

Care for babies exposed to antiepileptic medications



Introduction

Congratulations on becoming a mum! Whether this is your first or fifth baby, this will be a wonderful and exciting time for you and your whānau.

This booklet contains important information for all women who have been taking an antiepileptic medication during their pregnancy.

One of the areas this booklet addresses is the issue of withdrawal symptoms in babies that were exposed to antiepileptic medications in utero.

It is important to note that not all babies will experience withdrawal symptoms. Please consult with your healthcare professional for further guidance.

In addition, some (but not all) babies will have ongoing complications due to antiepileptic medication exposure – pages 8 and 9. Please refer to your healthcare specialist if you have concerns about this or are experiencing complications.

This booklet will give you information on:

Introduction	3
Care for yourself	4
Vitamin K	5
Withdrawal symptoms	6
Breastfeeding while on antiepileptic medication	7
Potential longer term effects of antenatal antiepileptic exposure	8
Foetal Anticonvulsant Syndrome	9
Support services	10
Resource	11



Care for yourself

This booklet is designed to guide you (along with your healthcare professional) in how to care for your baby if he or she has been exposed to antiepileptic medications. The first principle is for you to care for yourself, which is always hard after having a baby!

Some points to consider:

- Remember that not all babies exposed to antiepileptic medications during pregnancy will be affected. However if your baby is affected please remember it is as a result of the medication, something completely out of your control, **so do not blame yourself.**
- You need to have a trusted healthcare professional that you can openly talk with and ask questions of. If you do not have one, then find one.
- Ask for the support of your friends and family.
- After you have had your baby, ask your healthcare professional to review your medication to check your dose is correct.
- An excellent resource for you to have a copy of is: *Are you taking medicines for epilepsy, mood or pain? Information for females and their family and whānau.* (See page 11 for where to obtain a copy of this particular resource)

If you have any questions or need some clarification on any of the content in this booklet, ask your healthcare professional. If they are unable to assist you please contact:

Foetal Anti-Convulsant Syndrome NZ (FACS NZ)

Email: denise@facsnz.com

Phone: 021 189 4483

Website: www.facsnz.com

Facebook: www.facebook.com/facsnz

FACS NZ may be able to direct you to relevant healthcare professionals or support agencies.



Vitamin K

All new babies have low levels of vitamin K. Parents are advised to give their babies Vitamin K after birth. This can be either oral or intramuscular (injection) vitamin K injection at the time of birth. Vitamin K is very important because it helps to prevent bleeding.

It is particularly important for women who have been taking antiepileptic medications, such as phenobarbitone, phenytoin, carbamezpine and topiramate ^[1, 2] that their new-born babies receive vitamin K. This is because these medications also carry an increased risk for bleeding issues for babies. ^[3,4]

If you have any queries please consult with your healthcare professional about vitamin K.

[1] <http://epilepsy.org.nz/planning-for-a-baby>

[2] <http://www.adhb.govt.nz/newborn/Guidelines/Blood/VitaminK.htm>

[3] <https://www.midwife.org.nz/pdf/.../Consensus%20Statement%20Vit%20K.pdf>

[4] <https://www.kidshealth.org.nz/vitamin-k>



Withdrawal symptoms

Over the next few days after birth (maybe longer) your baby will need to be monitored to see if they are having withdrawal symptoms from exposure to an antiepileptic medication. Please remember that not all babies exposed to an antiepileptic medication will have withdrawal symptoms.

Withdrawal symptoms as described here can be referred to as “neonatal abstinence syndrome” and many medications can cause this.

If you are unsure as to whether your baby is having withdrawal symptoms please ask your healthcare professional.

Withdrawal symptoms may include:

- Baby is jittery (baby is shaking)
- Baby is irritable
- Muscle tone of baby is stiff and difficult to move, in particular the arms and legs (hypertonia)
- Baby is breathing fast (tachypnoea) or finding it hard to breath
- Baby has a larger than usual response to a sudden or unexpected noise, movement or touch (exaggerated startle reflex)
- Baby is vomiting
- Baby is having difficulties with temperature control

Babies that have been exposed to sodium valproate in pregnancy can also have:

- Low blood sugar or glucose (neonatal hypoglycaemia)

The symptoms of babies who are breastfed may vary due to the level of medication in the breast milk.

PLEASE DO NOT stop taking your medication to breastfeed. Refer to the following page and your healthcare professional for further guidance.

If your baby shows symptoms they will need to be assessed by a healthcare professional.

Breastfeeding while on antiepileptic medication

All antiepileptic medications will pass through your breast milk, which means your baby will still be exposed to your medication, but the level of exposure will vary. Your specialist, midwife or doctor is the best person to talk you through the benefits and risks involved in breastfeeding while taking an antiepileptic medication.

There are definite health benefits to breastfeeding, but your health is just as important. So please do not feel disheartened or less of a mother if it is recommended or jointly decided that breastfeeding is not the best option for your circumstances.

Besides the withdrawal symptoms as listed on page 6, some other signs that your baby might be affected by your medication are if baby:

- develops a rash
- is more sleepy than is usual (your Well Child provider can advise you if your baby is more sleepy than others)
- develops unusual symptoms that are worrying you (speak to your Well Child provider or healthcare professional about these).

If you have any concerns about your baby please have them checked by a healthcare professional. There can be other causes for these symptoms and the safest approach is to discuss them with your healthcare professional.

Some useful links regarding breastfeeding and medication are:

<http://www.infantrisk.com/>

<https://www.medsmilk.com/>

<https://toxnet.nlm.nih.gov/newtoxnet/lactmed.htm>

<https://www.breastfeedingnetwork.org.uk/drugs-factsheets/>

You can also download the app LactMed for more information.

Potential longer term effects of antenatal antiepileptic exposure

Over time your baby will need to be monitored to see if they are having any longer term effects from exposure to an antiepileptic medication. Please remember that not all babies exposed to an antiepileptic medication will have effects.

Depending on the antiepileptic medication your child was exposed to they may be affected in the following ways (please remember every affected baby or child will have different symptoms and some will have no effects):

- Physical malformations, such as; neural tube defects, spina bifida, limb and organ defects, cleft lip and/or palate, dysmorphic facial features, or other defects.
- Learning and developmental problems. These could include Autism Spectrum Disorder, lower intelligence level, developmental delay, attention, memory and processing problems, speech and language difficulties, gross and fine motor issues, and poor muscle tone.

Monitoring your child's development is important to identify any issues that might arise. If you are concerned about the ongoing development of your baby please first talk with your primary healthcare provider – usually your family doctor. They will be able to refer you to the appropriate specialists within your area. Please let them know that you were on an **antiepileptic medication during your pregnancy**.

Many babies who have had exposure to sodium valproate, or more than one antiepileptic medication during pregnancy, are seen by a child development unit or paediatric team, particularly if there are concerns. Early identification of developmental issues allow for early intervention, if they occur. ^[5]

Depending on what part of the country you are in, there may already be processes in place to monitor your child's development. Your healthcare specialist should be able to advise you about this. If not, please contact FACS NZ (contact details on page 9).

[5]

<http://www.adhb.govt.nz/newborn/Guidelines/Maternal/MothersOnAnticonvulsants.htm>



Foetal Anticonvulsant Syndrome

You may have come across the term Foetal Anticonvulsant Syndrome. This is where a group of characteristics combine together to form a syndrome. If you have been purely on one medication e.g. sodium valproate, then Foetal Valproate Syndrome may be diagnosed, otherwise it could come under the bigger heading of Foetal Anticonvulsant Syndrome.

Foetal Anticonvulsant Syndrome occurs when an antiepileptic medication has affected the baby during pregnancy. The syndrome needs to be diagnosed by a specialist when the mother has taken an antiepileptic medication during pregnancy and has a baby/child with a combination of dysmorphic (facial) features, physical malformations and/or neurodevelopmental or cognitive impairments *and* there is no other reason for these difficulties/impairments.

To the mums out there reading this and saying, “This is all my fault. I have done this to my child!” the next statement is very important to read, re-read and allow yourself time to process. This is not your fault. You did not do this to your child; it was the medication not you.

If you would like help Foetal Anti-Convulsant Syndrome New Zealand are able to provide support, education and awareness about foetal anticonvulsant syndromes, and are only a phone call or email away. Their contact details are:

Foetal Anti-Convulsant Syndrome NZ (FACS NZ)

Email: denise@facsnz.com

Phone: 021 189 4483

Website: www.facsnz.com

Facebook: www.facebook.com/facsnz



Support services

There are a variety of different organisations, services and help accessible to assist you with guidance, support and handy tips. Some are listed below.

- ADHD Association
<http://www.adhd.org.nz/>
- Altogether Autism
<http://www.altogetherautism.org.nz/>
- Autism New Zealand Inc.
<http://www.autismnz.org.nz/>
- CCS Disability Action
<http://www.ccsdisabilityaction.org.nz/>
- Cerebral Palsy Society of New Zealand
<http://www.cpsociety.org.nz/>
- Dyslexia Foundation of New Zealand
<http://www.dyslexiafoundation.org.nz/>
- The Dyspraxia Support Group of New Zealand
<http://www.dyspraxia.org.nz/>
- Epilepsy Association of New Zealand
<http://www.epilepsy.org.nz>
- Epilepsy Waikato Charitable Trust
<http://www.ewct.org.nz>
- GKSN: Grandparents of Kids with Special Needs
<http://gksn.org/>
- Healthline
Phone: 0800 611 116
- Heart Kids New Zealand
<http://www.heartnz.org.nz/>
- IHC
<http://www.ihc.org.nz/>
- The National Foundation for the Deaf Inc.
<http://www.nfd.org.nz/>

- The New Zealand Organisation for Rare Disorders (NZORD)
A link to the list of support organisations and groups that NZORD have collated is below

http://www.nzord.org.nz/support_groups

- Parent to Parent
<http://www.parent2parent.org.nz/>

- Plunket
<http://www.plunket.org.nz>



Resource

If you are considering having another child a resource that you would find useful is: Are you taking medicines for epilepsy, mood or pain? *Information for females and their family and whānau.*

<https://www.acc.co.nz/assets/provider/antileptic-medicine-females-family.pdf>

Alternatively you can obtain a copy of the above booklet in print by contacting FACS NZ.

