



Living with Leukaemias, Lymphomas, Myeloma & Related Disorders: Information & Support

A guide for patients, carers and
families



Leukaemia
Foundation

VISION TO CURE
MISSION TO CARE

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INTRODUCTION

The information provided in this booklet is designed to help you and your family and friends understand and cope with the complex practical and emotional issues that come with living with a blood or bone marrow cancer (such as leukaemia, lymphoma, myeloma or related disorders).

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be most useful at a particular point in time.

We hope that the information contained is helpful in answering some of your questions. It may raise other questions, which you should discuss with your doctor, specialist nurse, or social worker.

Some of you may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treating hospital.

We use the word *family* throughout this booklet to mean those who are closest to you. This may include your partner, parents, brothers and sisters, children or close friends.

Finally, we hope that you find this booklet useful and we would appreciate any feedback so that we can continue to serve patients and their families better in the future.

THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders. Since 1975, the Foundation has been committed to improving survival for patients and providing much needed support. The Foundation does not receive direct ongoing government funding, relying instead on the continued and generous support of individuals and corporate supporters to develop and expand its services.

The Foundation provides a range of **free** support services to patients and their carers, family and friends. This support may be offered over the telephone, face to face at home, hospital or at the Foundation's office or accommodation centres, depending on the location and individual needs. The Foundation provides practical and emotional assistance to patients and carers, including access to information, education and peer support through a variety of programs.

The Leukaemia Foundation funds leading research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders. Through its National Research Program, the Foundation has established the PwC Foundation Leukaemia and Lymphoma Tissue Bank and the Leukaemia Foundation Research Laboratory at the Queensland Institute for Medical Research. In addition, the Foundation also funds research grants, scholarships and fellowships for talented researchers and health professionals.

Support Services



"Foundation staff provide patients and their families with information and support across Australia"

The Leukaemia Foundation has a team of highly trained and caring Support Services staff with qualifications and/or experience in nursing or allied health that work across the country. They can offer individual support and care to you and your family when it is needed.

Support Services may include:

Information

The Leukaemia Foundation has a range of booklets, fact sheets and resources such as this one that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from the website. Translated versions (in languages other than English) of some booklets and fact sheets are also available from our website.

Education & Support programs

The Leukaemia Foundation offers you and your family disease-specific and general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment and how to support your general health and well being.

Emotional support/counselling

A diagnosis of a blood cancer/disorder can have a dramatic impact of a person's life. At times it can be difficult to cope with the emotional

stress involved. The Leukaemia Foundation's Support Services staff can provide you and your family with much needed support during this time. They may refer you or a loved one to a specialist health professional eg Psychologist if required.

The Foundation has established an on-line information and support group for people living with leukaemia, lymphoma, multiple myeloma, or a related blood disorder. Registration is free and participants can remain anonymous, see www.talkbloodcancer.com

Accommodation

Some patients and carers need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Foundation's fully furnished self-contained units and houses can provide a 'home away from home' for you and your family.

Transport

The Foundation also assists with transporting patients and carers to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

Practical Assistance

The urgency and lengthy duration of medical treatment can affect you and your family's normal way of life and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

Contacting us

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person's experience of living with these blood cancers and disorders is different. Living with leukaemias, lymphomas or myeloma is not easy, but you don't have to do it alone. Please call **1800 620 420** (Freecall) to speak to a local support service staff member or to find out more about the services offered by the Foundation. Alternatively, contact us via email by sending a message to info@leukaemia.org.au or visit www.leukaemia.org.au

THE DIAGNOSIS

There is no doubt that a diagnosis of a blood or bone marrow cancer is very serious and is often life threatening. It is important to remember however that these days, with treatment, many people can be cured of their cancer. For others, treatment can control their disease and they can remain well for a long time.

In this section of the booklet we explore some of the common reactions and responses to a diagnosis of a blood or bone marrow cancer, and offer some suggestions which we hope will help you and your family cope during this difficult time.

The impact of diagnosis

A diagnosis of cancer is often devastating, both for the person who receives the diagnosis and those around them. At this time people naturally fear for their own lives or that of the person they love. While it is sometimes difficult to avoid focusing on the possibility of death, it is important to remember that survival rates for many blood and bone marrow cancers have risen dramatically, and will continue to improve in the future.

Different people cope with a diagnosis of a serious condition like cancer in different ways, and there is no right, or wrong, or 'usual' reaction. For some people, the diagnosis may trigger a range of emotional responses.

People are often shocked by the diagnosis even if they have suspected for some time that there was something not quite right. It is normal to react with extreme fear, disbelief and confusion. You may become angry or even furious with the doctor or those around you. There may be a sense of numbness or that the situation is not real, that a 'mistake' has been made. Hearing the news of your child's diagnosis can be an extremely distressing experience.

As well as the emotions listed above, parents often feel a sense of powerlessness in the face of not being able to protect the sick child from the illness and the potential side-effects of the treatment they may need to go through. These are all normal and understandable initial reactions to such a serious threat to your life, or the life of someone you love.

The time immediately after such a diagnosis is often one of great anxiety, distress, uncertainty and confusion. You may feel a great sense of sadness and grief at the possibility of dying or losing loved ones. At times urgent decisions may need to be made regarding treatment soon after diagnosis and this can be very stressful. It is important to remember that emotions can run very high when you or someone close to you is diagnosed with cancer. This is all

normal and no one should feel ashamed or disappointed by his or her reactions at this very demanding time.

As the reality of the diagnosis begins to sink in, people often search for answers to why this has happened to them or what they have done to bring about such a serious illness. It is important to realise that in most cases it is not known what causes these forms of cancer.

It takes time to adjust to a diagnosis of cancer. However, with enough time, enough information and a great deal of support, the shock of the diagnosis will be replaced by the reality of your situation and what you need to do next. With help, you will learn to cope with your situation in an effective and positive way that gives you a sense of perspective and control over your own life. It is also important that family members remain optimistic and provide positive support for the people coping with a diagnosis of cancer.

“Sometimes the diagnosis of cancer can come so suddenly and there has been little evidence of it before. Then the need for treatment and the threat of death can be very stressful...at least it was for me - I was working full time up to a week before I was diagnosed.”

TELLING OTHERS

When and how to tell other people about the diagnosis is completely up to you. Some people initially prefer to deal with the diagnosis alone. They may wish to work out their own feelings before sharing their thoughts with others, even those closest to them. They may not wish to worry or burden others or they may not feel that there is anyone around them strong enough to 'take' the news, or who could understand what they are going through.

It is worth remembering that in most cases people cope better when they feel they are not dealing with a problem on their own. Even if you don't tell them, those closest to you are likely to sense that there is something wrong and worry anyway. In addition, they may feel left out or hurt that you could not confide in them earlier. In the long run it is often best to be honest with family and close friends. There is no easy way to deal with sharing the diagnosis. The following are some helpful suggestions.

Helpful suggestions

- Wait until you feel ready to tell people.
- Think about who should know and tell someone that you trust first.
- You may want to appoint someone you trust to tell other members of your family and other friends. This might be the same person who keeps loved ones informed during and after treatment, on how they can be of practical help to you and your family. This leaves you to concentrate on the treatment and your own wellbeing.
- Let people know what works for you. Those around you can be of more help if they understand when you need to talk or when you need some 'personal space'.
- You may wish to use an answering machine to screen your telephone calls for a while. This way you can have more control over whom you wish to speak to, and when.

Telling children

Children tend to be particularly sensitive to peoples' emotions. As such, they may sense that something is not quite right or they may believe that they have done something wrong to upset the other members of their family. In addition, children often take on an exaggerated level of responsibility for things happening around them. Unless they have some sense of what is happening and that it is not their fault, they may experience even more anxiety than if they are told the truth from the start.

It is not easy to tell a child about a diagnosis of cancer. The amount of information that can be given often varies with the child's age and level of emotional development. No one knows your child better than you and no one can tell you when or how to tell them about your illness. In general, it is important to have an open and honest approach, providing them with as much information as you are comfortable with and they can understand at the time.

Helpful suggestions

- The amount of information you give your child will depend on their age and level of intellectual and emotional development.
- Use simple language that makes sense to your child.
- Try to give them accurate information and answer their questions as honestly as you can.
- Try not to be overly pessimistic or overly optimistic.
- Give the child opportunities to talk about how they are feeling. It may be helpful to reassure them that their emotions are normal and are a result of the situation.
- Encourage them to write or draw to help sort out their feelings.
- Give the child opportunities to ask questions. This is a useful way to check their understanding and to determine what they are most worried about. They may need to have this clarified or for you to give reassurance about this.

- Reassure them that the illness is not their fault and that you always love them even if you have to be away from them for a while.
- It can be helpful to talk to the child's teacher/carer and let them know of the situation at home. Some schools have counsellors who can help.
- If it makes you feel more comfortable, allow another adult (parent or close friend) to tell your child about the diagnosis.
- Ask for some help from the hospital's social worker, counsellor or psychologist who may be able to help you prepare to speak to your child. There are books and videos available for children of different ages.
- If possible, bring children to the hospital or clinic if you feel that they are old enough to cope with the situation. The reality of what is happening there is often better than what children imagine.

Although it is not always possible, it is important to try to prepare children for any disruptions to their normal routines. For example, it is important that they understand at some level changes in roles and responsibilities within the family or alternative care arrangements that need to be made, sometimes at short notice.

INFORMATION

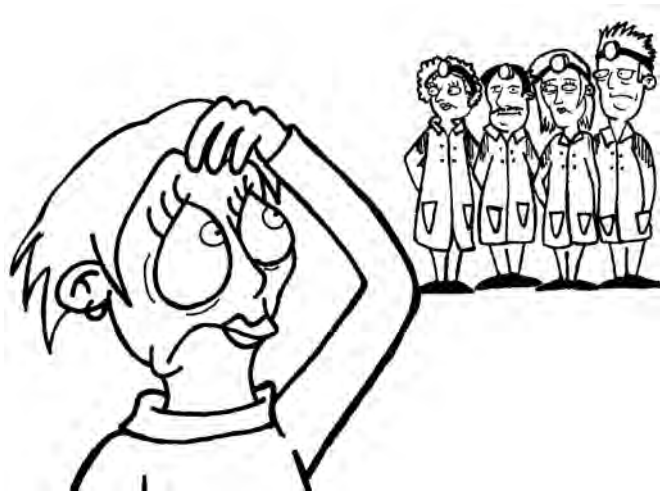
Many people may feel overwhelmed when they receive a diagnosis of a blood or bone marrow cancer. In addition, waiting for test results and then having to make decisions about treatments can be very stressful. Some people do not feel that they have enough information to make decisions while others feel overwhelmed by the amount of information they are given. It is important that you feel you have enough information about the illness and all of the treatment options available, so that you can make your own decisions about your situation.

Enough information?

There is no set amount of information that will satisfy everyone. Some people want to find out everything possible. Others will not want to know too much, and will avoid information. They only desire the basic facts to help them cope on a day to day basis. The majority of people fit somewhere in the middle and need to have a sound level of understanding of the disease and how it will impact on their lives now and in the future. This information helps them to cope on a day to day basis as well as planning the best way to cope with their treatment and any adjustments to their lives that may be needed.

The need for information can change over time. Usually people need a great deal of information before they begin treatment. Sometimes, everything seems to be going so fast that there isn't time to find out everything they want to know. This is particularly true for people who need to be treated very soon after they are diagnosed. You should feel that you or someone close to you has enough information to make the decisions that are in your best interests in a timely fashion.

Talking with your doctor



The specialist doctor (usually a haematologist or oncologist) who is responsible for your overall treatment is the best person to give you accurate information about your specific disease and prognosis. This is because he or she has the most information about your individual case. You may meet other people in the hospital or clinic who have the same type of disease as yours. While you may find it useful to talk to other people in a similar situation, it is important to remember that everyone is different and that their experience may not necessarily apply to you.

Anxiety, shock, denial or grief can make it difficult at times to absorb or remember discussions you have had with your doctor and it is common for people not to remember much of the information given to them at diagnosis. It is also common for people to want to avoid information until they have accepted or come to terms at some level with their diagnosis.

It is important to give health professionals like doctors and nurses clear indications of the amount of information you wish to have at a given time. If you want more information it is important that you indicate this clearly with questions and requests for further reading (booklets, websites) on the subject. If you want more information but find it difficult to ask, find a friend or family member who can ask on your behalf.

Helpful suggestions

- Sometimes it is hard to remember everything the doctor has said. It may help to bring a family member or a friend along who can write down the answers to your questions or prompt you to ask others, or simply be there to support you.
- Before going to see your doctor make a list of the questions you want to ask. It is handy to keep a notebook or some paper and a pen by your bedside as many questions are thought of in the early hours of the morning.
- Ask your doctor for written information or a summary letter.
- You may wish to tape record your initial discussions with your specialist doctor. It can be replayed later when you are in a better frame of mind to absorb the information.
- Don't be afraid to ask your doctor for clarification if you don't understand what he or she has said.
- Ask any questions you like, even the ones that sound silly or embarrass you a little. Every question is valid and important because it concerns you and your body.
- Allow yourself time to absorb information. A lot of the information you are receiving will be new and include lots of new terms which you will become familiar with over time.
- Remind yourself how far you have come.

Understanding the technical terms

These days, the care of people with blood and bone marrow cancers is highly technical, and sometimes it can seem as if the doctors and nurses are speaking a different language. Health professionals tend to use complex terms and mysterious abbreviations which at first can be very confusing. It is easy to forget the names of different tests or treatments you are having. In time, you will find that you become familiar with the language used and it will not appear so confusing or foreign to you.

“Health professionals sometimes forget that they use terms which you don't understand. Always ask - it's your right to fully understand what has been discussed.”

Helpful suggestions

- If people use terms you don't understand it is okay to ask them for an explanation.
- There is a series of booklets available from the Leukaemia Foundation which provide information on many of the common blood and bone marrow cancers.
- Remember that the support services staff at the Leukaemia Foundation are there to help answer your questions. They can talk to you about your disease, treatment and the many adjustments you and your family are making in coping during this time.



Informed consent

Giving informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you feel you have adequate information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you, or some aspect of your care (data collection). Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side-effects. Participation in a clinical trial is always voluntary.

If you have any doubts or questions regarding any proposed procedure or treatment do not hesitate to talk to the doctor again.

Information gathered from hundreds of other people around the world who have had the same disease helps to guide the doctor in recommending the best treatment for you. Remember however that no two people are the same. In helping you to make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Clinical Trials

These trials (also called research studies) test new treatments or 'existing' treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side effects. Clinical trials often give people access to new therapies not yet funded by governments.

If you are considering taking part in a clinical trial, make sure that you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor as they can guide you in making the best decision for you*.

Changing doctors

It is important that you feel comfortable with your specialist doctor. People often differ in the type of relationship they expect with their doctor. Some prefer their doctor to be the 'technical expert' and seek their emotional support elsewhere, while others want their doctor to give them emotional support as well. Many people want an honest, open and easy communication with their doctor. This helps to build trust which is an essential part of a good therapeutic relationship. You may want to be treated by a doctor and team that are closer to your home.

The doctor is an important member of the treating team but he or she cannot necessarily meet all of your physical, psychological, emotional and spiritual needs. Meeting these needs often involves input from other members of the team including the nurses, social worker, counsellor, psychologist and pastoral care workers.

If for any reason you are feeling uncomfortable with your specialist doctor, you can always ask to be referred to another doctor. Your general practitioner (GP) or the patient representative at the hospital may be able to help you with this if you don't wish to raise the issue directly. In some cases, discussing what you feel is 'not working' in your relationship with your specialist doctor can be helpful.

** You can also refer to the information sheets about clinical trials on our website. There are also questions that you can ask your doctor. See www.leukaemia.org.au*

Health professionals like doctors appreciate the importance of establishing a good therapeutic relationship with patients so don't be afraid to ask them to be referred to someone else if you feel this is necessary.

Remember, you can always request a second opinion regarding any aspect of your diagnosis or treatment if you feel this is necessary.

FAMILY MATTERS

A diagnosis of cancer can cause an extreme amount of stress within any family. Where children are involved, it can be especially difficult. The demands of treatment bring many disruptions to normal day to day lives. Family routines are often disrupted with frequent trips to the hospital for tests or treatment. It can be difficult to keep up with many of the activities the children previously enjoyed. In addition, there will be times of separation from family members for periodic hospital stays. In this section of the booklet we explore some of the challenges faced by families living with a diagnosis of a blood or bone marrow cancer and provide some suggestions which we hope are helpful.

Changes in roles and responsibilities

Normal family roles and responsibilities can be disrupted by a diagnosis of cancer. Members of the family may suddenly have to perform roles with which they are not familiar, for example cooking, cleaning, doing the banking and taking care of children. In other cases they may have to take on extra roles and responsibilities within the family, sometimes on top of their paid work. This can be both physically and mentally exhausting.

While it is important to try to maintain as normal a family life as possible, it is also important to have realistic expectations. Trying too hard may result in putting further stress on you and those around you. Realising that things will be different for some time can reduce stress and provide a realistic basis to cope with your situation.

Setting priorities

It can be helpful to set some priorities regarding what needs to be done to keep family life running as smoothly and as near to normal as possible. It is also important to think about allocating reasonable

responsibilities to various family members and friends. This might involve a cooking or cleaning roster, a roster for delivering and picking up children from school or day care, or simply taking care of the family pet. In most cases people are only too willing to help if they can, especially if they are guided by being given specific tasks.

Remember, people often don't know what to do when someone close to them has cancer. Asking them to provide some practical help is often a relief because they feel they are doing something to make the situation better.

Helpful suggestions

- Encourage family members including children to express how they are feeling about the current disruptions to their lives.
- Set priorities and identify strategies that can help maintain as normal a family life as possible. Someone outside the family, a friend or professional like a social worker may be able to help you with this.
- Keep family members informed about daily routines, rosters, who will be delivering or picking children up from school, etc.
- Don't be afraid to ask for help. People are generally only too willing to be involved and it is easier for them if they are given a specific job to do.
- When possible allow yourself to maintain as much of your familiar role as possible within the family. This may help to maintain some normality in the situation and give you and everyone else in the family a better sense of control and hope for the future.

Children

Having a serious illness in the family like cancer can pose special challenges for children. While children are resilient, disruptions to their normal routines, coping with separation from a parent or sibling and the changing roles and responsibilities within the family can all lead to some confusion and anxiety.

Children with a sick parent or sibling may feel confused and left out because they are not receiving the same amount of attention

and interest as they usually would receive. Behaving in unfamiliar ways or testing the boundaries on behaviors is understandable as the child tries to cope with the significant upheaval in their lives.

During this time children need a great deal of support, guidance and love. Sticking as much as possible to normal routines like bedtimes, applying the expected boundaries on behaviors and having a reasonable and consistent approach to discipline can help to make the child feel more secure, when so many other things appear to be changing within their family.

Caring for the 'well' sibling

When a child had been diagnosed with cancer the 'well' siblings (sisters and brothers) may experience many confusing emotions. The way in which they respond to these emotions will depend on their age and development level. They may worry about the sick sibling, and feel sad about family separations. It is normal for well siblings to feel that they are missing out, especially in the early stages of treatment when the parents have to spend a great deal of time at the hospital with the sick child. They may feel resentment at having their lives disrupted, jealousy about the amount of attention given to the sick child and guilt about having these negative feelings in the first place.

Helpful suggestions

- Reassure the siblings that they are loved.
- Giving the well sibling opportunities to talk about how they are feeling can be of assistance. It helps them to feel better about themselves if they are reassured that such feelings are normal and a result of the situation.
- Talk about the disruptions and reassure the child that your family is not alone in this regard.
- Ask other family members or friends to spend time with the sibling or take them on a special outing.
- Giving the sibling appropriate information about what is happening to the sick child and the family may help to reduce their anxiety and assist them to understand the reasons for the hospital visits and treatment.

- Including the sibling in some hospital visits can be helpful.
- Try not to expect too much of the well sibling during this stressful time. For example some children will want to help out with extra household chores while others will not.

It is important to remember that although there are many challenges for siblings of sick children, most do go on to adjust very well.

Impact on relationships

It is important to remember that everyone copes with stressful situations differently, especially where grief or fear are involved. Some may want 'time out' and personal space to sort through their feelings. Others will need to talk and discuss their feelings openly. It is important for your family to talk about what each person needs in the situation and to acknowledge that these needs can change overtime. If necessary you should seek help in dealing with the difficult issues you are facing.

Impact on partner relationships

Serious illness within a family can be very challenging for partner relationships. As well as dealing with the threat of losing a loved one, treatments make many demands on partners' time and emotional resources. Unfortunately relationships sometimes break down under the strain, especially if serious problems existed in the relationship prior to the diagnosis. Many people however report that they become closer, that they experience a strengthening of their relationship through facing this difficult time together. A changed attitude to life, which involves a heightened appreciation of everyday family life and close relationships, is also common.

During treatment most people are too busy to focus on their relationship. So, often problems do not arise until the end of treatment. Therefore it is important to be aware that treatment closure can be a very sensitive time when there is a need to deal with issues within your relationship. Many people benefit from receiving the support from someone outside the family who can help them deal with the issues which the illness has raised within their relationship and their family. The Leukaemia Foundation are there to support and understand your concerns and, if necessary, to refer you to other support or counselling services.

Helpful suggestions

- Effective communication is essential. Having some understanding about how you as individuals cope differently with this kind of stress can be helpful. Acknowledging and talking about the stress in the situation can also help. If you are having problems in your relationship, a counsellor may be of assistance to you both.
- Maintaining a sense of humour and perspective on life and the things that really matter is useful.
- Many treatment centres have a counsellor, psychologist, social worker and pastoral care workers who can assist you and your family in coping better with the practical and emotional difficulties you may be experiencing. They can also identify strategies that will help you and your family cope during and after treatment.
- The support staff at the Leukaemia Foundation are there to provide you with support and understanding. If necessary they can help to organise counselling for you and your partner.

Relocating to hospital for specialist treatment

Treatment for blood and bone marrow cancers often requires specialist care that may only be available at metropolitan and regional hospitals. As a result many patients and family members have to spend some time away from the comfort of their own home. It is often very stressful to have to leave home, especially on short notice when you and your family are already very distressed at the diagnosis you have been given. It is particularly difficult when your home is a long distance from the treatment centre. At this time it may be almost impossible to think clearly about the practical issues involved.

Helpful suggestions

- Pack your bag with a view to possibly needing to stay several weeks - include several changes of clothes, nightwear and personal toiletries.
- Ask family and friends to help with children or other family members left at home, collecting the mail, cancelling deliveries and taking care of the house and pets.

- Take some things to entertain yourself while you are in hospital including: a radio, CDs, books, phone cards, photographs of your family, maps of the city if you or your family come from out of town, familiar posters, a diary with phone numbers, letters from your family, etc.
- Take familiar comfort items like your pillow or cushion.

Accommodation

If you need to travel a long distance to the treatment centre, accommodation may need to be arranged for your family or close friends. You may also need some accommodation outside the hospital if you are being treated as an outpatient. For many, staying with family or friends who live near the hospital can be difficult over a prolonged time. Many treatment centres now have reasonably priced accommodation for you and your family, on site or close to the hospital. The Leukaemia Foundation also has 'home away from home' accommodation near many centres around Australia.

Helpful suggestions

- Contact the social worker at your treatment centre who can help you to arrange suitable accommodation even before you leave home.
- Ask your social worker about any government assistance schemes (each state is different) that can provide financial assistance for your travel and accommodation costs. The social worker can also assist you with any paperwork required when making claims for financial assistance.
- In some areas the Leukaemia Foundation has accommodation for patients and families. Contact the social worker or the Leukaemia Foundation in your state for more information.

Home - but just visiting!

It is usually possible to return home periodically between treatments. During these times many people experience a sense of relief at returning to the comfort of familiar surroundings and re-connecting with family and friends. Returning home for short spells can however be difficult especially if family members are confronted with the grief or sadness that has been 'on hold' while you were away.

For some, there is often a sense of visiting rather than returning. People often find it difficult to focus on the future with the need to return to the hospital for further treatment and then the ever-present fear of relapse in the future.

As you may be physically weak at times, some activities you enjoyed previously may need to be put on hold, even simple things like driving the car. In time most people will be able to return fully to these activities.

"It was so great to be there to help put the children to bed. I tried not to think about leaving them again... but sometimes I did and I cried a lot. When it was time to go back to the hospital we all cried and hugged each other but we knew that I needed to go back, so that I could come home for good the next time!"

Helpful suggestions

- Keep expectations realistic about what can be achieved during the times spent at home during or between treatments.
- Pace yourself - prioritise who you want to see and what you want to do.
- Allow yourself some space to deal with your own grief - it's okay to cry, retreat, be angry and upset, or share your experiences with a good friend, a counsellor, pastoral care worker, nurse or doctor.
- Try to take time out for an enjoyable activity with someone you love.
- Allocate a family member or friend to limit or organise the many people who will want to visit you, so that things don't get too hectic.

Schooling and study

In many cases a diagnosis of cancer is very disruptive to schooling and other studies. Children undergoing long-term treatments, for example for leukemia, may have interrupted school attendance during treatment and at other times when they are unwell. They may miss their school friends and the social life that comes with being a student. This may be true also for young adults attending university or other training institutions, and for well children, where the family has had to relocate for specialist treatment. At times the patient may feel bored, left behind or forgotten about by their friends. Visits from friends, classmates or teachers can be very beneficial.

If your child is undergoing treatment it is natural, as a parent, to feel that they may be missing out at school. Be assured however that children do catch up. In the meantime they often gain valuable experiences from their time away from school which can be a special bonding time with parents. The following are some suggestions which may be helpful for parents with school aged child undergoing treatment.

Helpful suggestion

- In the case of a child, try to keep some contact with the school and encourage the staff and students to maintain an ongoing interest in your child's welfare. This will not only benefit them now but will also make the transition back to school easier, after or between treatments. The child's teacher may be able to supply lessons from school.
- Keep the teacher/school informed of your child's progress. Encourage them to keep in contact with the child through visits, phone calls, letters from class mates, cards or posters with thoughtful messages, videos or emails which can be accessed through the hospital.
- When your child does return to school encourage the teachers and students to treat the child as 'normal' - just as one of the class - while at the same time discuss any special needs they might have. Tiredness and risk of infection are important concerns.

- Talk to the teacher about the possibility of tiredness and strategies to reduce exposure to infection.
- Prepare other students for the way the child may look (for example baldness), how they might feel about returning to school (anxious, excited, self-conscious) and how they might make things easier for their classmate (acceptance, inviting them to 'join in').
- Allow the child to talk about their feelings about missing school or returning to school. Offer them support and encouragement.
- Ask the social worker at the hospital about arranging a guest speaker who can explain the illness to classmates. Ask the Leukaemia Foundation for further information about help available to you and your child.
- In the case of university or other studies, contact your educational provider and ask about how they can help you to manage your studies. Extensions of time for assignments or deferring your studies may be an option.
- Most paediatric treatment centres have an educational psychologist, counsellor or school liaison officer who can help.
- Organisations like CanTeen, Starlight Children's Foundation and Make-a-Wish Foundation can be a useful source of information and peer support during this time.

SUPPORT

Practical and emotional support is essential for everyone living with the demands of a serious illness. The need for support continues throughout the illness but the nature and the amount of support required can change. During the initial stages it may be difficult to keep others informed and to respond to all offers of support. Many treatments are lengthy and the support available may lessen over time. Diagnosis and treatment are special times where you and your family need support but it is also important during times of relapse and recovery after treatment. There are many different types of support needed at different times.

These include:

- Emotional support - being there to listen and offer comfort, understanding and encouragement.
- Spiritual support - finding hope and consolation through spiritual beliefs.
- Practical support - help with housework, shopping, cooking and caring for children.
- Financial support - help with paying bills, paying for transport and accommodation costs.

In this section of the booklet we explore some of the issues involved in accessing the support you and your family may need while you are living with a diagnosis of blood or bone marrow cancer.

Making it happen

Regardless of your situation, effective support takes a great deal of ongoing planning and involvement and arrangements have to be made often at short notice. Most people rely on their personal network of family and friends for support. However some people have few family members or close friends on whom they feel they can rely. For others who have different cultural or language backgrounds, accessing support can be especially difficult.

If you are having trouble accessing support, talk to the nurses and doctors at your treatment centre. They will be able to put you in contact with the social worker, pastoral care worker, counsellor or psychologist who can help you cope better with any psychological, emotional or financial difficulties you may be experiencing. They

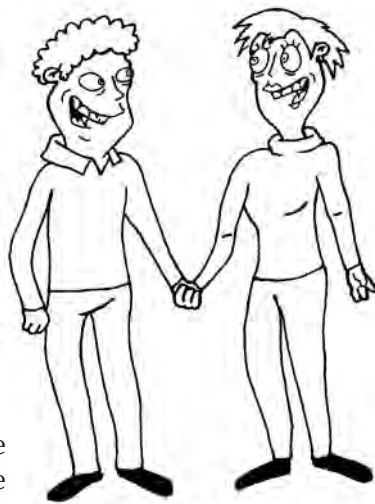
can also identify strategies that will help you and your family cope during and after your treatment. Translators can be arranged if needed and publications written in several different languages are also available. The Leukaemia Foundation has support staff to assist you in these matters.

It is important to remember that many reactions are normal within an abnormal situation like this. If however you have previously struggled, or you are currently struggling with anxiety or depression, you may find it even

more difficult to cope with this stressful situation. It is important that you speak to your doctor about how you are coping and request additional support from a counsellor or mental health professional if necessary.

There are a range of services and organisations (including the Leukaemia Foundation) available to provide practical, emotional and financial assistance for patients and families living with serious illness. Practical help is available through organisations such as meals on wheels, home care services, community nursing and palliative care services. Financial support is available through pensions and benefits to help with the costs of travel, accommodation and some drugs. Financial counselling is also available free of charge from many charitable organisations. The social worker at your treating hospital will be able to help you and your family access these services. Local church and community groups are another important source of support during this time.

Faith can be a great source of support for many people, especially during these difficult times. Many people achieve a sense of strength, peace and hope through prayer and through the support they receive from pastoral care workers and members of the clergy.



How can I help? Providing support

- One of the best ways to provide support is to be a good listener. If you feel overwhelmed or you 'don't know what to say' when talking to the person with cancer, tell them so. They will probably understand and appreciate that you are thinking about them, care for them and want to spend time with them.
- If you are unsure if the ill person needs help, it is best just to ask.
- It's natural to feel uncomfortable, nervous or overwhelmed at times. You may sometimes feel that you say insensitive or even stupid things in front of the person with cancer or their family. Chances are you are doing your very best to help. With time and some information you will probably start to feel more relaxed and able to help your loved one in more effective ways.
- Ask to speak to a support staff member at the Leukaemia Foundation who can explain what is happening and suggest ways in which you might be able to further support your loved one.

Accepting support

- Support is essential to help you and your family cope with the demands imposed by a serious illness. As such, consider accepting any genuine offers of help that you receive. People are not just trying to be polite. They are seeking clear direction about how they could make a difference to your situation because they care for you.
- If you do not need the help that is being offered to you at that time, keep the person in mind for other times or ask them to do something else to help you.
- Focusing on the things you can do to help yourself both practically and emotionally is also important. Looking to better times in the future, making plans and having hope are all important in maintaining a sense of control in a time of uncertainty. This is not easy but it is a skill you can learn and practice.

- Thank those who offer support as they may feel as awkward offering support as you do accepting it. This helps to maintain a good bond between you and your supporters.

Support groups

Many people find it useful to talk with other people who understand the complex feelings and kinds of issues that arise for people living with cancer. As such, support groups can offer a supportive and informative environment for people to discuss issues important to them. Ask your doctor or nurse if your treating hospital runs a support group which might be suitable. If not, they may be able to provide you with the details of a group being run in your area. The Leukaemia Foundation will also have information about relevant support groups. The Cancer Council runs programs in some states which offers practical information about many of the issues you may experience while living with cancer.

You can contact the Cancer Council by calling them on 13 11 20 or by visiting their website - www.cancer.org.au Or contact the Leukaemia Foundation for details of support groups on 1800 620 420 or www.leukaemia.org.au



LOOKING AFTER YOURSELF

Feelings

A diagnosis of cancer will have a high emotional as well as physical impact. Anxiety can be overwhelming at times. Initially many people feel a sense of loss of control and uncertainty about the future.

Helpful suggestions

- It is important that you talk about how you feel with someone you trust or feel comfortable with. This might be a friend or relative or it might be your doctor or nurse.
- It is worth remembering that information can often help to take away the fear of the unknown. The best source of information is often your doctor or nurse. He or she has the most information about your particular circumstances and should be able to give you the most accurate information about your prognosis or treatment.
- Some people find it useful to talk with other patients and family members (for example whilst hospitalised) who understand the different feelings and issues that come up for people living with cancer.

Anxiety and depression

In addition to coping with treatments and their side-effects, living with cancer can be enormously stressful and some people become anxious and depressed. If you are feeling anxious, down or sad most of the time, it is important that you speak to someone about it, like your doctor and the other health professionals caring for you. These people are concerned about both your physical and mental health and will be able to suggest ways that help you and your family gain a stronger sense of control in the present situation. You may benefit by talking with a counsellor or another mental health professional who can assist you to identify and use healthy coping mechanisms at this time. Counselling and anti-depressant drugs can also be very useful for some people.

It is worth remembering that most people feel very tired and fatigued during and for some time after their treatment. Feelings of tiredness and fatigue can contribute to feeling anxious and depressed.

Helpful suggestions

- Try to maintain a manageable daily routine - getting out of bed at a set time, having a shower, getting dressed, etc.
- Set yourself some realistic goals for each day and for the future.
- If possible, get out into the fresh air and take some light exercise every day.
- Try to stay positive about your situation.
- Take an active part in decision making about your wellbeing.
- Plan special enjoyable activities for the days you feel well (a walk on the beach, a visit from a special friend) - you can look forward to these good times on the days you are not feeling so well.
- Learn to relax. This is very important as it can help to take the strain off you and those around you. Relaxation is a skill that can be learned and practiced.
- If you feel you are simply not coping despite your best efforts, seek professional help sooner rather than later.

Coping with side-effects of treatment

Most people are very concerned about the possible side-effects of treatments like chemotherapy and radiation therapy. There have been significant improvements in recent years in the way side-effects are managed. Despite this, some side-effects can still be very unpleasant at times. It is important to recognise however that most of them are temporary and reversible, and a lot less serious than the condition being treated.

The type and the severity of side-effects experienced varies from person to person, depending on the treatment used and how an individual responds to it. In general side-effects tend to be more common and more severe following more intensive treatments (like high-dose chemotherapy or a stem cell transplant). Nausea,

vomiting and hair loss are some of the more commonly known physical side-effects of some treatments. Others include diarrhoea or constipation and increased risk of infection. There may also be psychological or emotional side-effects including mood swings and feelings of anxiety and depression.

Your doctor or nurse will advise you on how to care for yourself while you are receiving treatment, what to expect and how to cope with any side-effects that may occur. They may also be able to provide you with some very useful written information. It is important that you report any side-effects you are experiencing to your nurse or doctor immediately because many of them can be treated successfully if detected early, reducing unnecessary discomfort.

As a general rule, while you are having treatment you will need to contact your doctor or hospital immediately if you have any of the following:

- A temperature of 38°C or over (even if it returns to normal) and/or an episode of uncontrolled shivering (a rigor).
- Bleeding or bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Severe diarrhoea, stomach cramps or constipation.
- Coughing or shortness of breath.
- A new rash, reddening of the skin, itching.
- A persistent headache.
- A new pain or soreness anywhere.
- If you cut or otherwise injure yourself.
- If you notice pain, swelling, redness or pus anywhere on your body.

Relaxation and exercise

Feelings of tiredness and fatigue are common side-effects of treatments that can last for weeks or even months after treatment has finished. This is especially true for people who have had a stem cell transplant. Feeling like you have no energy can be very frustrating, especially if you are used to leading an active and busy life. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and may help to give you more energy. It is easy to underestimate the level of tiredness and fatigue you may be feeling so you should take care in the amount of exercise you do initially.

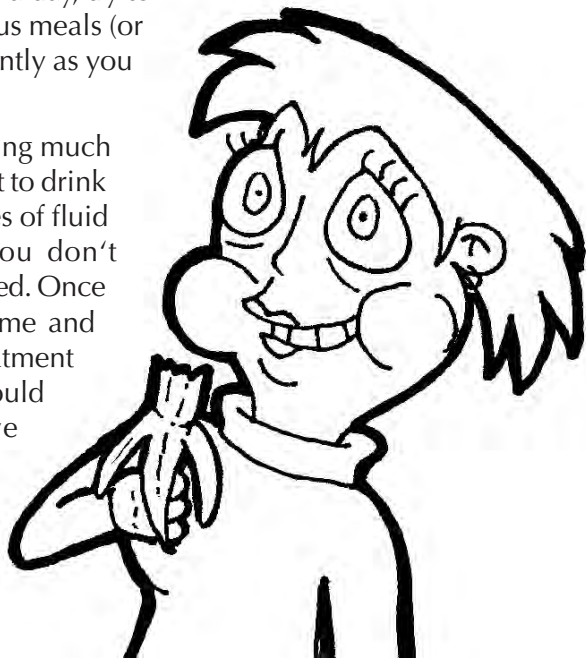
The type and the amount of exercise you choose will depend on how well you are on the day, and your general fitness level. Your doctor will be able to advise you about this. Some hospitals have exercise programs. Talk to the physiotherapist about an appropriate program of exercise for you.

Incorporating a sensible balance of relaxation and exercise in your daily routine may help to increase your sense of wellbeing and control. Most people feel better when they are relaxed within their body and mind. Many of us lead busy lives and have to learn how to relax. Relaxation techniques such as meditation and visual imagery can be very useful coping techniques that help you to gain more of a sense of control. Ask your doctor, nurse or social worker about any relaxation programs which may be run at the hospital. Alternatively they may be able to advise you where you can go for more information.

Diet

A well-balanced and nutritious diet is always important for your body. Good nutrition gives you energy and helps your body cope with the side-effects of cancer treatment. However, there are many reasons why you may not feel like eating during treatment and, in some cases, for some time after treatment has finished. Being nauseated, vomiting or finding that your sense of taste or smell has changed as a result of treatment can all cause a loss in appetite and interest in food. Feeling down or depressed can also affect how you are eating. If you are having problems eating it is important to talk to your doctor, nurse or hospital dietitian who can assess you and advise on ways of ensuring you are having a reasonable nutritional intake. Instead of having large meals three times a day, try to eat small nutritious meals (or drinks!) as frequently as you can tolerate.

If you are not eating much it is still important to drink six to eight glasses of fluid a day so that you don't become dehydrated. Once you are back home and finished your treatment your appetite should start to improve again.



There is a separate Leukaemia Foundation booklet called "Eating Well: a practical guide to people living with leukaemias, lymphomas and myeloma" that provides more detail.

Body image and sexuality

It is likely that the diagnosis and treatment and all that it entails will have some impact on how you feel about your sexuality. Hair loss, skin changes and fatigue can all reduce feelings of attractiveness. You may experience a decrease in libido, which is the body's sexual urge or desire, without there being any obvious reason. It may take some time for things to return to what you are happy to consider 'normal'.

"I think it's really important to realise that you won't look like a patient in a hospital bed forever... it takes time but you will feel and look normal again..."

Partners are sometimes afraid that sex might in some way harm the person who has cancer. This is not likely as long as the partner is free from any infections and the sex is relatively gentle. It is perfectly reasonable and safe to have sex when you feel like it, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant while you are receiving treatment and for some time afterwards. This is because some of the treatments given might harm the developing baby. You need to ensure that you or your partner use a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection.

Helpful suggestions

- Try to remember that over time your physical appearance will improve.
- In the meantime it is important to do things that make you feel good about yourself. This might include enjoying the company of friends and having regular exercise and regular relaxation.
- Simply touching the person that you love can give a powerful sense of acceptance and warmth and a sense that you are sharing their journey with them.

- Look Good... Feel Better is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments. Contact them on 1800 650 960 (freecall) or visit www.lgfb.org.au
- If you have any questions or concerns regarding sexual activity and contraception, don't hesitate to discuss these with your doctor or nurse or ask for a referral to a doctor or health professional who specialises in sexuality and fertility.

Fertility

Some types of chemotherapy and radiotherapy may cause a temporary or permanent reduction in your fertility. In women, some types of chemotherapy and radiotherapy can cause varying degrees of damage to the normal functioning of the ovaries. In some cases this leads to menopause (change of life) earlier than expected. In men, sperm production can be impaired for a while but the production of new sperm may become normal again in the future.

Helpful suggestions

- It is very important that you discuss any questions or concerns you might have regarding your future fertility with your doctor if possible before you commence treatment.
- There are some options for preserving your fertility, if necessary, while you are having treatment. For men, sperm banking is a relatively simple procedure whereby the man donates semen, which is then stored at a very low temperature (cryopreserved), with the intention of using it to achieve a pregnancy in the future.
- For women, egg, embryo, and ovarian tissue storage may be used to protect fertility. To date, egg storage and ovarian tissue storage are techniques which remain under investigation.
- The use of donor eggs might be another option to consider. These eggs could be fertilised using your partner's sperm and used in an attempt to achieve a pregnancy in the future.

- It is important to understand that for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of fertility methods above. In addition, some are time consuming and costly while others may simply not be acceptable to you or your partner for a variety of personal reasons.

Early Menopause

As some cancer treatments can affect the normal functioning of the ovaries, they can also lead to an early onset of menopause, even at a young age. The onset of menopause in these circumstances can be sudden and understandably, very distressing.

Hormone changes can lead to many of the classic symptoms of menopause including: menstrual changes, hot flushes, sweating, dry skin, vaginal dryness and itchiness, headache and other aches and pains. Some women experience decreased sexual drive, anxiety and even depressive symptoms during this time.

Helpful suggestions

- It is important that you discuss any changes to your periods with your doctor. He or she may be able to advise you, or refer you on to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.
- If you are experiencing vaginal dryness a lubricant can be helpful.
- There are complementary therapies available which can help you cope with the symptoms of menopause. However you need to inform your doctor of any 'over the counter' medications you intend using, as some of these may interfere with your treatment.
- Exercise, good nutrition, weight management and stress reduction can all have a positive impact on your health during this time.

FINISHING TREATMENT - LOOKING TO THE FUTURE

Most people look forward to the end of treatment as a time when they can return to a 'normal' existence. For many, finishing treatment means that family members are no longer separated from each other and the opportunity to re-engage with the world of work, education and leisure becomes a reality.

Some people believe that everything is over once the treatment ends. While for most people life does become easier and more satisfying, there are many adjustments associated with finishing treatment and returning home after specialist care. This section of the booklet explores some of the common issues that arise when treatment has finished.

Home at last - back to normal?

For most people, especially those who have been away from home for a long period, the end of treatment represents a new beginning rather than simply a return to their prior existence. Many people return to the security of strong and supportive family and friends. Family roles however, may have changed and may have to be re-negotiated. Relationships may need to be rebuilt away from the hustle and bustle of the hospital.

It is common to feel that others do not fully understand the difficult time you may have spent in the hospital setting. It is natural therefore to sometimes feel a sense that you have changed in ways that may have separated you emotionally from previously close family and friends upon returning home.

From the physical to the emotional

For up to a year following the end of treatment you may find that your focus moves from your physical to your emotional needs. It is normal to have mixed feelings about leaving the hospital and the treating staff. Some people experience a sense of grief about letting go of the intense and close relationships they have formed, as well as a nervousness about dealing with any physical problems they may experience away from the security of the hospital. You may feel vulnerable and uncertain about dealing with normal aches and pains, or coughs and colds which arise during this time.

In many cases feelings about the diagnosis and treatment may have been put 'on hold' during the demanding treatment period and may now surface and need to be dealt with. There may be an expectation from others however, that everything is over and that there shouldn't be any remaining distressing emotions to deal with.

Helpful suggestions

- Re-entry to 'normal' life takes time and adjustment. Allow yourself and your family time to get used to being together again and appreciate that there will be setbacks and challenges.
- Talk to someone who understands your situation. Perhaps someone who has been through a similar experience to yours.
- Think about what is the best next step for you. For some going back to work gives a sense of being productive and useful again. For others time to 'take stock' or go on a holiday are the best ways to get back on top of things.
- Understand that your friends or work colleagues may feel uncomfortable discussing your illness and that you may need to 'break the ice' first.
- The support staff at the Leukaemia Foundation will be aware of your adjustment needs and are there to offer support at this time.
- You may benefit from counseling. The Leukaemia Foundation support staff, hospital social worker, community nurse, or your general practitioner will advise you on available services in your area.

Follow up medical care

Once treatment has finished most people are advised to see their general practitioner (GP) for any necessary medical care. This can make some people nervous because they may fear that their GP may not be aware of the latest developments in haematology. In many cases, you may have more recent knowledge than your GP so it is important to share your experience and ask questions. Once your GP understands your concerns, he or she will be able to contact your specialist doctor for more information if necessary. It is also important to remember that your treating specialist will send information to your GP to keep him or her informed regarding your progress.

Specialist medical care and consultation is increasingly being provided in regional and rural settings and many people are now receiving part, if not all, of their treatment at their local hospital. In addition, many health professionals at local hospitals are undergoing training in the complex area of haematology.

SURVIVORSHIP ISSUES

As a result of advances in the treatment of blood and bone marrow cancers there are an increasing number of people who are being cured of their disease and/or surviving for much longer than previously expected. The majority of survivors are emotionally well-adjusted, optimistic people leading happy and meaningful lives. It is important to recognise that surviving cancer brings its own set of challenges and many people adapt to a different kind of 'normal'.

The following information is designed to be of assistance to people as they move forward in their lives, after they have finished treatment.

Returning to normal

As we mentioned previously it is usual for people with a blood or bone marrow cancer and their families to look forward to the end of treatment as a time when the hard part is over and life begins to return to normal. This is usually a time when the demands of treatment stop and hospital stays no longer separate patients from their families and friends. Survivors may begin to think about re-entering social, educational and employment activities.

It is now understood that very high expectations about life immediately after treatment can cause problems. Families need to be aware that this is a time of transition for all. The survivor may need considerable support and understanding as they move into this new phase of their lives.

There will be wide differences in the way individuals cope with adjusting to life after treatment. While some people feel more comfortable making sense of their experience on their own, others will appreciate sharing their thoughts and feelings with others. Many survivors are surprised by their need to talk about their experiences and will actively seek out opportunities to share these with others who have been on a similar journey.

*"It's as if people expect you to be really grateful (and I am) that you got over it and now they want you to really **get over it** and get on with your life...after a while no one wants to talk about it anymore - that part's finished...but it's not really...not for me."*

There can be significant obstacles to communication when, for example, attempts to talk are blocked by loved ones and others who believe it is best to encourage the survivor to 'get over it' and 'move on'. In these situations it is not uncommon for survivors to experience a sense of isolation, depression and anger.

Helpful suggestions

- Adjustment is always a gradual process so it is important to pace yourself and try to keep your expectations realistic.
- It is often useful to redefine your idea of normal. Life has changed - it is not a matter of going back to what was before but rather creating a new sense of what normal is.
- 'Time out' to engage in enjoyable activities or to talk about non-illness issues will refresh you and your family.
- Many survivors report that it is important to connect with others who share a positive perspective on life and their experiences.
- It is normal, as a result of undergoing such significant experiences, to be impatient with 'trivial' talk.
- Balance is important - it is helpful for survivors to look at both the positive and negative aspects of life.
- There are support groups where you can talk to others who have been through similar experiences.
- Remember everyone is different - comparisons with 'how well' other people seem to cope are not always helpful.
- Humour can be useful to lighten the load at times.

Is it normal to feel so tired?

One of the most difficult issues for survivors is the problem of fatigue. It is common to be concerned about the time it takes for energy levels to return to normal. Fatigue can affect many areas of adjustment and can make you feel quite depressed at times. Family and friends may not initially understand the impact that fatigue may have on your life.

Helpful suggestions

- Pace yourself - while it helps to remain positive and as active as possible, it is counterproductive to push yourself beyond your limits.
- It is important to have realistic goals around what you want to achieve each day - your body needs time to recover.
- Try to get plenty of rest but also try to take a little light exercise each day, such as walking or swimming.
- If you are concerned about the degree of fatigue you are experiencing talk to your doctor.

Sexual relationships

It is quite normal to experience difficulties adjusting to physical body changes caused by the illness or treatment. Many people feel a loss of confidence as a sexual partner. There can also be distress about potential infertility. It is important to remember that

adjustment takes time and that many people do go on to maintain, or create new, satisfying intimate relationships.

"I think the most important thing is to be open and honest with your partner and trust them to be honest with you."

Helpful suggestions

- Information helps. Talk to your doctor about any concerns you may have about the impact of the disease or its treatment on your sexuality or sexual functioning.
- Ask for a referral to a specialist if necessary.
- It often helps to talk about relationship problems. The support staff at the Leukaemia Foundation are there for support and referral to counselling if desired.

Employment issues

There are many factors that may impact on your ability to continue working during or after your treatment. These include the intensity of the treatment and side-effects and the level of fatigue you may be experiencing. In addition, the type and flexibility of your employment and having to relocate for treatment, for example to a metropolitan area, will all affect the decisions you make regarding work.

Helpful suggestions

- Any decision you make about your employment depends entirely on your own personal circumstances.
- Your doctor will be able to help advise you about when to go back to work and what work might suit you best (for example full time or part time, physical work or a desk job).
- If you experience financial hardship as a result of being unable to work, there are a range of services and organisations that can assist you. The social worker at the hospital and the support staff at the Leukaemia Foundation will be able to advise you on financial supports available.

Many people find significant benefits in continuing to work during their treatment or returning to work soon after their treatment finishes. These include maintaining a sense of normality, continuing social contacts, financial security and having a distraction from their illness. These benefits can sometimes be outweighed however by the tiredness and discomfort of having to deal with the emotional and physical demands of work. In addition, not all employment situations are suitable or appropriately supportive for people coping with serious illness, particularly if they involve outdoor work or physically demanding work.

Helpful suggestions

- Flexibility and support are the key factors in assisting people to continue or return to work.
- Discuss your employment options with your employer. They may be able to come up with suggestions you may not have considered.

- It is not unusual for employers to respond in creative and supportive ways with excellent outcomes for both the person dealing with the illness and the organisation.
- Organisations will differ in their response. There will be limits to what a person may want to confide to their employer about their illness. Decisions surrounding how much information to provide will depend on individual circumstances.
- In providing information, it may be important for you to emphasise the need for privacy and confidentiality.
- There is legislation that prevents discrimination based on health for individuals seeking work, and for those already in the work place.
- Pace yourself, and try to accept the limits of your situation.
- Remember, the support services staff at the Leukaemia Foundation will understand your concerns about work and are available to assist you.

Fear of relapse

People who have been successfully treated for a blood or bone marrow cancer can experience feelings of vulnerability to illness, uncertainty about the future and fear that their illness could return. The fear of a recurrence or relapse of cancer may cause some people to be more aware of physical symptoms than previously and prompt them to undergo numerous tests just to prove that they have not relapsed. Follow-up appointments after treatment has finished are often times of great anxiety as people wait for an 'all clear' from their doctor. As time passes and more distance is between you and your treatment the anxiety will reduce. People become more and more engaged in the activities of daily living rather than concentrating most of their attention on their previous illness.

Finding out that the cancer has relapsed can be devastating. Many people experience the same emotions as they did when they received the initial diagnosis, including fear, disappointment, uncertainty and anxiety. If the disease does relapse there are often ways of getting it back under control. It is important to know that your treating team never 'gives up' on you, or your loved ones. They will continue to offer you the most appropriate form of treatment

available. If necessary your doctor may discuss the option of palliative care. Palliative care is aimed at relieving any symptoms like pain, depression or nausea you might be experiencing as a result of your disease or its treatment. Palliative care is concerned with improving your quality of life, rather than trying to cure or control the disease.

Helpful suggestions

- You are not alone in fearing that your disease may relapse. This fear is shared by most people who have been successfully treated for cancer.
- Try to remain positive and concentrate on living well each day and allowing yourself to plan for the future.
- Speak to your doctor about your fears. He or she has the most information about your particular circumstances and can give you a realistic and honest opinion about the likelihood of relapse. Ask your doctor about the risk of relapse in your situation, the time period when you are most at risk and the symptoms which may be associated with relapse. In other words, what to look out for. Your doctor can also discuss the options for treatment available to you, if your disease does relapse.

Positive outcomes

Despite the challenges involved, many people report very positive outcomes from the experience of living with a life threatening illness like cancer. These include:

- A heightened appreciation of life and a desire to make the most of everyday experiences.
- Greater personal development such as increased confidence, calmness, serenity and assertiveness.
- Greater awareness of personal physical and emotional needs and an improved ability to move towards meeting them.
- An affirmation of the importance of their families and their intimate relationships.
- Deeper insights into the struggles of others - often accompanied by a heightened sense of selflessness and compassion.

LOSS AND GRIEF

A diagnosis of cancer poses many challenges both for the person diagnosed and their loved ones. Many adjustments have to be made as people are faced with unplanned changes and upheavals in their lives. Naturally people fear for the future and the potential or real loss of their lives as they once knew them, loss of life plans, loss of self-esteem, loss of relationships and even loss of employment. Grief is a natural reaction to this sense of loss and it is normal to experience grief at various stages along the way; once a person is diagnosed, throughout their treatment and beyond. Over time and with help, many people learn to cope with any losses they experience as they and their families make the necessary adjustments and plans to move forward in their lives.

Loss of a loved one

The death of a loved one is one of the most challenging losses we face in life. The following information is provided to help people who are coping with the loss of a loved one and the profound sense of grief this brings.

People react to grief in different ways. Some of the feelings that come up can be very intense and at times overwhelming. It is normal to feel any of the following, sometimes at the same time:

- shock and disbelief
- numbness and a sense it is not real
- despair
- a sense of being overwhelmed/hopelessness
- confusion
- loss of life plans
- loss of optimism
- fear and/or anxiety
- loneliness

- guilt or regret
- anger
- a sense of unfairness or bitterness
- a heightened concern about your own mortality
- a sense of relief.

Physical reactions including nausea, sleeplessness, chest pain, weight loss or gain are also common, especially in the early period after losing someone you love.

It is normal to have any or all of these feelings and reactions to loss. However there are some special circumstances that may require extra help. These include:

- the loss of a child
- multiple losses at the one time
- a sudden or unexpected death
- the loss of a parent in a young family
- where there is a previous history of drug or alcohol abuse
- where there is a previous history of anxiety and/or depression
- severe or continuing depression
- grief accompanied by thoughts of suicide. Anyone expressing suicidal thoughts needs to be assessed by a relevant health professional, such as a doctor, urgently.

It is particularly important to seek help if you are experiencing any of the situations listed above.

The early months

In the early months, it is common for many people to experience flashbacks or recurring images of treatment and the last days prior to the death of their loved one. These are sometimes invasive and people can have trouble sleeping and may feel overwhelmed by memories of those experiences. These do however usually become less frequent and less intense as emotional healing takes place.

If you have looked after someone during a long period of illness you may feel considerable fatigue especially during the first few months after their loss. You may be prone to infections and illness during this time. It's as though the body stays strong when it's needed and collapses and has to regroup afterwards.

Grief takes time

Processing grief takes time. Coming to terms with a significant loss can take many years. Unfortunately, there is little understanding of this and most bereaved people experience the pressure to 'get over it quickly'. To deal with this pressure you will need to know, and let those close to you know, that:

- **You will feel better in time.** It is common to feel 'trapped' in the difficult emotions of grief and despair. During the initial stages people can worry that they will never see 'the light at the end of the tunnel'. **These feelings will slowly pass.**
- You do not 'get over' the loss of a loved one. With help and in time you will learn to live with the loss. The memory of your loved one will always be a presence in your life.
- The work of grief is about building up a new life. This will happen, but it does take time, lots of time.

Helpful suggestions

- Feelings have a life of their own. The most helpful healing response from family and friends is to allow the grieving person to express their feelings in their own way and for as long as they need.
- Crying and laughter can have special healing powers.
- It is important to look after and nurture yourself at this time, to eat well, and exercise regularly.
- Reading books on grief and hearing the stories of others can be reassuring and helpful.

- Grief goes in cycles and it is normal to revisit intense feelings on special times of the day, for example meal times, and at special days of the year, such as birthdays, wedding anniversaries, or festive occasions. It is helpful to plan ahead and decide what you are going to do on that day. Lighting a special candle or having a family gathering may be helpful rituals.
- Distractions may help such as a short holiday, reading your favourite book, playing CDs, going to a suitable movie or a night out with friends, etc.

The grieving family

The loss of a loved one may have an impact not only on the immediate family but also on a wide circle of extended family and friends. Everyone involved will be dealing with their own feelings and this in turn will affect how they respond to each other.

In your own close family, remember everyone is grieving differently in their own time frame. Children especially will deal with their loss in their own way, depending on their age, their perception of the world, and their development level. It is important to maintain open and honest communication with children during this time. Parents and older extended family members often try to protect them from the pain and sadness of loss.

Teenagers may avoid expressing their grief for fear of upsetting the parent. It is healthy for the family to grieve openly together when possible, to talk about how each family member is feeling and especially to talk about the person who has died.

The need for support

It is common to experience an emotional void after the death of a loved one. This is a time when the expression of support and caring from others is essential. Demonstrating understanding and commitment to the grieving person will be greatly appreciated and can provide an opportunity to strengthen bonds of affection.

Offering support is not always easy. Some people can lack confidence and be unsure as to how to respond to the grieving person. The death of a loved one is often a time when families are already under stress. Tensions and unresolved conflicts can arise and interfere with giving or receiving the support that is necessary at this time.

It is very common for a bereaved person to feel that they are being avoided by family or friends who are unsure of what to say or how to react. They may find that support is offered initially but not maintained or that people give advice as a way of trying to be helpful.

Helpful suggestions

- Emotional and social support is essential during this time.
- The most effective way of demonstrating support for someone who is grieving is to just be there to listen. Sometimes they may not wish to talk about the specific loss, but about other things in life, and just listening to this can be of great comfort.
- Understanding when to respect someone's personal space and their need to be alone is also an important aspect of providing support.
- Other people who have had a similar life experience may be an important source of understanding and support.
- Tears are a healthy and normal part of expressing grief and other intense emotions.

Counselling and support groups

Individual and family bereavement counselling plays an important role in helping people to deal with grief and loss. During bereavement counselling many difficult emotions can be explored in a safe and supportive environment. Here you are given the emotional space to talk about 'real' feelings without the pressure to 'get over it quickly'. In addition, you are given useful information to help you understand the experience of bereavement.

Support groups are also important at this time. For many they provide important opportunities for mutual support, understanding and information. Sharing warmth, caring and laughter with members of the group can lead to a special bond with others who are facing similar challenges. Grief becomes normalised - that is, you will come to accept and understand the many intense emotions shared by others who have lost a loved one.

Many people find that the support they receive through counselling and support groups help them to gain a sense of hope for the future. They appreciate being understood by others who have had similar experiences and feelings. Over time many people develop a stronger sense of self-confidence, a deeper appreciation of what is important to them and an improved ability to deal with life's challenges.

Helpful suggestions

- Contact the Leukaemia Foundation for information on counselling and support groups in your area

USEFUL INTERNET ADDRESSES

- Aplastic Anaemia & MDS International Foundation, Inc.
www.myelodysplasticsyndromes.org
- American Cancer Society
www.cancer.org.
- CancerBACUP (A UK cancer information site)
www.cancerbacup.org.uk
- Cancer Council of Australia
www.cancer.org.au
- CanTeen (The Australian organisation for young people living with cancer)
www.canteen.com.au
- Centre for Grief and Loss
www.grief.org.au
- Leukaemia Foundation
www.leukaemia.org.au
- Leukemia & Lymphoma Society of America
www.leukemia-lymphoma.org
- Leukaemia Research Fund (UK)
www.lrf.org.uk
- Look Good... Feel Better program
[ww.lgfb.org.au](http://www.lgfb.org.au)
- Make-a-Wish Foundation
www.makeawish.org.au
- National Cancer Institute
www.cancer.gov/cancerinfo/
- North American Menopause Society
www.menopause.org

- Starlight Children's Foundation of Australia
www.starlight.org.au
- Talk Blood Cancer
www.talkbloodcancer.com



Leukaemia
Foundation
VISION TO CURE
MISSION TO CARE

A BEQUEST

Your planned gift to the Leukaemia Foundation

A wonderful way to make a significant gift is through a bequest in your will. After making due allowance for loved ones, a bequest of a specific amount or a proportion of the residue of your estate, is a way of leaving a real and lasting legacy to the future.

Your bequest to the Leukaemia Foundation will be used to support our mission to care for patients, carers and families and help us achieve our vision to find a cure for leukaemias, lymphomas, myeloma and related blood disorders.

Wording your bequest to the Leukaemia Foundation

You may choose to make a general bequest and allow the Leukaemia Foundation to decide how your bequest will be used, or you may prefer to make that decision yourself e.g. direct your bequest to patient support or research. Your legal adviser can provide further information on the different types of bequests, and on the appropriate wording for a bequest.

As a guide, the following wording may be useful:

'I give and bequeath free of all duties (here state the amount/percentage or share/residue or assets to be gifted) to the Leukaemia Foundation of (here insert the address) absolutely -

- for the general charitable purposes of the said Foundation (this is the Leukaemia Foundation's preferred option); or
- for the purpose of patient and family support; or
- for the purpose of research into the cause, cure or treatment of leukaemia, lymphoma, myeloma and related blood disorders

and I direct that a receipt of the proper officer for the time being of the Leukaemia Foundation shall be a good and sufficient discharge to my trustee/s'.

Please see the next page for the response form.



Response Form

- I have already made a bequest to the Leukaemia Foundation in my will
- I am considering/it is my intention to make (please circle) a bequest to the Leukaemia Foundation
- I would like more information about making a bequest and/or where to direct my bequest
- I would like to speak to the Planned Giving Manager about appropriate recognition for my bequest
- I would like to receive invitations to functions

Dr/Mr/Mrs/Ms/Miss:

Address:

..... Postcode.....

Telephone: (h).....

(w)

Email:

Please return this form to the:

Planned Giving Manager,
The Leukaemia Foundation,
GPO Box 9954,
in your Capital City
(marked Private & Confidential)

If you are interested in leaving a bequest to the Leukaemia Foundation in your will and you would like further information, without any obligation, in strictest confidence, please contact the Planned Giving Manager in your state on Freecall 1800 620 420 .





Leukaemia
Foundation
VISION TO CURE
MISSION TO CARE

Making a donation

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

You can help by making a donation. Please fill out the form below or visit www.leukaemia.org.au to make your gift online.

Dr/Mr/Mrs/Ms/Miss:

Address:

..... Postcode.....

Telephone: (h).....

(w)

Email:

Please accept my tax deductible donation for \$

My cheque, made payable to the Leukaemia Foundation, is enclosed, or please charge \$..... to my credit card:

Bankcard Visa Mastercard Amex Diners

_____/_____/_____/_____

Cardholder's name:

Cardholder's signature:

Expiry date:/.....

Contact telephone number: (...)

Please send to:

The Leukaemia Foundation
GPO Box 9954
In Your Capital City.



Need more information?

Please send me a copy of the following information booklets:

- Understanding Leukaemias, Lymphomas, Myeloma and Related Disorders
- Living with Leukaemias, Lymphomas, Myeloma and Related Disorders: Information and support
- Understanding Acute Myeloid Leukaemia
- Understanding Acute Lymphoblastic Leukaemia in Adults
- Understanding Acute Lymphoblastic Leukaemia in Children
- Understanding Chronic Lymphocytic Leukaemia
- Understanding Chronic Myeloid Leukaemia
- Understanding Hodgkin Lymphoma
- Understanding Lymphomas (Non-Hodgkin's lymphomas or B-cell and T-cell lymphomas)
- Understanding Allogeneic Transplants
- Understanding Autologous Transplants
- Understanding Myelodysplastic Syndromes
- Understanding Myeloma
- Young Adults with a Blood Cancer
- Eating Well: A practical guide for people living with leukaemias, lymphomas and myeloma

Or information about:

- The Leukaemia Foundation's Support Services
- Workplace giving
- Regular deduction scheme
- National fundraising campaigns
- Community fundraising opportunities
- Volunteering
- Receiving the Foundation's newsletters

Name:

Street or Postal Address:.....

Suburb.....

State/Postcode

Email: Tel: (.....).....

Please send to:

Leukaemia Foundation, GPO Box 9954, In Your Capital City

or Freecall 1800 620 420

or email: info@leukaemia.org.au

Further information is available on the Leukaemia Foundation's website

www.leukaemia.org.au





Leukaemia Foundation

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MISSION TO CARE

This information booklet is produced by the Leukaemia Foundation and is one in a series on blood cancers and related disorders.

Some booklets are also available in other languages. Copies of this booklet and the other booklets can be obtained from the Leukaemia Foundation in your state by contacting us on

Freecall: 1800 620 420
Email: info@leukaemia.org.au
Website: www.leukaemia.org.au

The Leukaemia Foundation is a non-profit organisation that depends on donations and support from the community.

Please support our work by calling 1800 620 420
or by mailing your donation to:
The Leukaemia Foundation
GPO Box 9954
In Your Capital City

May 2008

