

BLOOD CANCERS AND CONDITIONS

血癌和血液疾病

A guide for patients
and families

患者及家属指南



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

INTRODUCTION

This booklet has been written to help you and your family understand more about blood cancers and conditions when English is not your first language.

This booklet is laid out with English content on the left-hand side of the page, and Simplified Chinese content on the right-hand side. The content has been translated from English by a certified translation service.

You may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with a blood cancer or blood condition. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering

some of your questions. It may raise other questions, which you should discuss with your health care team.

This booklet is a generic resource for people who have been diagnosed with a range of conditions. This means that not everything mentioned in this booklet will necessarily be relevant to you.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your circumstances at all times with your doctor and treatment team.

Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family member or friend may assist. The hospital can organise a trained interpreter if needed.

简介

本手册旨在帮助母语不是英语的患者及其家属进一步了解血癌和血液疾病。

手册页面左侧为英文原文，右侧为译文。手册内容由经资格认证的翻译机构翻译。

当您或您的亲友诊断出患有血癌或血液疾病时，您可能会紧张不安或不知所措。这是正常反应。您可能已经开始治疗，也可能正与您的医生或家人商量不同的治疗方案。无论处于何种境况，我们都希望本手册所含内容能为您解答部分相关问题。阅读后您可能会有其他疑问，最好咨询您的医疗保健团队。

本手册所述内容为基本通用信息，供各类血液疾病患者参考。因此，有的内容可能与您的情况并不相关。

本文并非意图向您推荐某种具体的治疗方式。您需要随时与您的医生和治疗人员进行商讨。

口译员服务

《新西兰卫生和残疾法》(New Zealand's Code of Health and Disability)指出，每个人都有权在就诊时获得一名译员在场辅助。如果患者与其医疗保健专业人员使用的语言不同，可寻求家庭成员或朋友的帮助。如有需要，医院可组织专业译员。

HOW TO USE THIS BOOKLET



Important information



More information available online

There are many resources available at [leukaemia.org.nz](https://www.leukaemia.org.nz) such as fact sheets, booklets and more. Separate disease-specific booklets are available in English about each of the cancers and conditions mentioned in this booklet. Ask your LBC Support Services Coordinator for a copy of the relevant booklet so that your family or friends who read English can learn more.

本手册的使用方法



重要信息



在线提供更多信息

Leukaemia.org.nz网站提供简介文档、手册等更多其他资料。本手册中提及的各类癌症和疾病也各编撰英文手册说明。请咨询您的LBC支持服务协调员获取相关手册副本, 这样您的家人或朋友中能够阅读英文的人员也可以了解更多内容。

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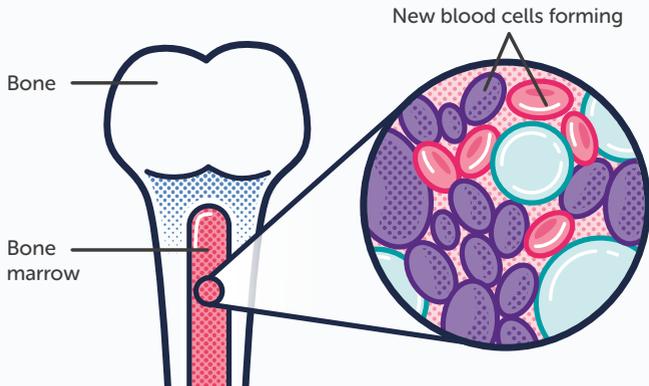
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BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).

All of your blood cells are made in your bone marrow. The process by which blood cells are made is called haemopoiesis. There are three main types of blood cells: red blood cells, white blood cells and platelets.

Figure
01
Bone marrow



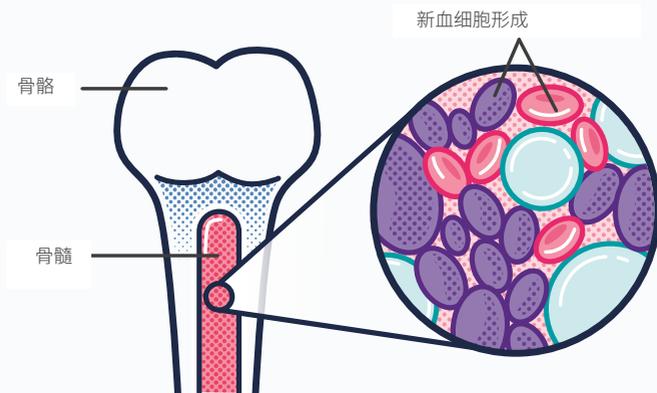
骨髓和造血干细胞

骨髓是骨骼中的海绵状物质(见图01)。

您的所有血细胞都在骨髓中生成。血细胞的生成过程即为造血作用。血细胞分三大类:红细胞、白细胞和血小板。

图01

骨髓



You might like to think of the bone marrow as the blood cell factory. The main workers of the factory are the blood stem cells. Blood stem cells create the new blood cells in your body. The two main functions of blood stem cells are to:

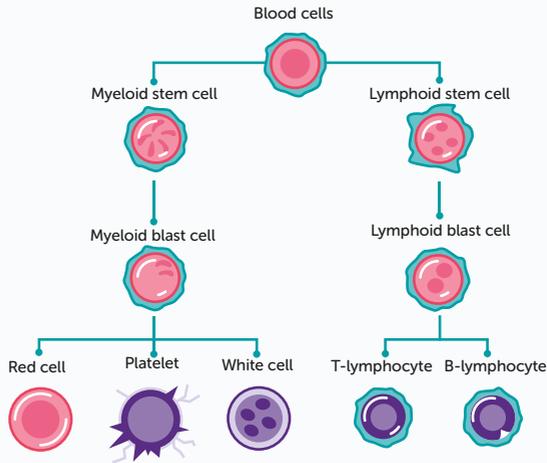
- Make exact copies of themselves.
- Divide and make two different cell groups: myeloid stem cells and lymphoid stem cells.

Myeloid and lymphoid stem cells create the blood cells for your body, including white blood cells, red blood cells and platelets.

In Figure 02 you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

Figure
02

The cells created from blood stem cells



骨髓可视为血细胞工厂。工厂中的主要工人是造血干细胞。造血干细胞在您的体内产生新的血细胞。造血干细胞的两种主要功能为：

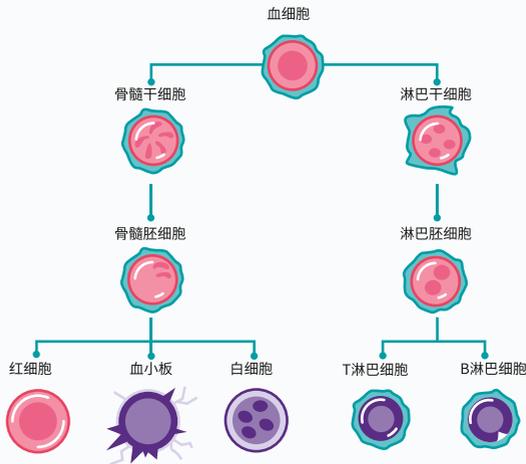
- 细胞完全自我复制。
- 分化成两种不同的细胞群：骨髓干细胞和淋巴干细胞。

骨髓干细胞和淋巴干细胞为您的身体产生血细胞，包括白细胞、红细胞和血小板。

在图02中您可以看到，造血干细胞分化产生骨髓干细胞和淋巴干细胞。您还可以看到这些细胞群所生成的血细胞。

图02

造血干细胞生成细胞



YOUR BLOOD

Blood is made up of plasma, red blood cells, white blood cells and platelets.

Plasma

Plasma is the light-yellow coloured fluid in which blood cells travel around your body.

Red blood cells

Red blood cells contain haemoglobin (Hb), which transports oxygen from the lungs to all parts of the body. Haemoglobin also carries carbon dioxide to the lungs where it is breathed out. A low level of haemoglobin in your body is called anaemia. Symptoms of anaemia are explained further on page 18.

White blood cells

White blood cells fight infection. For example, if bacteria entered your bloodstream through a cut, the white blood cells would attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Following is a list with the names of different types of white blood cells and what they do.

- Neutrophils (new-tra-fils) kill bacteria and fungi.
- Eosinophils (ee-o-sin-o-fils) kill parasites.
- Basophils (bay-so-fils) work with neutrophils to fight infection.
- T-lymphocytes (T-lim-fo-sites) (T-cells) kill viruses, parasites and cancer cells.
- B-lymphocytes (B-cells) make antibodies, which target harmful microorganisms (small germs).
- Plasma cells develop from mature B-lymphocytes. They play an important role in protecting the body against infection by producing immunoglobulins, which are also known as antibodies.
- Monocytes (mono-sites) work with neutrophils and lymphocytes to fight infection. They also help to produce antibodies that act as scavengers (cleaners) to remove dead tissue.
- Macrophages (mac-row-fages) monocytes are known as macrophages when they move to body tissue to help fight infection there.

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1.0 ($1.0 \times 10^9/L$), you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections. Symptoms of infection are explained further on page 18.

Platelets

Platelets help your blood clot and prevent bleeding. If a blood vessel is damaged (for example by a cut), the platelets gather at the site of injury, stick together and form a plug to help stop the bleeding.

Thrombocytopenia (throm-bo-sy-toe-pee-nee-a) is the term used to describe a reduction in the normal platelet count. If your platelet count is low, you are at a higher risk of bleeding and tend to bruise easily.

Children

In children, normal blood cell counts vary with age. If your child has been diagnosed with a blood cancer or condition, you can ask your doctor or nurse for a copy of their blood results, which should include the normal ranges for each blood cell test for a male or female child of the same age.

您的血液

血液由血浆、红细胞、白细胞和血小板组成。

血浆

血浆是淡黄色的液体，带着血细胞流动到体内各处。

红细胞

红细胞中含有血红蛋白(简称Hb)，血红蛋白将氧气从肺中输送到身体各个部位。它还会将二氧化碳运送至肺中，然后从肺中呼出。体内血红蛋白量过低即为贫血。更多贫血症状说明详见第19页。

白细胞

白细胞的功能为抵抗感染。例如，如果细菌通过伤口进入您的血液中，白细胞会在细菌扩散前对其展开攻击并将其消灭。如果体内白细胞计数较低，您受感染的风险将会增高。

下方列出了不同种类的白细胞及各自功能。

- 中性白细胞杀死细菌和病菌。
- 嗜酸性细胞杀死寄生虫。
- 嗜碱性细胞与中性白细胞一同抵抗感染。
- T淋巴细胞(简称T细胞)杀死病毒、寄生虫和癌细胞。
- B淋巴细胞(简称B细胞)产生抗体攻击有害微生物(小病菌)。
- 浆细胞由成熟的B淋巴细胞发育而来。浆细胞产生免疫球蛋白(也是一种抗体)，在保护机体防止感染的过程中扮演着重要角色。

- 单核细胞与中性白细胞和淋巴细胞一同抵抗感染。它们还有利于抗体的生成，抗体有如清道夫(清洁工)，清除坏死组织。
- 巨噬细胞：单核细胞转移到身体组织帮助抵抗感染时就成为了巨噬细胞。

中性白细胞减少症即为中性白细胞计数低于正常水平。如果您的中性白细胞计数低于1.0($1.0 \times 10^9/L$)，则视为患有中性白细胞减少症，并且有常受感染的风险，有时甚至会受到严重感染。更多感染症状说明详见第19页。

血小板

血小板帮助形成血凝块，进行止血。如果血管受伤(如割伤)，血小板会在受伤部位聚集、黏附，形成血栓进行止血。

血小板减少症指的是血小板计数低于正常范围。如果血小板计数很低，则更容易有出血症状和瘀斑。

儿童

儿童的正常血细胞量会因年龄而变化。如果您的孩子已经确诊患有血癌或血液疾病，您可以向医生或护士索要一份血液检查单，单据上会列有相同年龄男女儿童每项血细胞检测的正常范围。

THE LYMPHATIC SYSTEM

The lymphatic system is made up of a vast network of vessels, similar to blood vessels, that branch out into all the tissues of the body (see Figure 03).

These vessels contain lymph, a colourless watery fluid that carries lymphocytes, which are specialised white blood cells that fight infection. There are two types of lymphocytes, B-lymphocytes and T-lymphocytes (also called B cells and T cells). These cells protect us by making antibodies and destroying harmful microorganisms such as bacteria and viruses. The lymphatic system forms part of the immune system, which protects our bodies against disease and infection.

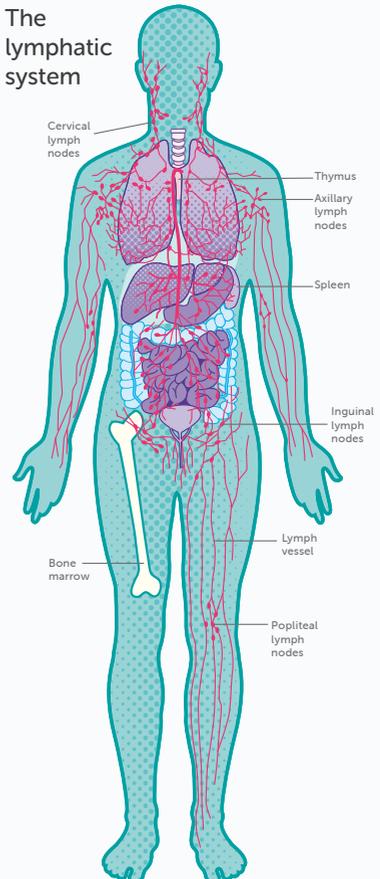
Clusters of small bean-shaped organs called lymph nodes (also known as lymph glands) are found at various points throughout the lymphatic system. The lymph nodes, which are filled with lymphocytes, act as important filtering stations, cleaning the lymph fluid as it passes through them. Here, bacteria, viruses and other harmful substances are removed and destroyed. When you have an infection, for example a sore throat, you may notice that the lymph nodes under your jawbone become swollen and tender. This is because the lymphocytes that live there become activated and multiply in response to the virus or bacteria causing the infection.

The spleen (an organ on the left side of the abdomen), thymus (a gland found behind the breastbone), tonsils and adenoids (glands in the throat) and bone marrow (spongy material inside bones) all contain lymphatic tissue and are therefore considered to be part of the lymphatic system. Lymphatic tissue is also found in the stomach, gut and skin.

Figure

03

The lymphatic system



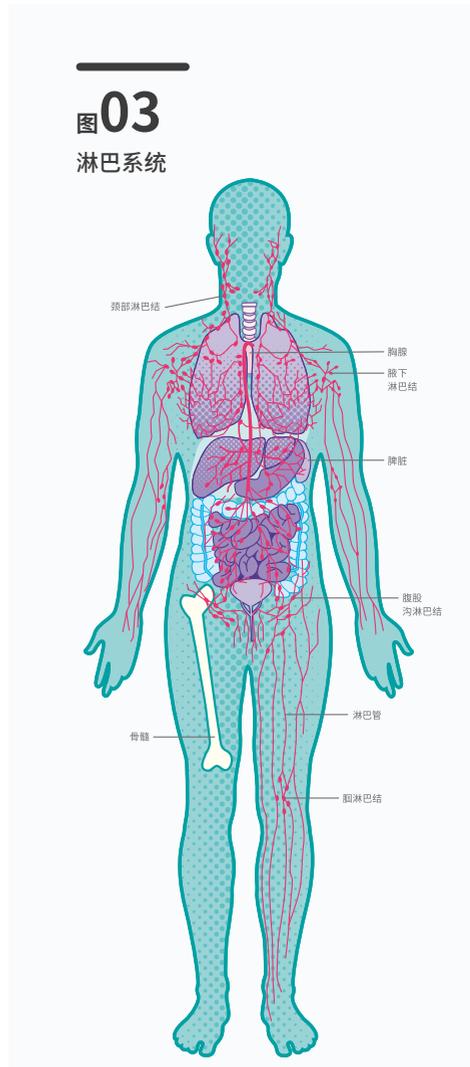
淋巴系统

淋巴系统由大量的淋巴管网络连接而成，网络类似延伸到身体各个组织部位的血管(见图03)。

淋巴管含有淋巴液，一种无色水状液体，其作用是运输淋巴细胞，即抵抗感染的白血细胞。淋巴细胞有两种类型，即B淋巴细胞和T淋巴细胞(亦称为B细胞和T细胞)。这些细胞通过产生抗体，消灭细菌和病毒等有害微生物，从而保护我们的健康。淋巴系统是免疫系统的一部分，保护我们的身体免受疾病和感染的伤害。

小豆粒状的器官群是淋巴结(亦称淋巴腺)。淋巴结分布于整个淋巴系统的不同点。淋巴结中含有淋巴细胞。这些细胞作用重大，相当于一个个过滤站。当淋巴液通过时，它们对淋巴液进行过滤。这样，可以清除并摧毁细菌、病毒和其它有害物质。如果您受到感染，例如，喉咙疼痛，您可能发现您颌骨下的淋巴结肿胀了起来，触摸时会痛。因为这个地方的淋巴细胞发生了作用并且进行增殖，以对抗引发感染的病毒或细菌。

脾脏(腹部左侧的器官)、胸腺(胸骨中的腺体)、扁桃体和扁桃腺(喉咙中的腺体)和骨髓(骨骼中海绵状物质)全部包含淋巴细胞，因此都是淋巴系统的组成部分。淋巴组织还存在于腹部、内脏和皮肤中。



BLOOD CANCERS AND CONDITIONS

In this section we provide a brief overview of blood cancers and blood conditions. It is important to note that the information provided here is of a general nature and may not necessarily apply to the specific type or severity of disease that you or your family member have been diagnosed with.

Leukaemia

Leukaemia is a group of cancers that affect the blood and bone marrow. Leukaemia always starts in the bone marrow where developing blood cells undergo a malignant (cancerous) change. This means that they multiply in an uncontrolled way, crowding the bone marrow and interfering with normal blood cell production. Increasing numbers of abnormal cells (called blast cells or leukaemic blasts) eventually spill out of the bone marrow and travel around the body in the bloodstream. In some cases, these abnormal cells accumulate in various organs including the lymph nodes, spleen, liver and central nervous system (brain and spinal cord).

Types of leukaemia

The different types of leukaemia are classified by how quickly the disease develops, and by the type of blood cell involved.

- Acute leukaemia develops quickly and needs to be treated urgently.
- Chronic leukaemia develops more slowly and may not need to be treated for some time after diagnosis, if at all.
- Myeloid leukaemia arises from myeloid cells and are characterised by the accumulation of cancerous cells called myeloblasts.
- Lymphoid leukaemia arises from lymphoid stem cells and are categorised by the accumulation of cancerous cells called lymphoblasts.

The four main types of leukaemia are:

- Acute myeloid leukaemia (AML)
- Acute lymphoblastic leukaemia (ALL)
- Chronic myeloid leukaemia (CML)
- Chronic lymphocytic leukaemia (CLL)

Acute myeloid leukaemia (AML)

Acute myeloid leukaemia is characterised by an accumulation of abnormal immature myeloid cells. It develops and progresses very quickly, which is why it is called 'acute'. Once AML is diagnosed, treatment starts very quickly to reduce symptoms and kill the leukaemic cells.

Acute myeloid leukaemia is rare in children and more common in adults.

Acute lymphoblastic leukaemia (ALL)

ALL is characterised by abnormal immature lymphoid cells and also develops very quickly like AML. ALL is more common in children than adults but can affect people of all ages.

Chronic myeloid leukaemia (CML)

CML is characterised by the slow accumulation of abnormal myeloid cells. The onset is gradual and progression is generally over months and years. Many people may have no symptoms when they are diagnosed and only found out about their condition by coincidence from a routine blood test.

CML can occur at any age but it is more common in adults over age 40 and slightly more common in men. Over time CML may

血癌和血液疾病

这一部分将简介血癌和血液疾病。请注意，这里介绍的只是通用常识，不一定适用于您或您的家庭成员诊断的疾病类型或其病症严重程度。

白血病

白血病是多种影响血液和骨髓的癌症统称。大多数白血病的病因都由骨髓而起，即骨髓中的血细胞产生了恶性(癌性)病变。这就是说血细胞的增殖不受控制，在骨髓中大量聚集，干扰了正常的血细胞生长。异变细胞(胚细胞或肿瘤细胞)数量增加最终会溢出骨髓之外，然后在体内血液中循环。某些情况下，这些异常细胞会在不同的器官中聚集，包括淋巴结、脾脏、肝脏和中央神经系统(大脑和脊髓)。

白血病种类

白血病是根据病情变化速度和病变的血细胞类型而分类。

- 急性白血病病变扩散很快，需要立即进行治疗。
- 慢性白血病病变扩散较慢，确诊后一段时间内可能不需要进行治疗。
- 骨髓白血病是因髓系细胞而起，主要特征表现为原粒癌细胞的聚集。
- 淋巴白血病是因淋巴干细胞而起，主要特征表现为淋巴癌变细胞的聚集。

白血病主要有四类：

- 急性髓性白血病(AML)
- 急性淋巴性白血病(ALL)
- 慢性粒细胞白血病(CML)
- 慢性淋巴细胞性白血病(CLL)

急性髓性白血病(AML)

急性髓性白血病的主要特征表现为不成熟的异常骨髓细胞的聚集。该病变扩散十分迅速，因此称之为“急性”。一旦确诊，应立即开始治疗以减缓症状发生并杀死白血病细胞。

急性髓性白血病在儿童身上很少见，更常见于成年人。

急性淋巴性白血病(ALL)

ALL主要特征表现为不成熟的异常淋巴细胞，且与AML一样，发病十分迅速。ALL更常见于儿童而非成年人，但所有年龄段人群均可能患病。

慢性粒细胞白血病(CML)

CML主要特征表现为不成熟的异常粒细胞的缓慢聚集。该病发展缓慢，病程长达数月甚至数年。很多人在确诊时可能没有症状，一般是在定期验血时才偶然发现病情。

CML的发病人群覆盖所有年龄段，但在40岁以上的成年人身上更为常见，且男性发病率稍高于女性。CML随着时间推移可能发生急变，发展成与急性白血病类似、更具侵袭性的疾病。

progress to a more aggressive type of disease resembling acute leukaemia.

Chronic lymphocytic leukaemia (CLL)

CLL is a slow-growing type of leukaemia that affects the lymphoid blood cell line. Many people are diagnosed without experiencing any symptoms and may not immediately start treatment. Some people with CLL may just be monitored through regular blood tests and appointments with their doctor.

The majority of people with CLL are over the age of 60 but it can be diagnosed in younger people around the age of 40 years.

Cause

The cause of leukaemia is usually unknown and there are likely to be a number of factors involved.

Like all cancers, leukaemia may result from a change in one or more of the genes that normally control the growth and development of blood cells.

Some risk factors for leukaemia are:

- High levels of radiation
- Exposure to chemicals
- Previous chemotherapy for another cancer
- Inherited genetic disorder

Pre-existing blood conditions may have a higher chance of developing leukaemia. For example, MDS and CML can develop into acute leukaemia if unmanaged.

Signs and symptoms

The main symptoms of leukaemia are caused by lack of normal blood cells.

Low red blood cells (anaemia) may cause the following symptoms:

- Lack of energy
- Feeling tired all the time
- Dizziness
- Shortness of breath
- Pale skin

Low platelets (thrombocytopenia) may cause the following symptoms:

- Bruising easily
- Frequent and severe nosebleeds
- Unusually heavy periods in women
- Bleeding, e.g. bleeding gums
- Red or purple pinhead-sized skin spots (called petechiae)

Low white blood cells, specifically low neutrophils (neutropenia), may cause the following symptoms:

- Fever
- Reoccurring infections



Important information

If you have a low white blood cell count, you are at risk of getting potentially serious infections. The body's immune system that usually fights infection doesn't work so a small skin infection can quickly get worse and become fatal. It is important to call the hospital if you are feeling unwell or have a high

temperature. Check with your haematologist or nurse about how to check your temperature properly with a thermometer, and what is considered to be a 'high temperature'. They will usually want to start intravenous (IV) antibiotics and take blood tests as soon as possible.

慢性淋巴细胞性白血病(CLL)

CLL是一种发展缓慢的疾病，会影响淋巴血细胞系。很多人在确诊时并未表现出任何症状，甚至在刚开始治疗时也没有症状。有的CLL患者可能只是在常规验血时发现患病才去医院就诊。

大多数CLL患者都在60岁以上，但40岁上下的更年轻群体也可能患病。

病因

白血病的病因通常都不明确，且可能涉及多种因素。

和所有癌症一样，白血病的病因可能是控制血细胞生长和发育的一项或多项基因发生了突变。

白血病的一些风险因素包括：

- 高强度辐射
- 暴露于化学物质
- 之前治疗其他癌症时接受过化疗
- 遗传疾病

患上过血液疾病的人患白血病的风险也会更高。例如，MDS和CML患者如果不经治疗，可能发展成急性白血病。

体征和症状

白血病的主要症状由缺乏正常的血细胞引起。

红细胞量低(贫血)可能引发以下症状：

- 乏力
- 经常感觉疲倦
- 头晕
- 呼吸短促
- 皮肤苍白

血小板计数低(血小板减少症)可能引发以下症状：

- 皮肤易起瘀斑
- 鼻腔经常大量出血
- 女性经期出血过量
- 出血，如牙龈出血
- 皮肤出现针头状红紫色斑点(即瘀斑)

白细胞计数低，尤其是中性白细胞(嗜中性白血球减少症)，可能引发以下症状：

- 发烧
- 反复感染



重要信息

如果体内白细胞计数较低，您就有受到严重感染的风险。由于身体的免疫系统无法如常对抗感染，因此即使是小小的皮肤感染也可能迅速恶化甚至致命。如果您感觉不适或体温偏高，请务必致电联系医院。请咨询您的

血液科医生或护士，了解如何正确使用体温计测量体温，以及体温多高就必须联系医院。有关医生和护士一般会及早为您静脉输注抗体以及验血

Treatment

Treatment varies depending on the exact type of leukaemia you have and other factors like age, general health and severity of the disease.

The main treatment for leukaemia is chemotherapy. This is given to destroy the leukaemia cells and allow the bone marrow to function normally again. Usually people are given a combination of chemotherapy treatments that work together to kill the leukaemia cells.

The different treatment options are explained in more detail on page 38.

Lymphoma

Lymphoma is cancer of the lymphatic system. Lymphoma arises when developing lymphocytes (a type of white blood cell) undergo malignant (cancerous) change and multiply in an uncontrolled way. Increasing numbers of abnormal lymphocytes (called lymphoma cells) accumulate and form collections of cancer cells (also called malignant tumours) in lymph nodes and other parts of the body.

Types of lymphoma

There are many different subtypes of lymphoma. Five of these subtypes belong to a group of diseases called Hodgkin lymphoma. All other subtypes are commonly grouped together and called non-Hodgkin lymphoma.

Non-Hodgkin lymphoma

Non-Hodgkin lymphoma actually represents many different subtypes of lymphoma.

Each subtype can act differently and their treatment and monitoring is likely to be different as well. In addition, lymphoma can arise from a B-lymphocyte (most common) or a T-lymphocyte. Non-Hodgkin lymphoma can be broadly divided into two groups, indolent lymphoma or aggressive lymphoma.

Indolent (low grade) lymphoma is a type of lymphoma that grows slowly. It may cause few symptoms and may not need to be treated urgently. Follicular lymphoma is one type of indolent lymphoma. It is the second most common type of lymphoma.

Aggressive (high grade) lymphoma is a type of lymphoma that grows quickly and treatment is needed at the time of diagnosis. Because these lymphomas grow quickly, they tend to respond well to chemotherapy and radiotherapy. Diffuse large B-cell lymphoma is the most common type of lymphoma.

Hodgkin lymphoma

In terms of presentation and treatment, this lymphoma is most similar to diffuse large B-cell lymphoma. It has five different subtypes. The chemotherapy combination is different to that of other aggressive lymphomas so the correct histologic diagnosis is important in distinguishing lymphoma types.

Cause

The incidence of lymphoma is increasing every year. In most cases we don't know why but there are likely to be a number of factors involved. Like all cancers, lymphoma may result from a change in one or more of the genes that normally control the growth and development of blood cells. We know that

治疗

治疗方式取决于具体的白血病类型以及其它因素,如患者年龄、整体健康状况和患病严重程度。

化学疗法是治疗白血病的主要方法。其作用是摧毁肿瘤细胞,让骨髓恢复正常功能。通常患者会接受多种化疗,以共同作用杀死白血病细胞。

更多不同的治疗方案详见第39页。

淋巴瘤

淋巴瘤是一种淋巴系统癌症。淋巴瘤因淋巴细胞(一种白血细胞)产生了恶性(癌性)病变并且异常增殖而引起。异常淋巴细胞(即淋巴瘤细胞)数量增加,不断聚集,然后产生癌细胞群,即在淋巴结和身体其它部位产生恶性肿瘤,使这些部位的淋巴节肿大。

淋巴瘤类型

淋巴瘤有多种不同的子类型。其中五种可归为一组,称为霍奇金淋巴瘤。其他所有子类型通常归到一组,称为非霍奇金淋巴瘤。

非霍奇金淋巴瘤

非霍奇金淋巴瘤事实上是多种不同子类型的淋巴瘤合集。其中每种子类型都有不同症状,治疗和检测方法也不尽相同。同时,淋巴瘤可能由B淋巴细胞(最常见)或T淋巴细胞引起。非霍奇金淋巴瘤大致可分为两类,惰性淋巴瘤和侵袭性淋巴瘤。

惰性(低度恶性)淋巴瘤的生长缓慢。这类淋巴瘤症状可能很少,且无需采取紧急治疗。滤泡性淋巴瘤就是一种惰性淋巴瘤。这是第二常见的淋巴瘤。

侵袭性(高度恶性)淋巴瘤是一类生长迅速的淋巴瘤,确诊后需立即接受治疗。由于此类淋巴瘤生长迅速,多半对化疗和放疗有良好的反应。弥漫性大B细胞淋巴瘤是最常见的淋巴瘤类型。

霍奇金淋巴瘤

此类淋巴瘤的症状和治疗与弥漫性大B细胞淋巴瘤最为相似。霍奇金淋巴瘤分成五种子类型。其化疗方式与其它侵袭性淋巴瘤不同,因此组织学诊断结果的正确性对于区分淋巴瘤类型十分重要。

病因

淋巴瘤的发病率逐年上升。大多数情况下,我们仍不清楚其病因,但可能的发病因素有多个。和所有癌症一样,淋巴瘤的病因可能是控制血细胞生长和发育的一项或多项基因发生了突变。我们知道,免疫系统虚弱(或因免疫缺乏症或抑制免疫系统功能的药物所致)的人患淋巴瘤的风险较高。特定类型的病毒感染也可能导致该病,尤其是免疫系统虚弱者。

people with a weakened immune system (either due to an immune-deficiency disease or drugs that suppress the function of the immune system) are at an increased risk of developing lymphoma. Certain types of viral infections may also play a role, especially in people with a weakened immune system.

Signs and symptoms

Lymphoma commonly presents as a firm painless swelling of a lymph node (swollen gland), usually in the neck, under the arms or in the groin. Lymphoma may develop in the lymph nodes in deeper parts of the body like those found in the abdomen (causing swelling and pain), or in the chest (causing coughing, discomfort in the chest and difficulty breathing).

Other symptoms may include:

- Recurrent fever
- Excessive sweating at night
- Unintentional weight loss
- Persistent lack of energy
- Generalised itching
- New skin rashes
- Fatigue
- Unexplained and/or persistent cough
- Abdominal swelling and pain

The signs and symptoms of lymphoma can often be mistaken for other less-serious illnesses.

Treatment

Treatment will vary depending on the type of lymphoma diagnosed, how fast it is likely to grow and cause problems in the body, as well as the person's age and general health.

Some types of lymphoma grow slowly and cause few troubling symptoms, and may

not need to be treated urgently. Others grow more quickly and need to be treated as soon as they are diagnosed. Treatment can involve chemotherapy, radiotherapy and immunotherapy. Occasionally, a stem cell transplant is used to treat lymphoma that has relapsed (come back), or where there is a high likelihood that the lymphoma will relapse in the future.

There is more information about these treatments on page 38.

Myeloma

Myeloma (also known as multiple myeloma) is a cancer of the plasma cells. Plasma cells are mature B-lymphocytes that live predominantly in the bone marrow and normally produce antibodies to help fight infection. In myeloma, plasma cells undergo a malignant (cancerous) change and multiply in an uncontrolled way, causing problems in different parts of the body. Large numbers of abnormal plasma cells, called myeloma cells, collect in the bone marrow and may interfere with blood cell production, and damage adjacent bones, causing pain. Myeloma cells produce an abnormal type of antibody called a paraprotein that can usually be detected in blood and/or urine.

Each year in New Zealand approximately 400 people are diagnosed with myeloma. The majority of those diagnosed are over the age of 50 years.

Cause

In most cases, the cause of myeloma remains unknown, but there are likely to be a number of factors involved. Like all cancers, myeloma may result from a change in one

体征和症状

淋巴瘤通常表现为某个淋巴结出现肿块(肿胀腺体),无疼痛感。通常出现在脖子上、腋下或者腹股沟处。淋巴瘤还会进一步扩散到身体其它部位的淋巴结,例如腹部(引起肿胀和疼痛)或者胸部(引起咳嗽、胸部不适和呼吸困难)。

其它症状可能包括:

- 反复发热
- 夜间大量出汗
- 体重骤减
- 长期乏力
- 全身瘙痒
- 新发皮疹
- 疲乏
- 原因不明的咳嗽和/或持续咳嗽
- 腹胀腹痛

淋巴瘤的体征和症状导致其经常被误诊为其它不太严重的疾病。

治疗

治疗方式根据确诊的淋巴瘤类型、体内病变扩散和恶化的速度、患者年龄及其整体健康状况而有不同。

有些淋巴瘤发展缓慢,症状不明显,可能不需要采取紧急治疗。有些淋巴瘤则发展迅速,一经确诊,必须及时进行治疗。治疗方式有化学治疗、放射治疗和免疫治疗。有时候,该病复发或者将来很可能复发时,会采用干细胞移植进行治疗。

关于该病的治疗详情,请参阅第39页。

骨髓瘤

骨髓瘤(亦称为多发性骨髓瘤)是浆细胞癌症。浆细胞是发育成熟的B淋巴细胞,普遍存在于骨髓中,通常作用是产生抗体,抵御感染。骨髓瘤中,浆细胞发生了恶性(癌性)病变且其繁殖不受控制,给身体不同部位带来了问题。大量的异常浆细胞,即骨髓瘤细胞,聚集在骨髓中,会干扰血细胞的生产,并破坏相邻的骨骼,产生疼痛。骨髓瘤细胞生成异常的抗体,即病变蛋白,通常通过血液和/或尿液检查诊断。

在新西兰,每年约有400人确诊患上骨髓瘤。大多数确诊患者年龄都在50岁以上。

病因

大多数病例中,骨髓瘤的病因仍不得而知,但可能与多种因素相关。和所有癌症一样,骨髓瘤的病因可能是控制血细胞生长和发育的一项或多项基因发生了突变。少数情况下,暴露于大量的放射治疗中以及不断暴露于特定的工业或环境化学物质中,都有可能导致该病。

or more of the genes that normally control the growth and development of blood cells. In a small number of cases, exposure to high doses of radiation and ongoing exposure to certain industrial or environmental chemicals may be involved.

Signs and symptoms

The most common symptoms of myeloma are:

- **Bone pain and/or fractures**
Often myeloma cells can interfere with the normal bone maintenance process and cause holes, or lesions in some bones. This can make the bones more fragile and at risk of getting fractures.
- **Fatigue**
Persistent fatigue or an overwhelming tiredness is common in myeloma. It might be caused by the disease itself or from myeloma treatment.
- **Recurring infection**
Infections can be more common because myeloma and its treatments lower the immune system, making you at higher risk of getting infections.
- **Anaemia**
Anaemia is when you have a low number of red blood cells, which can happen with myeloma or as a side effect of treatment.
- **Hypercalcaemia (high calcium levels)**
High levels of calcium in the blood can occur as a result of bone damage, which releases too much calcium into the bloodstream. Symptoms of hypercalcaemia can include thirst, nausea, vomiting, confusion and/or constipation.
- **Kidney damage**
Myeloma produces an abnormal protein (called paraprotein) that can damage the kidneys.

- **Peripheral neuropathy (damage to nerves in hands and/or feet)**

Peripheral neuropathy can be caused by myeloma itself or as a side effect to some common treatments used for myeloma. The nerves that are affected can cause tingling, altered sensation and pain.

It is important to remember that not everyone will experience all of these signs and symptoms.

Treatment

The main form of treatment is chemotherapy, usually in combination with other drugs. Steroids and other types of anti-myeloma drugs are often used in combination with chemotherapy, which work effectively together.

High-dose chemotherapy followed by an autologous stem cell transplant is also used for younger patients who are fit enough and would benefit from this type of treatment.

Drugs called bisphosphonates are a standard part of therapy used to strengthen bones affected by myeloma.

Radiotherapy may also be used to prevent and treat problems caused by bone damage.

There is more information about these treatments on page 38.

Myelodysplastic syndrome

Myelodysplastic syndrome (MDS) is a condition that affects normal blood cell production in the bone marrow. In MDS, the bone marrow does not produce enough red blood cells, white blood cells and/or platelets, and can produce an excess of immature blood cells known as blast cells.

体征和症状

最常见的骨髓瘤症状为：

• 骨骼疼痛和/或骨折

骨髓瘤细胞常可能会干扰正常的骨质更新，在某些骨骼中造成穿孔或损害。这会使骨骼更加脆弱，增加骨折风险。

• 疲乏

持续性疲劳或过度疲倦对于骨髓瘤患者都十分常见。这些症状可能是由疾病本身造成，也可能是由骨髓瘤治疗引起。

• 反复感染

由于骨髓瘤和相关治疗会削弱免疫系统，增加受感染的风险，因此骨髓瘤患者会更容易受感染。

• 贫血

贫血，即红细胞量过低，可伴随骨髓瘤发生，也可能是治疗造成的副作用。

• 高钙血症(血钙过高)

血液中钙浓度过高可能是骨骼受损引起，因为骨骼受损时会向血液释放过量钙。高钙血症的症状可能包括口渴、恶心、呕吐、神志不清和/或便秘。

• 肾功能损害

骨髓瘤产生异常蛋白质(即副蛋白)，可能损害肾功能。

• 周围神经病变(手和/或脚神经损伤)

周围神经病变可能是由骨髓瘤本身造成，也可能是一些常见治疗措施产生的副作用。受到影响的神经可能产生麻刺感，感觉和疼痛感发生变化。

请谨记，并非所有患者都会有以上所述的体征和症状。

治疗

主要的治疗方式是化疗，通常还会结合药物治疗。类固醇和其他抗骨髓瘤类药物经常与化疗结合，共同用于治疗。

对于年纪较轻的患者，若体质良好且适合此类治疗，则可以进行高剂量化疗，然后进行自体干细胞移植。

骨骼受到骨髓瘤损害后，通常会使用双磷酸盐这一标准治疗药物来强化骨骼。

放射治疗也可用来防止和治疗由骨骼损坏而导致的问题。

关于该病的治疗详情，请参阅第39页。

骨髓发育不良综合症

骨髓发育不良综合症(简称MDS)是一种影响骨髓中血细胞正常生成的疾病。患上MDS时，骨髓生成的红细胞、白细胞和/或血小板计数不足，而发育不良的血细胞(胚细胞)量太多。

MDS症有多种类型。病症的严重程度及其血细胞生长的受损程度会因人而异。部分患者可能症状较少(例如贫血)，另一些患者则可能出现血细胞计数低，导致发生感染、产生瘀斑、流风和严重贫血的风险升高。

在MDS患者中，高达30%的患者可能发展成急性髓性白血病(AML)。虽然MDS可发生于任何年龄，但主要发病年龄段为60岁以上。

There are several different types of MDS. The disease can vary in its severity and the extent to which blood cell production is disrupted. Some people may have few symptoms, (for example anaemia), while others might have very low numbers of blood cells causing increased risk of infection, bruising and bleeding, and severe anaemia.

In up to 30 per cent of people with MDS, it can progress to a type of leukaemia called acute myeloid leukaemia (AML). While MDS can occur at any age, the majority of cases develop over the age of 60 years.

Cause

MDS occurs as a result of a change (or mutation) in one or more of the genes that normally control the growth and development of blood cells. The exact reason for this change remains unclear but there are likely to be a number of factors involved. Increasing age remains the greatest risk factor for developing MDS. Exposure to high doses of radiation and ongoing exposure to certain industrial or environmental chemicals may be linked to the development of MDS.

People who have been previously treated for cancer or other conditions with cytotoxic chemotherapy are at an increased risk of developing what is called secondary or treatment-related MDS.

Signs and symptoms

In general, the types of symptoms you might experience depend on the severity of your disease, and the type of blood cell that is affected.

In many cases, MDS develops slowly and may be picked up with a routine blood test if you have no symptoms.

The most common symptoms are those caused by anaemia (low red blood cells). These symptoms include:

- Persistent tiredness or fatigue
- Dizziness
- Paleness
- Shortness of breath when physically active

Other symptoms may include frequent or repeated infections and slow healing, and increased or unexplained bleeding or bruising.

Treatment

Treatment for MDS will vary depending on several factors, including the severity of disease.

Many people, particularly in the early stages of MDS, don't have any symptoms and don't need to be treated. In these cases, the doctor may simply recommend regular blood tests to carefully monitor health and blood levels.

In more severe or progressive disease, chemotherapy may be used to control a rising blast cell count, and allow the bone marrow to resume normal blood cell production. This may involve low-dose chemotherapy given in tablet form, or more intensive treatment using a combination of drugs given subcutaneously (injected under the skin like an insulin injection).

The main treatment for the majority of people with MDS is supportive care. This involves the use of antibiotics to treat infection and (where necessary) blood transfusions to replenish

病因

MDS的病因是由控制血细胞生长和发育的一项或多项基因的异变(或突变)造成的。这一异变的确切原因尚不清楚,但可能与多种因素有关。年龄增长是导致MDS的最大风险因素。暴露于大量辐射以及持续暴露于特定的工业或环境化学物质中,都有可能导致患病。

曾经接受过癌症治疗或其它细胞毒素化疗的患者,患上继发性MDS症或治疗并发MDS症的风险更高。

体征和症状

通常情况下,患者的症状与其病症严重程度和受影响最大的细胞类型有关。

很多情况下,MDS症发展缓慢,患者没有显现任何症状,只是在常规血液检查中诊断出该病症。

最常见的症状是贫血(红细胞量低)症状。这些症状包括:

- 总是感到疲惫或疲倦
- 头晕
- 苍白
- 身体活动时呼吸短促

其它症状可能还包括:经常性或反复感染、愈合缓慢、出血或产生瘀斑增加或原因不明。

治疗

MDS症的治疗方式取决于多种因素,如病症严重程度。

许多人,尤其是早期MDS症患者,并没有任何症状,不需要进行治疗。这种情况下,医生可能只会建议进行常规血液检查,以严密监测患者健康状况和血液情况。

若病症比较严重或恶化速度快,则需采用化疗来控制病变细胞量的增加,使骨髓恢复到正常的血细胞生长水平。可能会以药片形式进行低剂量的化疗,或者通过皮下注射(像胰岛素一样进行皮下注射)多种药物进行强化治疗。

大多数MDS患者的主要治疗方式是支持性护理。这包括采用抗体防止感染,(必要时)进行输血,以便使红细胞和血小板计数恢复正常。部分病例中,也会使用生长因子来促进骨髓中正常血细胞的生成。

身体健康的年轻患者,也可以进行干细胞移植治疗。这类强化治疗可提高治愈几率。

关于该病的治疗详情,请参阅第39页。

vital numbers of red blood cells and platelets. Some people might need growth factors that are used to promote normal blood cell production in the bone marrow.

A stem cell transplant may be used in younger patients who have good general health. This type of intensive treatment may increase the chance of a cure.

There is more information about these treatments on page 38.

Myeloproliferative neoplasms (MPN)

MPNs are a group of diseases that affect normal blood cell production in the bone marrow. The bone marrow produces too many blood cells (either red blood cells, white blood cells or platelets). When present in large numbers, these cells cannot function properly and cause various problems in the body.

There are four main types of chronic myeloproliferative neoplasms:

- **Essential thrombocythaemia (ET)**
An overproduction of platelets.
- **Polycythaemia vera (PV)**
An overproduction of red blood cells as well as platelets and white blood cells.
- **Primary myelofibrosis (MF)**
Excessive blood cell production damages bone marrow tissue and is gradually replaced with abnormal fibrous tissue.
- **Chronic myeloid leukaemia (CML).**

In most cases, these blood cancers develop slowly and get worse gradually over many years. In some people it can progress to acute myeloid leukaemia (AML).

While MPNs can occur at any age, the majority of cases occur between the ages of 40 and 60 years. They are uncommon under the age of 20 years and rarely occur in children.

Cause

The exact cause of MPNs remains unknown but there are likely to be a number of factors involved, including a mutation in one or more of the genes that normally control the growth and development of blood cells.

Signs and symptoms

Symptoms vary depending on the particular type of MPN involved. Symptoms of an enlarged spleen (splenomegaly) are common, which include feelings of discomfort, pain or fullness in the upper left side of the abdomen. Excess circulating blood cells can cause easy bruising and bleeding, or blood clotting problems.

Treatment

Treatment will vary depending on the type of MPN you have, the severity of your symptoms, your age and general health. Treatment is generally aimed at reducing excess numbers of blood cells in the bloodstream and preventing and/or treating any symptoms and complications of the disease. It may include the use of oral chemotherapy drugs or other agents such as interferon, aspirin or anagrelide.

Sometimes people may also need to have a procedure called venesection, which is the removal of blood (a very similar procedure to donating blood).

骨髓增殖性肿瘤(简称MPN)

MPN是影响骨髓中正常血细胞生成的一类疾病总称。骨髓制造了过多血细胞(红细胞、白细胞或血小板)。如果数量过多,这些细胞会无法发挥正常功能,在体内造成各种问题。

慢性骨髓增殖性肿瘤主要有四种类型:

- **原发性血小板增多症(ET)**
血小板过量。
- **真性红细胞增多症(PV)**
过量生成红细胞、血小板和白细胞。
- **原发性骨髓纤维化(MF)**
血细胞生长过量损坏了骨髓组织,由异常纤维组织逐渐取而代之。
- **慢性粒细胞白血病(CML)。**

大多数情况下,血癌发展缓慢,多年以后才逐渐恶化。有些患者可能会发展成急性髓性白血病(AML)。

虽然MPN可在任何年龄发生,但大多数病例的年龄介于40至60岁之间。20岁以下年龄的患者不常见,儿童患者也很罕见。

病因

MPN的确切病因仍然未知,但可能与多种因素有关,包括控制细胞生长和发育的一项或多项基因发生了突变或病变。

体征和症状

症状与具体的MPN类型有关。常见症状是脾脏肿大,也包括左上腹不适、疼痛或圆胀。循环血细胞过量会导致非常容易产生瘀斑、出血或者凝血等问题。

治疗

治疗方式根据MPN的类型、症状严重程度、患者年龄和整体健康状况而有所不同。通常情况下,治疗旨在减少血液中过量的血细胞,防止和/或治疗疾病的各类症状和并发症。治疗方式还包括采用口服化疗药物或者其它干扰素、阿司匹林或阿那格雷(抗凝血药)等药物。

有时,患者可能还需要进行静脉放血(流程与献血十分相似),来减少体内血量。

TESTS AND INVESTIGATIONS

There are several common tests your doctor will ask you to have that will help them make a diagnosis.

These tests are:

- Blood tests
- Bone marrow biopsy
- X-rays and other imaging tests

Blood tests

The main blood test used to diagnose blood cancers is called a full blood count (FBC) or complete blood count (CBC). Blood is taken from a vein in your arm and sent to a laboratory where it is looked at under a microscope.

The doctor might also ask to test your blood chemistry, which may include your levels

of calcium, creatinine or different proteins important for detecting some blood cancers. Very specialised genetic testing can be done to confirm the diagnosis of certain blood cancers (i.e. MPNs).

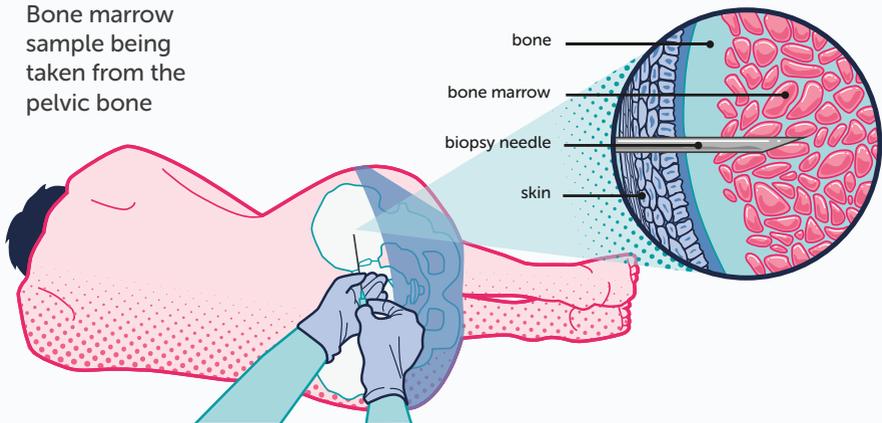
Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a laboratory to be looked at under a microscope. A sample of bone marrow is usually taken from the back of your hip bone (the iliac crest) (see Figure 04).

Figure

04

Bone marrow sample being taken from the pelvic bone



检查和调查研究

医生可能要求您进行几项常规检查,以帮助其做诊断。

这些检查包括:

- 血液检查
- 骨髓活体组织检查
- X射线和其它影像学检查

血液检查

用于血液癌症诊断的主要血液检查称为全血细胞计数(简称FBC或CBC)。从您手臂的静脉取血后,您的血样将被送到实验室在显微镜下观察。

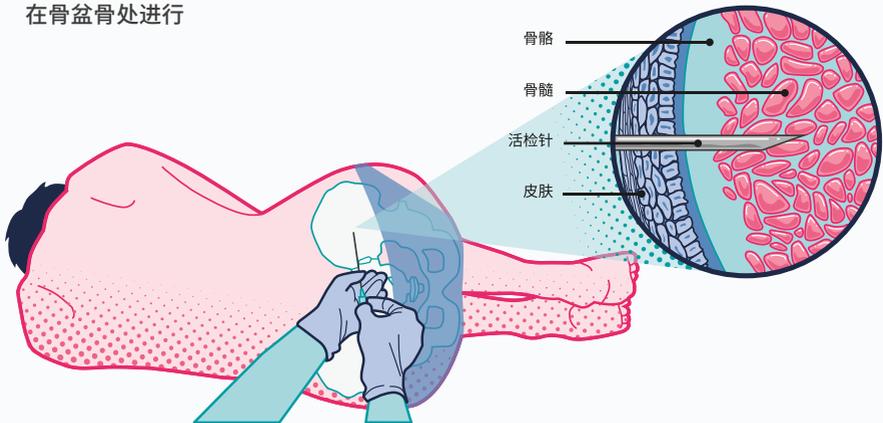
医生可能还会要求检查您的血液化学成分,包括您的钙水平、肌酸酐或其它对于检测血癌十分重要的蛋白。也可能进行一些专门的基因检测,以确诊某种血癌(即MPN)。

骨髓活体组织检查

在骨髓活体组织检查时,医生会对您的骨髓进行取样,然后送到实验室在显微镜下观察。通常是在您的髌骨后方(髌嵴)进行骨髓取样(见图04)。

图04

骨髓取样是在骨盆骨处进行



To do a bone marrow biopsy, the doctor puts a long needle through your numbed skin into the bone and then into the bone marrow. Bone marrow has liquid and solid parts. A small sample of your bone marrow liquid is taken out. This is called a bone marrow aspirate. A sample of the solid part of the bone marrow is also taken. This is called a bone marrow trephine (tre-fine).

Some people who have had a bone marrow biopsy say that it was painful and other people describe it as uncomfortable. Everybody is different. We recommend that you bring a support person with you when you have a bone marrow biopsy. If you have a sedative, you will still feel a bit drowsy afterwards. Your support person can make sure you get home safely.

After the biopsy, your doctor or nurse will put a plaster or small dressing over the biopsy site. You may need paracetamol to help ease some discomfort in the area afterwards. Your doctor or nurse will talk to you about this.

X-rays and other imaging tests

Many people require x-rays or other imaging tests as part of being diagnosed with a blood cancer and also for ongoing monitoring.

These might include:

- Chest x-ray to detect a chest infection or any other abnormalities.
- Electrocardiogram (ECG) and echocardiogram (ECHO) to see how well your heart is working.
- CT scan (computer-assisted tomography scan) or ultrasound may be used if there is concern about specific localised involvement or damage caused by the disease.
- MRI scan (magnetic resonance imaging scan) may be used in diagnosis and monitoring.
- A full-body x-ray or skeletal survey may be done to check for any evidence of bone damage. X-rays are usually taken of your skull, spine (backbone), ribs, pelvis (hips), legs and arms.
- PET scan (positron emission tomography scan) uses a specialised type of intravenous (IV) contrast and CT scan technique to look for areas where there may be increased tissue activity due to disease involvement. PET scan is less commonly used in New Zealand but may be requested by your haematologist.

Your haematologist will inform you of what tests they recommend you have and why. Everyone is different so tests may vary from person to person.

具体方法如下：麻醉后，医生会用长针刺入您的皮肤，穿过骨骼进入骨髓。骨髓中既有液体也有固体成分。从您骨髓中的液体成分中取出少量样本。此即骨髓穿刺液。再从骨髓中的固体部分取出少量样本。此即骨髓换钻检查。

一些做过骨髓活检的人表示过程中疼痛感明显，另外一些人则仅表示有不适感。每个人的感受都不一样。建议您进行骨髓活检时请人陪同。如果您在检查时注射了镇静剂，之后可能会有晕眩感。这时，陪同人员将护送您安全到家。

活检后，您的医生或护士将在穿刺部位贴上膏药或敷料。如果感到不适，您可以使用醋氨酚来缓解。您的医生或护士会告知您这些细节。

X射线和其它影像学检查

很多医生在诊断血癌时会要求进行X射线检查或其它影像学检查，也便于进行持续性监测。这些检查可能包括：

- 胸部X光，检查是否有胸部感染或其它异常。
- 心电图(简称ECG)和超声心动图(简称ECHO)，检查心脏功能情况。
- 如果担心特定的局部区域受累或该病引起损伤，可以进行CT扫描(计算机辅助断层扫描)或超声检查。
- MRI扫描(磁共振成像扫描)，用于诊断和监测。
- 全身X光检查或骨骼检查，用于检查是否有骨骼损伤。通常用X光来扫描您的头骨、脊骨(脊柱)、肋骨、骨盆(髌)、双腿和手臂。
- PET扫描(正电子发射计算机断层扫描)，使用专门的静脉(IV)造影和CT扫描技术，来检查由于疾病受累引起组织活动增加的区域。PET扫描在新西兰不太常见，但您的血液科医生可能仍要求做该检查。

您的血液科医生将告知您建议您做的检查及原因。每个人的身体情况都不一样，检查项目也会因人而异。

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

You will meet a range of health professionals who are part of your health care team.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will give you and your family the best treatment and support so that you can live as well as possible following a blood cancer diagnosis.

Some of the health professionals you will meet are, in alphabetical order:

- **Charge nurse** – A senior nurse in charge in the outpatient department or on the hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of cancer care. This person works closely with you and members of your health care team to help you manage the symptoms and side effects of your blood cancer and treatment.
- **Dietitian** – A dietitian will advise on what to eat and drink to minimise symptoms or side effects from your treatment. A dietitian may prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor might already be involved with your blood cancer diagnosis. They will be informed throughout your diagnosis and will work together with other health professionals to support you at home, in the community and after treatment.
- **Haematologist** – A doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist will be in charge of overseeing your treatment and follow-up.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in the clinic.
- **Pharmacist** – Prepares and checks your medications. A pharmacist can advise you on how to take your medicine and the possible side effects.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility. A physiotherapist (or physio) can help you regain independence and fitness.
- **Psychologist** – Specialises in helping you manage the emotional challenges of a blood cancer diagnosis, such as stress, anxiety and depression.
- **Registrar** – A doctor who is training to become a haematologist. You will often see your registrar on the ward and in the clinic. Your registrar works very closely with your haematologist.

诊断后我会见到哪些医疗专家？

您将见到多名医疗专家，他们都是您的医疗保健团队成员。

每位医疗专家在癌症和癌症护理方面都有自己的专攻领域。这些医疗专家将共同为您和您的家人提供最佳的治疗和支持，让您在确诊血癌后也能尽可能保证生活质量。

您将见到的医疗专家包括(以字母先后顺序排列)：

- **护士长** — 负责门诊或病房的高级护士。
- **临床护理专家(简称CNS)** — 在癌症护理某一领域有高级技能的护士。此人将与您和您的医疗保健团队紧密合作，帮助您管理血癌和治疗过程中的症状和副作用。
- **营养师** — 营养师将给您提出饮食建议，最大程度减少您在治疗过程中出现的症状和副作用。营养师可能会开一些营养补充剂，确保您的卡路里和营养摄入正常。
- **全科医生(简称GP)** — 家庭和社区医生，可能已经参与了您的血癌诊断过程。他们将全程了解您的诊断情况，并与其他医疗专家一道为您在家、在社区和术后的生活提供支持。
- **血液科医生** — 专门负责血癌或血液疾病治疗的医生。血液科医生将负责监督您的治疗过程和随访。
- **职业治疗师** — 帮您管理日常活动并完成您想做或需要解决的事项。
- **门诊护士** — 为您提供门诊治疗或在诊所为医生提供帮助。
- **药剂师** — 负责准备并检查您的药物。药剂师会告知您服药方式及可能的副作用。
- **物理治疗师** — 专门负责维持和改善身体运动和活动能力。物理治疗师(或理疗师)可以帮助您恢复健康和独立生活能力。
- **心理学家** — 专门帮助您解决血癌诊断中遇到的情绪问题，如压力过大、焦虑和抑郁。
- **专业注册医师** — 正在接受培训准备成为血液科医生的医生。您将经常在病房和门诊见到您的专业注册医师。其与您的血液科医生密切合作。

- **Social worker** – Helps you manage the practical and emotional impact of having a diagnosis of a blood cancer, such as advice about managing at home, employment or school.
- **Ward nurse** – A nurse who looks after you during your stay in hospital.

Other people you might hear about or meet are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of blood cancers, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-Governmental organisation (NGO)** – Gives emotional and practical support for those affected by cancer, e.g. Leukaemia & Blood Cancer New Zealand.
- **Leukaemia & Blood Cancer New Zealand Support Services Coordinator**, a professional who provides education as well as practical and emotional support. Phone 0800 15 10 15.

- **社会工作者** — 帮您处理血癌诊断造成的实际影响和情绪影响, 如给您在家、在工作场所和在学校的的生活提出建议。

- **病房护士** — 在您住院期间为您提供照顾。

其他您可能听说或见到的人包括：

- **姑息治疗团队** — 由医生、护士和其他医疗保健专家组成, 其职责包括控制血癌症状、帮助改善您的生活质量并提供临终关怀。

- **精神关怀和文化支持** — 满足您个人的文化、精神和宗教需求。

- **非政府组织(简称NGO)** — 给癌症患者提供情感支持和实际支持, 如新西兰白血病与血癌机构。

- **新西兰白血病与血癌支持服务协调员**, 该专家会提供相关教育, 实践支持情感支持。
电话:0800 15 10 15。

TREATMENTS

In this section we provide a brief overview of treatments for blood cancers and blood conditions. It is important to note that the information provided here is of a general nature and may not necessarily apply to the specific type or severity of disease that you or your family member might have been diagnosed with.

Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxic (cell toxic) drugs because they kill cells, especially ones that multiply quickly such as cancer cells.

Chemotherapy usually involves a combination of drugs (combination chemotherapy). The names of different combinations of drugs are commonly derived from the first letters of each of the drugs used.

Chemotherapy is often given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body to recover from the side effects of chemotherapy.

How is chemotherapy given?

There are many ways of giving chemotherapy. It can be given through a vein (intravenously or IV), usually in your arm or hand, under the skin (subcutaneously) or in a tablet form (orally).

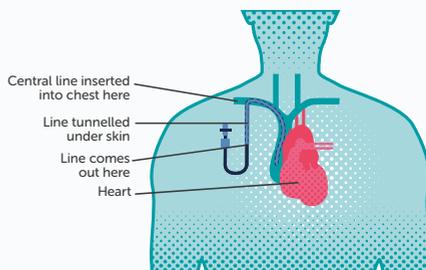
If you are having several cycles of chemotherapy, your haematologist may recommend that you have a central venous catheter (also called a central line) or portacath inserted (see Figure 05). A central venous catheter is a special line inserted

through the skin into a large vein in your arm, neck or chest. Once it's in place, chemotherapy and any other IV drugs can be given through the line and blood tests can also usually be taken from the line, without needing frequent needle pricks. There are several different kinds of central lines used, some are intended for short-term use while others remain in place for months and even years.

Figure

05

Central line placement



Most people don't need to be admitted to hospital for IV chemotherapy, instead it is usually given in the outpatient department of the hospital. Sometimes, however, you may need to be admitted to the ward for a short while.

治疗

这一部分将对**血癌和血液疾病的治疗**进行简单的介绍。介绍内容为一般通用常识，不一定适用于您或您的家庭成员可能诊断的疾病类型或其病症严重程度。

化学治疗

顾名思义，化学治疗即是采用化学药物的治疗。许多化学治疗药物也称为细胞毒素药物，因为此类药物杀死细胞，尤其是繁殖快速的癌细胞。

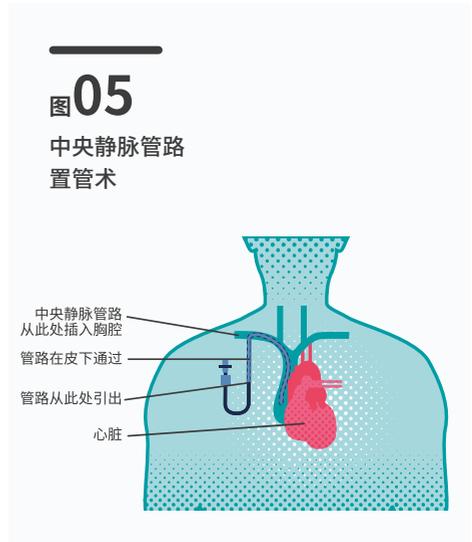
化学治疗通常采用多种药物配合(合并用药化疗)。不同合并药物的名称通常以所采用药物的首字母组合而成。

化疗通常分几个周期(疗程)进行，各疗程之间会有数周的休息时间。这是为了让身体从化疗的副作用中恢复过来。

如何进行化疗？

化疗方式有很多种。可以通过在手臂或手上进行静脉注射(简称IV)、皮下或口服药品形式进行。

如果要进行数个疗程的化疗，您的血液科医生可能会建议您插入静脉管路或内植式中央静脉管路(见图05)。中央静脉管路是通过皮肤插入到您手臂、脖子或胸部的静脉中的特殊管路。插入后，则可以通过该管路输入化疗或者其它静脉注射药物，也可以从该管路进行血液检测，这样可免除繁杂的针头穿刺。所用的中央静脉管路有几种。有些供短期使用，有些则能保留几个月甚至几年。



大多数患者不需要为静脉注射化疗住院，通常在医院门诊部门进行即可。但是，有时候，您可能需要短期住院。

Side effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as cancer cells. It also causes damage to fast-growing normal cells including hair cells and cells in your mouth, gut and bone marrow. The side effects of chemotherapy occur as a result of this damage.

The types of side effects and their severity vary from person to person depending on the type of chemotherapy given and how you respond to it. There is no doubt that side effects can be very unpleasant at times but it is good to remember that most of them are temporary and reversible. It is important that you report any side effects that you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

Effects on the bone marrow

Chemotherapy temporarily affects the bone marrow's ability to produce adequate numbers of white blood cells, platelets and red blood cells. As a result, your blood counts will generally fall within a couple of weeks of treatment. The length of time it takes for your bone marrow and blood counts to recover mainly depends on the type of chemotherapy given. The three main complications of low blood counts are:

- Increased risk of infection
- Bruising and bleeding
- Anaemia

Infection

Your white blood cell count is at its lowest usually between 10 to 14 days after having your chemotherapy, during which time you will be at a higher risk of developing

an infection. A blood test will sometimes be arranged for you during this time to check your blood count. At this stage you will also be neutropenic, which means that your neutrophil count is low. Neutrophils are important white blood cells that help us to fight infection. While your white blood cell count is low you should take sensible precautions to help prevent infection, which include the following:

- **Being around other people**
Stay away from crowds of people and avoid people with infections that are contagious (for example head cold, flu, chicken pox).
- **Preparing and eating food**
Your haematologist or nurse will tell you what foods to avoid if your white blood cell count is low. They may suggest you have a 'neutropenic' diet or 'clean' diet. This type of diet protects you from germs found in some food and drinks. It is important to be very careful when preparing and cooking food. You need to:
 - Always wash your hands before preparing or eating food.
 - Tell your family to wash their hands when preparing food.
 - Prepare food in a clean place.
 - Wash fruit and vegetables well.
 - Make sure reheated food is very hot.
 - Do not reheat food more than once.
 - Eat food before its best before/ use-by date.
 - Prepare raw meat on a separate chopping board and make sure it is then cooked properly.



**More information
available online**

化疗的副作用

化疗会杀死所有快速繁殖的细胞，例如癌细胞。但是，也可能损坏快速生长的正常细胞，包括头发细胞、口腔细胞、内脏及骨髓。因为这些损害，产生了化疗的副作用。

副作用的类型及其严重程度因人而异，具体取决于您进行的化疗方式和您的身体反应。毫无疑问，有时候这些副作用让人非常苦恼，但是大多数副作用都是暂时的，过后可以恢复正常。您必须向您的护士或医生汇报您的副作用情况，因为大多数副作用都能治好，减少不必要的痛苦。

对骨髓的影响

化疗会暂时影响骨髓生成适当的白细胞、血小板和红细胞数量的能力。因此，您的血细胞计数通常会在治疗几周后就下降。骨髓和血细胞计数恢复正常所需时间，会因接受的化疗种类而异。血细胞计数低会引起三种主要的并发症：

- 感染几率上升
- 瘀斑和流血
- 贫血

感染

您的白细胞计数通常在化疗后10到14天到达最低点，这个期间内，您受到感染的风险更高。这个时期内，有时候会给您进行血液检查，以观测您的血细胞计数。这一期间，您可能还会产生中性白细胞减少症，也就是说您的中性白细胞计数很低。中性白细胞是帮助我们抵抗感染的重要白细胞。当您的白细胞计数较低时，您应当采取适当措施防止感染，包括以下几点：

- **与他人在一起时**
远离人群聚集处，避免与患有传染病(如感冒、流感或水痘)的人接触。
- **准备食物和吃饭时**
您的血液科医生或护士将告知您，当您的白细胞计数低时，应有哪些忌口。他们可能会建议您实行“中性白细胞减少”饮食和“清洁”饮食计划。这种饮食可以保护您免受某些食物和饮品中含有的病菌的伤害。在准备和烹饪食物时请十分小心。您需要做到以下几点：
 - 准备食物前或饭前必须洗手。
 - 让您的家人在准备食物前洗手。
 - 确保准备食物的区域干净。
 - 仔细清洗水果和蔬菜。
 - 确保再加热的食物已充分加热。
 - 避免反复加热食物。
 - 在食物保质期 / 最佳使用日期之前食用。
 - 以专用砧板处理生肉，将生肉彻底煮熟。



在线提供更多信息

- **Keeping yourself clean**

When you have a low white blood cell count, you are more likely to get an infection from germs on your body. You need to:

- Have a shower or bath every day.
- Use a clean towel.
- Wash your hands after using the toilet and ask family members to do the same.
- Clean your teeth regularly with a soft brush.
- If you have a central IV line, make sure it stays clean and check for signs of infection such as redness, swelling, pus or pain.

- **Gardening**

Garden soil can cause infections in people with a low white blood cell count. You need to:

- Wear gloves, as soil and potting mix can have harmful germs in it.
- Wash any cuts you get from gardening very thoroughly.

- Wear a mask to avoid breathing in particles.

- **Pets**

When you have a low white blood cell count, you may get an infection from pets. You need to:

- Always wash your hands after touching animals.
- Do not let a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Don't touch the litter tray or dog poo.

Your haematologist and nurse will advise you on how to reduce your risk of infection while your white blood cell count is low.

If you do develop an infection you may experience a fever (high temperature), which could be accompanied by an episode of rigor, where you shiver uncontrollably. Infections while you are neutropenic can be quite serious and need to be treated with antibiotics as soon as possible.



Important information

It is important that you contact your haematologist or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience any of the following:

- A temperature of 38°C or over and/or an episode of shivering.
- Bleeding or bruising, for example blood in your urine, faeces or sputum, bleeding gums or a persistent nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or constipation.
- Coughing or shortness of breath.
- The presence of a new rash, reddening of the skin, itching.
- A persistent headache.
- New pain or soreness anywhere.
- If you cut or otherwise injure yourself.
- If you notice pain, swelling, redness or pus anywhere on your body.

• 保证个人卫生

当您的白细胞计数较低时，您更容易受到自身病菌的感染。您需要做到以下几点：

- 每天洗澡。
- 使用干净的毛巾。
- 上完厕所后洗手，并要求家人也这么做。
- 用软毛牙刷定时刷牙。
- 如果您有插入中央静脉管路，请确保管路清洁，并检查是否出现感染迹象，如发红、肿胀、流脓或疼痛。

• 进行园艺工作时

对于白细胞计数较低的人而言，园土会引感染。您需要做到以下几点：

- 戴好手套，因为土壤和盆栽混合土中含有有害病菌。
- 如果在园艺过程中受伤，请彻底清洗伤口。

- 戴好口罩，避免吸入颗粒物。

• 宠物

当您的白细胞计数较低时，您可能被宠物感染。您需要做到以下几点：

- 摸完动物后洗手。
- 不要让宠物舔您的脸。
- 保持宠物干净，宠物感染蠕虫和跳蚤后要及时治疗。
- 不要触摸猫砂盘或狗粪便。

您的血液科医生和护士会为您提供建议：在白细胞计数低的情况下，该如何降低感染。

如果受到感染，您可能会发高烧(体温过高)，伴有寒战症状，即身体不受控制地发抖。中性白细胞计数低的时候遭受感染，情况会变得很严重，必须采用抗体及时治疗。



重要信息

如果觉得不舒服，或者出现下列任何一种情形，必须立即(不论白天或晚上)联络您的血液科医生，寻求帮助：

- 体温在38摄氏度或以上，和/或不停发抖。
- 出血或产生瘀斑，例如，大小便和痰中出现血液，牙龈出血或持续流鼻血。
- 反胃或呕吐，因此无法进食或喝饮料，或无法正常服用药物。
- 腹泻、腹部痉挛或便秘。
- 咳嗽或呼吸短促。
- 皮肤不断出现红斑、红肿、瘙痒。
- 头疼不已。
- 全身疼痛或酸痛。
- 割伤或伤到自己。
- 身体部位出现疼痛、肿胀、红肿或出脓。

Bruising and/or bleeding

Your platelet count may also be affected and you could become thrombocytopenic (a low number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time, it is helpful to avoid sharp objects in your mouth such as potato chips as these can cut your gums. Using a soft toothbrush also helps protect your gums. In some severe cases, a transfusion of platelets is given to reduce the risk of bleeding until the platelet count recovers.

Anaemia

If your red blood cell count and haemoglobin levels drop you may become anaemic. When you are anaemic you feel more tired and lethargic than usual. Other symptoms of anaemia include weakness, dizziness, pale skin and feeling short of breath when exercising.

If your haemoglobin level is very low, your doctor may prescribe a blood transfusion.

Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy. You will be given anti-sickness drugs (otherwise known as antiemetics) before and for a few days after your chemotherapy treatment. Be sure to tell your haematologist if you think the antiemetics are not working for you and you still feel sick. There are many different types of antiemetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you relax but it might make you a little sleepy.

Some people find that eating smaller meals more frequently during the day, rather than a few large meals, helps to reduce nausea and vomiting. Drinking ginger ale or soda water and eating dry toast may also help if you are feeling sick. Getting plenty of fresh air, avoiding strong or offensive smells and taking the prescribed anti-sickness drugs as recommended by the nurse and doctor should also help.

Mucositis

Mucositis occurs when chemotherapy breaks down the rapidly divided epithelial cells lining the gastrointestinal tract (which goes from the mouth to the anus). This leaves the mucosal tissue (mucous membrane) open to ulceration and infection. More commonly the mouth and throat are affected and can cause pain, ulcers and increased saliva.

Mucositis can be quite painful and may require you to take pain relief medications. Mouthwashes/rinses are also helpful. Please ask your nurse for the hospital's recommended mouthwash guidelines as some products that you can buy at the supermarket might not be suitable.

Bowel changes

Chemotherapy can cause damage to the lining of your bowels, which can cause cramping and diarrhoea. Be sure to tell your health care team if you are experiencing these symptoms. It is also important to tell them if you are experiencing constipation, discomfort or tenderness when you are going to the toilet. Some treatment can cause constipation but there are medications to help prevent or fix this. It's important to drink plenty of water to stay well hydrated.

瘀斑和/或流血

您的血小板计数也可能受到影响,并可能患上血小板减少症(血液中循环的血小板计数较低)。血小板计数非常低时,您会很容易产生瘀斑和出血。这段期间,最好避免食用尖锐食品,例如土豆片等容易割破牙龈的食品。使用柔软牙刷也利于保护您的牙龈。有些病例中,采取血小板输血的方式来降低出血风险,直到血小板计数恢复正常为止。

贫血

如果您的红细胞计数和血红蛋白量降低,则可能会贫血。如果出现贫血,您会感觉比平常更疲倦,更困倦。贫血的其它症状还包括虚弱、晕眩、皮肤苍白以及运动时呼吸短促。

如果血红蛋白量很低,您的医生可能会让您进行输血。

反胃和呕吐

化疗通常会出现反胃和呕吐。化疗前和化疗后数日,医生会给您一些止吐药。如果止吐药不起作用或者您仍感到不适,请务必告知您的血液科医生。您可尝试多种不同的止吐药。此外,可能还会使用轻度镇静剂,帮助您消除不适感觉。这会让您感觉放松,但也会有点昏沉。

部分患者发现一天中少食多餐有助于减少反胃和呕吐症状。感觉不适时,喝姜汁饮料或苏打水以及吃干的吐司也会有所帮助。多呼吸新鲜空气,避免强烈或刺激的气味,服用医生和护士建议的止吐药,也会有所帮助。

黏膜炎

当化疗破坏胃肠道(从口腔到肛门)快速分裂的上皮细胞时,就会引起黏膜炎。黏膜炎使得黏膜组织(黏膜)容易溃疡和感染。更常见的症状包括口腔和喉咙受影响感到疼痛、产生溃疡且唾液变多。

黏膜炎可能会很痛,您需要服用止痛药。漱口剂也会有帮助。由于超市购买的某些产品可能不适合,请咨询您的护士,了解医院建议购买的漱口剂。

肠道变化

化疗会损坏您的肠道黏膜,会引起腹部痉挛和腹泻。如果出现这类症状,请务必告知您的医疗保健团队。如果上厕所时便秘、感到不适或疼痛,也请务必告知他们。一些治疗可能会造成便秘,但有药物可以预防或解决该问题。多喝水很重要,可保持水分充足。

Hair loss

Alopecia (or hair loss) is a very common side effect of some types of chemotherapy drugs. It is usually temporary and your hair will start growing back after you stop chemotherapy. You may lose hair all over your body including eyebrows, eyelashes and pubic hair.

There are several things you can do to make yourself more comfortable if you lose your hair, which include:

- Wear a warm hat or beanie outside or overnight to keep your head warm.
- Wear a sunhat and apply sunscreen when you are outside as your skin will be sensitive to the sun and can burn easily.

Fatigue

Most people experience some degree of tiredness following chemotherapy. Extreme tiredness and fatigue is one of the most common symptoms and can be distressing and hard to manage. Fatigue is not relieved by rest and affects you physically, psychologically and socially. It may improve when treatment is finished but for some people it may last for months or years.

It is important to eat well, drink plenty of water and remain active by doing gentle exercise. It is important to talk to your nurse and doctors about your symptoms of fatigue and how you are coping.



**More information
available online**

Radiotherapy

Radiotherapy (also known as radiation therapy) uses high-energy x-rays to kill cancer cells and shrink tumours. Radiotherapy is generally regarded as local therapy because it only destroys cancer cells in the treated area.

The radiation field is the area of the body that is being treated. Common radiation fields include the mantle field (neck, chest and armpit), the upper abdominal field (abdomen and sometimes the spleen) and the pelvic field (hips and groin). Due to improvements in technology, the radiation field can often be individualised to maximise treatment and reduce side effects. This is termed 'involved field' or 'involved site' radiation therapy.

What is involved in radiotherapy?

Before you start radiotherapy, a radiation specialist (a doctor who specialises in treating people with radiotherapy) will carefully calculate the correct dose of radiation therapy for you. The areas of your body that need to be treated will be marked with tiny ink dots on your skin. Sometimes a mould will need to be made, which helps hold you in place during the radiotherapy session.

Radiotherapy is usually given in small doses (also known as fractions) each weekday (Monday to Friday) over a few weeks in the radiotherapy department of the hospital. You do not usually have to be admitted to hospital for this treatment, but if you live far away you may need to organise some accommodation for this time. The social worker or nurses can assist you with this.

脱发

秃头症是部分化疗药物的常见副作用。通常是暂时性脱发，在停止化疗后，头发会恢复正常生长。您全身的毛发可能都会脱落，包括眉毛、睫毛和阴毛。

脱发后，您可以采取以下几种办法来避免不适：

- 出门戴暖和的帽子或无檐小便帽，以保持头部暖和。
- 由于您的皮肤对阳光更加敏感，更容易晒伤，所以出门时请戴好太阳帽并涂防晒霜。

疲劳

化疗后，大多数人都觉得有一定程度的疲倦。极度疲劳和疲倦是最常见的症状之一，会让人感到忧虑，且难以克服。这种疲劳无法通过休息缓解，还可能影响您的生理、心理健康和日常社交。当治疗结束后，这种情况可能会得到缓解，但对于部分患者，这种状态会持续数月甚至数年。

每天健康饮食、喝足量的水并做柔和的运动来保持身体活跃，这些都十分重要。同时，请告知您的护士和医生您的疲乏症状和应对方式。



在线提供更多信息

放射治疗

放射治疗是采用高能量的X光杀死癌细胞并缩小肿瘤。放射治疗通常被视为局部治疗，因为它只能消灭治疗部位的癌细胞。

放射区域是需要治疗的身体部位。常见的放射区域包括外膜区域(颈部、胸部及腋下)、上腹部(腹部或脾脏)、骨盆区域(臀部和腹股沟)。由于治疗技术改进，放射区域可以针对单个患者进行个人化设计，以最大化治疗效果并减少副作用。这在放射治疗中的术语为“受累野”或“受累部位”。

放射治疗包括哪些内容？

开始放射治疗之前，放疗师(放射治疗专业医生)会为您仔细地计算放射治疗的正确用药量。您需要治疗的身体部位将在您的皮肤上用小黑点标记出来。有些情况下，需要制作模具，帮助您在放疗疗程期间保持不动。

放疗疗程通常在医院的放疗科进行，每个工作日(周一至周五)进行少量用药，为期数周。进行放射治疗，您不需要住院，但是如果您住得比较远，可能治疗期间需要安排住宿。社区工作者或者护士可以帮助您安排住宿。

在进行放射治疗时，您通常要躺在放射治疗仪器下的工作台上，治疗仪按预先定好的药量放射治疗。重要的器官(例如您的心脏和肺)必须尽可能加上防护，避免非治疗部位受治疗损伤。放射治疗是无痛的——事实上，治疗过程中，您既看不到也感觉不到任何东西。治疗过程中，您需要保持不动，维持数分钟。您可以自带音乐，让自己放松。

When you are having radiotherapy you usually lie on a table underneath the radiotherapy machine, which delivers the planned dose of radiation. Important structures such as your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless – in fact, you do not see or feel anything during the actual treatment. You will need to stay very still for a few minutes while the treatment is taking place. You might like to bring along some music to help you relax.

Side effects of radiotherapy

Radiotherapy can cause similar side effects to those caused by chemotherapy including nausea and vomiting, hair loss and fatigue. These are described in the previous section on page 40.

Skin reactions

Radiotherapy can cause a reddening of the skin that may also flake and become itchy. The staff at the radiotherapy department will advise you on how to care for your skin while you are having treatment. Gentle washing (avoiding perfumed products like scented soaps) and drying (patting rather than rubbing) is often recommended. You should also avoid any creams or moisturisers that contain traces of metals. Check with the radiotherapy department staff if you are unsure.

It is best to avoid direct sunlight on any area of skin that has received radiotherapy, even after the therapy has finished. This is because radiotherapy makes your skin more vulnerable to the damaging effects of the sun (i.e. sunburn and skin cancers).

Stem Cell Transplant

High doses of chemotherapy and radiotherapy destroy stem cells and your body cannot recover on its own. If you have a stem cell transplant, you are given high-dose chemotherapy followed by stem cells through a drip to replace the ones that were destroyed. The stem cells you are given may come from someone else (a donor) or may be your own stem cells that were frozen before the high-dose chemotherapy.

A stem cell transplant may also be called a bone marrow transplant or a peripheral blood stem cell transplant.

There are two types of stem cell transplant:

- **An autologous transplant** involves collecting your own stem cells, usually from your bloodstream, storing them and then returning them after you have received high doses of chemotherapy.
- **An allogeneic transplant** is where the stem cells are donated by another person, usually a sibling or unrelated matched donor. These donated stem cells replace your immune system with the immune system of the donor.

Having a stem cell transplant is a high-risk treatment option and a lot of things are taken into consideration before it is offered by your haematologist.

放射治疗的副作用

放射治疗会产生和化疗类似的副作用,包括反胃和呕吐、脱发以及疲倦。此类副作用已经在上一部分(第39页)描述。

皮肤反应

放射治疗会导致皮肤变红,也可能会脱落、瘙痒。放疗科的工作人员会建议您在治疗期间如何护理您的皮肤。通常会建议您轻柔地清洗(避免使用有香气的肥皂等产品)和擦干(轻拍,不要摩擦)。您还要避免采用含有金属成分的乳霜或润肤液。如果有问题,请咨询放疗科工作人员。

最好避免放射治疗部位皮肤直接暴露在阳光下,即使在治疗结束后亦应避免。因为放射治疗会使您的皮肤更容易受到太阳的伤害(例如晒伤和皮肤癌)。

干细胞移植

高剂量的化疗和放疗会破坏干细胞,且这种情况下您的身体无法自愈。如果要进行干细胞移植,则在接受高剂量的化疗后滴注干细胞来替换被破坏的干细胞。您获得的干细胞可能来自于他人(捐献者)或是您在接受高剂量化疗前冷冻的自己的干细胞。

干细胞移植也叫做骨髓移植或外周血干细胞移植。

干细胞移植有两种:

- **自体移植**是采集您自己的干细胞,通常从您的血液中获得并储存,然后在您进行高剂量化疗后再输回。
- **异体移植**是由别人捐献干细胞,通常来自兄弟姐妹或匹配的非亲缘捐献者。这些捐献的干细胞用捐献者的免疫系统替换了您本身的免疫系统。

干细胞移植是一种高风险的治疗方案,您的血液科医生在向您做此提议前会考虑很多因素。

Palliative Care

The palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of blood cancers. They aim to improve quality of life through support and services as you face a life-limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end-of-life care. The palliative care team supports all people with blood cancers, including end-of-life care.

Complementary Therapy

Complementary therapies are not considered standard medical treatment, however many people find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies. Examples include:

- Yoga
- Exercise
- Meditation
- Prayer
- Acupuncture
- Relaxation
- Massage
- Homeopathy
- Visualisation
- Aromatherapy
- Reiki
- Art therapy
- Music therapy
- Tai chi

Complementary therapies should 'complement' or assist with recommended medical treatment. They are not recommended as an alternative to medical treatment. It is important to realise that no complementary or alternative treatment has been proven to be effective against blood cancers and conditions. It is also important to let your haematologist know if you are using any complementary or alternative therapies in case they interfere with the effectiveness of chemotherapy or other treatments you may be having.

姑息治疗

姑息治疗团队由专门研究血癌症状的医生、护士和其他医疗保健专家组成。他们的工作是，为时日无多的病患提供支持和服务以改善其生活质量。姑息治疗团队可能会为您提供支持性护理。

很多人会将“姑息”与临终关怀联系在一起。姑息治疗团队为所有血癌患者都提供支持，包括提供临终关怀。

辅助治疗

辅助治疗不属于标准药物治疗，但很多患者发现其有助于积极应对治疗和疾病康复。辅助治疗有多种类型。例如：

- 瑜伽
- 锻炼
- 冥想
- 祈祷
- 针灸
- 放松
- 按摩
- 顺势疗法
- 可视化
- 芳香疗法
- 灵气疗法
- 艺术治疗
- 音乐治疗
- 太极

辅助治疗必须“辅助”或有利于血癌及血液疾病建议采用的药物治疗。可是，不建议以辅助疗法取代药物治疗。切记目前尚未证实有任何辅助治疗或替代治疗可以有效地治疗血癌和血液疾病。如果您采用了辅助治疗或替代治疗，必须告知您的血液科医生，以免干扰您的化疗或其它治疗的疗效。

MAKING TREATMENT DECISIONS

Many people are overwhelmed when they are diagnosed with a blood cancer or blood condition.

In addition to this, waiting for test results and then having to make decisions about proceeding with the recommended treatment can be very stressful. Some people do not feel that they have enough information to make such decisions, while others feel overwhelmed by the amount of information they are given. It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make your own decisions about which treatment to have.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current haematologist, about getting a second opinion.

Questions to ask your health care team

Before going to see your haematologist, make a list of the questions you want to ask. It may be useful to keep a notebook or some paper and a pen handy so you can write down questions as they come to mind.

Bring a support person

Sometimes it is hard to remember everything the doctor has said. It may help to bring a

family member or friend along who can write down the answers to your questions or prompt you to ask others, be an extra set of ears or simply be there to support you.

Being in a clinical trial

Your doctor might ask if you would like to take part in a clinical trial (also called research studies). Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available.

Taking part in a clinical trial is voluntary, which means that you do not have to take part if you do not want to. If you do not want to be part of a clinical trial, your decision will be respected. You do not have to give any reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or health care team.

Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist and other members of the health care team before signing the consent form.



**More information
available online**

选择治疗方案

许多人在确诊血癌或血液疾病后会觉得茫然失措。

除此之外,等待检测结果,然后对建议的治疗方案作出抉择,都会让人备感压力。部分人会觉得缺乏信息,难以做决定;有些人则觉得信息太多,不知所措。详细了解您的病症和治疗选项对您很有帮助,这样您就可以决定要采取的治疗方案。

第二医疗意见

您可以寻求第二意见。第二意见指的是到不同的血液科医生处就诊,让其对您进行诊断和/或治疗。关于第二意见,您可以向卫生保健团队中的任何成员(包括您现在的血液科医生)处寻求意见。

需要医疗保健团队解答的问题

在去看血液科医生前,列出您要询问的问题清单。可以随身携带笔记本、纸和笔,这样您就可以随时写下想出的问题。

在他人陪同下进行

有时候,很难记得医生说过的所有事项。您可以让家人或亲友陪同看医生,他们可以写下您问题的答案,或者提醒您询问其它问题,他们可以成为您的另外一双耳朵,也可以仅仅到场支持您。

参与临床试验

您的医生可能会问您是否愿意加入临床试验(也称为调查研究)。临床试验可以帮助了解新的治疗方法或不同的治疗提供方式是否比现有治疗方案效果更好。

参与临床试验是自愿的,也就是说,如果您不想参加,不会强制您参加。如果您不想参与临床试验,您的决定也会得到尊重。您也无需给出任何理由说明您为何不愿参与,医院或医疗保健团队对待您的态度也不会改变。

请确保您理解了临床试验的原因和内容。您需要签署临床试验知情同意书。在签署之前,请与您的血液科医生和医疗保健团队其他成员讨论该试验。



在线提供更多信息

RELATIONSHIPS

A diagnosis of a blood cancer can have a positive and negative impact on relationships with family and friends.

Good communication is essential to supporting your relationships with your partner, children or friends.

Talking to your children

Helping children understand your diagnosis and how this will affect them can help them to cope with the changes and challenges.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For preschool or school-age children, it is a good idea to speak with their teachers and let them know about your diagnosis and how this is affecting family routines and relationships.



More information available online

Sexual relationships

You cannot give cancer to another person when you have sex with them.

People who have a blood cancer diagnosis and treatment can experience changes in their sex life. The reasons for this include:

- Extreme tiredness (fatigue)
- Side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety

- Changes to your body image due to hair loss, weight change
- Changes to your libido
- Vaginal dryness or difficulty getting an erection

After your treatment, your sex life should start to return to how it was before your diagnosis.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

Contraception

If you are having treatment for a blood cancer, you should always use a condom when having sex.

Even if you are beyond child-bearing age or no longer need birth control, it is still important to use a condom. The two main reasons for this are:

1. To protect yourself from getting an infection. Your low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, your bowel motions and other body secretions such

人际关系

确诊血癌会对与家人和朋友间的关系产生积极和消极的影响。

良好的沟通对于维护您与伴侣、孩子和朋友间的关系是十分必要的。

与孩子交谈

帮助孩子理解您的诊断有何含义，以及对他们有何影响，这能帮他们更好地面对将要发生的变化和挑战。

如果您担心您的孩子无法应对，我们可以提供咨询和心理支持。咨询您的医疗保健团队或LBC支持服务协调员获取更多信息。

对于学前或学龄儿童，跟他们的老师进行交流并告知您的病情，以及病情如何影响家庭的日常生活和关系，也不失为一种好的做法。



在线提供更多信息

性关系

与他人发生性行为不会传播癌症。

正在接受治疗的血癌患者的性生活会发生改变。有以下几点原因：

- 极度疲惫(疲倦)
- 治疗的副作用，如恶心
- 情绪变化，如焦虑

- 由于脱发或体重改变造成的身体形象改变
- 性欲改变
- 阴道干燥或勃起困难

治疗后，您的性生活应开始恢复到确诊之前的状态。

您应该跟您的伴侣交流一下性生活以及确诊和治疗中的感受。如果您的性生活出现问题，且已经影响到了你们的亲密关系，或是您担心无法开始新的亲密关系，请咨询您的医疗保健团队成员。他们可以提供更多信息或是将您转介他人获取帮助。

避孕

如果您在接受血癌治疗，那么在发生性行为时请始终使用安全套。

即使您已超过生育年龄或早已不需要控制生育，您仍应该使用安全套。有以下两个主要原因：

1. 保护您自己免受感染。由于白细胞计数较低，您受到感染的风险会更高。
2. 由于您在接受化疗，这么做可以保护您的性伴侣。化疗药物会通过尿液、肠道运动和其它身体分泌物(如精子或阴道分泌物)从您的身体中分泌出来(排出体外)。少量的化疗药物会刺激到您伴侣的皮肤(皮疹或瘙痒)。

as sperm and vaginal secretions. The small amounts of chemotherapy can cause irritation (a rash or itching) to your partner's skin.

If you are having sex and also receiving treatment for a blood cancer then there is a high risk of damage to an unborn child, so the appropriate contraception is essential.

Sex when you have a low platelet count

Speak with your doctor or nurse about sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea for women to use a lubricating jelly ('lube') such as KY Jelly.

KEEPING IN GOOD HEALTH AFTER YOUR DIAGNOSIS

After a diagnosis of a blood cancer, it is important to look after your health. When you feel well enough, regular exercise and eating healthy food are very important.

So that you do not have complications from your treatment or long-term side effects, the following health changes should be made immediately:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol (or cut down)

Ask your doctor or nurse about support to help you stop smoking and to reduce or stop drinking alcohol.

Your health care team can advise you on how to keep well. The physiotherapist can advise you about the exercise that is right for you. The dietitian can advise you about eating well, especially if your treatment is making you feel sick or you have taste changes.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.

如果您在接受治疗时发生性行为，很可能对未出生的孩子造成伤害，因此正确的避孕是非常必要的。

当您的血小板计数低时发生性行为

如果您的血小板计数很低，请向您的医生或护士咨询性行为相关信息，由于您出血难以止住，在发生性行为时需要非常小心。女性最好也使用凝胶润滑剂(即“润滑剂”)，如KY润滑剂。

确诊后保持身体健康

确诊血癌后，务必照顾好身体。当您感觉良好时，应定期进行锻炼并注重饮食健康。

这样可以避免产生并发症或长期的副作用。为您的健康着想，您应该立即做出以下改变：

- 戒烟
- 防晒
- 戒酒(或减少饮酒量)

向您的医生或护士寻求帮助，帮助您戒烟、减少饮酒或戒酒。

您的医疗保健团队会告知您如何保持良好状态。物理治疗师会告知您适合您的锻炼方式。营养师会告知您如何健康饮食，尤其是如果您的治疗使您感到不适或您的口味发生改变时。

如果想获取更多关于您所在的区域的锻炼选择，请联系您的LBC支持服务协调员。

THE FUTURE

A diagnosis of a blood cancer can affect many areas of your life such as work or school, your emotions, relationships and finances.

For some people, a diagnosis of a blood cancer can mark a turning point in their life. For other people a diagnosis means they feel their life has been put 'on hold'. The length of time it may take to recover emotionally and physically from a diagnosis or treatment is different for everyone.

Getting back to your previous routine of work, school or childcare, for example, may be a goal or may not be what you want anymore. You may need to make a few adjustments to your life.

Once your treatment has finished, you will have regular check-ups with your haematologist and health care team. You will also be encouraged to go back to see your general practitioner (GP). Your health care team will send regular letters to your GP

to tell them about your progress and what needs to be followed up, e.g. blood tests and vaccinations. If your GP has any questions, they are able to contact your haematologist for advice.

Your health care team and LBC Support Services Coordinator can help you manage:

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with family, friends and colleagues.
- Emotional effects from your disease and treatment, including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and your family cope.

未来

确诊血癌会影响到您生活中的很多方面,如工作、学业、情绪、人际关系和财务状况。

对于一些人而言,确诊血癌是他们人生的转折点。有的人则会觉得,确诊意味着生活“暂停”了。从确诊或治疗中恢复(心理和生理)的时间长短因人而异。

例如,您可能想回到之前的工作、学校或育儿生活,但也可能改换了目标。您可能需要对自己的生活做出一些调整。

在治疗结束后,您的血液科医生以及医疗保健团队将定期对您进行检查。建议您回去见见您的全科医生(简称GP)。您的医疗保健团队会定期给您的GP写信,告知他们您的状况和需要后续完成的事项,例如血液检查和接种疫苗。如果您的GP有任何问题,他们可以跟您的血液科联系获取建议。

您的医疗保健团队和LBC支持服务协调员会帮助您处理以下事情:

- 包括工作、旅行和旅行保险在内的日常实际问题。
- 与家人、朋友和同事的人际关系处理及沟通。
- 患病和治疗产生的情绪影响,如害怕复发和对未来感到不确定。

您可以获取多方面支持,帮助您和您的家人应对这些问题。

ACKNOWLEDGEMENTS

Leukaemia & Blood Cancer (LBC) New Zealand would like to thank everybody who has helped in the development of this booklet: those who have experienced a blood cancer, their personal supporters, health care team members and LBC staff.

Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is the leading organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants. We do not receive government funding.

LBC is committed to improving the quality of life for patients and their families living with these blood cancers and conditions by providing patient support services, investing and supporting research, providing information, raising awareness and advocating on behalf of patients and their families.

致谢

新西兰白血病与血癌机构(Leukaemia & Blood Cancer, 简称LBC)在此感谢所有帮助编写本手册的成员:血癌患者、他们的个人支持者、医疗保健团队成员和LBC的工作人员。

新西兰白血病与血癌机构

新西兰白血病与血癌机构是新西兰致力于支持白血病、淋巴瘤、骨髓瘤和相关血液疾病患者及其家属的主要组织。

自1977年以来,我们一直通过募捐活动以及个人、企业、信托基金及捐赠等各界的慷慨资助而展开工作。我们没有获得政府的资助。

LBC致力于通过为患者提供支持服务、投资和支持研究、提供信息、提高认知度并代表患者及其家属进行倡导,以改善血癌患者及其家人的生活品质 and 状况。

HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road, Takapuna	(09) 486 8900
Auckland City Hospital	Park Road, Grafton	(09) 367 0000
Starship Hospital	Park Road, Grafton	(09) 367 0000
Middlemore Hospital	Hospital Road, Otahuhu	(09) 276 0044
Waikato Hospital	Pembroke Street, Hamilton	(07) 839 8899
Thames Hospital	Mackay Street, Thames	(07) 868 0040
Tauranga Hospital	Cameron Road, Tauranga	(07) 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	(07) 348 1199
Hastings Hospital	Omahu Road, Hastings	(06) 878 8109
Whakatane Hospital	Stewart Street, Whakatane	(07) 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	(06) 356 9169
Wellington Hospital	Riddiford Street, Newtown	(04) 385 5999
Nelson Hospital	Tipahi Street, Nelson	(03) 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	(03) 364 0640
Dunedin Hospital	Great King Street, Dunedin	(03) 474 0999
Invercargill Hospital	Kew Road, Invercargill	(03) 218 1949

新西兰血液学中心

中心	地址	电话
Whangarei Hospital	Hospital Road, Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road, Takapuna	(09) 486 8900
Auckland City Hospital	Park Road, Grafton	(09) 367 0000
Starship Hospital	Park Road, Grafton	(09) 367 0000
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Dunedin Hospital	Great King Street, Dunedin	(03) 474 0999
Invercargill Hospital	Kew Road, Invercargill	(03) 218 1949

Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, and our Support Services Coordinators are here to help.

Freephone 0800 15 10 15

Telephone 09 638 3556

Facsimile 09 638 3557

Email info@leukaemia.org.nz

National Office

6 Claude Road, Epsom 1023
PO Box 99182, Newmarket 1149
Auckland, New Zealand

联系我们

新西兰白血病与血癌机构在新西兰境内提供相关服务与支持。每个人与血癌或血液疾病抗争的经历都不尽相同。白血病、淋巴瘤、骨髓瘤和相关血液疾病患者的生活都不容易，我们的支持服务协调员随时待命提供帮助。

免费电话 0800 15 10 15

电话 09 638 3556

传真 09 638 3557

电子邮箱 info@leukaemia.org.nz

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Vision to Cure. Mission to Care.