

Managing Your Medication

New treatments are what give the greatest hope in making CML a manageable disease. It's important to treat them with respect and do everything you can so that they can give you the most possible benefit, with the least possible side effects. Here are some tips:

- Take your medication as instructed. This sounds obvious, but it can be difficult to ensure you take your medicine every time, at the right time and in the right way (*with a meal, after a meal, depending on your medicine*). Work out ways to ensure you are reminded when it's time.
- Particularly if you are doing something out of your normal routine, plan in advance a way to be reminded to take your medicine, perhaps by asking someone you will be with to remind you or by carrying a portable alarm, such as those available on many mobile phones.
- Look for any side effects and record mild ones to tell your doctor at your next visit. Contact your doctor right away if you develop severe side effects, such as fever or chills or other signs of infection, bleeding or bruising or increasing shortness of breath.
- Keep yourself as healthy as possible, and give your medicine the best chance of helping you, by eating healthy, well-balanced meals and getting plenty of rest.
- Don't take any "natural" medicines or supplements without first asking your doctor. For example, St. John's wort, which is taken by many to treat depression, can greatly lessen the impact of certain CML treatments so must be avoided.

WHAT does that mean?

Some medical terms explained

Blast cell: An immature white blood cell that does not function properly.

Blood count: The number of red and white blood cells and platelets in a blood sample.

Bone marrow: The soft tissue inside bones that produces blood cells.

Bone marrow test: A simple procedure involving collecting a small sample of cells or tissue from the bone marrow.

Chromosome: An organized structure of DNA and protein that is found in cells.

FISH Assay (*fluorescence in situ hybridization*): is a cytogenetic technique that allows scientist to localize the presence or absence of specific DNA sequences on chromosomes. In our case it finds the Philadelphia Chromosome.

International Scale: A standardization process to ensure that all laboratories performing PCR testing on CML patients cell samples adhere to the same standardization process.

Leukemia: A broad term generally used to refer to a variety of cancers of the blood and bone marrow.

Log Reduction: It is a mathematical term used to express the reduction of CML cells in your body and how well you may be responding to treatment.

PCR (*Polymerase chain reaction*): A molecular duplicating process that creates millions of copies of a desired portion of DNA through repeated cycling of a reaction using heating/cooling. This process enables scientists to obtain DNA information from small specimens. **Watch the CML Society of Canada educational video "What is PCR" on Youtube: <http://www.youtube.com/watch?v=ZwgynKh6J5U>**

Philadelphia chromosome: The chromosome abnormality that causes CML caused by pieces from two different chromosomes breaking off and joining together to create this new, abnormal chromosome.

Platelets: The blood cells that promote clotting to help stop bleeding.

Prognosis: A medical term referring to the chance of a patient's recovery and the doctor's prediction of how that patient will progress.

Remission: The disappearance of the signs and symptoms of disease.

White blood cells: Blood cells that help fight infections

FEELING WELL



Living with
Chronic
Myelogenous
Leukemia

Thanks to new treatments,

many people with CML are able to manage their disease for many years while enjoying full and satisfying lives.

You can help your chances of getting your disease under control and minimizing possible side effects of treatment by helping your body fight the disease.

The main way is by living in as healthy a manner as possible – eating well, getting appropriate exercise, getting enough rest, minimizing stress and enjoying the company of family and friends.

It also helps to learn and record as much as you can about your disease, the tests and treatments involved and the ways you can help your doctor provide the best care possible.

DEAR DIARY...

Managing a disease like CML can be overwhelming, but there is hope. It's important to recognize, however, that this represents a change in your life and the lives of your family members and those close to you. There are bound to be difficult days and strong emotions.

A diary is a great place to work out your thoughts, fears and concerns. Hold nothing back. Take a few healing deep breaths and spill out your deepest thoughts about how you have been feeling, your fears, and your dreams. Your diary can become your private sanctuary, the one place to which you can always turn to deal with your emotions and let things out.

You can also use your diary to record how you have been feeling physically each day and any side effects or problems you have been having. You can then re-read this information before a doctor visit and write down relevant details to give your doctor, which will help him or her with any adjustments to your treatment.

That's what friends are for

While close friends and family members will likely also be having a difficult time adapting to your disease, they can be an immense source of strength and support as you go through difficult times – and to help you celebrate successes and progress! Emotional support from others is vital, so seek it out.

If you haven't got close friends or family available to you, there are numerous online chat groups that are useful for information and support, or seek out a counsellor or religious leader with whom you can discuss your thoughts and emotions.

Don't keep your feelings bottled up!

FOOD & HEALTH TIPS

It's important for everyone to eat regular, well-balanced meals with healthy ingredients (*fruits, vegetables, grains, etc.*), but it's even more important if you have CML so your body has the best chance to fight the disease.

- Drink plenty of water (*8 glasses a day*), especially when you take your medication.
- Drink alcohol only in moderation, or not at all.
- If your medication causes nausea, try eating smaller meals, but more frequently.
- Be even more careful about avoiding infections because your disease may make you more at risk – wash your hands often and ensure good cleanliness in your surroundings.
- Restrict your exposure to the sun and use sunblock (*SPF 15 or higher*) when outside because CML medications can make your skin more sensitive.

MAKE THE MOST OF YOUR DOCTOR VISITS

Your doctor visits are a vital part of your management of CML and it's important to make the most of them. Here's how:

Preparing for the visit

- Between doctor visits, keep a sheet of paper handy headed "Things to ask my doctor". When you think of something, write it down, then bring the list to your doctor visit. Leave room on the sheet to record the doctor's responses.
- Keep a record of side effects you have had, such as fatigue, nausea, diarrhea or tingling sensations in your limbs. An accurate record will help your doctor adjust your treatments to try to minimize side effects.

For the visit

- Ask a friend or family member to accompany you to act as a notetaker, recording answers to your questions and any new instructions. It's very difficult to take in all that information by yourself, and it's good emotionally to have someone to talk it over with later.

After the visit

- Take time with your notetaker to review all the notes from the meeting and to discuss what the doctor said.
- If you have any doubts about the instructions you've been given, call or e-mail your doctor to get them clarified.
- Make a note in your calendar of dates for future appointments or tests and prepare a new "Things to ask my doctor" sheet.

KNOWLEDGE IS POWER

Living with a disease like CML can be scary and overwhelming. Building your knowledge and understanding of the disease, the tests and treatments, and other information is a great way to fight back. The more you know, the better you will be able to make the changes necessary in your life to increase your chances of overcoming the disease.

Seek out information on the internet, but only from trusted and reputable sources such as medical institutions or patient and disease societies. When you find information about treatments, ensure the information is meant for Canadians, as different countries have different treatments and policies.

Established in 2006, the CML (Chronic Myelogenous Leukemia) Society provides support, education and information on CML, current and emerging treatments and research initiatives for people living with CML and their families. Through these efforts and ongoing advocacy, the mission of the CML Society is to help reduce suffering and improve care and the quality of life of CML patients.

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