
Relapse in Chronic Myeloid Leukaemia (CML)

A Guide for
Patients

Introduction

A relapse is the return of leukaemia after treatment. Specifically, this booklet is about a relapse in chronic myeloid leukaemia (CML).

You may be feeling frightened, disappointed and upset after going through your treatment only for it to return.

This booklet aims to help you understand better what relapse means, what the next steps are, what your options are regarding treatment, how to deal with loved ones, how to manage emotions, and what help and support is available to you.

The booklet was written by our Patient Information Writer, Isabelle Leach, and peer reviewed by Professor Mary Frances McMullin. We are also grateful to our patient reviewer, Mike Blackmore, for his valuable contribution.

If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.30am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be

found on our website at **www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/**

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/**

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call

08088 010 444 or email
support@leukaemicare.org.uk

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, **www.leukaemicare.org.uk**, as well as speak to one of our care advisers on our online support

service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemicare.org.uk**

Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to **www.leukaemicare.org.uk/communication-preferences/**

What is chronic myeloid leukaemia?

In chronic myeloid leukaemia (CML), myeloid cells start overmultiplying in the bone marrow leading to large numbers of abnormal, immature myeloid cells called blasts, which prevent the bone marrow from producing enough healthy blood cells of all types.

Myeloid cells are a subgroup of white blood cells which include granulocytes, monocytes, macrophages, and dendritic cells. Any of these cells can increase in great numbers in CML, but granulocytes are the cells which are commonly known to expand in the bone marrow.

Granulocytes are the most common myeloid cells and consist of three types of cells (neutrophils, eosinophils and basophils), all of which have small granules within the body of their cell, hence their name granulocytes. These granules contain proteins used for helping to fight off viruses and bacteria.

CML can occur at any age, but is more common in middle-aged

and older people, and very rare in children and adolescents. At diagnosis, the median age of patients with CML is 60 to 65 years, and it occurs more commonly in men than women.

CML incidence, which is approximately one to two per 100,000 of the population per year, is known to increase with age. CML represents approximately 15% of newly diagnosed cases of leukaemia in adults, but only accounts for 2% of newly diagnosed cases of leukaemia in children younger than 15 years.

There are three separate stages in the development of chronic myeloid leukaemia:

- **Chronic phase:** Generally, no symptoms are noticed during this phase, but myeloid blast cells are present in the blood and bone marrow. Patients can remain in this phase for several years before proceeding to the second, accelerated phase.
- **Accelerated phase:** Increased numbers of blast cells are

present in the blood and marrow, with the number of normal cells decreasing accordingly. The accelerated phase normally lasts from three to nine months.

- **Blast phase:** This is the final phase of CML which is also called the 'blast crisis'. The disease is similar to acute myeloid leukaemia during this stage with more than 30% of bone marrow and blood cells being blast cells. Unless it is treated, death will occur within three to six months of entering the blast phase.

What is a relapse?

Relapse for CML is the return of CML in patients who have already undergone treatment and reached remission.

Remission can be established by examining:

- **Blood samples (haematological remission):** Blood counts return to within the normal range.
- **Blood and marrow at the cell level (cytogenetic remission):** Diseased cells have been greatly reduced, or no longer appear, in the bone marrow.
- **Blood and marrow at the molecular level using sensitive tests such as polymerase chain reaction analysis or flow cytometry (molecular remission):** No evidence of disease in the blood cells and/or bone marrow is seen at all.

When a relapse occurs, the blasts in the bone marrow start overmultiplying again, reaching levels higher than those appropriate for remission, whichever type of the remissions above are being considered.

After the introduction of the tyrosine kinase inhibitors (TKIs), survival of patients with CML was greatly improved, and response rates for patients treated with the first tyrosine kinase inhibitor, imatinib, increased to around 60%. In these patients, the European LeukemiaNet for CML recommends lifelong maintenance of treatment with tyrosine kinase inhibitors. However, treatment with tyrosine kinase inhibitors for life has several disadvantages including side effects, impaired quality of life for patients, especially younger patients, and the cost of the drugs.

In recent trials (including DESTINY), stopping treatment with kinase inhibitors was attempted and approximately half of the patients who had achieved molecular remission maintained their remission off treatment. The STIM (Stop Imatinib) study assessed the risk of relapse in patients who had achieved complete molecular remission for more than two years while on imatinib treatment. Initial results showed that nearly 40% of the

patients maintained a molecular remission after cessation of imatinib despite persistent leukaemic cells at a low level in most patients.

The six-year follow up of the STIM trial concluded that imatinib could safely be discontinued in patients with a continued molecular remission and who did not have a late response. Moreover, almost all patients were able to achieve complete molecular remission again once imatinib therapy was restarted.

Why does relapse happen?

The current treatment for CML is targeted therapy with tyrosine kinase inhibitors. The first tyrosine kinase inhibitor available was imatinib, which substantially improved the survival of patients with CML. Approximately 60% of patients treated with imatinib achieved good responses. However, with time, approximately 15-30% of patients relapsed or failed to respond to initial treatment (also known as refractory treatment),

mainly due to resistance to the tyrosine kinase inhibitors.

The resistance of patients with CML to imatinib has been linked to having the BCR-ABL1 mutation. CML is characterised by the presence of a mutation known as the Philadelphia chromosome, which is caused by a swap of DNA material between chromosomes 9 and 22 (translocation) that leads to production of the cancer protein BCR-ABL. The BCR-ABL protein causes overproduction of myeloid cells and prevents them from being destroyed, thereby allowing them to increase in number.

The Philadelphia chromosome is present in 95% of patients with CML, with the remaining 5% having other types of mutations that have similar effects. Some biological factors have been shown to increase the risk of relapse after discontinuation of treatment with tyrosine kinase inhibitors. This is currently a topic of research that is ongoing.

Detection of these mutations during treatment with imatinib has allowed prediction of

What is a relapse? (cont.)

subsequent relapses or poor response. Patients with these mutations will require a change in treatment.

How often does relapse occur?

After discontinuation of treatment with imatinib, around 60% of patients with CML will relapse. The majority of these relapses happen within the first six months. However, patients often respond to re-initiation of imatinib.

Following an allogeneic stem cell transplantation (ASCT), relapse is reported at varying rates of up to 8%. The latest relapse reported after an ASCT was 18 years.

What are the symptoms of relapsed CML?

Approximately 85% of patients are diagnosed in the chronic phase, which is associated with an increase in the number of white blood cells and an enlarged spleen. These symptoms are often discovered incidentally during a routine blood test or general physical examination. More advanced phases are associated

with bone marrow failure and carry a poor prognosis.

The full list of symptoms with relapsed CML are similar to those for newly diagnosed CML, and include:

- Fatigue
- Weight loss
- Loss of energy
- Decreased exercise tolerance
- Enlarged spleen, liver, or both
- Decreased food intake due to enlarged spleen
- Fever
- Excessive sweating
- Bone pain (this occurs mainly during the blast phase)
- Bleeding, bruising easily, petechiae (small red spots on skin) (this occurs mainly during the blast phase)

In children, the presentation of CML is more aggressive and features a hugely enlarged spleen, very high cell counts and blast cell percentages.



How is relapsed CML diagnosed?

The majority of CML cases are diagnosed during the chronic phase in which the patient's condition can stay constant for a long period of time. In due course, the CML may progress into an 'accelerated' and then into the 'blast' phase.

The diagnosis of relapsed CML is similar to that of the initial diagnosis using the following tests:

- **Complete blood count** to show the number of red blood cells, white blood cells and platelets.
- A **peripheral blood smear** where a sample of blood is viewed under a microscope to count different circulating blood cells, and to see whether the cells look normal. In relapsed CML patients, there will be an excess of blast cells.
- **Bone marrow aspiration and biopsy** where the aspiration procedure removes a liquid marrow sample and the biopsy removes a small amount of bone filled with marrow. Medication is given to numb the area, or a general anaesthetic is

performed, to remove a sample from the hip bone. The following can be examined:

1. Percentage of myeloid cells in your bone marrow
 2. Any abnormalities of the myeloid cells
 3. Immunophenotyping: This procedure identifies the types of proteins on the surface of the myeloid cells to find out if they are myeloid B-cells or T-cells
- **Lumbar puncture** to determine if the myeloid cells are in your central nervous system (brain and spinal cord).
 - **Chromosomal analysis** (also called cytogenetic analysis) is a blood smear sample that can be used to identify certain changes in the number and size of chromosomes within cells that might have led to the relapse.
 - **X-rays** to monitor the presence of CML in any organs.



How is relapsed CML treated?

For patients with relapsed CML, the goal of treatment is to return to the chronic phase. Before tyrosine kinase inhibitors were available, the only treatment choices for patients with CML were drugs that reduced the number of myeloid cells such as interferon alpha, hydroxycarbamide and busulfan, or an ASCT. The reduction of myeloid cells was primarily supportive care (palliative care) which did not alter the course of the CML.

With the advent of imatinib and the newer tyrosine kinase inhibitors (nilotinib, dasatinib, bosutinib and ponatinib), CML is now controllable, enabling patients to reach long-lasting remission even after relapse. These tyrosine kinase inhibitors have prompted the development of a new concept in the evaluation of CML patients known as Treatment-free Remission (TFR).

Evidence from clinical trials has shown that up to 40% of patients who have had a molecular remission stay in remission after stopping treatment. The future of CML treatment will be to establish

safe and effective criteria for discontinuing tyrosine kinase inhibitors, while increasing the number of patients who would be able to take advantage of this option. However, until these criteria have been defined, discontinuing therapy should be restricted to clinical trials.

Tyrosine kinase inhibitor therapy

Relapsed or refractory CML is normally managed using targeted therapy with a tyrosine kinase inhibitor. If you are currently receiving targeted therapy but you have had a relapse, the dose may be increased, or a different tyrosine kinase inhibitor or other type of treatment may be tried.

Targeted therapy drugs used for relapsed CML

Imatinib is the first-line therapy and is currently considered as standard treatment.

- If resistance (20-30% of patients) occurs with imatinib, or poor tolerability (5-10% of patients) becomes a problem, the new second-generation tyrosine kinase

inhibitors (nilotinib, dasatinib and bosutinib) or the third-generation tyrosine kinase inhibitor ponatinib may be used.

New tyrosine kinase inhibitors

These drugs are more effective, have different unique side effects, and are more likely to achieve good responses as acquiring BCR-ABL mutations is also reportedly lower with these drugs.

- **Nilotinib:** This a potent BCR-ABL1 mutation inhibitor, which can be given as a first line therapy, but is also of great value for patients whose CML is resistant to imatinib, or patients who cannot tolerate the side effects of imatinib.
- **Dasatinib:** As with nilotinib, this drug may be used as a first line therapy, or for patients whose CML is resistant to imatinib or who cannot take the side effects. In the Phase 3 DASISION study of 519 patients in the chronic phase of CML with a 3-year follow-up, dasatinib 100mg daily resulted in faster responses and increased overall survival compared with imatinib 400mg daily.
- **Bosutinib:** This is a substitute tyrosine kinase inhibitor for patients whose CML is resistant to imatinib, dasatinib or nilotinib or who cannot tolerate the side effects of any of these drugs. Bosutinib appears to achieve responses in CML with most known mutations that cause imatinib resistance, except for T315I mutation.
- **Ponatinib:** This is a highly potent third-generation tyrosine kinase inhibitor that is used if the CML is resistant to other targeted therapies or because the myeloid cells have the T315I mutation.

The development of second and third generation tyrosine kinase inhibitors was aimed at creating drugs with efficacy against the various forms of the BCR-ABL mutation. When CML transforms into an acute form of leukaemia (blast crisis), it is characterised by added mutations in myeloid cells. This has lead researchers to suggest that combining tyrosine kinase inhibitors may be more effective in controlling a rapidly evolving CML in patients.

How is relapsed CML treated? (cont.)

Allogeneic stem cell transplantation (ASCT)

New tyrosine kinase inhibitors have enabled patients to achieve excellent levels of response, and these patients are likely to have a relatively normal life expectancy, although a number of patients may probably need lifelong drug treatment. However, as resistance to tyrosine kinase inhibitors emerges, mostly in the late phases of CML, an ASCT may be a practical option for patients in the blast crisis phase and certain patients in the chronic phase.

Results of an ASCT can be enhanced by preparing patients with tyrosine kinase inhibitors, chemotherapy conditioning regimens, BCR-ABL monitoring, and relapse management during the period, prior and after the ASCT; although the ideal timing of these procedures remains a subject for debate.

In reduced-intensity transplants, where older patients or those not healthy enough to withstand the side effects of a normal transplant, lower chemotherapy doses or less intense radiation

therapy compared with normal ASCTs can be a good alternative.

Although an ASCT consistently eradicates cancerous myeloid cells in most patients, this option is restricted to patients with an available donor, and does carry a considerable risk of complications, mainly due to infections and respiratory problems.

The European LeukemiaNet for CML recommends that ASCT should be limited to patients who are resistant or intolerant to at least one second generation tyrosine kinase inhibitor, or for patients in the blast phase. Nevertheless, young patients with newly-diagnosed high risk CML and patients who have not responded to first-line tyrosine kinase inhibitors may gain advantage from an early low-risk ASCT which would result in higher rate of remissions, shorter treatment time, and longer survival.

Your doctor will advise you of the best transplant options and timing, and will usually prepare for the transplant by improving

your blood cell counts and getting your CML to return to the chronic phase prior to the transplant procedure.

Chemotherapy

Chemotherapy can be useful for relapsed CML in patients who cannot tolerate the side effects from targeted therapy or if the CML is, or has become, resistant to targeted therapy. However, chemotherapy is mainly used for lowering very high white blood cell counts or enlarged spleens. Chemotherapy can also be given as part of the preparation of patients for an ASCT.

Chemotherapy drugs used in CML include the following:

- Hydroxycarbamide (Hydroxyurea)
- Cytarabine or high-dose cytarabine
- Cyclophosphamide
- Vincristine
- Busulfan

Omacetaxine is a protein synthesis inhibitor, which was approved in the United States for

the treatment of CML that has progressed to the accelerated phase and has become resistant to two or more tyrosine kinase inhibitors or has the T3151 mutation.

Biological therapy

Biological therapy is offered for relapsed CML for patients who cannot tolerate or are resistant to targeted therapy with tyrosine kinase inhibitors. Biological therapy can be used alone or in combination with chemotherapy. The most common biological therapy used is interferon alfa.

Supportive therapy

Supportive therapy or palliative care is valuable during treatment in each phase of CML to offset any complications. Supportive therapies given during treatment for relapsed CML may include antibiotics, antivirals, or antifungals to combat infection, and leukapheresis to separate out large numbers of white blood cells from the blood. For more details on palliative care, see our section on **palliative care** later in the booklet.

How is relapsed CML treated? (cont.)

Prognosis

The ten-year overall survival of patients with CML is currently 80 to 95% largely due to the introduction of the tyrosine kinase inhibitors around the year 2000, when overall survival was 10-25%. Younger people tend to have a better prognosis than older people, with around 97% of patients aged between 15 and 64 years having a five year survival.

Your prognosis will vary according to the phase of your CML (chronic, accelerated or blast phase), your response to treatment and your state of health. It is possible that if you are in a chronic phase, your CML will progress slowly and remain controlled with targeted therapy. Alternatively, you may go into remission for many years, during which time you may not have any symptoms and your blood tests will be clear.

In the event of a relapse, you will be offered further treatment to attempt to reach a second remission. If targeted therapy with your existing or different tyrosine kinase inhibitors is not successful, you may be offered

intensive treatment with an ASCT.

If you have reached the accelerated phase or blast phase, treatment is more challenging. However, with treatment it is possible that you may return to the chronic phase where managing your CML is more feasible. Alternatively, an ASCT is your best option.

An ASCT from a healthy donor achieves a complete eradication of myeloid cells in most patients. The main predictor of survival following an ASCT is the phase of your CML during which you undergo your transplant. Five-year survival of patients with CML transplanted during the chronic phase is around 80% and 40% to 50% during the accelerated phase. Transplantation during a blast crisis is only successful in 10-20% of CML patients. If transplantation is performed during remission after a blast phase (also called a second chronic phase), the survival outcomes are similar to accelerated phase cases.



Seeing your doctor

Your symptoms

Whatever symptoms you have, make sure you write a list of all of them to share with your doctor as they may be important to your treatment.

Your appointment

Arranging an appointment with your GP will be one of the first things you will need to do when you start to notice symptoms. Pick a time convenient for you that you know you will be able to attend. If there is a chance that you might be experiencing a relapse, you will be referred to the hospital who will be able to confirm this through tests.

Your preparation

It is important to know exactly what you would like to ask your doctor. Make a list of your questions and leave spaces for the answers so you can write them down when you see the doctor. This way you can go into the meeting ready and prepared.

Examples of questions to ask the doctor:

- How do I know if I my CML has come back?
- What tests will I need to have?
- What will the tests show?
- How long will it take to get the results back?
- How common is it to have a relapse?
- What sort of treatment will I need?
- How long will my treatment last?
- How will I know if my treatment has worked this time?
- What will the side effects be?
- Are there any food or medications I need to avoid?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- Where can I get help dealing with my feelings?

Talking to your doctor

Be honest with your doctor; they have seen and heard everything before, so there is no need to feel embarrassed about anything. If you saw your healthcare team before seeing your doctor, be sure to share with your doctor everything your healthcare team told you about your relapse, the blood tests you had performed, and the next steps in your CML journey. Ask also if you will receive more intensive treatment or palliative care.

Your support

If it helps, take a family member or friend in with you for support. Some people take a pen and paper in to make notes, and repeat back to their doctor everything they have been told to ensure that they are both on the same page and that nothing has been missed or forgotten.

The next steps

Always ensure that you leave the GP surgery, or the hospital, having shared everything you know

about your condition, with all of your questions answered, and knowing exactly what the next steps are, whether it is more tests, further treatment or palliative care. You can ask for a summary letter of the consultation to have everything in writing. Your doctor will generally send a letter like this to your GP.

Furthermore, be sure to access all of the other support available to you as this may be able to help you with your feelings towards your diagnosis and treatment.

Telling your family

Planning who to tell

Telling your family and friends that you have suffered a relapse can be difficult, especially since you already went through it with your initial CML diagnosis. One positive aspect to this is that you already have your team in place, so once they know your situation, they can help and support you like they did before.

You may want to create a list of people you want to tell, starting with close family and friends, and then extending it beyond, from your colleagues at work to friends in your neighbourhood.

Planning what to say

It is important to know what you want to say and exactly how much you want people to know. Being clear in your mind about that before speaking to anyone will make this a much smoother experience. Know your story that you want to tell, the diagnosis, the prognosis, the next treatment steps, and what you expect to be going through physically and emotionally. Be sure to speak to people in an environment where

both of you can hear each other clearly and where there are likely to be no interruptions.

How to say it

Using a conciliatory tone will help keep both yourself and the other person calm. Deliver what you have to say slowly, calmly, concisely, and sentence by sentence to allow the other person time to take in the information. Be sincere, and hold their hands if you need to.

You can use the following sentences to help you articulate what you need to say:

- "This is going to be difficult, but I need to tell you something."
- "I've had some bad news but there's a good chance that everything will be okay after I've had treatment."
- "You know I've been feeling unwell for a while. I've had some tests and they've found out what's wrong."

How to respond

You may receive similar

responses to when you told people about your initial diagnosis. Naturally they will feel sad and concerned for you. Everyone deals with this type of news in their own way, from shock and silence, to questions and support.

Invariably, people respond positively, which in turn means you will respond back positively.

Accepting help

Sometimes people feel guilty for their cancer relapsing, that they weren't strong enough, and that they will be a burden on those around them. This is where your loved ones come in, so make sure you do ask for and accept offers to help and support you in the next stages of your CML journey. Do not try to cope on your own. If they offer to help, tell them that you will get in touch when you need them.

Repeating yourself to different people can become burdensome, which is where your network of family and friends can help you out, by telling those beyond them about your current situation.

You can receive help from us on how to deal with your family and friends with relapse. You can visit www.leukaemiacare.org.uk, or call **08088 010 444**, to find out more.

Managing your emotions

Being told that your cancer has returned may be difficult for you to deal with, especially after all your time and effort during treatment and remission.

Indeed, you may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of your CML. However, you may experience a range of emotions, including uncertainty, isolation, anxiety, anger, sadness and depression. Understanding each emotion and developing ways that help you deal with them will help you move forward with your life.

Uncertainty

You may think "What happens next?" You may be unsure about your health and what the future holds for you. You may or may not have had meetings with your healthcare team to discuss the next steps following your relapse. Once you have a clear path set out in front of you, you will be able to develop a clearer picture of where you are headed. Gaining a sensible balance between being vigilant about your symptoms following

relapse and carrying on with your life will help ease any anxieties. Help, care, kindness and support will be available to you from your healthcare team, and you will have access to counsellors and therapists when you need it.

Isolation

If you have received a diagnosis of relapse, and the next steps don't involve intensive treatment, you may feel a break in your routine. You may feel alone because you will no longer enjoy regular meetings with your healthcare team who provide you with information and reassurance, or fellow patients who can provide you with empathy and compassion.

Alternatively, you may feel this break in routine allows you to be around those closest to you, and follow your regular routine of work and play. Being around those closest to you, such as your family and friends, can be both positive and negative.

Let them know what you do and don't want to do, how you do and don't wish to be treated,

and what you do and don't feel comfortable talking about. Sometimes, it is difficult for your family, friends and colleagues to understand what you are feeling and going through. Being clear will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

Anxiety

Being fearful of the unknown, especially when we are feeling threatened, is natural. You may experience an increased heart rate, rapid breathing, and muscle tension. These things help us to face a danger or run away. These changes in you are part of the 'fight or flight' response. Any feeling of discomfort, pain or even another appointment with your healthcare team may elicit such responses, and give you sleepless nights or feelings of worry. This is completely natural.

Such reflexes and responses will ease over time with the building of daily routines and planning things for the future, which will help you to cope with the physical

effects of anxiety. Cognitive behavioural therapy (CBT) can help you deal with your worrying thoughts.

Anger

Feeling angry after a relapse is natural and normal. You may be angry with yourself, your body, with the healthcare team or with family and friends. You may display your anger as impatience, irritability and frustration with people and things that would not normally bother you.

Understanding exactly what is making you angry will help you deal with your feelings effectively. In addition, setting yourself achievable goals that stretch you will help reduce the anger and impatience you feel, especially with each passing success. Don't forget to congratulate yourself for each successfully completed task, however small.

Physical exercise is a great way to release your anger and frustrations, and channel your energy positively with no negative impact on your body. Talking

Managing emotions (cont.)

about your feelings, letting them out, will also help stop you lashing out at people and keep you calm.

Sadness and depression

Relapsing will bring back some, if not all, of the feelings you felt when you were first diagnosed with your CML. You may feel a sense of loss of the person you used to be, and how safe you felt. You may also feel that your illness is a heavy burden on those around you. You might be feeling low, which is a natural effect of your illness, treatment and recovery. However, if this low mood persists for more than several weeks, and you feel hopeless and lose interest and pleasure with things in life, then you may have depression.

Your first steps should be to speak to your loved ones around you about your mood and state of mind, and then contact your GP. You may lift the way you feel by engaging in activities that you were enjoying before your relapse and initial diagnosis, to connect back with your life. Only do as much as can and try and

talk about your thoughts and feelings. This will help lighten your burden and put things into perspective. If you have made any acquaintances or friends in the same position as you, talk to them over coffee as they will exactly understand what you are facing.

Self-confidence

Being forced to readjust from your daily routine during remission, back into one involving multiple visits to the hospital for further treatment, or moving into palliative care, can take its toll. This interruption of your life, along with your lack of energy because of your CML and the effects of your treatment, can impact on how you feel about your appearance and how you feel emotionally. In turn, this can knock your self-confidence and self-esteem. Your feelings of relief, hope and optimism have just been replaced with their polar opposites.

You can gradually build your self-confidence and self-esteem back up by engaging in the activities you did before your diagnosis, and

socialising with family, friends, and fellow patients. This will help create a supportive atmosphere to get you back to your old self.

Mindfulness and relaxation

Simple practices from mindfulness and relaxation techniques can help you calm the mind, release tension and ease any pain in your muscles.

- Put yourself in a relaxing environment, sitting or lying down comfortably.
- Loosen your clothing so you can move more freely.
- Calmly breathe in through your nose, and out through your mouth, developing a steady natural rhythm, focusing on your chest and abdomen as you do so.
- Visualise that you are inhaling positivity and exhaling negativity.

By taking some time out of your day to do these exercises, you can help quieten your mind and remove the stress of coming to

terms with your diagnosis, so you feel calmer and more relaxed.

Survivorship

Someone who is living with or is beyond a cancer diagnosis can be considered a cancer survivor.

Survivorship can be defined as:

"...cover[ing] the physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, secondary cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience."

When living with cancer, especially if you are relapsing after remission, you will face new challenges to cope with from physical to psychological and social ones. Survivorship aims to provide personalised care based on your need to improve your health, wellbeing, quality of life, and your confidence and motivation, to help you manage. Survivorship also focuses on your

health and life with cancer after the end of treatment until the end of life. At this point, your routine of meeting frequently with your healthcare professionals also ends, so you may feel a mixture of emotions from relief to fear, anxiety and uncertainty about the future. You may wonder how you will slot back into your life after coming through the treatment period.

Your survivorship pathway began at the point when you were diagnosed with CML. By this point, you will have been starting to receive support for work, finance, and personal relationships through to managing pain, fatigue and making positive lifestyle changes, such as starting a healthy diet and gentle exercising.

Your individual needs as a patient will be identified and addressed, including:

- Dealing with the emotional impact of receiving a diagnosis of relapse which may have created feelings of uncertainty, fears of recurrence and difficulties in planning for the

future. These will be discussed with you to develop your individualised care plan with support from social care staff and therapists, as you need it.

- Improving your quality of life through efficient and co-ordinated care during your treatment, with effective communication within the treatment team, and a positive attitude.
- Taking care of any co-morbidities – that is, other medical conditions and diseases – and offering you cancer rehabilitation based on your clinical needs as assessed by informed professionals, and ensuring compliance with the National Cancer Rehabilitation Pathways and Rehabilitation Peer Review requirements.
- Providing you with a treatment summary from diagnosis of your relapse to the end of your treatment. This would include any ongoing medication and noting possible symptoms that may occur in the future. You would also be provided details of who to contact in addition to your GP for any concerns you

may have.

- Preparing you fully for the impact of relapse and treatment, the physical and physiological side effects of treatments and the psychological impact of CML relapse in general. You will be provided physical equipment, and taught about various coping strategies to adapt to your new situation.
- Supporting you with advice for social and financial difficulties, including caring responsibilities, your inability to participate in social activities, any debt and financial worries from not being able to work, and perhaps the need to return to work before you feel ready.
- Receiving health and nutrition advice from a nutritionist on following a healthy and balanced diet to help improve your general health and wellbeing. The World Cancer Research Fund published a report for cancer survivors which suggests that even small dietary and lifestyle changes can produce large health benefits.

Palliative care

Palliative care in relapsed CML

If you have relapsed, and your healthcare team feel that further treatment will not help with your CML, then you will be offered palliative care. Palliative care, also known as supportive care, involves a holistic or "whole person" approach, which includes the management of your pain and symptoms as well as psychological, social and spiritual support for you and your loved ones.

Rather than looking for a cure using intensive treatment, palliative care aims to reduce your symptoms, control your CML, extend your survival, and give you and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps.

Who provides palliative care?

Your palliative care will be provided by a team of health and social care professionals trained

in palliative medicine who will coordinate your care.

These professionals can include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists, and religious leaders, if you would like this. Your palliative care services may be provided by the NHS, local council or a charity. You may receive day-to-day care at your home and at the hospital.

What is the clinical course?

You will have experienced a protracted cycle of relapses and remissions, and be prone to frequent infections because of the CML and the impact of your treatments. Your chemotherapy may continue because of potential remission and/or useful palliation.

You may experience various pains and other clinical complications such as:

- **Bone pain:** Radiotherapy and/or oral steroids, and sometimes non-steroidal anti inflammatory drugs (NSAIDs) may be used, although these are used with caution because they can interfere with your immune system and kidney function.
- **Bone marrow failure:** Blood and platelet transfusions are provided to prevent and fight recurrent infections and bleeding episodes.
- **Oral problems:** Analgesic mouth washes and topical ointments may help with ulceration. Chewing gum and mouth washes have been shown to help with dry mouth, tooth decay, and oral thrush.
- **Night sweats and fever:** These can place a heavy burden on carers because of so many changes of night clothes and bedding.
- **Back pain from wedge and crush fractures of the vertebrae of the spinal column:** Treatments can include

analgesics, antidepressants and/or anticonvulsant medication used in tandem with opioids.

- **Hypercalcaemia:** Treatment is usually with intravenous hydration and intravenous bisphosphonates.
- **Loss of appetite:** Low-dose steroids may temporarily boost the appetite, while small, frequent and appetising meals and supplement drinks will also help.

End of life care

When does end of life care begin?

If you have relapsed and are going through palliative care, you will be offered end of life care. End of life care begins when you need it and may last a few days, months or years.

What does end of life care involve?

End of life care is support for people who are in the last few months or years of their life. The aim is to help you enjoy a good quality of life until you die, and to die with dignity. The professionals looking after you will ask you about your wishes and preferences on how to be cared for and put these into action. They will also provide support to your family, carers and loved ones. You will be able to decide where you will receive end of life care, be it at home or in a care home, hospice or hospital. The same will be true of where you would like to die. Wherever you are, you will receive high quality end of life care.

Who provides end of life care?

A team of health and social care professionals may be involved in your end of life care, including hospital doctors and nurses, your GP, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists or complementary therapists, and religious leaders, if you would like this. If you are being cared for at home or in a care home, your GP will have overall responsibility for your care with the support from community nurses, along with your family and friends.

What choices do I have in terms of end of life care?

Deciding where you want to die can be a difficult choice to make. Working out what you and your loved ones want, together with seeing what services are available to you can help to make the decision a little easier.

- **Staying at home:** A place of

familiarity, surrounded by your loved ones, may be something that you will find reassuring. External care professionals will be able to visit you at home to make sure your symptoms are looked after.

- **Hospices:** Specialised in looking after those with life-limiting illnesses and those who are coming to the end of their life, hospices are staffed with care professionals who are able to keep an eye on you, make sure that your symptoms are controlled and offer you a number of services to make your stay as comfortable as possible. For more information on the care that they can provide, go to <https://www.hospiceuk.org/>
- **Residential care/nursing homes:** If you think that your stay may be a few months or more, then a nursing home may be more suitable than a hospice. These can be private or run by a charity or the local council so be sure to check if there are any fees.
- **Hospitals:** Although you may be used to staying in a hospital

ward, the care routine cannot always be tailored to your specific needs. Pressures on the NHS mean that your stay will only be as long as strictly required. As soon as the condition you were admitted for has resolved, you will need to go back to your home or nursing home. However, a number of specialists will be available to help look after you for specific problems, and a number of hospitals also have a designated palliative care team for patients who require them.

Whatever your choice, speak with your GP or healthcare team who will be able to help you put everything into place.

Glossary

Chemotherapy

A form of cancer treatment that uses one or more anticancer drugs as part of a standardised chemotherapy regime.

Chronic Myeloid Leukaemia (CML)

A cancer that affects the blood and bone marrow defined by the presence of BCR-ABL translocation.

Immunophenotyping

A set of tests to indicate the number of leukaemia cells in blood and bone marrow samples.

Palliative care

Also known as supportive care, this is a type of care that focusses on improving the quality of life for a patient with a life-threatening illness and their loved ones.

Relapse

The return of an illness after treatment has been completed.

Remission

When all tests indicate the absence of an illness.

Stem cell transplant

A medical procedure which involves replacing faulty or damaged bone marrow cells.

Survivorship

A focus on the life of someone with cancer after diagnosis and treatment.

Tell us what you think!

If you would like to give us some feedback about this patient information booklet, please hover over the code to the right using your phone or tablet's camera. Click the link as it appears and this will take you to a short web form to fill in.

Suitable for Android, iPhone 7 and above.



Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
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Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

