

Have Your Say on Drug Shortages

“Your medication isn’t available”. This shocking news from your pharmacist comes out of the blue with little time to seek solutions. Unfortunately, it’s often the first notice that people receive that there is a drug shortage and many people with epilepsy cannot simply change their medication safely on short notice.

Over the past five years there have been frequent drug shortages in Canada, including multiple shortages of epilepsy medications. The situation is not getting better. If nothing is done to identify and address the causes of drug shortages we expect the situation to get worse in the coming years.

There is a website run by the pharmaceutical companies, drugshortages.ca, that provides information about current and past shortages. However, reporting on that site is voluntary, and we are often left with confusing or incomplete warnings, if any at all. Drug shortage notices on the website sit there with little effect. Most people still learn about a drug shortage from their pharmacist when they need their prescription refilled. Patients are often the first to inform health care providers about a drug shortage. People are still scrambling at the last minute to try and find solutions.

How can this change? We believe a mandatory system, where drug manufactures have to report shortages early, with clearer explanations of the situation, will provide the most options for patients and doctors to prevent a dangerous situation.

It doesn’t stop there. The posting of a drug shortage notice on a website should not be the beginning and the end of drug shortage management in Canada. ***Early notification is required as part of a complete plan to prevent drug shortages and manage them when they do happen.***

Health Canada is holding a public consultation on the current approach to drug shortages from May 22 to July 5, 2014. The Canadian Epilepsy Alliance encourages everyone concerned about drug shortages to participate.

The online consultation takes about 10-20 minutes to complete and will go a long way to making sure decision makers hear from the people most affected by drug shortages. You can also download the consultation questions and mail in your response. The consultation has additional background information before each question that you might find useful as well.

Link to the public consultation on drug shortages:

English: www.hc-sc.gc.ca/dhp-mps/consultation/drug-medic/consult_shortages-penuries-eng.php

French: www.hc-sc.gc.ca/dhp-mps/consultation/drug-medic/consult_shortages-penuries-fra.php

Questions about drug shortages? Contact your local epilepsy agency or call 1-866-EPILEPSY (866-374-5377)

Here are the questions in the consultation along with some suggestions and ideas that the Canadian Epilepsy Alliance believes are the key issues. Remember, these are just suggestions and providing your own experiences and ideas about drug shortages is incredibly important.

Question 1) For the purposes of this consultation, please indicate the type of group you are representing. **Select “Interested Canadian” unless one of the other categories better describes you**

Question 2a) Prior to this public consultation, had you visited www.drugshortages.ca? **Answer Yes or No**

Question 2b) If yes, how often and what information were you looking for? Were you able to find it/access it? (maximum 250 words)

On the website, was it easy to find the information you were looking for? Was it easy to understand the information? Was there any information explaining what you should do? What could be added that would be useful?

Question 3) Prior to this public consultation, were you familiar with the approach to drug shortage notification in Canada? **Answer Yes or No**

Following this question there are notes from Health Canada about how the system is supposed to work. The next question asks how the system actually works.

Question 4a) The notification of drug shortages should be timely, reliable and comprehensive. In your experience, is the current system meeting these objectives? **Answer Yes, No, or Not enough knowledge to make an assessment**

Question 4b) If no, please explain how the current system is not meeting these objectives. (maximum 250 words) **If you have personal experiences of how the current system isn't working well please share them.**

Canadian Epilepsy Alliance perspective:

No. The information is not timely, reliable, or comprehensive. We have no confidence in [drugshortages.ca](http://www.drugshortages.ca) as a one-stop shop for information on drug shortages. Some shortages are reported and some aren't, resupply dates often change, are missing, or are unrealistic.

Notification and updates seem to come a long time after the drug manufactures should be aware of them, or after drugs are already in short supply. There is no way for patients, pharmacists, or physicians to get automatic updates for the drugs relevant to them, and they must visit the site on a frequent basis and search for their particular drugs.

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Question 5a) Based on your experience, please explain how the current approach

Question 7a) If you support a voluntary approach to drug shortage notification for the Canadian system, please explain your reasons. (maximum 250 words)

Question 7b) If you support a mandatory approach to drug shortage notification for the Canadian system, please explain your reasons. (maximum 250 words)

Canadian Epilepsy Alliance perspective:

The Canadian Epilepsy Alliance supports a mandatory approach to drug shortage notification. The voluntary approach has been in place for over 2 years and it is not working.

The current notification system is unreliable. There have been multiple failures to provide advance notice of epilepsy drug shortages, including with divalproex sodium (Epival), clobazam (Frisium), and Celontin.

Late notification defeats the whole purpose of an “early warning” system and makes it unlikely that a shortage could be avoided or better managed by government, drug manufacturers, pharmacists, physicians, and patients.

Some companies do not provide notifications at all. For example, two companies that market clobazam in Canada have yet to provide any notification on drugshortages.ca even though their products are currently unavailable.

Question 8a) Please indicate for which of the following drug product categories advance notification of shortages and discontinuances should be provided. [Note: Please check all that apply]

- Critical medicines only (drugs determined to be medically necessary and deemed to have the greatest impact on human health)
- All prescription drugs (e.g., heart medications, antibiotics, and anti-anxiety medications)
- All medicines

All Question 8b) Please provide any additional comments you may have, if any, on the question above. (maximum 250 words)

Share your thoughts about which drugs should have advance notice of shortages.

What would happen if you are unable to get the medications you need?

Question 9) Please provide any additional comments you may have regarding this document or drug shortage notification processes and/or approaches. (maximum 250 words)

Share your stories, experiences, and ideas about drug shortages.