Donor-derived Acute Leukaemia and/or donor-derived Myelodysplastic Syndrome

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with donor-derived acute leukaemia (DD-AL) and/or donor-derived myelodysplastic syndrome (DD-MDS) can be a shock, particularly when you have never heard of them. If you have any questions about DD-AL and/or DD-MDS – including what causes them, who they affect, how they affect your body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

The booklet was compiled by our Patient Information Writer, Isabelle Leach. It was then peer reviewed by Professor Mufti, King's College Hospital. We are also grateful to Nicola Byrnes for her valuable contribution as a patient reviewer.

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

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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In this booklet

About Leukaemia Care

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

Our services

Helpline

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

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

Nurse service

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

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at **www.leukaemiacare.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.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group/**

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some

way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

Online Forum

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

Patient and carer conferences

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

Website

You can access up-to-date information on our website, **www.leukaemiacare.org.uk**.

Campaigning and Advocacy

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

Patient magazine

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

Stem cell transplants

A stem cell transplant (SCT) is a procedure to help patients whose bone marrow has been damaged and can no longer produce healthy blood cells. The most common reason for a SCT is if patients have a cancer that can only be cured with high doses of chemotherapy. These high doses of chemotherapy destroy the cancer cells but also destroy the patient's stem cells in the bone marrow.

In a SCT, stem cells are transplanted from the same individual (autologous SCT) or a donor (allogeneic SCT) to restore the bone marrow's function. Stem cells are the most basic cell in the body and have the ability to develop into any of the body's specialised cell types from muscle cells to brain cells.

Autologous SCT (ASCT)

In this SCT, the transplanted stem cells are from the same person that is receiving the transplant. Before the patient's treatment with high doses of chemotherapy, the stem cells are collected and stored. After the chemotherapy treatment, the stem cells are returned to the patient via a drip infusion. The stem cells then travel to the bone marrow and start making new blood cells.

Allogeneic SCT (allo-SCT)

The stem cells transplanted in this SCT come from a matching donor, often a family member, or a closely matched unrelated donor. In an allo SCT, the donor stem cells provide the bone marrow with healthy stem cells. They also provide the donor's immune system, which helps recognise and remove any remaining cancer cells and prevents cancer coming back (relapsing).

Limitations associated with SCTs

SCTs have the potential to cure the treatment of patients with acute leukaemia, MDS, myelomas, lymphomas and congenital or acquired haematological conditions such as sickle cell anaemia, thalassaemia and aplastic anaemia.

However, there are a number of limitations associated with SCTs, including:

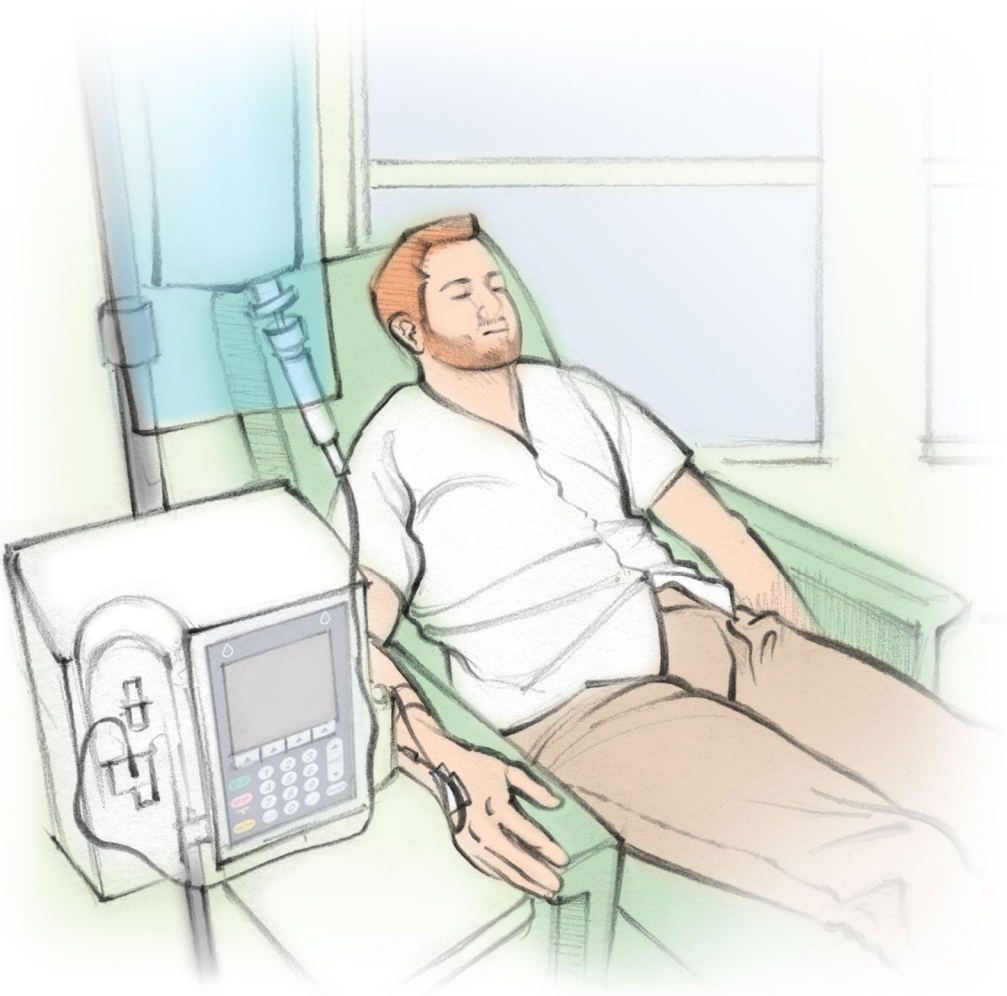
- **Side effects due to the conditioning chemotherapy** – Nausea and vomiting, oral mucositis (sore mouth), diarrhoea, parotitis (mumps), hair loss, organ damage and possible infertility.
- **Risk of infection** – Chemotherapy and immunosuppressant drugs weaken your immune system, making you more vulnerable to infections. Your risk of infection will continue for the following months until your immune system recovers.
- **Stem cell (graft) failure** – This occurs when the donor stem cells fail to populate your bone marrow, or they do it only for a short period of time. This is an uncommon complication that can be overcome through the infusion of additional stem cells.
- **Engraftment syndrome** – This is the appearance of a series of signs and symptoms at around the time your neutrophils are recovering. The symptoms are thought to be caused by substances produced by the immune system which lead to leaking from blood vessels and organ dysfunction. This is a mild complication that can be resolved within a few days if diagnosed and treated properly.
- **Graft versus host disease (GVHD)** – This side effect is only applicable to allogeneic stem cell transplants. The donated T-cells consider the body as something foreign and attack the patient's body and organs. There are two types of GVHD: acute (which mainly affects the skin, gut and liver) and chronic (which can occur in the skin, liver, eyes, mouth, lungs, gut, your nerves and muscles, or your reproductive and urinary systems).
- **Relapse** – A relapse is said to occur when a patient initially responds to treatment, but after six months or more, the response stops. This is also

Stem cell transplants (cont.)

sometimes called a recurrence. A relapse is more likely to happen in the first two years after transplant, and is less likely after five years. You will have regular checks to ensure your disease is not returning but, if it does, your medical team will discuss the most appropriate treatment for you (more chemotherapy, or a second stem cell transplant, for example).

- **Cancers following SCTs** - In patients who have had a SCT, a wide range of secondary cancers such as skin, thyroid, breast and blood cancers have been reported. The solid cancers occur usually within 10 years or more of the transplant.

For more information about autologous and allogeneic stem cell transplants, you can read our booklets on the website at **www.leukaemiacare.org.uk**. Alternatively, you can order a hard copy by calling **08088 010 444.**



What are donor-derived acute leukaemia and donor-derived myelodysplastic syndrome?

Acute leukaemia

Acute leukaemia is a rapidly progressing leukaemia. The cells in the bone marrow which normally mature into white blood cells (lymphoid or myeloid cells) start multiplying uncontrollably resulting in high numbers of abnormal, immature white blood cells called blasts or leukaemia cells. These leukaemia cells prevent the bone marrow from making other important cells such as red blood cells (cells that carry oxygen to the tissues of the body) and platelets (cells that form clots to prevent/stop bleeding). Acute leukaemia cases are classified as acute lymphoblastic leukaemia (ALL) if the origin of the leukaemia cells is lymphoid, or acute myeloid leukaemia (AML) if the leukaemia cells are myeloid in origin.

Myelodysplastic syndromes (MDS)

MDS are a group of cancers where bone marrow cells of all types reproduce uncontrollably and have dysplastic (abnormal) changes. MDS are characterised by a poorly functioning bone marrow and a likelihood for developing into AML. Approximately 30% of patients with MDS will develop AML during the course of their disease.

Donor-derived acute leukaemia and donor-derived myelodysplastic syndromes

Donor-derived acute leukaemia (DD-AL) and/or donor-derived myelodysplastic syndrome (DD-MDS) are rare side effects of a stem cell transplant (SCT) in which the normal donor cells become an acute leukaemia or a myelodysplastic syndrome.

Blood cancers such as acute leukaemia or MDS which are seen mainly in recipients of autologous SCTs tend to occur earlier than solid cancers, usually within three to seven years. These cancers

can occur whatever the reason for performing the SCT. The most common acute leukaemia seen after SCTs is AML.

DD-AL, DD-MDS and/or both (DD AL/MDS) can occur after a SCT using stem cells from various donor sources such as their bone marrow, the umbilical cord of a newborn or peripheral blood stem cells. DD-AL/MDS also occurs where the donors have been related or unrelated to the recipient.

In DD-AL/MDS, the donor's stem cells undergo a cancerous transformation once implanted in the bone marrow of the patient. Although rare, it is important to distinguish DD-AL/MDS from a relapse of the patient's original condition because it will have implications on future treatment.

Who is affected by DD-AL and/or DD-MDS?

By definition, patients who develop DD-AL/MDS must have had a previous SCT as part of treatment for a cancer or haematological condition.

Incidences for DD-AL/MDS have been estimated at between 0.12% and 2%. To put this into context, since the first case of DD-AL/MDS reported in 1971, only a few hundred cases have been reported. However, the true incidence is likely to be higher because DD-AL/MDS can be mistaken for a relapse of the original condition. In addition, the incidence of DD-AL/MDS may have been underestimated because clinicians did not regularly examine the leukaemia cells of patients to distinguish whether they were from the donor or the recipient.

The incidence of DD-AL/MDS is similar whatever the source of the donor's stem cells. In a large study of patients who had an allo-SCT, the incidences of DD-AL/MDS were 0.53% in patients receiving donor cells from the bone marrow, and 0.56% in patients where the donor cells came from either peripheral blood or the umbilical cord blood.

What causes DD-AL and/or DD-MDS?

The development of DD-AL or DD-MDS following SCTs is still poorly understood.

Interestingly, the incidence of DD-AL/MDS following an allo-SCT from a donor is less common compared with the incidence of DD-AL/MDS with an ASCT where the donor is the same individual.

A number of possible causes that have been considered are:

- Stress and pressure on the donor cells to multiply after the SCT might increase the likelihood of chromosome mutations within the cells and lead to the development of DD-AL/MDS.
- When the donor cells become cancerous, they may escape monitoring by the patient's immune system which is still weakened following the high doses of chemotherapy before the transplant.
- The donor may have transferred concealed leukaemia cells or cells with mutations during the SCT leading to the development of DD-AL/MDS in the future. However, DD-AL/MDS is known to occur in recipients and the donors remain free from acute leukaemia and/or MDS.
- Development of DD-AL may be related to the origin of stem cells. The time between the cancerous transformation to acute leukaemia and the SCT is approximately 14 months for stem cells from the umbilical cord compared with approximately 36 months when the donor's stem cells are from the bone marrow.
- The transplantation process itself may be a factor in the development of DD-AL/MDS because its incidence is higher after an allo-SCT than after conventional chemotherapy and radiation therapy.

Unfortunately, the above are only theoretical causes because the small number of cases of DD-AL and DD-MDS have not allowed researchers to find reliable evidence for the causes of these donor-derived blood cancers.

Only further research into DD-AL and DD-MDS – particularly any possible genetic predispositions – will provide information to help indicate what the actual causes are.

How are DD-AL and/or DD-MDS diagnosed?

The diagnosis of DD-AL/MDS depends on demonstrating that the leukaemia cells are definitely derived from the donor's cells provided during the SCT. Until recently this was extremely difficult but new medical technologies have enabled haematologists to identify different DNAs in the new leukaemia cells to that of the patient who received the SCT.

A bone marrow biopsy or aspirate is the best method to collect a sample for examination of the donor-derived cells. A bone marrow aspirate consists of taking a sample of the liquid part of the soft tissue inside your bones using a syringe and is less invasive, but in patients with MDS, where fibrosis of the bone marrow is common, it is difficult to get sufficient aspirate. Peripheral blood can also be used in MDS if required.

If the donor of the SCT was of the opposite sex to the recipient, then a simple DNA test to demonstrate chromosomes of different sex in the donor-derived cells will establish the diagnosis.

If the donor of the SCT was of the same sex as the recipient, a specialised test called Short Tandem Repeat Polymerase Chain Reaction (STR-PCR) can be performed because it is highly sensitive, fast and can determine areas of the patient's chromosome profile that are independent of the patient's sex.

Accurate diagnosis of DD-AL/MDS is important as it can be mistaken for relapse of the original disease in patients who have had a SCT for acute leukaemia or MDS. An indication that a relapse has occurred is that it appears generally within the first 18 months after diagnosis, whereas the time for donor stem cells to become leukaemic is longer with a median time of 26 months.

What are the symptoms of DD-AL and/or DD-MDS?

The symptoms of donor-derived blood cancers depend on the diagnosis.

Patients with DD-AL will have symptoms of acute leukaemia which include:

- Anaemia
- Tiredness or fatigue
- Easy bruising or bleeding
- Fever and infections
- Enlarged lymph nodes
- Enlarged liver and spleen
- Joint pain
- Weight loss
- Shortness of breath

The symptoms of patients with DD-MDS result from the damaged bone marrow which results in low levels, and poor function, of the mature blood cells produced by the bone marrow.

Symptoms can be variable and include:

- Anaemia, fatigue, weakness and shortness of breath (low levels of red blood cells)
- Increased incidence of infections and fever (low levels of white blood cells)
- Easy bruising or bleeding (low levels of platelets)

What are the treatment options for DD-AL and/or DD-MDS?

Because it is so rare, there is no standard treatment for DD-AL/MDS, which can pose a challenge. In order to develop a standard care for this cancer type, more research must be conducted.

Currently, treatment options include:

- Intensive chemotherapy
- Second SCT using a different donor
- Hypomethylating agents - Drugs that inhibit methylation of DNA which is required for cell division

Despite varied results reported with intensive chemotherapy and hypomethylating agents, the only potential cure currently available is a second allo-SCT using a different donor.

Evidence for the efficacy of the treatment options comes from analyses of previous case reports of DD-AL/MDS. Unfortunately, as well as small numbers of patients in the analyses, a shortage of information on their previous treatments and inconsistent follow-up of cases must be taken into account. Nevertheless, two recent reviews of case reports of patients with DD-AL/MDS are available.

Chemotherapy vs. second SCT

In a review of 64 case reports of patients with DD-AL/MDS, 47 patients received intensive chemotherapy and 17 patients were given a second allo-SCT. Of the patients receiving intensive chemotherapy, 57% reached complete remission and 41% of patients who had a second allo-SCT achieved complete remission. Of all the patients, irrespective of their treatment, 34 patients (53%) died within a median of 5.5 months. Of the remaining 30 patients (47%) who were still alive after 14 months, 73% achieved complete remission, 17% were still receiving treatment and 10% were awaiting an allo-SCT.

In a more recent review of 137 patients with DD-AL/MDS, 84% of patients received intensive chemotherapy and 16% of cases received a second allo-SCT. After a median follow-up time of eight months, 44% of all patients were still alive and 56% had died (43% from progression of their DD-AL/

MDS and 13% from infections and complications following the second allo-SCT). Of the 16% of patients who received a second allo-SCT, 11 died due to progression of their disease or complications with the transplant, and 11 remained alive.

Hypomethylating agents

The use of hypomethylating agents is based on the benefits seen in patients whose acute leukaemia or MDS has relapsed, rather than being a new case of DD-AL/MDS. However, hypomethylating agents, such as azacitidine, alone or followed by a donor lymphocyte infusion (DLI), have not achieved a response in any case reports of DD-AL/MDS. A DLI consists of infusing the patient with lymphocyte white blood cells from the blood of the donor who provided the stem cells for the SCT with the hope that the donor lymphocytes will destroy remaining cancer cells. Treatment with azacitidine may be effective in patients with DD-AL who are unable to have intensive chemotherapy due to organ damage or complications after SCT.

In the treatment and management of patients receiving SCTs, it is important that recipients and donors of SCTs are followed up in the long-term so as to pick up any development of DD-AL/MDS.

What is the prognosis for DD-AL and/or DD-MDS?

Prognosis can be very difficult to predict given the small number of cases of DD-AL/MDS reported, the range of different treatments historically used in patients and a lack of consistent follow-up of cases.

Generally, the prognosis for patients with DD-AL and DD-MDS is usually poor, with a median survival time of 5.5 months following a diagnosis of DD-AL and less than 12 months for DD-MDS.

In two recent reviews of patients with DD-AL/MDS, survival of patients after five years was just less than 50% irrespective of their treatment of intense chemotherapy or a second allo-SCT.

Living with DD-AL and/or DD-MDS

Seeing your doctor

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

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

Examples of questions to ask the doctor are:

- What tests will be needed?
- What will the tests show?
- How long will it take to get the results back?
- How common is this condition?
- What sort of treatment will be needed?
- How long will the treatment last?
- How will I know if the treatment has worked?
- What will the side effects be?
- Are there any foods or medications that need to be avoided?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- Where can I get help dealing with my feelings?

Your support

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

The next steps

Always ensure that you leave the GP surgery, or the hospital, having shared everything you know about your condition, with all of your questions answered, and knowing exactly what the next steps are. You can ask for a summary letter of the consultation to have everything in writing. Your doctor will generally send a letter like this to your GP.

Telling your loved ones

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

How to say it

It is important to know what you want to say and exactly how much you want people to know. Being clear in your mind about that before speaking to anyone will make this a much smoother experience. Deliver what you have to say slowly, calmly, concisely, and sentence by sentence to allow the other person time to take in the information.

How to respond

Naturally people will feel sad, and concerned for you. Everyone deals with this type of news in their own way, from shock and silence, to questions and support. Invariably, people respond positively, which in turn means you will respond back positively.

Accepting help

Sometimes people feel guilty if they get cancer, that it's their fault, and that they will be a burden on those around them. This is where your loved ones come in, so make sure you do ask for and accept offers to help and support you. Do not try to cope on your own. If they offer to help, tell them that you will get in touch when you need them.

Managing your emotions

Being told that you have cancer may be difficult for you to deal with.

You may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of the condition. However, you may experience a range of emotions. Understanding each emotion and developing ways that help you deal with them will help you move forward with your life.

Uncertainty

You may be unsure about your health and what the future holds for you. Once you have a clear path

Living with DD-AL and/or DD-MDS (cont.)

set out in front of you, you will be able to develop a clearer picture of where you are headed. Gaining a sensible balance between being vigilant about your symptoms and carrying on with your life will help ease any anxieties. Help, care, kindness and support will be available to you from your healthcare team, and you will have access to counsellors and therapists if and when you need it.

Isolation

If you have received a diagnosis of DD-AL/MDS, you may feel alone. Sometimes, it is difficult for your family, friends and colleagues to understand what you are feeling and going through. Being clear will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

Anxiety

Being fearful of the unknown, especially when we are feeling threatened, is natural. You may experience an increased heart rate, rapid breathing, and muscle tension. These changes in you are part of the 'fight or flight' response. Any feeling of discomfort, pain or even another appointment with your healthcare team may elicit such responses, and give you sleepless nights or feelings of worry. This is completely natural. Such reflexes and responses will ease over time with the building of daily routines and planning things for the future.

Anger

Feeling angry at the cancer diagnosis is natural and normal. You may be angry with yourself, the healthcare team or your family and friends. You may display your anger as impatience, irritability and frustration with people and things that would not normally bother you. Understanding exactly what is making you angry will help you deal with your feelings effectively. Talking about feelings and letting them out will also help to stop you from lashing out at people and keep things calm.

Sadness and depression

You may feel a sense of loss about how safe you once felt. You may also feel that your illness is a heavy burden on those around you. You might be feeling low, which is a natural effect of your situation and the illness, treatment and recovery

process. However, if this low mood persists for more than several weeks, and you feel hopeless, and lose interest and pleasure with things in life, then you may have depression. Your first steps should be to speak to your loved ones around you about your mood and state of mind, and then contact your GP.

Self-confidence

Being forced to adjust from your daily routine during the visits to the hospital for treatment can take its toll. This interruption of your life can impact on how you feel about your appearance and how you feel emotionally. In turn, this can knock your self-confidence and self-esteem. Your feelings of relief, hope and optimism have just been replaced with their polar opposites. You can gradually build your self-confidence and self-esteem back up by engaging in the activities you did before the diagnosis, and socialising with family, friends, and those in the same position as you. This will help create a supportive atmosphere to get you back to your old self.

Mindfulness and relaxation

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

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

By taking some time out of your day to do these exercises, you can help quieten your mind and remove the stress of coming to terms with your diagnosis, so you feel calmer and more relaxed.

Living with DD-AL and/or DD-MDS (cont.)

Survivorship

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

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

When living with cancer, you will face new challenges to cope with from physical to psychological and social ones. Survivorship aims to provide personalised care based on improving your health, wellbeing, quality of life, and your confidence and motivation, to help you manage. Survivorship also focuses on your health and life with cancer after the end of treatment until the end of life.

Palliative care

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

Palliative care aims to reduce the symptoms, control the cancer, extend survival, and give you and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps. Palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate the care. These professionals can include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists, and religious leaders, if you would like this. The palliative care services may be provided by the NHS, local council or a charity. You may receive day-to-day care at your home and at the hospital.

End of life care

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

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

Glossary

Acute Leukaemia

Leukaemia is mainly a cancer of the white blood cells. Acute leukaemia means it progresses rapidly, and usually requires immediate treatment.

Acute Lymphoblastic Leukaemia

Acute lymphoblastic leukaemia is a cancer of early white blood cells. Normal white blood cells divide and grow in an orderly and controlled way; however, in leukaemia this process is disrupted. This means signals that stop the body making too many cells are ignored. Cells continue to divide but do not mature into normal lymphoid cells.

Acute Myeloid Leukaemia

Acute myeloid leukaemia is a type of blood cancer that starts from the myeloid cells in the bone marrow. Myeloid cells have the ability to develop into any of the blood cells (red, white or platelets).

Allogeneic Stem Cell Transplant (allo-SCT)

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

Autologous Stem Cell Transplant (ASCT)

A patient's own blood forming cells are collected and returned to the patient following high-dose chemotherapy.

Chemotherapy

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

Complete Remission

This means that tests, physical examinations and scans show that all signs of cancer are gone. There is no evidence of disease.

Graft Versus Host Disease (GVHD)

A condition that might occur after an allogeneic stem cell transplant. In GVHD, the donated blood marrow or peripheral blood stem

cells view the recipient's body as foreign.

Graft-versus-leukaemia (GVL) Effect

The GVL effect is a result of the T-cells from the donor being capable of recognising and rejecting leukaemia cells following an allogeneic stem cell transplant. The GVL effect is important for reducing the risk of relapse.

Leukaemia

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

Myelodysplastic Syndromes (MDS)

A group of disorders where bone marrow cells of varying types reproduce abnormally, causing the bone marrow not to make enough healthy blood cells.

Peripheral Blood

This is the circulating, flowing blood within which the cellular components of blood, red blood cells (erythrocytes), white blood cells (leucocytes), and platelets, are found.

Prognosis

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

Relapse

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

Remission

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

Stem Cell Transplant (SCT)

A stem cell transplant is a treatment for some types of cancer as well as other blood

Glossary (cont.)

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.

Stem Cells

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

Useful contacts and further support

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

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

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

Leukaemia Care

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

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

Bloodwise

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

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

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

0808 800 4040
www.cancerresearchuk.org

Macmillan

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

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

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

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

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

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

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).
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Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity