
Aplastic Anaemia (AA)

A Guide for
Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with aplastic anaemia (AA) can be a shock, particularly when you may have never heard of it. If you have questions about AA, such as what causes it, who it can affect, how it affects your body, what symptoms to expect and likely treatments, this booklet covers this for you.

You will also find useful advice about how to get the best from your haematologist, plus practical advice on how to help important people in your life understand such a rare condition. For more information, talk to your haematologist or clinical nurse specialist.

This booklet was originally compiled by Ken Campbell, MSc (Clinical Oncology) and the rewrite was completed by Lisa Lovelidge. It was then peer reviewed by Professor Judith Marsh, King's

College Hospital, London. We are also grateful to patient reviewer Sarah Cheeseman, founder of the Central Line Holder, for her valuable contribution.

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

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About Leukaemia Care

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

Our services

Helpline

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

Nurse service

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

Patient Information Booklets

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

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

Support Groups

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

Buddy Support

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

08088 010 444 or email
support@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**, as well as speak to one of our care advisers on our online support

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

Campaigning and Advocacy

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

Patient magazine

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

What is Aplastic Anaemia?

The "aplastic" in aplastic anaemia (AA) describes the fact that the bone marrow fails to produce blood cells normally. Anaemia is misleading in this case because it normally refers to a reduction in the number of red blood cells. But, in AA, all three major types of cells are reduced.

To understand AA it will be helpful to understand how blood cells are normally produced. Blood cells are formed in the bone marrow, which is spongy tissue found inside bones. Blood-forming stem cells divide to produce either more stem cells or immature cells that become mature blood cells over time. Only about one in 5,000 or fewer of the cells in the bone marrow is a stem cell. Each day, the bone marrow produces more than a trillion new blood cells to replace those that are worn out.

Blood stem cells, also called haemopoietic stem cells, may become a myeloid stem cell or a lymphoid stem cell.

A myeloid stem cell becomes one of three types of mature blood cells:

1. Red blood cells that carry oxygen and other substances to all tissues of the body.

2. Platelets that form blood clots to stop bleeding and bruising.
3. White blood cells (granulocytes) that fight infection and disease. The shortest-lived white cells are called neutrophils.

A lymphoid stem cell becomes a lymphoblast cell and then one of three types of lymphocytes (white blood cells):

1. B lymphocytes that make antibodies to help fight infection.
2. T lymphocytes that help B lymphocytes make the antibodies that help fight infection.
3. Natural killer cells that attack cancer cells and viruses.

AA is not a form of cancer – it is a condition in which the bone marrow fails to produce blood

cells.

In AA, all types of blood cells are reduced. This is called pancytopenia - *pan* means *all*, *cyto* means *cells* and *penia* means *few*.

A bone marrow sample, which would normally contain large numbers of immature (young) blood cells, will contain very few of these cells in a patient with AA. This is called hypoplastic or hypocellular marrow, and is important to help distinguish between AA and conditions in which cells are being destroyed in the blood or bone marrow or lost by bleeding. The number of neutrophils is used to indicate low white cell production. In AA, the numbers of lymphocytes are not usually reduced below normal.

A below normal number of red cells is called anaemia, reduced numbers of platelets is called thrombocytopenia and reduced numbers of neutrophils is called neutropenia.

Types of AA

There are several different types of AA, including:

Acquired AA

This is the most common form of AA where there is often no obvious or known cause. This is the type of AA described in this booklet.

Inherited bone marrow failure syndromes

There are many rarer, inherited conditions that may cause AA. In these syndromes, AA is only one problem that patients experience. The most common of these include Fanconi anaemia and the telomeropathies. These types of AA are not discussed in this booklet, so if you would like any more information on these, speak to your doctor.

A bone marrow condition called myelodysplastic syndrome (MDS) occurs in several forms. In one form, called hypoplastic MDS, there is also a marked reduction in production of blood cells, and this type of MDS may sometimes be very difficult to distinguish from AA. The main difference between AA and hypoplastic MDS is that there is abnormal blood

What is Aplastic Anaemia? (cont.)

cell development (maturation) in hypoplastic MDS only.

How common is AA?

AA is a rare disease affecting about 120 to 150 people each year in the United Kingdom, that is about two to three people per million each year. Although AA can affect anyone at any age, it is most common between about 10 and 20 years old and in people aged over 60-65 years old. One problem, especially in older patients, is ruling out other bone marrow disorders that can cause low blood cell counts.

What causes AA?

It is generally accepted that most, possibly all, cases of acquired AA are caused by the body's immune system damaging stem cells in the bone marrow. When the immune system attacks the body's own cells, this is called an autoimmune disease.

In about three-quarters of all cases there is no obvious underlying reason why the immune system is damaging stem cells. This is called

idiopathic AA. Idiopathic is a term used to describe conditions with no known cause.

In the remaining quarter of cases there may have been some recent exposure that is thought to have triggered the development of AA. The main factors are viral infection, some chemicals, and occasionally certain drugs. The drugs involved are medicines which may cause AA in a very small percentage of patients receiving them.

An example of a medicine that may cause AA is the antibiotic chloramphenicol. This is safe when given as eye drops but if given by mouth or as an injection there is a fear, which is difficult to quantitate, that it can cause AA. Today, chloramphenicol is only rarely used for life-threatening infections that are resistant to other antibiotics.

Exposure to high-levels of a chemical called benzene is known to cause AA. However, in the UK, this probably accounts for very few cases as there are strict limits on exposure to benzene.

AA can happen because the patient's stem cells have some surface proteins that are similar to those on the virus. The immune system becomes 'confused' and produces antibodies that are targeted at the virus, but also damage blood-forming stem cells.

The Aplastic Anaemia Trust is the only charity in the UK dedicated solely to research into aplastic anaemia and allied rare bone marrow failures. They also provide practical information and advice to patients and their families, as well as peer-to-peer support.

For further information on the latest research and to access information and support, please contact The AAT via their website www.theaat.org.uk

Symptoms and diagnosis

How does AA affect your body?

Bone marrow contains blood stem cells that in time develop into mature blood cells, including red blood cells to carry oxygen, white blood cells to fight infection and disease, and platelets to form blood clots. One of the indications that the marrow is producing blood cells normally is the presence of immature red blood cells called reticulocytes. The importance of reticulocytes is that when red cell counts are low because of bleeding or cell destruction, the number of reticulocytes will be high. When blood cell production is reduced, the number of reticulocytes will be low, even if the red count is low.

In AA there is damage to blood-forming stem cells, leading to reduced production of blood cells. In acquired AA, the blood cells that are produced are normal, work normally and have a normal life span in the blood. In related conditions such as MDS, the blood cells that are produced often do not work properly and do not last long in the circulation. An important feature of AA is that the marrow is

hypocellular, which means that it contains very few blood-forming cells compared with a normal marrow. There may be 'pockets' of normal marrow cells left, which means that a single normal marrow sample may not always be enough to make a diagnosis of AA.

Classification of AA

AA is classified as non-severe, severe or very severe. This is based on how low the numbers of blood cells have fallen. Although this is a useful way to decide what treatment, if any, is needed, it is important to understand that even very severe AA can often be treated very effectively. The classification is based on the results of a simple blood count.

To make a diagnosis of AA, at least two of the following must be present:

- Haemoglobin less than 100g/L
- Platelet count less than $50 \times 10^9/L$
- Neutrophil count less than $1.5 \times 10^9/L$

Non-severe AA

Meets the above criteria for AA, but does not meet the criteria for severe or very severe AA.

Severe AA

Hypocellular bone marrow and any two of:

- A low platelet count (less than $20 \times 10^9/L$)
- A reticulocyte count less than $60 \times 10^9/L$
- A neutrophil count less than $0.5 \times 10^9/L$

Very severe AA

Hypocellular bone marrow and any two of:

- A low platelet count (less than $20 \times 10^9/L$)
- A reticulocyte count less than $60 \times 10^9/L$
- A neutrophil count less than $0.2 \times 10^9/L$

The difference between severe and very severe AA is how low the number of neutrophils falls. The lower the number of neutrophils, the greater the risk of severe

infection.

Hypocellular bone marrow is defined as bone marrow cells $<25\%$, or $25-50\%$ with less than 30% of stem cells in your bone marrow.

What are the most common symptoms of AA?

The symptoms of AA are not caused by damage to stem cells but by the lack of normal blood cells. The most common symptoms are those of anaemia or of bleeding due to low platelet counts, but infection may also be a symptom at diagnosis, especially if the neutrophil count is very low.

- **Anaemia due to lack of red blood cells** - Weakness, tiredness, shortness of breath, light-headedness, palpitations.
- **Bleeding and bruising due to lack of platelets** - Purpura (small bruises in skin), nosebleeds, bleeding gums, vision problems (bleeding in the retina). Severe bleeding is not common but requires urgent treatment as it can cause serious and sometimes life-

Symptoms and diagnosis (cont.)

threatening internal bleeding, such as in the brain or gut/intestine.

- **Infections due to lack of white blood cells** - Infection may be a significant problem at the time of diagnosis. Severe infection requires urgent treatment.

What happens next?

Management of AA depends on the severity of the condition. If you have non-severe AA, you may not require any treatment initially, but your treatment options are discussed with your medical team. It also depends on the cause, in terms of whether you have the more common acquired type rather than the rarer inherited type. Other factors such as your age and other medical conditions also need to be taken into account in discussions about your treatment with your haematologist.

You will have a number of tests to rule out other causes of bone marrow failure and to check for other medical problems, such as infection. You can ask for information about any of these tests and about the meaning of the

results. Some tests, such as your blood count, and possibly bone marrow samples, will need to be repeated at certain times to see how well treatment is working.



Treating Aplastic Anaemia

The aim of treatment is to restore blood cell production. If the patient has been taking a drug that may cause AA, this should be stopped immediately. In some cases, it may be reasonable to wait a short time and see whether the marrow returns to normal. If this applies to you, then your healthcare team will discuss the situation in detail and explain what is planned.

Non-severe AA sometimes clears up without treatment (spontaneous recovery), but this is not common. Some patients with non-severe AA may not require any treatment initially if they do not need transfusions – often referred to as ‘watch and wait’ or active monitoring. If spontaneous recovery has not happened by the time all tests have been done and treatment plans discussed, it is unlikely to happen, and it is normal to start treatment if you need blood and/or platelet transfusions.

All patients with severe or very severe AA are likely to need blood and platelet transfusions

and treatment to prevent/control infections. This is called supportive care and is discussed separately from treatment to control or cure your AA, which is known as definitive treatment.

Our booklet on Watch and Wait tells you all you need to know. Get your copy by calling **08088 010 444**, emailing **support@leukaemiacare.org.uk** or downloading at **www.leukaemiacare.org.uk/support-and-information/help-and-resources/information-booklets/**

Supportive care

There are three elements to supportive care when it comes to AA:

Treatment of anaemia

There are no options available to prevent anaemia, but it can be treated with transfusions.

Red blood cell transfusions are recommended to enable patients to carry out normal daily activities. If a patient needs to have a large number of red cell transfusions over many months they may have a build-up of iron in the body. This can be treated with drugs that help the body to get rid of excess iron. Prevention of bleeding is described later on – this may help to prevent anaemia becoming worse due to blood loss.

Prevention and treatment of infection

Infection in patients with AA is always a serious problem. If the neutrophil count is below $0.2\text{--}0.5 \times 10^9/\text{L}$, antibiotics and antifungal drugs may be given to reduce the risk of infection. You will be given detailed advice on precautions to reduce the risk of infection.

If you develop a fever or any other symptoms that might indicate infection, it is very important that you contact your doctor or specialist nurse immediately as early treatment is necessary.

Prevention of bleeding

Bleeding problems in AA are caused by low platelet levels. Although the normal range of platelets is between 150 and $450 \times 10^9/\text{L}$, the count can fall far below this before bleeding becomes a problem. Regular platelet transfusions are given if the count falls below $10 \times 10^9/\text{L}$ (or $20 \times 10^9/\text{L}$ in the presence of fever and/or infection or bleeding).

If a patient with severe or very severe AA needs surgery, then the surgical team will work with the haematology team to plan platelet cover and any other measures that may be needed to prevent or control bleeding.

Definitive treatment

Definitive treatment is treatment aimed at:

- Controlling damage to bone marrow stem cells (immunosuppression)
- Replacing damaged stem cells with healthy cells from a donor (stem cell transplant, also

Treating Aplastic Anaemia (cont.)

called bone marrow transplant)

- Stimulating any remaining stem cells with a drug called eltrombopag

The only potentially curative treatment is a stem cell transplant, but it is riskier in older or less fit patients. The choice of treatment is based on severity of AA, on age and general health of the patient, and the availability of a bone marrow donor. If you are being considered as a candidate for a bone marrow transplant, any potential donors will be checked to see if they are a match. This does not mean that your doctors have already decided you should have a transplant, it is to save time if this is your best treatment option.

Stem cell transplant

For younger/fitter patients who have a fully-matched sibling (brother or sister), a sibling donor stem cell transplant is the first treatment of choice. This involves doses of chemotherapy and an antibody to suppress the body's immune cells so that they do not reject the new healthy stem cells

that they receive in the transplant from the donor. This treatment is reported as offering a 75% to 90% chance of a long-term cure. It has been reported that a transplant from a matched unrelated donor (MUD) has almost the same chance of success as a transplant from a related donor. It has also been reported recently that stem cell transplantation is a possible option in a good proportion of patients who might be elderly, but are otherwise fit and healthy.

Sibling or MUD transplants may be considered for older patients who are in good general health, if immunosuppression has not been successful. In all cases, the risks and possible benefits of treatment will be discussed in detail before any treatment decision is made.

If you have received a stem cell transplant, you should receive all recommended vaccinations as normal. You will be given advice on when vaccinations should be given by the transplant team.

If you need a transfusion after a stem cell transplant, it is

important that you are given irradiated blood cells. You will also be given an alert card to carry with you at all times to inform medical services that you require irradiated blood products should you require them. This will protect against a possible reaction called transfusion-related graft versus host disease (GVHD).

Graft Versus Host Disease (GVHD) is a rare complication of a donor stem cell transplant that can occur when the new donor cells react against your own. The effects of GVHD are usually mild, but in some cases can be severe or life threatening. GVHD can affect the skin, bowel, liver, mouth and stomach, and the first signs can appear any time from four days until six months after your transplant. You will be given immunosuppressant drugs for a period of time after the transplant to prevent or reduce GVHD. Your consultant will be able to give you more information; however, any signs of rash, fever and diarrhoea should be reported immediately to your doctor.

Immunosuppression

Immunosuppression is the use

of drugs to control the activity of the immune system and reduce the damage being done to marrow stem cells. This is the preferred treatment for:

- Patients with non-severe AA
- Patients with severe or very severe AA who are over 35 to 50 years old
- Patients with severe or very severe AA who are not fit enough for a transplant
- Patients who do not have a fully matched donor available to donate stem cells

The most widely used combination of drugs is an antibody called anti-thymocyte globulin (ATG) combined with a drug called ciclosporin (CSA). Thymocyte is another name for T-lymphocytes, which are the type of white blood cell that attack marrow stem cells in AA. Ciclosporin is a widely used drug for suppression of the immune system. This combination is successful in around 70% of patients. Although it does not completely cure the condition, when it works it can enable

Treating Aplastic Anaemia (cont.)

patients to return to a good quality of life with no need for regular blood and platelet transfusions. Patients who are treated with immunosuppressive drugs may develop a condition called paroxysmal nocturnal haemoglobinuria (PNH) in which red blood cells are broken down too quickly. Patients also have a higher risk of later developing some forms of leukaemia, other cancers or MDS.

If you are being given this form of treatment, you may also be given a steroid drug called prednisolone to control possible side-effects of ATG. This is not the same as the steroids sometimes used by athletes and bodybuilders.

If you are treated with immunosuppression, the treatment does not work straightaway – it takes on average three months before the blood counts start to slowly rise (and occasionally can take up to six months). Your response at three to four months will be assessed and your doctors will decide whether to continue with ciclosporin or to consider a transplant or modified

form of immunosuppression. If you have a good response at three months, ciclosporin is continued for a year or more, then slowly tapered off. If your condition has not responded, you may be considered for a stem cell transplant or alternative drug treatment, such as eltrombopag.

If you have severe or very severe AA and you are not a candidate for a matched sibling stem cell transplant, your initial treatment will be with ATG and CSA. If this produces a good response at three months, you will continue on CSA, which will gradually be tapered off after a year or more. If you have no response at three months and you are in good health, you may be considered for a stem cell transplant from an unrelated but tissue-matched donor. If you are not eligible or there is no fully-matched donor, then you may be treated with eltrombopag. Other options include re-treatment with ATG and CSA, or you may be considered for a transplant from an alternative donor, such as a haploidentical (half-matched) family donor or a cord blood transplant. Other

possible options are clinical trials and your specialist will be able to discuss the options with you.

If you have received immunosuppressive treatment, you should not have any vaccinations, live or non live, including the annual flu vaccination. This is because there is a theoretical risk that vaccinations might cause your AA to return (relapse). If your GP, or another doctor, strongly recommends vaccination, you should ask them to discuss this with your haematologist.

If you need a transfusion during or after immunosuppressive treatment, it is important that you should be given irradiated blood cells. This will protect against the possible development of GVHD. To prevent this, your doctor/nurse will inform the blood transfusion service about the immunosuppressive treatment that you have received. This will also be recorded on your hospital records.

Eltrombopag

Eltrombopag is a drug which

was originally developed for patients with severe deficiency of platelets due to reduced production or destruction of platelets. Unexpectedly, it was found that in some patients with AA, eltrombopag could increase production of red cells and white cells, as well as platelets. Approximately one-third of patients with AA do not respond to immunosuppression, and this drug is licensed for patients who have not responded to ATG/CSA. There is a European clinical trial running, including in certain UK centres, to see if results are improved by adding eltrombopag to standard immunosuppression treatment for severe or very severe AA. Your consultant will be able to provide you with more details about this.

Other drugs

Alemtuzumab

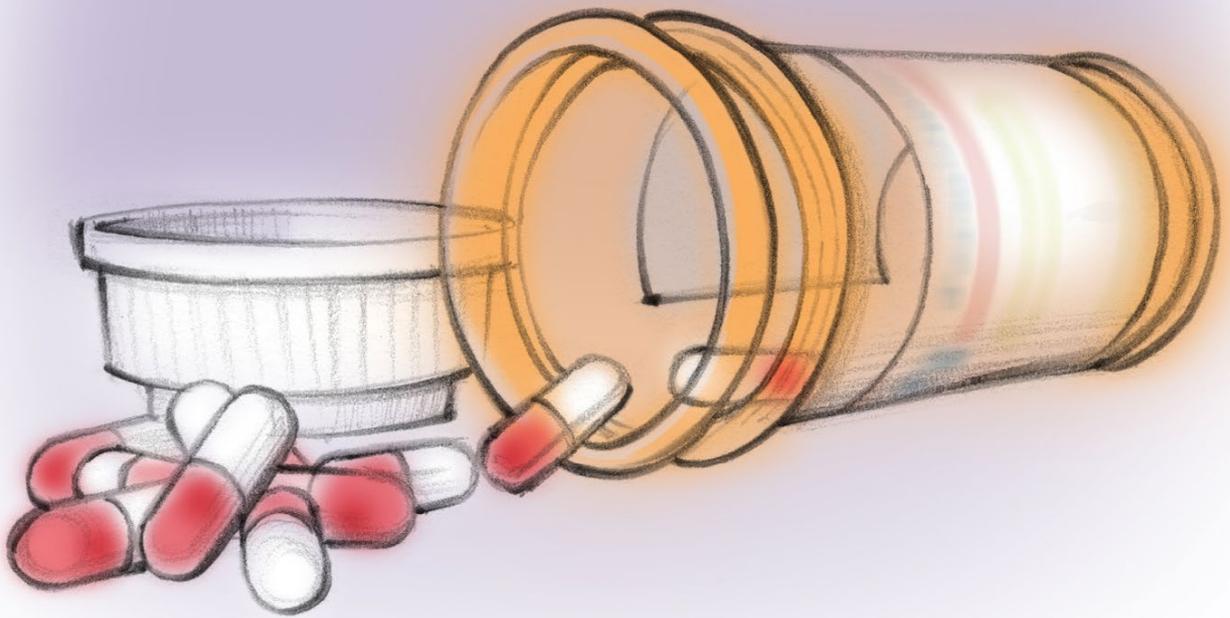
Alemtuzumab is an immunosuppressive drug that can be used for immunosuppression in AA. This may be a possible treatment if a repeat of standard immunosuppressive treatment

Treating Aplastic Anaemia (cont.)

or a stem cell transplant are not considered good options, but it can increase the risk of viral infections. It may also be preferable for patients with poor kidney function, as it works well without CSA.

Danazol

This drug is an anabolic steroid that is more effective in inherited AA, but is still occasionally used in acquired AA when other drugs haven't worked. It can sometimes upset the liver function.



Living with Aplastic Anaemia

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

Emotional impact of AA

Being told you have a serious blood disease can be very upsetting. Although the outlook for most AA patients is a positive one, it is a serious and rare condition, and, because of this, you may need emotional, as well as practical, support. Being diagnosed with a rare disease can affect the whole of you, not just your body, and can impact 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. It is important to know that these feelings are all valid and a normal response to your illness.

"There was a total overwhelming feeling of helplessness and being out of control of my normal everyday life. But I had to carry on regardless for everyone else."

If you feel like you may need some sort of support, perhaps through counselling or a support group, at any point during your journey, speak to your consultant who will be able to tell you about the services, including aftercare, on offer. Alternatively, you can call our Patient Advocacy team on **08088 010 444**.

Looking after you

You can live a long and normal life with AA, but you may want to make changes to your lifestyle to try to stay as well as possible after your diagnosis and during treatment. Do not try to change too much at once. Adopting a healthy way of living is about making small, manageable



Living with Aplastic Anaemia (cont.)

changes to your lifestyle.

A healthy lifestyle includes having a well-balanced diet and being physically active. With some of the side effects you may be experiencing, the idea of getting out and being active may be the last thing you want to do, but it is important to try and stay as active as possible to make you feel better and reduce some of the symptoms or side effects you may be experiencing.

One of the most commonly reported effects of anaemia is fatigue. This is not normal tiredness and often does not improve with rest or even sleep.

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.
- Reserve your energy for what you find important and build rest periods around those times.
- 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.
- Talk about your worries with family, friends or your doctor or nurse, or patient support groups.
- Discuss your fatigue with your doctor or nurse.

"Don't get me wrong, it's hard living with a chronic condition. I get tired a lot and have to be careful of picking up infections, as my immune system is lower than others. But all in all, I will not let it take over my life. I don't intend on fighting it; it will have to fight me."

You can find more information about looking after you (including diet, exercise, complimentary therapies and appearance) on our website: www.leukaemiacare.org.uk/support-and-information/information-about-blood-

cancer/living-well-with-leukaemia/

Practical support

Work and finances

Being diagnosed with AA can sometimes lead to difficulties relating to your work life. 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 your employers to confirm your diagnosis and the effects it may have on your work life. It is often worth taking time to explain AA to your employer, as it is likely they will never have heard of the disease.

It is important for you to know that most people with any form of disability are covered by law by the Equality Act. This means that legally your employer

cannot discriminate against you and must make reasonable arrangements and adjustments relating to your disease.

Macmillan has published a booklet about financial support following a diagnosis of cancer, which may also be valuable to you, even though AA is not a cancer. They can also give you personal advice over the phone via their helpline and you can discuss which benefits you are eligible for. 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.

If you would like more information about some of the things you may be entitled to, you can speak to our Advocacy Officer by emailing advocacy@leukaemicare.org.uk or by calling 08088 010 444.

Talking about Aplastic Anaemia

Talking to your haematologist

AA is a very rare condition. It is important for you to develop a good working relationship with your haematologist, so you are given the best treatment possible for you.

The following gives advice on working well with your haematologist:

- If it is an initial consultation, take along a list of your current and recent 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. This will help the discussion with your haematologist.
- It can be useful to repeat back what you have heard so that you can be sure that you fully understood.
- Note information down to help

you remember what was said.

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

Other tips:

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

You need to tell your haematologist if...

You are 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 AA. 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 AA.

Talking to other people

Telling people you have a rare condition like AA 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 or a booklet like this one about AA if they want to know more in-depth details.

"I made a conscious decision to be very open about my illness. Telling family was tough. But I encouraged people to ask questions."

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 is 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, encouraging you to look ahead and stay positive is not 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

Talking about Aplastic Anaemia (cont.)

someone to talk to)

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

- **Find out more** - The more you know, the more you can share. Try to find out as much as you can about your condition, from reliable internet sources, charitable organisations or your consultant haematologist. This includes sources that are accredited by the Information Standard (like this booklet) which will include a publication date and a review date, so you can clearly see if the information is accurate and up-to-date.
- **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.
- **Explain your needs** - Try and be clear about what your needs may be. Perhaps you need help with the weekly food shop, 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.

- **Be open about how you feel** - Do not 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.

If you're struggling to come to terms with your diagnosis and prognosis, you can speak to us on our helpline. Call us on **08088 010 444**.

Glossary

Anaemia

A medical condition in which the red blood cell count or haemoglobin is less than normal.

Autoimmune Disease

A condition arising from an abnormal immune response to a normal body part. Your immune system attacks healthy cells in your body by mistake.

B lymphocyte (or B-Cell)

A type of lymphocyte (white blood cell) which produces antibodies to fight infection.

Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

Bone Marrow Transplant

A procedure to replace damaged or destroyed bone marrow with healthy bone marrow cells (stem cells).

Cancer

A group of diseases involving

abnormal cell growth with the potential to invade or spread to other parts of the body.

Ciclosporin (CSA)

A drug that inhibits the function of the immune system (immunosuppressant) used in organ transplantation to prevent rejection.

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly or chronic and persist.

Full Blood Count (FBC)

A blood test that counts the number of different blood cells.

Immunosuppression

The partial or complete suppression of the immune response of an individual. It is induced to help the survival of an organ after a transplant operation.

Lymphocytes

A type of white blood cell which forms the body's immune system.

Pancytopenia

Deficiency of red cells, white cells

Glossary (cont.)

and platelets in the blood.

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 type of lymphocyte (a subtype of white blood cells) that plays a central role in cell-mediated immunity. 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.

Virus

An infective agent that typically consists of a nucleic acid molecule in a protein coat, is too small to be seen by light microscopy, and is able to multiply only within the living cells of a host.

Tell us what you think!

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

Suitable for Android, iPhone 7 and above.



Useful contacts and further support

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

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

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

Leukaemia Care

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

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

Bloodwise

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

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

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

0808 800 4040
www.cancerresearchuk.org

Macmillan

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

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

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

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

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

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

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

support@leukaemicare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

