
Adult T-Cell Leukaemia/ Lymphoma (ATL)

A Guide for
Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with Adult T-Cell Leukaemia/Lymphoma (ATL) can be a shock, particularly when you have never heard of it. If you have any questions about ATL, including what causes it, who it affects, how it affects your body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

The booklet was compiled by Dr Sonia Wolf and peer reviewed by Dr Lucy Cook and Professor Graham Taylor.

For more tailored information, talk to your haematologist, clinical nurse specialist or hospital pharmacist.

Disclaimer: All of our information has to adhere to a standardised

process that ensures it is of the highest quality. Unfortunately, due to the rarity of ATL, we were unable to complete all of the reviews as part of the production process. However, we assure you that this information was created with the same values as that which has.

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 8:30am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:30pm.

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 or over the phone on **08088 010 444**.

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@leukaemiacare.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.leukaemiacare.org.uk**.

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@leukaemiacare.org.uk**

Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

What is ATL?

Adult T-cell leukaemia/lymphoma (ATL) is a rare kind of blood cancer that occurs in people who have the Human T-lymphotropic virus type 1 (HTLV-1). It occurs in a kind of white blood cell called a T-lymphocyte which recognises and fights infection. ATL is very rare in the UK, with approximately 30 cases per year, although it is much more common in parts of the world where HTLV-1 is commonly seen.

In ATL, abnormal T-cells infected with HTLV-1 increase in your blood or lymph nodes (glands). If the abnormal cells are mainly in the blood, it is called leukaemia. If they are mostly in the lymph nodes, it is called lymphoma. Abnormal cells, in both the leukaemia and lymphoma types, can spread to the bone marrow, skin or other organs such as the liver and spleen.

Who gets ATL?

ATL only occurs in 1 in 20 carriers of the HTLV-1 infection. ATL does not occur without HTLV-1 infection. We do not know precisely why

some carriers get ATL, whilst the majority remain healthy. The average age at diagnosis is 54 years.

Risk factors for ATL

- People who have been infected with HTLV-1 at birth or in early childhood.
- Having a family member who has had ATL.
- It is slightly more common in men than women.
- It is slightly more common in smokers.
- Environmental risk factors such as diet, air quality, radiation or toxic chemicals do not put you at a higher risk.

What is HTLV-1?

HTLV-1 is a virus that is found most commonly in the Caribbean, Japan, west Africa, the Middle East and Romania. People who are from these countries and their descendants may carry this virus. The virus is passed from mother to child through pregnancy or

breastfeeding, or between adults through sexual intercourse without condoms, or through infected blood products.

Over 90% of people who carry this virus have no symptoms. However, around 5% will develop ATL over the course of their lifetime. The highest risk is in people infected at birth or in early childhood, or who have had a family member with ATL.

If you are worried that any of your family members or your sexual partners may have HTLV-1, they can be tested at a Sexual Health Clinic or referred to the National Centre for Human Retrovirology for testing. Further information and referral details can be found at www.htlv.eu

What are the types of ATL?

There are four main types of ATL.

Acute ATL

This accounts for around 3 in 20 cases of ATL. There is a high number of abnormal T-cells in the blood, although you may have the disease in the skin, bone marrow and lymph nodes as well. You may also have abnormal blood test results, such as high calcium levels and a high level of an enzyme called lactate dehydrogenase (LDH). High calcium levels may cause dehydration, constipation, confusion and bone pains.

ATL Lymphoma

This accounts for around 13 in 20 cases of ATL. The abnormal T-cells are in the lymph nodes, as well as some other organs like the liver, spleen or tonsils.

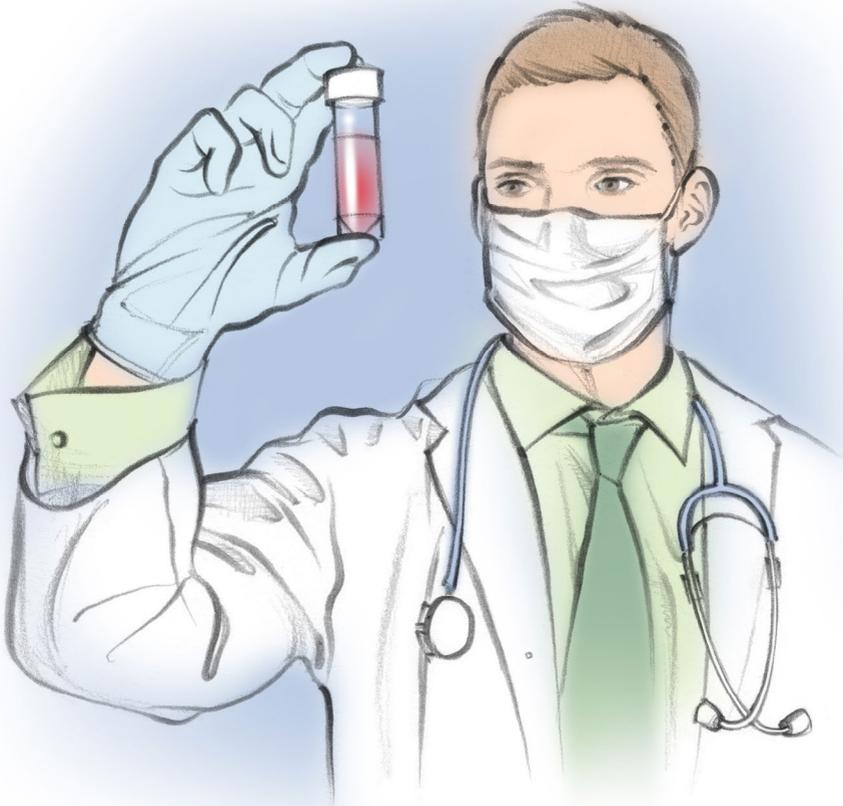
Chronic ATL

This is where you have abnormal T-cells in the blood, although they may not be as high as in acute ATL. You may have the disease in some other organs, but will not have it in the central nervous system, bones or gastrointestinal

tract. You do not have high calcium or LDH. This accounts for 3 in 20 cases of ATL.

Smouldering

This is where you have abnormal T-cells in the blood, but not a very high number ($<4 \times 10^9/l$). There may be disease in the skin or lungs, but not in any other organ. You do not have high calcium or LDH. This accounts for around 1 in 20 cases of ATL.

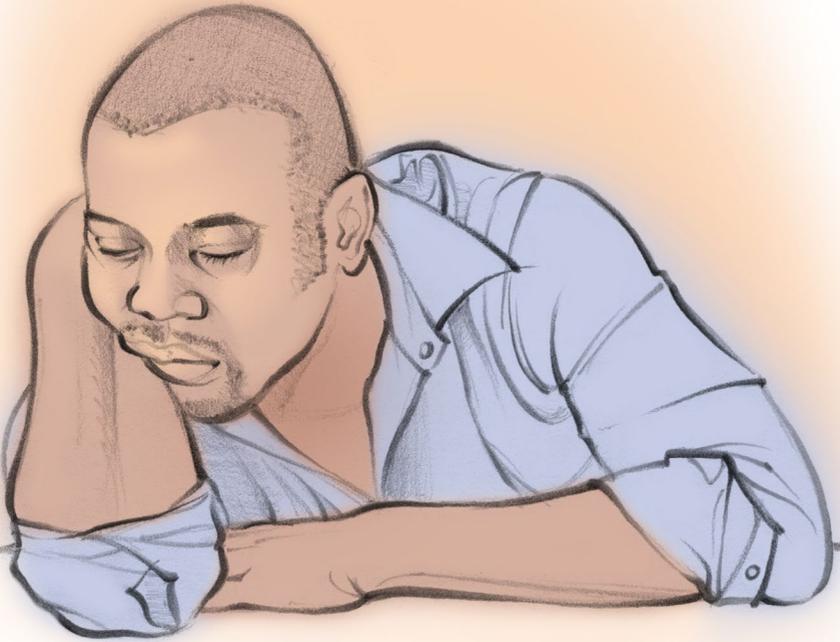


What are the symptoms of ATL?

This depends on the subtype but can include:

- Fatigue
- Swollen lymph glands. This is usually found in ATL lymphoma but can also be found in acute or chronic ATL as well.
- Tiredness
- Fevers with or without night sweats
- Itchy skin or rash
- Weight loss
- Confusion

It is also possible to not experience any symptoms before diagnosis. For example, chronic ATL is often diagnosed on a routine blood test without symptoms and smouldering ATL may be diagnosed during investigation of a skin rash.



How is ATL diagnosed?

Acute, chronic or smouldering ATL is usually diagnosed by:

Blood tests

These are used to:

- Find a raised white blood cell count due to an increased number of lymphocytes.
- See the abnormal ATL cells ('flower cells') under a microscope.
- Confirm that you have the HTLV-1 infection and that the abnormal cells are infected with it.

Immunophenotyping

This is when you look for protein markers on the cell surface using special stains. It is done through a normal blood test. In ATL, cells express markers called CD4, CCR4 and CD25. Sometimes treatments can be used to target these protein markers.

Lymph node biopsy

In ATL lymphoma, a biopsy is taken from the enlarged lymph gland. This is sometimes done while you are awake with a needle

and local anaesthetic, but usually it is done as a short procedure while you are asleep (general anaesthesia).

What happens if I am diagnosed with ATL?

You will need some more tests to find out if the ATL has spread to other parts of your body.

CT (Computerised topography) scan of your body (from neck to groin)

This is a special kind of three-dimensional X-ray that provides detailed cross-sectional pictures. This is to see whether the ATL has spread to other glands and organs such as the spleen or liver.

Bone marrow biopsy

This is where bone marrow cells are taken from inside the bone by a doctor, usually from the back of your pelvis. You will be given a local anaesthetic for this. This is to see whether the ATL is in the bone marrow.

Lumbar puncture

This is a procedure where cerebrospinal fluid is taken

from the fluid around the spinal cord, usually at the base of your spine. You will be given a local anaesthetic for this. This is to look for ATL in the brain or spinal cord.

Treatment

There are lots of different options for treating ATL, depending on subtype, whether you have symptoms and whether there are any clinical trials available. You should ask your doctor about this.

Patients with slower growing types of ATL (smouldering or chronic) may be offered antiviral treatment (interferon alpha injections with zidovudine tablets). The aim of this treatment is to prevent the ATL from changing into a more aggressive subtype of ATL.

If you have acute or lymphoma ATL you will need treatment. With acute types, treatment will involve either antiviral therapy or chemotherapy. In ATL lymphoma this will be chemotherapy. If you have chronic or smouldering ATL with symptoms, you will also need treatment, probably with antiviral therapy.

Antiviral therapies

This is a combination of two drugs.

The dosing used may be different depending on the type of ATL.

In patients with chronic or smouldering ATL the doses are relatively low. For acute leukaemic ATL the doses are much higher because the cancer is growing quicker.

Interferon-alpha (IFN- α) is a naturally occurring substance made by blood cells to fight infections. This is given through an injection under the skin (subcutaneous). Patients and their relatives can learn to administer it.

Side effects include:

- Flu-like symptoms
- Fever
- Tiredness
- Muscle aches
- Depression
- Loss of appetite
- Low blood counts

Paracetamol can help with some of these symptoms.

Zidovudine (also known as AZT) is an antiviral drug, given as a tablet. The most serious reaction

can be low blood counts. If this happens, the drug may need to be stopped or reduced.

Other common side effects include:

- Headache
- Nausea and vomiting
- Muscle aches
- Raised levels of liver enzymes

These often get better in the first few weeks of taking it.

Chemotherapy

The most common chemotherapy used in the UK is called CHOP. CHOP stands for four chemotherapy drugs: cyclophosphamide, vincristine, doxorubicin and prednisolone. It is usually given as a 21-day course (also known as a cycle) and you will usually have six to eight cycles. On day one, you will go to a hospital and have cyclophosphamide (as an infusion/drip or a slow injection/bolus into a vein), doxorubicin as a slow injection into a vein and vincristine as an infusion. You will be given prednisolone tablets to

take on days one to five.

The most common side effects are:

- Nausea and vomiting
- Tiredness
- Hair loss
- Sore mouth
- Constipation
- Diarrhoea
- Low blood counts

Prednisolone is a steroid and this can have side effects such as increased appetite, mood changes and fluid build-up in the legs. If you have diabetes, speak to your diabetic nurse or doctor, as steroids can make your blood sugar go up.

Low blood counts can make you feel very tired (anaemia), have bleeding or bruising (low platelets) and increase your risk of infection. If you do get an infection while you are having chemotherapy, it can be very serious. If you feel unwell, check your temperature. If it is over 37.5°C then go straight to A&E

Treatment (cont.)

and tell them that you are having chemotherapy.

Central Nervous System Prophylaxis

Patients with ATL have around a 10% risk of disease in the central nervous system (brain and spinal cord), especially in the lymphoma subtype. If you have acute or lymphoma ATL, you may be given some extra treatment to prevent spread to the central nervous system. This can either be with high dose methotrexate in a drip, or with intrathecal methotrexate, where chemotherapy is given into the fluid around the spinal cord. These are both given in an outpatient chemotherapy unit, and you will be able to go home the same day.

Other Medications

If you are having chemotherapy or a stem cell transplant, you are at higher risk of infections. You will be put on medication to prevent some kinds of bacterial, viral and fungal infections. You will also be given medication to prevent side effects such as nausea and

vomiting.

Allogeneic Stem Cell Transplant

If you have acute or lymphoma ATL, you may be offered a stem cell transplant.

This is recommended after your first line of treatment when you are in remission. A stem cell transplant involves having intensive chemotherapy followed by some stem cells which are given as an infusion. These stem cells come from a donor, who may be related to you (usually a sibling, although in some cases it can be a parent or a child) or an unrelated donor. It can be harder to find an unrelated donor if you are from a black or minority ethnic background. Ideally, it is preferable for the donor to be HTLV-1 negative, but if there is no other suitable donor, an HTLV-1 positive donor can be used.

Stem cell transplants are very intensive and require a long stay in hospital. There may be complications such as infections and you will need to

stay on medication for a long time afterwards. For this reason, stem cell transplants are not for everyone. Talk to your doctor about whether it is an option for you.

For more information, have a look at our booklet on Allogeneic Stem Cell transplants. This is available on the website, or you can order a copy by calling **08088 010 444**.

Newer treatments: Mogamulizumab

Mogamulizumab is a monoclonal antibody treatment against CCR4, a cell surface receptor found on ATL cells. In some small clinical trials, it has shown benefit to patients with ATL. It is not currently licensed in Europe/UK; however, it may be licensed in the future or available in the context of a clinical trial.

Prognosis

ATL is an aggressive type of blood cancer and is prone to coming back after treatment. This is why your doctor may recommend a stem cell transplant. There is an urgent need to find new and better treatments to cure ATL and research is continuing around the world to look for ways in which we can improve survival in ATL.

Patients who have a matched stem cell transplant have a three-year survival rate of 33%.

Living with ATL

After a diagnosis of ATL, you may find that it affects you both physically and emotionally. This section will talk about both of these aspects.

Emotional impact and management of an ATL diagnosis

Being told you have cancer can be very upsetting. ATL is a rare condition and, because of this, you may need emotional, as well as practical, support. Being diagnosed with a rare disease can affect you as a whole, not just your body, and can impact on you emotionally at any point of your journey. It is likely that you will experience a range of complex thoughts and emotions, some of which may feel strange or unfamiliar to you. These may include uncertainty, isolation, anxiety, anger, sadness and depression, fears of recurrence and difficulties in planning for the future. It is important to know that these feelings are all valid and a normal response to your diagnosis.

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. This 'fight or flight' response is completely natural and helps us to face a danger or run away. Talk to your doctor and clinical nurse specialist about any anxiety you might be feeling.

You may also react by feeling angry at the cancer diagnosis, yourself, the healthcare team or family and friends. This is again a natural response felt by many patients. Understanding exactly what is making you angry will help you deal with your feelings effectively. Setting yourself achievable but demanding goals will help reduce the anger and impatience, 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 energy positively with no negative impact on the body.

These 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 and anger. Cognitive behavioural therapy can help you deal with your worrying thoughts.

Understanding each emotion and developing ways that help you deal with them will help you move forward with your life. 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 and carrying on with your life will help ease any anxieties.

You may also find yourself feeling low, which is a natural effect of your situation and the illness, treatment and recovery process. 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 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 the

diagnosis and connecting back with your life. Only do as much as you can and try and talk about your thoughts and feelings. This will help lighten your burden and put things into perspective.

Staying active

One of the symptoms of ATL can be fatigue. This is not normal tiredness and does not improve with sleep. Fatigue is a tiredness and weakness that makes you unable to work or perform usual activities. The idea of getting out and being active may be the last thing you want to do when you are experiencing fatigue, but it is important to try and stay as active as possible as it could help with your symptoms. Discuss your fatigue with your doctor or nurse.

Some general tips on how to deal with fatigue include:

- Have a regular lifestyle – try going to bed and waking up approximately the same time every day and try to avoid lying in.
- Take part in regular, gentle exercise to maintain your fitness levels as much as possible.

Living with ATL (cont.)

- Reserve your energy for what you find important and build rest periods around those times. Set yourself realistic goals and take some time between tasks.
- Before going to bed avoid stimulants such as alcohol, coffee, tea or chocolate, or using laptops, tablets or mobile phones.
- Keep your bedroom quiet and at a comfortable temperature.
- Prioritise and pace yourself. You can gradually build your self-confidence and self-esteem by engaging in the activities you did before the diagnosis, and socialising with family, friends, and those in a similar position to you.

Simple practices based on mindfulness and relaxation techniques can help you calm the mind, release tension and ease any pain.

- 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.

Taking time out of your day to do these exercises will help quieten your mind and remove the stress of coming to terms with your diagnosis, making you feel calmer and more relaxed.

Talking about ATL

Talking to your haematologist and healthcare team

It is important for you to develop a good working relationship with your haematologist and healthcare team so you receive the best treatment possible.

The following gives advice on working well with your haematologist and healthcare team:

- At your initial consultation, take along a list of your current medications and doses, and

a list of any allergies you may have.

- If you have a complicated medical history, take a list of diagnoses, previous procedures and/or complications.
- Make a list of questions to take to your appointment.

Examples of questions to ask the doctor are:

- What tests will be needed?
- What will the tests show?
- How long will it take to get the results back?
- How common is this condition?
- What sort of treatment will be needed?
- How long will the treatment last?
- How will I know if the treatment has worked?
- What will the side effects be?
- Will any intensive treatment or palliative care be needed?

- Are there any foods or medications that need to be avoided?
- 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?

It can be useful to repeat back what you have heard so that you can be sure that you fully understood or even write it down during the appointment.

Be open when you discuss your symptoms and how you are coping. Good patient doctor communication tends to improve outcomes for patients.

Other tips include:

- Bring someone along to your appointment. They can provide support, ask questions and take notes.
- Don't be afraid to ask for a second opinion – most haematologists are happy for you to ask.

Living with ATL (cont.)

You need to tell your haematologist if...

- You're having any medical treatment or taking any products such as prescribed medicines, over the counter treatments or vitamins. It is important to understand that treatments, including complementary therapies which are perfectly safe for most people, may not be safe if you are being treated for ATL.
- Remember, if you choose to start any form of complementary therapy outside of your medical treatment, consult your haematology consultant or clinical nurse specialist, prior to beginning it.
- It is important to understand the difference between complementary therapies, used alongside standard treatment, and alternative therapies, used instead of standard treatment. There is no evidence that any form of alternative therapy can treat ATL.

Talking to family and friends about your ATL

Telling people that you have a rare condition like ATL can be hard to explain. You might find it useful to let your close family and friends, as well as your employer know about your health condition. It might be easier to provide people with basic information and give them information leaflets about ATL like this one if they want to know more in-depth details.

It is probably best to focus conversations on the symptoms that you are experiencing, how the condition affects you and how you feel about it. Often people misunderstand and, unfortunately, it will mostly fall to you to educate them as best as you can. Where possible, it's advisable to let people know what you find helpful and unhelpful, in terms of what others say and do. Often people make assumptions and do what they think helps. For example, saying you look well, recounting stories of others they know with a similar diagnosis and encouraging you to look ahead and stay positive isn't

always what people really want to hear. In many ways, the more you communicate with them the better.

These points may help you:

- Explain that you have a condition that means your bone marrow does not function properly, and this affects the number of blood cells it produces.
- Explain your symptoms (maybe you are tired, or have a lot of pain).
- Explain what you need (maybe more help day-to-day, or someone to talk to).
- Explain that you are more prone to infection and suggest ways that they can help to prevent this (regular hand washing and not visiting when they have a cold or are ill).

When telling people about your diagnosis, 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 could also consider the following when telling people about your diagnosis:

- 1. Find out more** - This isn't for everyone, but sometimes trying to find out more about your condition can help you to cope with your diagnosis and may be of some comfort to you and the people around you. It is important to obtain information from reliable internet sources, charitable organisations or your consultant haematologist. The more you know, the more you can share.
- 2. Have a print-out to hand** - It may help to have a factsheet to hand to share with family and friends. This will take the pressure off you having to remember everything they may want to know.
- 3. Explain your needs** - Try and be clear about what your needs may be. Perhaps you need help with the weekly food shop,

Living with ATL (cont.)

help with cooking dinner, or someone to drive you to and from appointments. You may find that friends and family are pleased that they can do something to help you. Sometimes people feel guilty if they get cancer, that it's their fault, 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. 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.

- 4. Be open about how you feel -** Don't be afraid of opening up about how you feel, as people who care will want to help you as best they can. Talk as and when you feel comfortable, so those around you will know when you need them most. Talk about your worries with family, friends or patient support groups. Let people 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.

Repeating yourself to different people can become burdensome. 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 telling your family and friends. You can visit www.leukaemiacare.org.uk, or call **08088 010 444**, to find out more.

More Information

The National Centre for Human Retrovirology is based at Imperial College Healthcare NHS Trust at St Mary's Hospital, London. It is the largest centre for studying HTLV-1 related diseases, including ATL, in Europe. Many patients are referred there from all over the UK, and it sometimes offers patients the chance to take part in clinical

trials.

If you or anyone in your family have been diagnosed with ATL, you can ask your doctor to refer you there, or you can find out more information on the website: **www.htlv.eu**

Work arrangements

Being diagnosed with ATL can sometimes lead to difficulties relating to your work life. You may need to ask for special adjustments at work, for example, to help you avoid infections, especially if your job brings you into close contact with people more likely to carry infections. Your diagnosis may lead to temporary sick leave or a reduction in working hours but it can also mean that you have to stop work altogether.

You may need to make an arrangement with your employer for times when you may need to go into hospital or for those times when you may not be well enough to go into work.

Your consultant or your GP can arrange letters to confirm your

diagnosis and the effects it may have on your work life to your employer. It is often worth taking time to explain ATL to your employer, as it is likely they will never have heard of the disease. It is important for you to know that people with any form of cancer are covered legally by the Equality Act. This means that your employer cannot discriminate against you and must make reasonable arrangements relating to your disease.

Financial help

You can speak to our Patient Advocacy team on **08088 010 444** who can provide you with general advice about what benefits you may be entitled to. If you would like more personal advice, Macmillan can offer this via their helpline on **0808 808 00 00**. Some Macmillan centres can arrange face-to-face meetings with a benefits advisor. They can also provide financial assistance in the form of grants – ask your nurse in the hospital how to apply.

As ATL is regarded as a cancer, you will also be entitled to apply for

Living with ATL (cont.)

a medical exemption certificate which means that you are entitled to free NHS prescriptions. Your GP or clinical nurse specialist at the hospital can provide you with the details on how to apply for this. Prescriptions in Northern Ireland are already free.

Survivorship

Survivorship is a term to describe someone who is living with or beyond a cancer diagnosis.

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, you will face new challenges to cope with from physical to psychological

and social ones. Survivorship aims to provide personalised care based on improving 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.

Palliative care

Palliative care, also known as supportive care, involves a holistic or "whole person" approach, which includes the management of pain and symptoms as well as psychological, social and spiritual support for you and your loved ones.

Palliative care aims to reduce the symptoms, control the ATL, extend 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. Palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate the 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. The 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.

End of life care

If the various treatment options have not worked and you are going through palliative care, end of life care may be offered. End of life care begins when it is needed and may last a few days, months or years.

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 patients enjoy a good quality of life until they die, and to die with dignity. The professionals looking after you will ask 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 this is, you will receive high quality end of life care.

Glossary

Allogeneic Stem Cell Transplant

Stem cells are collected from a matching donor and transplanted into the patient to eradicate the disease and restore the patient's immune system.

Antigen

A toxin or other foreign substance which induces an immune response in the body, especially the production of antibodies.

Central Nervous System (CNS)

The CNS is part of the nervous system consisting of the brain and spinal cord.

Cerebrospinal Fluid (CSF)

A clear, colourless body fluid found around the brain and spinal cord.

Chemotherapy

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

Clinical Trial

A medical research study involving patients with the aim of improving treatments and their side effects. You will always be told if you are taking part in a

clinical trial and you can leave it at any time.

Complementary Therapies

These are treatments used alongside conventional western medicine.

Immunophenotyping

Immunophenotyping is used to help diagnose and classify blood cell cancers, such as leukaemias and lymphomas, and to help guide their treatment. Antibodies are used to identify cells by detecting specific antigens on the surface of these cells, which are known as markers.

Intrathecal Injection

A route of administration for drugs via an injection into the CSF within the intrathecal space of the spinal column. It is useful in spinal anaesthesia, chemotherapy, or pain management applications.

Intravenous Injection (IV)

Some medications must be given by an IV injection or infusion. This means they're given directly into your vein using a needle or tube. In fact, the term intravenous means *into the vein*. With IV

administration, a thin plastic tube called an IV catheter is inserted into your vein.

Leukaemia

A cancer of the bone marrow/ blood with many different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the bone marrow, usually white blood cells, which stop the bone marrow working properly.

Lumbar Puncture

A medical procedure where a needle is inserted into the lower part of the spine to test for conditions affecting the brain, spinal cord or other parts of the nervous system. During the procedure, pressure is measured, and samples of CSF are taken.

Lymph Node or Lymph Gland

An oval-shaped component of the lymphatic system that helps to destroy viruses and bacteria. It contains white blood cells that fight infections.

Lymphocyte

A type of white blood cell which

forms part of the body's immune system.

Monoclonal Antibodies

Antibodies that are made by identical immune cells that are all clones of a unique parent cell. They therefore all bind to the same part of an antigen that is recognised by the antibody.

Prognosis

An indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or other timepoint of the disease.

Prophylaxis

The treatment given or action taken to prevent disease.

Relapse

Relapse occurs when a patient initially responds to treatment, but after six months or more, the disease recurs.

Remission

A period of time when illness is less severe or is not affecting someone because the cancer cells have been substantially decreased by treatment.

Glossary (cont.)

Stem Cells

The most basic cells in the body that have the potential to develop into many different or specialised cell types.

Stem Cell Transplant (SCT)

A stem cell transplant is a treatment for some types of cancer as well as other blood diseases and disorders of the immune system. A stem cell transplant involves the administration of chemotherapy plus or minus radiotherapy as conditioning followed by infusion of stem cells. The stem cells engraft and form a new immune system.

T-lymphocyte (or T-cell)

A T-cell is a type of lymphocyte white blood cell that plays a central role in attacking viruses and other infections. T-cells can be distinguished from other lymphocytes, such as B-cells and natural killer cells, by the presence of a T-cell receptor on the cell surface.

White Blood Cells

These are a type of blood cell that help fight bacteria, viruses and toxins. They are also involved in inflammatory responses. There are several types of white blood cells. The two most common types are neutrophils and lymphocytes.

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.leukaemicare.org.uk
support@leukaemicare.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.leukaemicare.org.uk

support@leukaemicare.org.uk

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Registered charity
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Leukaemia Care
YOUR Blood Cancer Charity