

## Appendix D

### Information for women with epilepsy

#### *1.1 Information to be discussed at different life stages of women with epilepsy*

This checklist is intended as an example that can be adapted for local use.

Life stage	Topics to discuss
Diagnosis	<ul style="list-style-type: none"> <li>• Type of epilepsy</li> <li>• Length of treatment</li> <li>• Seizure triggers</li> <li>• Standard epilepsy advice</li> <li>• Injury prevention/limitation</li> </ul>
Adolescence/childbearing potential	<ul style="list-style-type: none"> <li>• Confirm diagnosis</li> <li>• Take menstrual history</li> <li>• Possible effect of monthly cycle on seizures</li> <li>• Effect of AEDs on monthly cycle (PCOS)</li> <li>• Sexual activity and contraception</li> <li>• Enzyme inducing AEDs interaction with contraceptive pill and depot injection</li> <li>• Seizure risks (alcohol/sleep/recreational drugs)</li> <li>• Cosmetic side effects</li> <li>• Cognitive side effects</li> <li>• Return for pre-pregnancy counselling</li> </ul>
Planning a pregnancy	<ul style="list-style-type: none"> <li>• Confirm diagnosis</li> <li>• Fertility</li> <li>• Obtaining optimal seizure control</li> <li>• Risks of withdrawal of AEDs</li> <li>• Drug regimen (withdrawal and substitution)</li> <li>• Folic acid supplementation 5mg per day</li> <li>• Teratogenic effect of AEDs</li> <li>• Effect of pregnancy on seizure control</li> <li>• Effect of epilepsy on foetus</li> <li>• Risk of child developing epilepsy</li> </ul>

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Life stage	Topics to discuss
Pregnant	<ul style="list-style-type: none"><li>• Pain control during labour</li><li>• Importance of taking medication into hospital</li><li>• Post natal exhaustion and seizure frequency</li><li>• Breast feeding and AEDs</li><li>• Looking after the child</li></ul>
Menopausal	<ul style="list-style-type: none"><li>• Obtaining optimal seizure control</li><li>• AEDs and osteoporosis</li><li>• AEDs and HRT (need for progesterone)</li><li>• Possible interaction of AEDs with evening primrose oil</li><li>• Effect on seizure control</li></ul>

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*Adapted from the Epilepsy Action Women with Epilepsy Checklist*

## **1.2 Practical information for Mothers' with Epilepsy**

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Epilepsy is a very individual condition. A person's seizure or types of seizure, including frequency, duration and severity can vary enormously from one person to another. In addition, the implications of having epilepsy are not only different between individuals but for that same individual may vary over time and at different stages in their lives.

Most women with epilepsy who have children experience no greater difficulties in looking after their children than women in general.

Some new mothers with epilepsy have particular concerns with issues such as tiredness, breastfeeding and safety issues. Being well informed supported and counselled provides many women with epilepsy with the confidence and understanding to manage what is generally a very happy time, but one which can also be tiring and stressful.

### **OVERPROTECTION**

Identifying and introducing some carefully considered safety precautions in the home can help to reduce risks, build confidence and enables most mothers to care for their babies safely.

Although there may be some concerns about how a mother's epilepsy may affect her ability to safely care for her baby, 'overprotection' of a new mother however well intentioned, affects vital bonding of mother and child, and therefore is to be avoided wherever possible.

## **SAFETY**

There are many wide ranging precautions which any mother might wish to consider when having a new baby or young child to care for. This equally applies to women with epilepsy. Introducing a few simple safety precautions may significantly reduce the risk of accidents and minimise anxiety. An approaching birth can be an ideal opportunity to review and consider the best and most helpful measures to attempt to ensure the maximum safety for both mother and baby.

A change to the frequency of seizures or seizure pattern may occur for some women. A mother who has seizures involving loss of consciousness will need to take more care than a mother who rarely has seizures or one who has reliable and sufficient warning before a seizure. It is therefore important to identify a safe convenient area for the baby if the mother should feel unwell. e.g. playpen, cot or other safe place.

## **FEEDING**

Except in very rare instances, breastfeeding for most women taking anti-epileptic drugs is perfectly safe and should be encouraged, as it increases the bonding between mother and child. However, each mother needs to be supported in the choice of feeding method which best suits her individual family.

Breastfeeding can be very tiring, as many babies need feeding every few hours. If a mother expresses her breast milk by means of a breast pump her partner may then be able to take over some of the feeds giving the mother an opportunity to rest. Irregular feeding patterns resulting in lack of or frequently interrupted sleep for the mother may act as a 'trigger' and increase the likelihood of seizures for some mothers.

Mothers need to feel comfortable and secure before feeding their baby.

Whether the mother is breast or bottle feeding, the risk of dropping the child

can be reduced by sitting on the floor with the mothers back to the wall for adequate support. Well positioned cushions placed on either side can help reduce the risk of the child falling far or onto a hard floor should the mother have a seizure. If a mother always falls in the same direction, then holding the baby on the opposite side whilst bottle feeding will enable the mother to fall away from the baby.

If the mother who is breastfeeding has any concerns that her baby is particularly drowsy or sleepy she should talk to her GP.

Most high chairs are adaptable, and by setting the chair at its lowest level and placed where it is least likely to be knocked over, allows the mother to safely feed the child as the baby grows older.

## **BATHING**

Bathing a child is the one task that mothers are generally advised should not be carried out whilst she is alone, but only when someone else is there for support.

As an alternative, sponging the baby down on a changing mat or towel at floor level is a safer option. Using a bath stand may be hazardous, so putting the baby bath on the floor or in the big bath could be considered. Unless there is somebody in the bathroom with the mother, it is never advisable for the mother to have their baby in the bath with them.

## **CHANGING THE BABY**

For mothers at risk of seizures it is safer to always change the baby at floor level. The use of a changing unit is not recommended. It is customary for some mothers to change their baby on the bed, but there may be risks to bear in mind such as the baby may wriggle and fall off the bed.

## **CARRYING THE BABY/CHILD**

For mothers who have seizures involving loss of consciousness or loss of awareness, carrying a baby or child should be kept to a minimum. It is advisable to keep a supply of baby changing materials both up and down stairs to avoid the need to carry the baby/child up or down stairs unnecessarily. If possible, ask another family member to carry the baby or child on the stairs, but, where it is unavoidable, carrying the baby secured in a carrycot may reduce the risk of injury to the baby in the event of being dropped.

## **INSIDE THE HOME**

Safety gates and other safety accessories e.g. cooker guards are sometimes recommended but these may need to be adapted.

Taking particular care with the making / or holding of hot drinks may also need to be considered.

## **OUTSIDE THE HOME**

When taking the baby outside the home a length of cord tied to the mother's wrist will stop the pram from running away, should the mother lose awareness or consciousness. The cord should be long enough to ensure the pushchair is not pulled over. Alternatively, a brake can be fitted which operates to halt the pushchair when the handle is released. It may be helpful for the mother to consider ways to minimise the risk of her child wandering either within or out of the house if she becomes unconscious.

When the child is older, walking with a wrist rein may help to prevent the toddler from wandering off. The mother may wish to consider some form of

Identification. This is available in various forms i.e. jewellery items or identity cards. (Refer to the National Society for Epilepsy - Safety Leaflet)

Children can be taught to dial 999 at home – the family address will automatically be displayed at the emergency services call centre. Three red dots on the nine digit and some time spent teaching a child on a play telephone will mean even a very child can dial the emergency services.

## **SAFETY OF MEDICINES**

It is strongly recommended as with any medicines that anti epileptic drugs should be locked away from children at all times.