

Manage your life, not your disease

"Life is what happens to you while you're busy making other plans."

– John Lennon

This famous song lyric is a good thing for people with CML to remember. Once the disease has been brought under control by treatment, it's time to ensure your focus is on your life, not your disease.

Of course, for the period after diagnosis and while you're still seeking the right treatment for you, it's natural that the disease will dominate your life. Fortunately, many people with CML can reach the stage where their health can resume taking a backseat to their life. It's important to recognize that moment, relish it, and plunge into whatever life might offer you, or whatever you've been dreaming about.

Do you want to go back to school? Find a new job? Pursue a new hobby or activity? This is the time in managing your CML to seize on all the possible opportunities you can to build a life as much without CML as possible, even though the disease will remain with you.

At this stage of managing your CML, you will have learned a lot about the disease, how it and your treatment have affected your body. It's vital to stay in tune with your body, take care of it with good nutrition, rest and exercise, and to be alert to signs of anything changing.

But at the same time, you need to move on. Stop thinking of yourself as a "patient" and become a "person" again. You've faced a major health threat and overcome it, so you know the value of feeling good and being able to choose what you want to do, instead of having your disease choose for you. So, go ahead, and as that famous ad slogan says, *"Just do it!"*

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

LONG - TERM LIVING



Living
your life
not
the disease

TIPS ON THE MANAGEMENT of Chronic Myelogenous Leukemia

After the shock of diagnosis of CML comes treatment. And for many patients, treatment can be a great success, making the disease chronic but manageable – while research continues towards a cure.

That's where challenges arise, in making CML a disease you can manage, without having it manage your life.

While we expect a cure for this disease, for the meantime you need to be able to live your life with the disease, and a variety of things can help you do just that, as outlined in this pamphlet.

USE YOUR KNOWLEDGE

In your journey with CML, you've likely found that learning more about your disease and your treatments has made things easier. Knowledge is, indeed, power – power to overcome fear and the unknown.

As you continue in your encounter with CML, it's important to remain informed about the disease, new research and treatments, and to work to ensure that our public health system makes the newest and best treatments readily available to Canadians – including you – who need them.

Being involved with a CML group, either in person or online, joining online chat rooms, or just following news online and through other sources can be tremendously useful and empowering, particularly if or when you start facing new challenges in fighting your own disease.

*So stay informed,
stay connected – and stay
empowered
to face your future!*

GIVING CML YOUR BEST SHOT

Once you've found a treatment that works for you, and you've managed to get your CML under control, it's vital to do everything you can to try to keep things in that good state.

Here are some tips:

Regular doctor visits

Make sure you keep up your doctor visits, and bring to each one a record of how you've been feeling (*track it in a diary so you don't forget*) and any questions you have. Bring a friend to take notes of the doctor's comments and to help you remember what you are told – or just to be someone to talk things over with later.

Keep on treatment

If getting on the right treatment is what has made you feel better, don't stop! Keep taking your treatment regularly, as prescribed. Don't make the mistake of thinking that because you feel better, you don't need medicine any more. Don't make any changes without the instructions of your doctor.

Watch your lifestyle

Your body has been through a lot with CML, and continues to need all the support it can get. Eat a healthy, balanced diet with lots of fresh fruit and vegetables. Of course, treat yourself now and then, but within reason. Exercise as much as you can and as you are able to build your body's strength.

Usually, the kinder you are to your body,
the kinder it will be to you.

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.

Tel: 1-866-931-5165

www.cmlsociety.org



THE VALUE OF GIVING BACK

"So just call on me brother, when you need a hand, we all need somebody to lean on."

– “Lean on Me” by Bill Withers

When you go through something as difficult as facing a diagnosis of CML and getting yourself feeling better again, you realize the truth of that song – we do “all need somebody to lean on.”

But it's not a one-way street, and often the person who is being leaned on gets as much out of the experience as the one doing the leaning.

That's why, when your health and strength return, it can be tremendously satisfying and fulfilling to find a cause to give yourself to, in as small or as large a way as you wish.

Having traveled the path you have, you have a wealth of experience and knowledge that can be incredibly valuable to others who are just starting their journey with CML and are, like you probably were, scared about and questioning what is happening to them. Consider helping out with the various organizations that help persons who have lived the CML experience for some time match up with the newly diagnosed. Some wonderful long-term relationships are developed from such encounters.

But don't feel you have to limit yourself to involvement with others with CML. It can be equally fulfilling to work with any number of volunteer or community organizations. Working with others can be tremendously therapeutic in helping you forget your own issues and problems, while helping others at the same time.

*What a great
double-edged benefit!*