.g. from fire or traffic
- Try to restrict movement or lift the patient
- Place anything in the mouth or give anything by mouth.

During a tonic-clonic seizure, bystanders should:
- Leave clear space around the patient
- Put something under the head and neck to give support
- Turn the patient on one side in order to assist breathing and aid general recovery once the seizure has taken its course; wipe away any mucus
- Time the seizure

Emergency treatment should be sought if a single seizure persists for longer than 5 minutes, if there are multiple seizures (three or more seizures in an hour) or if injury has occurred.

Rectal diazepam is well tolerated and effective in first-line treatment of prolonged seizures and is recommended for the majority of cases. For many individuals and in many circumstances, buccal midazolam is more acceptable than rectal diazepam and is easier to administer. It should be used according to an agreed protocol drawn up by a specialist and only used following training.

*Buccal midazolam is currently unlicensed for treatment of prolonged or repeated seizures.*
**Bereavement and SUDEP**

After a sudden death the GP should contact the bereaved family to offer condolences and invite them to meet to discuss the death, and give the family the contact details of Epilepsy Bereaved. The GP should also inform any other health professional who was involved in the management of the patient’s condition.

**Empowering the patient**

Utilisation of the knowledge and experience of patients themselves could greatly benefit the quality of patients’ care and ultimately their quality of life. Surveys have suggested that there is a demand from patients for better provision of information, and there is also evidence that this information is especially valued when provided by nurses.

The NICE clinical guideline also recognises that people with epilepsy and their families and/or carers should be empowered to manage their condition as well as possible. Healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific need.

The SIGN guideline also highlights the importance of patient involvement. It recommends that:

- Information be given in an appropriate manner with sufficient time to answer questions
- Information be repeated over time and reinforced to ensure understanding
- When providing information, the most suitable format should be considered, e.g. leaflets, factsheets, video or specialised material for specific patient groups
- A checklist should be used to help healthcare professionals provide patients and carers with the information they need in an appropriate format.

Health care professionals should highlight the Expert Patient Programme (www.expertpatients.nhs.uk) to individuals with epilepsy who wish to manage their condition more effectively.

A practice can also benefit by giving the patient copies of referral letters and seeking their opinion on service delivery.

Giving patients the skills to manage their illness can have a major beneficial impact on their lives. Patients will often have beliefs about the diagnosis and medication that are contradictory to those of the health professional. Unless an agreement can be negotiated about what is and is not acceptable to, and achievable by, the patient, the medicines will not be taken optimally. In some cases they will not be taken at all.
Concordance

In the management of epilepsy, there are a number of factors that influence whether a patient takes their medication.39 These include side effects, memory problems, concerns about consistency of supply and decisions taken based on quality of life issues. One study found that 28 per cent of people with epilepsy did not take their AEDs as prescribed.39

Concordance defined

Concordance is an agreement reached after negotiation between a patient and a healthcare professional, that respects the wishes and beliefs of the patient in determining whether, when, and how medication is to be taken.38

Concordance brings the patient into the decision-making process, as an informed partner, and results in greater benefits for the patient. This should result in improved relationships between doctor and patient, and hence improved health and quality of life for the patient.

Consistency of supply

In some people with epilepsy, consistent, stable serum concentrations of AED medication are required to maintain seizure control. Switching between different formulations of the same AED could put a patient at risk of losing seizure control.40,41 The reasons for this are uncertain – they could be psychological or due to pharmacokinetic differences. This could result in loss of seizure control and could in turn lead to loss of driving licence or employment for patients, and an increased workload and cost for the NHS.40

The Department of Health (DoH) has recently (March 2005) issued guidance on the Lamictal (lamotrigine) patent expiry and generic substitution. The DoH acknowledges that there is a viewpoint that there should be no switching of products used in the treatment of epilepsy. Whilst the DoH recognises that in the case of lamotrigine there is “no compelling evidence to suggest that switching from the originating brand to a generic alternative will have an adverse clinical outcome”, they do state that “it is open to prescribers to modify their usual generic prescribing practice if, in their judgement, the circumstances of individual patient warrants such action.”42
Specific patient groups

This section addresses issues relating to specific groups of people with epilepsy.

Women

The majority of women with epilepsy have problem-free pregnancies and healthy babies; however the diagnosis of epilepsy and the use of AEDs in women can present particular problems:13

- Major (e.g. neural tube defects such as spina bifida) and minor (e.g. underdevelopment of the mid-face resulting in features such as a broad nasal bridge) congenital malformations occur more commonly in infants exposed to AEDs during pregnancy.2,43

- Women taking enzyme-inducing AEDs and the combined oral contraceptive (COC) pill are at increased risk of pill failure due to accelerated oestrogen metabolism. This may result in breakthrough bleeding and/or unplanned pregnancy.2

- Some AEDs can produce cosmetic side effects such as hirsutism and coarsening of the facial features with phenytoin,31 and weight gain with sodium valproate.30

Women with epilepsy who are of child-bearing age therefore need additional advice and counselling about issues such as contraception and pregnancy.1,2,13

Contraception

Advice on contraception for young women with epilepsy should ideally be given before they become sexually active, in order to avoid unplanned pregnancies and the attendant risks of damage to the fetus and/or a change in seizure frequency.1,2 Therefore all women with epilepsy of child-bearing age should be advised to plan their pregnancies.2

Some AEDs induce hepatic enzymes that speed up the way in which the contraceptive pill is broken down by the liver (Table 5).2 This is likely to reduce the effectiveness of hormonal contraception. The NICE guideline emphasises that the possibility of interaction with oral contraceptives should be discussed and an assessment made as to the risks and benefits of treatment with individual drugs,1 while the SIGN guidance states that if a patient is using oral contraception, an AED that does not induce hepatic enzymes is preferred.2
### Table 5: AEDs and their effects on hepatic enzymes

<table>
<thead>
<tr>
<th>AEDs that induce hepatic enzymes</th>
<th>AEDs that do NOT induce hepatic enzymes</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Carbamazepine</td>
<td>* Acetazolamide</td>
</tr>
<tr>
<td>* Oxcarbazepine</td>
<td>* Benzodiazepines</td>
</tr>
<tr>
<td>* Phenobarbital</td>
<td>* Ethosuximide</td>
</tr>
<tr>
<td>* Phenytoin</td>
<td>* Gabapentin</td>
</tr>
<tr>
<td>* Primidone</td>
<td>* Levetiracetam</td>
</tr>
<tr>
<td>* Topiramate</td>
<td>* Tiagabine</td>
</tr>
<tr>
<td></td>
<td>* Valproate</td>
</tr>
<tr>
<td></td>
<td>* Vigabatrin</td>
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<td></td>
<td>* Zonisamide</td>
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</table>

New data exists that suggests an interaction between combined oral contraceptives and lamotrigine may occur, which may result in:

- reduced effectiveness of hormonal contraceptives
- reduced seizure control in women on a stable lamotrigine dose who start an oral contraceptive, or
- adverse effects of lamotrigine following withdrawal of an oral contraceptive.45

A hormonal contraceptive should only be used as the sole method of contraception if there is no other alternative. If the oral contraceptive pill is chosen as the sole method of contraception, women should be advised to promptly notify their physician if they experience changes in menstrual pattern (e.g. breakthrough bleeding) while taking lamotrigine as this may be an indication of decreased contraceptive efficacy. Women taking lamotrigine should notify their physician if they plan to start or stop use of oral contraceptives or other female hormonal preparations.33
### Table 6: Recommendations on type of contraception for women with epilepsy\(^{1,2,13,46,47}\)

<table>
<thead>
<tr>
<th>Contraceptive type</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| Combined oral contraceptive | If a patient is using the COC, an AED that does not induce hepatic enzymes is preferred.\(^2\)  
When COC is given with an enzyme-inducing AED, one containing a minimum of oestrogen 50 µg should be used; women should be warned that its efficacy is reduced and barrier methods should also be used if maximal contraceptive effect is required.\(^1,2\)  
If breakthrough bleeding occurs with 50 µg of oestrogen the dose should be increased and “tricycling” of the COC should be considered.\(^1,2,13\) |
| Progestogen-only pill        | The progestogen-only pill is not recommended for women taking hepatic enzyme inducing AEDs.\(^{1,2,13}\)                                                                                   |
| Progestogen injections       | Depot injections of progestogen may be used with enzyme-inducing AEDs but should be given every 10 weeks.\(^{1,2,13}\)                                                                       |
| Progestogen implants         | Progestogen implants are not suitable for women taking enzyme-inducing AEDs.\(^{1,2,13}\)                                                                                              |
| Emergency contraception     | The dose of levonorgestrel for emergency contraception should be increased to 1.5 mg and 750 µg 12 hours apart in women taking enzyme-inducing AEDs.\(^{1,2}\)                                    |
| Intrauterine devices         | If an intrauterine device (IUD) is the preferred method of contraception there is a small risk of reflex seizure during fitting of the device. The person carrying out the procedure should be aware of this small risk.\(^{46,47}\) |

**Pre-pregnancy counselling**

Pre-pregnancy counselling involves making women with epilepsy aware of the issues relating to a future pregnancy, including:\(^{13}\)

- Methods and consequences of prenatal screening
- Folic acid
- Risk of congenital malformation (teratogenicity)
- Labour
- Caring for the baby.

The aim is to ensure that women with epilepsy are fully aware of the risks and benefits of continued AED treatment during pregnancy and are able to make informed choices throughout the pregnancy, delivery and subsequent child care. Pre-pregnancy counselling should be given to all women with epilepsy of child-bearing age and should be repeated at review appointments.\(^{1,2}\)
Regular folic acid supplements have been shown to protect against neural tube defects developing in the fetus. Current guidelines recommend that all women with epilepsy who are planning to become pregnant should be prescribed folic acid supplements of 5 mg per day from pre-conception and throughout the first three months of pregnancy.

**Pregnancy**

A major concern of many pregnant women with epilepsy is the effect that taking AEDs may have on their baby. In the general population the risk of major congenital malformations, including neural tube defects, is 2–3 per cent. In women taking a single AED, this is increased two to three times, therefore expert assessment is required in order to make a judgement of the relative risks of seizures versus the risks associated with the use of AEDs in pregnancy. There is evidence that suggests the relative risk of congenital malformations may vary between different AEDs and for some AEDs the level of risk may be affected by the total daily dose. In addition, it has been consistently reported that women who take polytherapy are more at risk than those who take monotherapy. However, the majority of women with epilepsy will have a normal pregnancy and delivery.

Ideally, a woman with epilepsy should conceive on the lowest dose of AED that still controls her seizures. If the woman has been seizure-free for some time, the risk of recurrent seizures is low and she is aware of the risks of recurrent seizures, it may be possible to withdraw medication prior to conception.

The rate of withdrawal of AEDs should be slow, usually over a few months, and any changes to AED therapy should be made before contraception is stopped.

An initiative has been developed to register every pregnancy in women with epilepsy onto a nationwide database. It is hoped that the relative risks of all available anti-epileptic drugs will then become clearer. To register with the UK Epilepsy Pregnancy Register, the patient should phone 0800 3891248.

Advice on breastfeeding depends on the AED the mother is receiving. For further information, the relevant prescribing information should be consulted. Blood levels of AEDs are probably lower in the breast-fed infant than exposure in utero, and breastfeeding and subsequent weaning usually allow for a gradual withdrawal.

**HRT**

During the menopause, some women may experience an increase in seizure frequency. Women should be counselled that their seizure pattern may change at the time of the menopause, and HRT should be prescribed for the same indications as in women who do not have epilepsy.
Patients with learning disabilities

Learning disability defined

When measuring intellectual impairment learning disability is defined as an IQ of less than 70.50.

The prevalence of epilepsy varies in direct proportion to the severity of the learning disability, with up to 50 per cent of those with a profound learning disability (IQ < 20), having the disorder. A reasonable estimate of the prevalence in patients with moderate to severe learning disabilities probably ranges between one in four and one in five such patients. People with epilepsy who have learning disabilities should receive the same support and care for their epilepsy as the general population. In addition, those with learning disabilities also need the care of the learning disabilities team.1

In the management of people with learning disability and epilepsy, the following considerations should be made:2

- Allow time for the consultation
- Ensure that the patient is accompanied by a carer who knows the patient and who can bring information about seizure type and frequency, possible side effects of medication, and general health and behaviour
- Provide information in an accessible format
- Establish a multidisciplinary approach to care that is delivered by professionals with an expertise in epilepsy. Community learning disability nurses have an important role in liaising between the specialist services and patients and carers.

If the practice is planning to improve services for patients with learning disabilities and epilepsy there are initiatives that offer incentives to do so. The Primary Care Trust can advise the practice on whether they have a Local Development Scheme (LDS) for improving services for patients with learning disabilities. If they do then the small amount of extra work involved in meeting the criteria of the LDS will result in the practice receiving the associated financial incentives.52

Children

In contrast with adults, in whom symptomatic epilepsy is predominant, three-quarters of epilepsy in children is unrelated to other illness. Most children diagnosed with epilepsy will see a paediatrician and remain within hospital-based paediatric services until they reach adulthood. This is backed up by professional guidance. However, in a postal survey carried out by the CSAG, 28 per cent of children with epilepsy had not been to a hospital clinic within the previous 12 months. It is therefore important that primary care includes children when identifying their patients with epilepsy, as some may otherwise be over-looked.
There are a number of issues specific to the management of epilepsy in children. These include:

- Paediatric neurology is a relatively new speciality, so the majority of children will be managed by general and community paediatricians.

- As epilepsy has a significant impact on a child’s ability to learn and participate fully in educational activities, it is vital that good links are forged with educational services.

- The transition from paediatric to adult care is a difficult time. A transition clinic can be offered, based in an epilepsy centre or, if this is not possible, direct referral should take place, including a transfer of detailed information.

- Anti-epileptic treatment for children is less well supported by clinical trial data than for adults and drugs are more likely to be used outside of their licensed indications.

The physical, psychological and social needs of young people with epilepsy should always be considered by healthcare professionals. Attention should be paid to their relationships with family and friends and at school.

The new SIGN guideline pertaining to children and young people suggests:

- The diagnosis of epilepsy should be made by a paediatric neurologist or a paediatrician with expertise in childhood epilepsy.

- Review should take place at least annually, even for those with well-controlled epilepsy, to identify problems, ensure discussion on issues such as withdrawal of treatment and minimise the possibility of becoming lost to follow-up.

- All children and their carers should be given information appropriate to their condition.

- Each child should have an individual management plan agreed with the family and primary care team.

**Young adults**

Adolescence is a particularly critical time to review the diagnosis and treatment of epilepsy. At least 10 per cent of teenagers thought to have epilepsy are misdiagnosed and may have other underlying diseases, so confirming the diagnosis at this stage is important. Young adults are at higher risk of SUDEP than any other age group, and as they reach maturity and become more independent, issues such as relationships, contraception, consequences of AED treatment, employment, driving and psychosocial aspects need to be discussed.

Puberty can be a difficult time due to social, hormonal and psychological changes. Frequent seizures during childhood can interfere with growth and endocrine systems so a proportion of teenagers with epilepsy will be obese, shorter than average and, in girls, have a later onset of menstruation than their counterparts. Young women with epilepsy need to be made aware that their condition and the treatment they are taking may affect their future fertility.
The cosmetic side effects of some AEDs may also be a particular problem in young adults, for whom the coarsening of facial features, gum changes, acne, inappropriate hair growth (in girls) and weight gain can be a specific concern.\textsuperscript{13}

The psychological and emotional impact of epilepsy during this sensitive time may lead to low self-esteem and a lack of self-confidence. The timely and accurate provision of advice and counselling is therefore recommended.\textsuperscript{13}

The needs of young people (aged > 13 years) and their transition to the adult service should be addressed. A dedicated young people clinic is a suitable setting for discussion of issues appropriate to the age group.\textsuperscript{3}

**Elderly patients**

Almost a quarter of people with newly diagnosed epilepsy are over 60 years old.\textsuperscript{11} In one UK study based on a large primary care computerised database, the overall prevalence of epilepsy in people aged over 60 was 11.8 per 1000 and the overall annual incidence in those over 60 was 117 per 100,000.\textsuperscript{55}

Cerebrovascular disease is the most common cause of seizures in patients over 60 years old who are newly diagnosed with epilepsy. Otherwise unexplained epilepsy occurring for the first time may be an early presentation of cerebrovascular disease.\textsuperscript{56,57}

The NICE guidance recommends that the choice of treatment, access to investigations and the importance of regular monitoring of effectiveness and tolerability are the same for older people as for the general population.\textsuperscript{1} This is supported by the emphasis in the National Service Framework for Older People on dismissing age discrimination.\textsuperscript{58}

Epilepsy in older people poses several additional problems for the provision of services compared with the rest of the population:\textsuperscript{11}

- Diagnostic difficulties – especially in differentiating syncopal attacks from seizures.
- Susceptibility to AED side effects and toxicity, and increased likelihood of interaction with other medication – close monitoring is needed.
- Psychosocial and generational difficulties – increased feeling of stigma and impact on ability to drive.
- Physical restrictions to lifestyle – seizures that cause falls are more likely to cause injury in older people.
- Multidisciplinary service requirements in the community – liaison nurse, social worker, occupational therapist.
References


Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work includes:
- providing information to anyone with an interest in epilepsy
- improving the understanding of epilepsy in schools and raising educational standards
- working to give people with epilepsy a fair chance of finding and keeping a job
- raising standards of care through contact with doctors, nurses, social workers, government and other organisations
- promoting equality of access to quality care

Epilepsy Action has a network of local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...
You can help us in our vital work by becoming a member. All members receive our magazine Epilepsy Today, free cover under our unique personal accident insurance scheme and access to our services and conferences.

Getting more information
Call our Freephone Helpline on 0808 800 5050
Freefax 0808 800 5555
Email helpline@epilepsy.org.uk