MUSC Patient Handout
Frequently Asked Questions About Anti-Seizure Medicine
AS AN ACADEMIC MEDICAL CENTER, MUSC offers benefits to the residents of South Carolina and beyond. The highly dedicated, professional team focuses on providing the most effective therapies available while also striving to develop new therapies within a highly active basic and clinical research program. These efforts are backed by facilities with the latest technology. This resource was developed to help patients understand more about their condition, treatment, or procedure. This handout is meant to be used as a guide to supplement your healthcare providers instructions. It is not intended to be used as a substitute for professional medical care. Only your physician can diagnose and treat a medical condition. Please consult your physician if you have any questions.

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1. **Q: How can I get refills?**
A: For MUSC pediatric patients, ask your pharmacist to fax us a refill request at 843-792-3220. Make sure to give us five business days notice. For MUSC adult patients, ask your pharmacist to fax us a refill request at 843-792-2419. Make sure to give us five business days notice. Refills may take longer than 5 business days to process if your insurance carrier requires a “prior authorization.”

**IMPORTANT:** We typically will NOT refill medications for children who have not been seen in clinic for more than 6-12 months, or adults who haven’t been seen in 12 months, so do not put off your follow up visit for too long! We regret that some of our clinics have a 3-4 month waiting period.

2. **Q: What should I do if I miss a dose?**
A: If a dose is missed, take it as soon as you can. If it is almost time for your next dose, wait until then to use the medicine and skip the missed dose. Do not use extra medicine to make up for a missed dose.

3. **Q: Should I bring my medicine to my appointments?**
A: Yes! Please bring all of your medications in the original bottles to every appointment. If you are on a lot of medication you should also talk with your pharmacist about possible interactions between your medicines. Ask him or her to call your health care provider to discuss any concerns they have. Also, your provider will be very grateful if you keep track of how many refills you have left on each medication!

4. **Q: What are the risks of using a medication?**
A: All medications can have unwanted side effects. Unfortunately, untreated epilepsy often has even more serious risks, including injury from seizures, poor attention and learning in school, and depression. To learn more about the possible side effects from a medication, talk with your health care provider, pharmacist, and always read the information that comes with the medicine.

5. **Q: How will this medicine make me feel?**
A: Medicine affects everyone differently. However many seizure medications can make you feel tired and clumsy, especially when you first start taking it. This usually goes away as your body “gets used to” the drug. Until you know how this medicine will affect you, avoid driving, using heavy machinery, or doing anything else that could be dangerous if you are not alert. You should also avoid driving if you have had a seizure within the last 6 months.
6. **Q:** What signs should I look for when starting a new medicine or increasing the dose?

**A:** Anytime there are painful skin changes, such as a red rash, blisters, or mouth sores, or any unexplained swelling or trouble breathing you should tell a health care provider immediately. If you cannot reach your usual health care provider(s), go to the ER and ask to be evaluated for a “possible drug reaction.” Make sure you bring your medicine to the ER with you!

You should also report the following:

- Extreme sleepiness, confusion, unsteady walking or slurred speech (looking “drunk”)
- Vomiting or severe decrease in appetite
- Sudden worsening in seizures
- Unexplained bleeding, bruising more than usual, blood oozing from gums, bloody or black stool or urine
- Yellowing of the skin, eyes
- High fever with a sore throat
- An increased number of infections or illnesses
- Severe muscle pain
- Thoughts of suicide
- If you suspect someone has accidentally taken too much medication, call 911 immediately.

Keep all medicine out of reach of children and pets.

7. **Q:** How should I store my medicine?

**A:** Most medicine should be kept at room temperature, away from direct sunlight. ALWAYS keep the medicine in the bottle it came in, and avoid the temptation to mix old and new pills in the same bottle.

8. **Q:** What would happen if I stopped taking my medicine?

**A:** Suddenly stopping seizure medicine can put you at high risk for severe seizure. If the side effects are very bad and you want to stop taking the medicine, PLEASE call your health care provider first so we can help you transition SAFELY. Also, some medications can not be restarted at the full dose if you haven’t been taking them for more than a day or so. The biggest example of this is lamotrigine. If you have not been taking this medicine for more than several days you should call your provider and get instructions on how to start back slowly.
9. Q: How can I tell if a problem is caused by a medication?
A: If the problem existed before the medicine was started, it is probably not being caused by that medicine. If it began shortly after the medicine was started, or shortly after a dose increase, it may be a side effect. It may also be a side effect if it gets worse as the medicine is increased to higher doses. If you are concerned you should let your health care provider know. If a problem starts after you have been using the medicine for several months or longer, it is probably not a side effect, but you should still let your health care provider know if you are concerned. Anytime there are painful skin changes, such as a red rash, blisters, or mouth sores, or any unexplained swelling or trouble breathing you should tell a health care provider immediately.

10. Q: What is the best time of day to take anti-seizure medication?
A: It is best to take medications at about the same time every day. If you take a medicine two or three times a day, try to spread it out as evenly as you can. Some people do best if they set an alarm to take their morning medicine at the same time everyday, but other people are more likely to have a seizure if they are startled awake, and should take the medicine whenever they wake up naturally. You may need to discover what times work best for you by trial and error, but try to be consistent whenever you can.

11. Q: Can I split or crush my pills?
A: Each medicine is different, but here are some general guidelines:

- It is okay to split any medication with an indentation or “score mark” down the middle – if there is no score mark you should probably not split it.
- Any pill that comes in an extended release form (“ER” or “XR”), should not be split or crushed. These pills will also not work as well if they are chipped or broken.
- Do not split any pill more than once (i.e. do not try to split a pill in quarters or thirds).
- Most pills that can be split will also work if crushed, but you should ask your pharmacist to make sure this is alright before you try it.
12. Q: What is the best way to make sure I don’t forget a dose?
A: Use a pill box and leave your medicine sitting someplace you will always see it, but not someplace where children or pets cannot get into it. If the medicine is not in the box for that day, you know you have taken it. If it is still sitting there you know you still need to. This avoids accidentally missed doses or overdoses. The only exception is for “disintegrating tablets,” which should be left in their blister packs until you are ready to take them. Set a timer on your cell phone to remind yourself. Try not to be too annoyed if other people remind you about your medicine. They are just trying to help, and everyone needs reminders sometimes!

13. Q: Are brand name medications better than generic?
A: In some cases, brand is preferred. It is the position of the Epilepsy Foundation of America, that brand name medications are preferable for the treatment of seizures. The quality of generic medications may be just as good, but the consistency or reliability is not. This is because many different companies can make a generic version of the same drug, and they may all be slightly different. In most people this difference is not significant enough to cause a problem. The trouble is, some people need very precise and consistent amounts of medication, and they may not do as well if they are taking a different generic every month. We encourage patients to try generic for financial reasons (generic drugs are much less expensive). However, if your seizure control has been very difficult to achieve, and you have been doing well on a brand name medication, your provider may not want you to switch. If you are taking generics, ask your pharmacist to give you the “NDC” number (national drug code) for each prescription you pick up. Keep a record of this in your seizure diary, to make it easier to track if you have any changes after trying different generics.

14. Q: How can I tell if I have been getting brand or generic?
A: All drugs have at least two names. One is considered the “generic” name, and the other is the “Brand” name. Sometimes there are more than two names! This can be confusing because some people may refer to brand medication using the generic name and vice versa. This is another reason why you should bring all your medication bottles to appointments with you. Below are examples of the brand and generic names of anti-seizure medications, although some of them are not commonly used. Check to see what is written on your bottle from the pharmacy.
<table>
<thead>
<tr>
<th>Generic Names</th>
<th>Brand Names</th>
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<tbody>
<tr>
<td>Carbamazepine</td>
<td>Carbatrol, Tegretol, Tegretol XR</td>
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<tr>
<td>Clobazam</td>
<td>Frisium</td>
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<tr>
<td>Clonazepam</td>
<td>Klonopin</td>
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<tr>
<td>Clorazepate</td>
<td>Tranxene</td>
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<tr>
<td>Diazepam</td>
<td>Valium or Diastat</td>
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<tr>
<td>Ethosuximide</td>
<td>Zarontin</td>
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<tr>
<td>Felbamate</td>
<td>Felbatol</td>
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<tr>
<td>Fosphenytoin</td>
<td>Cerebyx</td>
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<tr>
<td>Gabapentin</td>
<td>Neurontin</td>
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<tr>
<td>Lacosamide</td>
<td>Vimpat</td>
</tr>
<tr>
<td>Lamotrigine</td>
<td>Lamictal, Lamictal XR, ODT</td>
</tr>
<tr>
<td>Levetiracetam</td>
<td>Keppra, Keppra XR</td>
</tr>
<tr>
<td>Lorazepam</td>
<td>Ativan</td>
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<tr>
<td>Oxcarbazepine</td>
<td>Trileptal</td>
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<tr>
<td>Pregabalin</td>
<td>Lyrica</td>
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<tr>
<td>Primidone</td>
<td>Mysoline</td>
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<tr>
<td>Phenobarbital</td>
<td>Luminal</td>
</tr>
<tr>
<td>Phenytoin</td>
<td>Dilantin</td>
</tr>
<tr>
<td>Rufinamide</td>
<td>Banzel</td>
</tr>
<tr>
<td>Tiagabine</td>
<td>Gabitril</td>
</tr>
<tr>
<td>Topiramate</td>
<td>Topamax</td>
</tr>
<tr>
<td>Valproate, valproic acid, divalproex sodium</td>
<td>Depakote, Depakene</td>
</tr>
<tr>
<td>Vigabatrin</td>
<td>Sabril</td>
</tr>
<tr>
<td>Zonisamide</td>
<td>Zonegran</td>
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</table>
15. Q: How should I take my medicine?
A: Your health care provider will tell you how much of this medicine to use and how often. Do not use more medicine or use it more often than your health care provider tells you to.

- You can take most seizure medications with food to avoid an upset stomach.
- If you are giving medication mixed in food or a drink, only use a small amount of food incase the person doesn’t finish a whole serving. Follow up with another swallow of food or drink to make sure all the medicine is swallowed
- If you are taking an extended release tablet (e.g. a medication with “ER” or “XR” after the name), do not crush, break, or chew it. Avoid using “ER” or “XR” tablets that is cracked or chipped. If they are cracked or chipped when you buy them, your pharmacist should replace the damaged pills.
- If you are taking an “XR” capsule (e.g. Carbatrol XR), you may swallow it whole or open it and pour the “beads” into a small amount of soft food such as pudding, yogurt, or applesauce. Swallow the food without chewing.
- Some medications come in “sprinkle capsules.” These can be opened, and the beads or “sprinkles” inside can be mixed into a bite or two of soft food and swallowed (Do NOT chew the sprinkles!).
- If you are taking zonisamide (Zonegran), you can open the capsules and squeeze out the contents, but this is not ideal.
- If you are taking the liquid, shake it very well before each use, and measure it with a marked measuring spoon, oral syringe, or medicine cup.

16. Q: Will this medicine interfere with my birth control?
A: Maybe. Some seizure medicines make hormonal birth control (like the pill, depo shots, and nuva ring) less effective or ineffectve. If you are taking any of the following medications you should AL-WAYS use barrier methods such as condoms/diaphragms with spermacide to “back up” your hormonal birth control: topiramate, carbamazepine, oxcarbazepine, phenobarbital, phenytoin, primidone, rufinanamide.
17. Q: Will my baby be safe if I take this medicine while I’m pregnant?
A: It depends. Newer medication such as Lamotrigine and Levetiracetam (Lamictal and Keppra) are thought to be safer choices if you are thinking about becoming pregnant. Women who are taking valproate (Depakote), carbamazepine, phenytoin, phenobarbital, primidone when they first become pregnant are more likely to have a child with a birth defect. Any woman who is sexually active or thinking about becoming sexual active should talk with her health care provider if she is on any of these medications, even if she plans to use birth control (remember, NO birth control is 100% effective!). If possible, she should probably be switched to a different medicine. Of course, all women with epilepsy should take 1 milligram (=1,000 micrograms) of folate every day, to reduce the chance of birth defects even more! It is important to start the folate BEFORE you become pregnant.

18. Q: Can I breastfeed while taking this medicine?
A: All seizure medications cross into the breast milk, but that does not mean you cannot breastfeed in every case. It is recommended that you avoid all breastfeeding if you are taking phenytoin, Phenytoin, carbamazepine. If your baby seems overly lethargic you should ask his or her pediatrician to draw a drug level to ensure he or she isn’t “toxic.” If they are getting too much of the drug you should consider bottle feeding only, or at least cutting back on breast milk and using some formula in between breastfeeding.

19. Q: Is it safe to take medications for other conditions?
A: Make sure all of your health care providers are aware of all medications and supplements (whether they are prescribed or “over-the-counter”). You should always double check you’re your pharmacist to learn more about drug safety. There are many medications which can increase the risk of seizures. Avoid over the counter sleeping pills, and try to avoid over the counter antihistamines, or cold/allergy medicine. Medicines like acetaminophen (Tyleol), ibuprofen (Motrin), saline nasal spray, Robitussin DM or Duratuss, and humidifiers/vaporizers are OK.
Most cold medicines, for example, as well as medicine for “attention deficit” can increase the risk of seizures. On the other hand, being absolutely miserable with a cold can also increase your risk for a seizure. If you are feeling really badly, you are probably better off taking something to make you feel better. Likewise, if your grades or work is poor because you can’t concentrate, you may find the possible reward of taking medicine for your attention/hyperactivity is worth the small risk of promoting your seizure. Your health care provider should help you decide (and ONLY YOU can make the decision!), if the rewards of taking a medicine are more or less than the risks.
Estrogen can promote seizures in some people. The best birth control for someone with seizure disorders is to combine a low estrogen hormone therapy, like “Depo” shots or low estrogen birth control pills, with a barrier method such as condoms/diaphragms with spermicide. If you are going through menopause you and your women’s health provider may decide estrogen replacement is needed. This is OK, but you should report any increase in seizures to your neurologist and women’s health provider.

20. Q: Can I drink alcohol or take drugs with this medicine?
A: Alcohol and stimulant drugs (like cocaine) can increase your risk of having a seizure. If you are going to consume alcohol, do so with extreme moderation. Also avoid staying up late and getting over tired on nights you have alcohol, since being tired will increase the risk even more. All drugs, including opiates and marijuana are unhealthy for your brain cells, which are already at risk because of your seizure disorder. Think of it this way: you have an extra good reason to avoid doing something that isn’t good for you anyways!

21. Q: How often should I have my blood tested when I’m on anti-seizure medicine?
A: Medications that may require frequent monitoring are phenytoin (Dilantin) and Phenobarbital. Other medications may require some blood tests to make sure the medicine is well tolerated by your body. Once you have been on a medication awhile you should not need frequent blood tests. Your health care provider may only check your blood if you have had a recent increase in seizures, if you are showing signs of “toxicity” (too much medicine in your body), or if you are doing really well (just to record what drug levels work best for you).

22. Q: If I feel great but my medicine level is high in my blood, do I still have to lower my dose?
A: Probably not. If you are not having any problems on a higher level of medicine, then there may be no need to change your dose. Your provider can monitor you in case a problem develops, but many people need a higher than usual level of medicine to feel their best.
23. Q: Is it true that anti-seizure medication can increase the risk of suicide?
A: Many medications have been said to increase sad feelings and even thoughts about suicide. Experts disagree on whether or not anti-seizure medications cause this problem. At most, it may affect up to 0.2% of people taking anti-seizure medications. No matter what medication you are taking, always let your health care provider know if you have any of these symptoms:
• Attempts to commit suicide or thoughts about suicide or dying
• New or worsening depression, anxiety, panic attacks, mood swings, or irritability
• Feeling agitated or restless
• Trouble sleeping (insomnia)
• Acting on dangerous impulses or acting aggressive, being angry, or violent
• An extreme increase in activity and talking (“mania”)
• Other unusual changes in behavior or mood

24. Q: What is the best way to dispose of old medication?
A: A program called Smarxt Disposal (http://smarxtdisposal.net/#note) has tips to prevent children, pets, & others from accidentally taking old medication without polluting our planet!

1) DO NOT FLUSH unused medications and DO NOT POUR them down a sink or drain.*
2) When discarding unused medications, ensure you protect children and pets from potentially negative effects:
   a) Pour medication into a sealable plastic bag. If medication is a solid (pill, liquid capsule, etc.), crush it or add water to dissolve it.
   b) Add kitty litter, sawdust, coffee grounds (or any material that mixes with the medication and makes it less appealing for pets and children to eat) to the plastic bag.
   c) Seal the plastic bag and put it in the trash.
3) Remove and destroy ALL identifying personal information (prescription label) from all medication containers before recycling them or throwing them away.
4) Check for Approved State and Local Collection Programs. In certain states, you may be able to take your unused medications to your community pharmacy or other location for disposal.

*Note: Follow any specific disposal instructions on the drug label or patient information that accompanies the medication.