GETTING MY LIFE IN ORDER

The journey from diagnosis to recovery

Financial and practical considerations for patients with leukaemia, lymphoma, myeloma and related blood disorders.
Introduction

The information in this booklet is designed to help you, your family and friends cope with the complex practical and financial issues that come from being diagnosed with a blood cancer such as leukaemia, lymphoma, myeloma or related blood disorder.

The information in this booklet aims to assist you with some of the personal, financial, employment and other issues that arise from the time of diagnosis, through the period of treatment and on to recovery – a period which may extend from several months to several years.

The Leukaemia Foundation has long recognised that the path to recovery and beyond may be rocky and reducing the burden and anxiety associated with these practical issues is vital to a patient’s well-being.

The Leukaemia Foundation’s Support Services staff are available to guide and support you through trying times.

**Please call if we can assist you on freecall 1800 620 420.**
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Practical implications of a diagnosis

Being diagnosed with a potentially life-threatening illness will generally leave you in a state of shock and disbelief. You will probably feel like your life has been completely turned upside down. At this very difficult time there are a number of practical and financial considerations you and your family members will be faced with.

Remember you are not alone. The Leukaemia Foundation has highly-trained Support Services staff who can help you explore these issues and assist you with information and support.

What are your treatment options?

Beginning treatment can be a confronting and confusing time and you may feel that you are being bombarded with unfamiliar medical terms and information.

Your treatment options will vary depending on your particular disease, whether it needs treatment immediately or whether there is time to wait, and other factors which will be explained to you by your specialist.

Often your specialist will outline a protocol for treatment which will extend over a period of time and then be reviewed at the end of that period. Depending on blood tests and other kinds of tests, the next phase of the treatment protocol will then commence. Some diagnoses require treatment that will extend over a long period of time.

Do you have to travel to another city for treatment?

Patients requiring specialist treatment who don’t live in the treating centre’s location can apply for financial assistance with accommodation and transport through Patient Assisted Travel Schemes available in each state of Australia. These government schemes provide financial help for accommodation and travel for patients who are required to travel outside of their local area to receive specialist treatment. For further information regarding this support you should contact the Patient Travel Clerk at your local hospital.

Where possible, the Leukaemia Foundation provides free accommodation for patients and their family members who need to travel outside of their
local area for specialist treatment. For more information on accommodation, contact the Leukaemia Foundation on 1800 620 420.

**How will your family be affected?**

The ripple effect of a blood cancer diagnosis can be enormous for your whole family. Adapting to change and loss is hard for most of us, and not only do we need to consider the loss of the individual’s health but also the many other losses that occur as a result of a diagnosis. Some of the losses patients and their loved ones commonly face include loss of life as we knew it, loss of home, loss of income, loss of lifestyle as we knew it, loss of friendships, loss of routine, loss of familiar surroundings and loss of social networks for support.

While many families discover an inner strength and resilience, feelings of vulnerability, fear, sadness and resentment are also common. The Leukaemia Foundation Support Services staff are available to nurture and guide you through these trying times.

**Are you able to continue working?**

Some patients with a blood cancer cannot participate in full-time work commitments due to a range of side effects including fatigue, compromised immune system and a general feeling of being unwell. Patients need to review their capabilities and seek appropriate support and clarity regarding their working roles. Depending upon your work history and the type of work you are involved in, you will need to assess whether or not you are physically able to continue with that type of work, and what available sick leave, long service leave and other leave entitlements are available to you. Then, once you are able to determine what entitlements are available, you can make the appropriate application to Centrelink when you are no longer being paid by your employer or from other sources.

The following chapters give you more detailed information on the range of financial issues you may need to consider as a result of your diagnosis.
A financial stocktake

When you become aware that you may lose your income or suffer a reduced income as a result of the ill health of you or an immediate family member, the first step should be to take a quick ‘financial stocktake’.

In a later chapter we discuss preparing a budget but at this time your concern should be just a quick assessment of how you are going to cope with the immediate future.

First, assess what income you can expect or what financial resources you have available. Possibilities may include:

» Are you or your partner able to work part-time?
» Do you have sick leave or long service leave?
» Do you have Income Protection or Trauma Insurance, either as a stand alone policy or part of a life policy? This may be included in a policy you have purchased or you may find that your superannuation fund provides this type of cover.
» Do you have money in the bank or a line of credit against your mortgage which can be drawn against?
» Can any investments be accessed? You may not need to dispose of them immediately but just assessing your position is helpful.

The second step involves checking on important expenses which need paying in the immediate future, including:

» rent or mortgage payments
» electricity, gas and phone accounts
» school fees and other education expenses
» car and other loan repayments
» medical and other insurance policies – it is important not to let these lapse when health is a problem
» day-to-day living costs, such as food.
When you are under financial pressure you should avoid or defer all unnecessary expenses – these can be paid when circumstances permit.

Endeavour to avoid making charges to credit cards unless you know you will be in a position to repay the full amount by the due date. Most credit cards have very high interest rates, some as high as 20 per cent, and if they are not paid in full each month the interest just continues to compound until the amount owing becomes excessive.

Help is available in these circumstances and we discuss some of your options in the next chapter.
Seeking help

Centrelink

If you expect to lose all or most of your income or your partner’s income, the first organisation to contact is Centrelink, a division of the Commonwealth Government Department of Human Services. Depending on your circumstances, you may not be eligible for benefits immediately but frequently benefits are back-dated to the date of application. So the earlier you make an application, the sooner you may receive some relief payments.

Centrelink benefits are too complex for us to explain here in detail and the conditions and payment amounts change regularly. If you have employment to return to this will affect the basis of your benefit. Your partner may also be eligible for a Carer Payment or Carer Allowance, so be sure to enquire about this.

When completing Centrelink forms it is very important to be accurate and provide all the required details. Failure to supply all their requirements may result in lengthy delays in obtaining your benefits.

The Leukaemia Foundation support staff will be happy to help you with this procedure but it is your responsibility to provide full and accurate information.

Financial institutions

When you are unable to make your regular payments on your mortgage as a result of serious ill health, it is important that you let the relevant organisations know as soon as possible. Most banks and other financial organisations have special arrangements for customers in financial hardship as a result of ill health.

It is preferable to write to the head office of the financial institution and explain your circumstances, giving details of your health problem and how the loss or reduction of income will prevent you from making your regular payments. You should ask for specific assistance such as suspension of your payments for six months. If you are not in a position to write then you may telephone them and ask for the “Financial Hardship” department.
If your mortgage is paid by regular debit to your bank account, you will need to make sure they do not continue to debit your account once you have advised them of your situation. Otherwise you may find that money in the account you are planning to use for food and other essentials is still taken for the mortgage.

Similar procedures apply when you cannot make the minimum repayments on your credit cards or personal loans. It is always preferable to approach the lender before you become overdue. Most financial organisations are understanding when they are aware of your difficulty but once an overdue account is referred to a collection agency it can be harder to resolve.

**Local authorities**

Most local councils will be tolerant if you are having difficulty keeping up your property rates. Arrangements vary between local government bodies, but many have a Rate Arrears Tribunal to assist ratepayers who are in financial hardship. As with other organisations, you are likely to receive a more sympathetic hearing if you approach them before your account is overdue.

**Your landlord**

If you rent your home, don’t forget to speak with your landlord. Even though they may not be obligated to help you, you might be surprised at the consideration you receive when he knows your situation. When your income is greatly reduced due to ill health, payment of your rent should be one of your highest priorities as private property owners are not obliged to be lenient regarding your payments.

**Other sources of help**

Do not hesitate to discuss your financial circumstances with your treatment centre or your private insurer. They may be able to assist with less costly options or advice on deferring payments.

It may be possible to draw some money from your superannuation fund to help with emergency payments. See page 16 for more details.

Don’t forget to check if your superannuation has income replacement insurance as one of its features. If you are not sure give their helpline a call.
Managing your money

Managing your money efficiently, or making your money work for you, is one of the most important contributors to a happy and successful lifestyle, and it becomes even more important when income and expenses are affected by a life-threatening disease.

As soon as you are in a position to think about your finances, the first step is to prepare a family budget.

The term ‘budget’ can be off-putting but it is really very simple and is at the heart of managing your money successfully. All it means is making a list of where you expect your income to come from and where you expect to spend it and then, over time, recording the actual figures. We will explain some of the aids that are available to help you.

The concepts we discuss here should apply throughout your lifetime so that you can plan for the future. However, when family life is disrupted by loss of income as a result of ill health, it is critical that you know your financial position and how you can ‘make ends meet’ now and in the future.

When times are tough, every extra dollar of income you obtain and every expense spared helps to make those ends meet.

When normal income is disrupted you may receive special payments such as income insurance, Centrelink benefits, sick pay, leave or long service leave, and investment income. Every single dollar is important. For example, if you have money in the bank make sure it is in an account with the highest possible interest rate to suit your requirements.

When you have your list of anticipated expenses written down, look through it carefully to see what items can be cut back or deferred to a later time.

Having these figures available will also help if you make special requests for financial assistance.

There are three basic ways to establish your budget:

Manually – The following illustration of a Handy Budget Planner is easy to complete and the instructions indicate each step.

Computer spreadsheet – You can easily set up your own spreadsheet following a similar form to the manual budget planner. Alternatively, several are available on the internet. The Australian Government website
moneysmart.gov.au has a Budget Planner which can be downloaded free of charge and comes complete with help for first time users.

**Commercial software** – Several commercial packages are available that have the advantage that you can record all your transactions and see your exact financial situation at any time. An example of such software is *Quicken*. The ‘Personal’ edition is fine for most family situations but if you have multiple investments ‘Personal Plus’ may suit you better.

When you get used to recording your income and expenses you will find it an invaluable help in future planning. When you recover your health, and your income returns to normal, the budgeting habit you have formed will help with planning future events such as your retirement.

This illustration of preparing a budget is provided by the Australian Bankers’ Association and it is possible to download the working papers, and other helpful information, from their website bankers.asn.au

**Taking the first step**

You can start a budget by simply writing down your income. Remember income can come from many sources not just your salary or wages. For example, you might also receive dividends from shares you own, rent from an investment property or board from an adult child. If you receive government benefit payments you should also include these payments as income.

The next task of listing your expenses is more time consuming. Writing down your expenses will identify what you are spending in the major expense categories such as housing, groceries, transportation, utilities, medical/health, insurance, clothing, entertainment, education, travel, etc. It may sound arduous but the effort really pays off.

Here are two different methods to list your expenses:

1. **Keep a daily diary**

   The most accurate approach is to note down every cent you spend on a daily basis over a three month period. You could simply record your expenses by hand using a separate page for each week or you could use a spreadsheet. If you can, divide your expenses into the major categories as this could help you identify areas where you can cut back. If you use this approach, also think about including your annual expenses, for
example your insurance premiums. The advantage of this approach is that it allows you to see exactly how much you are spending. If you have never done this before you will probably be astonished by how much you actually spend, and what you actually spend your money on.

2. Refer to your records

You could also use your bank records, such as credit card and bank statements, to establish this information. If you use your credit card to pay for most things and have direct debits set up from your bank account for your regular expenses, this approach can be an effective way to gather information on your expenses. Your credit card in particular will itemise your expenses such as groceries, restaurants, clothing purchases, etc. The advantage of this approach is that it allows you to begin your budget now without having to collect information over the next few months.

Alternatively, you could use bills, such as utility bills or school charges, to calculate expenses. If you use this approach it is important that you make sure you collect all the information to include in your budget.

Getting the timing right – weekly, fortnightly or monthly?

It’s a good idea to match your budget to your pay period which may be weekly, fortnightly or monthly. That way you can use your budget to help you manage every income payment effectively.

Converting the numbers

Not all of your income and expenses will be for the same timeframe, so you’ll need to convert some of them to make sure your budget figures are accurate. If you pay a certain bill by the month, but your budget is for a fortnight, you might find it easy enough to work out what the fortnightly cost of this bill would be. But some of the conversions might be a bit tricky to do in your head. The conversion guide below will help you to make your budget accurate (and so will a calculator!).
<table>
<thead>
<tr>
<th>Make my weekly amounts fortnightly:</th>
<th>Make my weekly amounts monthly:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiply your weekly amounts by two – the result is the fortnightly amount.</td>
<td>Multiply your weekly amounts by 52. Divide the answer by 12 – the result is the monthly amount.</td>
</tr>
<tr>
<td>Example: If your weekly income is $1100 and you want to have a fortnightly budget multiply $1100 by 2 to find your fortnightly income is $2200.</td>
<td>Example: If your weekly income is $900 you multiply this by 52 to obtain your annual income ($46,800) and divide this by 12 to arrive at your monthly income of $3900.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Make my monthly amounts fortnightly:</th>
<th>Make my fortnightly amounts monthly:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiply your monthly amounts by 12. Divide the answer by 26 – the result is the fortnightly amount.</td>
<td>Multiply your fortnightly amounts by 26. Divide the answer by 12 – the result is the monthly amount.</td>
</tr>
<tr>
<td>Example: If you receive a telephone expense account each month of $80 and you want to put it in a fortnightly budget, multiply $80 by 12 ($960) then divide that by 26 to find that the fortnightly amount is $36.92.</td>
<td>Example: If your fortnightly income is $1500 and you want to budget on a monthly basis, multiply $1500 by 26 to find the annual amount of $39,000, then divide that by 12 to arrive at a monthly income of $3250</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Make my yearly amounts fortnightly:</th>
<th>Make my yearly amounts monthly:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divide your yearly amounts by 26.</td>
<td>Divide your yearly amounts by 12.</td>
</tr>
<tr>
<td>Example: If you receive a yearly rates bill of $3000 and you want a fortnightly budget, just divide $3000 by 26 to find your fortnightly expense of $115.38.</td>
<td>Example: If you have an annual insurance premium of $2100, the monthly amount will be $175.</td>
</tr>
</tbody>
</table>
Some tips on getting more accurate budget results include:

» Use after-tax income figures (this may require you to make an adjustment if deductions have not been taken into account), e.g. imputation credits for dividends paid on shares.

» Do not include irregular income that may not be reliable, e.g. annual performance bonus, gifts of money.

» Calculate using consistent expense periods, e.g. weekly, fortnightly, monthly.

Regular income

The next step is to complete a budget planner. You can use this table, create your own or use one of the many made available by banks and other financial institutions. You can find these ready-made planners online or ask for a printed version from your bank. Remember to select a timeframe for your budget - weekly, fortnightly or monthly.

<table>
<thead>
<tr>
<th>Type of income</th>
<th>Amount received each period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary or wage (after tax)</td>
<td>$</td>
</tr>
<tr>
<td>Pension or Government allowance</td>
<td>$</td>
</tr>
<tr>
<td>Child support or other payments</td>
<td>$</td>
</tr>
<tr>
<td>Regular interest from bank deposits</td>
<td>$</td>
</tr>
<tr>
<td>Regular income from investments (such as rent from an investment property or distributions from a managed fund)</td>
<td>$</td>
</tr>
<tr>
<td>Other</td>
<td>$</td>
</tr>
<tr>
<td><strong>A: Total income for this period</strong></td>
<td><strong>$</strong></td>
</tr>
</tbody>
</table>

Regular expenses

Use this table to write down your expenses. There is also room to include any savings you set aside and any regular debt payments. Start by filling in your fixed expenses – they are the ones that don’t change from period to
period such as your rent or loan repayments. Your variable expenses are trickier as they will go up and down. You will need to work out the amount for each period. We’ve left some blank spaces at the end of each category in case you need to add any other expenses.

<table>
<thead>
<tr>
<th>Household expenses</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rent</td>
<td>$</td>
</tr>
<tr>
<td>Repairs</td>
<td>$</td>
</tr>
<tr>
<td>Gas</td>
<td>$</td>
</tr>
<tr>
<td>Electricity</td>
<td>$</td>
</tr>
<tr>
<td>Water</td>
<td>$</td>
</tr>
<tr>
<td>Telephone</td>
<td>$</td>
</tr>
<tr>
<td>Cable/broadband</td>
<td>$</td>
</tr>
<tr>
<td>Furniture</td>
<td>$</td>
</tr>
<tr>
<td>Appliances</td>
<td>$</td>
</tr>
<tr>
<td>Groceries</td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td>Transport expenses</td>
<td></td>
</tr>
<tr>
<td>Car</td>
<td>$</td>
</tr>
<tr>
<td>Public transport</td>
<td>$</td>
</tr>
<tr>
<td>Parking</td>
<td>$</td>
</tr>
<tr>
<td>Fuel</td>
<td>$</td>
</tr>
<tr>
<td>Repairs</td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td>Personal expenses</td>
<td></td>
</tr>
<tr>
<td>Clothes and shoes</td>
<td>$</td>
</tr>
<tr>
<td>Hair and beauty</td>
<td>$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>School fees</td>
<td>$</td>
</tr>
<tr>
<td>Uni fees</td>
<td>$</td>
</tr>
<tr>
<td>Books and uniforms</td>
<td>$</td>
</tr>
<tr>
<td>Camps and excursions</td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td>Other expenses</td>
<td></td>
</tr>
<tr>
<td>Child care</td>
<td>$</td>
</tr>
<tr>
<td>Gifts and donations</td>
<td>$</td>
</tr>
<tr>
<td>Pet care</td>
<td>$</td>
</tr>
<tr>
<td>Hobbies</td>
<td>$</td>
</tr>
<tr>
<td>Sports</td>
<td>$</td>
</tr>
<tr>
<td>Subscriptions</td>
<td>$</td>
</tr>
<tr>
<td>Eating out</td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td></td>
<td>$</td>
</tr>
<tr>
<td>Savings</td>
<td></td>
</tr>
<tr>
<td>Personal super contributions</td>
<td>$</td>
</tr>
<tr>
<td>Regular savings account instalments</td>
<td>$</td>
</tr>
<tr>
<td>Regular instalments into investments</td>
<td>$</td>
</tr>
<tr>
<td>Christmas clubs etc</td>
<td>$</td>
</tr>
<tr>
<td>Holiday savings</td>
<td>$</td>
</tr>
</tbody>
</table>
### One last step – are you balanced?

Now that you’ve completed the income and expenses tables, you can clearly see how much regular income you receive, and where all that money goes over your chosen period. Using the totals (A and B) from each table, subtract your total expenses from your total income:

<table>
<thead>
<tr>
<th>Your total income</th>
<th>Your total expenses</th>
<th>Your net result</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B: Total spending for this period

```
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Money for emergencies</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical expenses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dentist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialists</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debt repayments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mortgage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car loan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HECS payments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Credit cards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal loan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Store cards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lay-bys</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home &amp; contents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health cover</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income protection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
```

B: Total spending for this period

= $
If you still have money left over after doing this calculation, you’re living within your means and your income is greater than your expenses – this means you could be saving some money.

If your answer is zero, your income equals your expenses – you may want to consider reducing some expenses in order to build up some savings.

If you get a negative number, you are currently spending more than you earn – you need to review your expenses carefully to see if you can correct the situation.

A little effort in establishing and working with a budget can help give you peace of mind during your illness and recovery period. The experience gained will then be invaluable in managing your finances in the future.
Accessing superannuation

Superannuation is designed to provide for your retirement, so you can generally only access it when you reach the age of 65. However there are some very limited circumstances where it may be available earlier.

Between the ages of 55 and 65 special arrangements apply, depending on your age and personal circumstances. You need to obtain personal advice in this regard and you should approach your superannuation fund for guidance.

Prior to age 55 you can only access your superannuation in very limited circumstances. These include:

1. If you have a terminal medical condition or are permanently incapacitated, you can apply to your super fund to access your benefits regardless of your age. You will need to meet all the requirements set out by your superannuation fund. This includes providing two medical certificates worded in the approved form.

2. If you have been on Centrelink benefits for six months or more and can prove that you are experiencing severe financial hardship, you can apply to your super fund for an amount up to $10,000. You will need a certificate from Centrelink to support your application.

3. You may also be able to apply to the Australian Government Department of Human Services for a release on compassionate grounds. These are:
   - to pay for medical or dental treatment for you or a dependant, which is not available in the public health system
   - to pay for transport to and from medical treatment for a life-threatening illness
   - to prevent your home being sold by the lender that has a mortgage over it
   - to modify your home or vehicle to accommodate your own needs or the needs of a dependant in the case of severe disability
   - to pay for palliative care
   - to pay for funeral expenses.
4. If your superannuation includes insurance cover you may be able to take this as an income. Talk to your superannuation fund to discuss your options.

Applications have to be prepared carefully with attention to accuracy and ensuring all the necessary attachments are included. Where medical certificates are required, these must include the exact wording stipulated in the documents.

Initial information may be obtained from your superannuation fund. Assistance in completing the application may be available from the Leukaemia Foundation Support Services staff or from financial counsellors (see the Appendix for contact details).

Careful study of your last annual superannuation statement will usually enable you to determine what, if any, insurance benefits you may be entitled to.
Future planning

Once you start to recover from your treatment you will need to look ahead and think about getting life back on track. There are likely to be hurdles to cross but help is at hand and you should adopt a positive attitude to the future.

Here we consider some of the questions that may arise.

Will you be able to return to your usual occupation?

Following any long journey with a blood cancer there will be obstacles to overcome. Some patients may be able to resume the work they were doing prior to diagnosis, while others will have to resign from their previous employment and look at learning new skills to obtain future employment. This is a very difficult time as a large percentage of patients post treatment and transplant suffer from fatigue, which prevents them from working long hours. The patients who have undergone a bone marrow transplant might also have to come to terms with graft vs host issues. All in all the journey post treatment is a very individual one and returning to work can present some very confronting issues for the patient.

Things to consider when looking at returning to work:

» Are you able to work full time?
» Is your current employer aware of your capabilities?
» Are you able to negotiate shorter hours if needed?
» Does your Centrelink payment affect your options?

To discuss your current benefit payments and eligibility for benefits if you return to work, contact Centrelink on 13 27 17 or go to humanservices.gov.au.

This is a very emotional time and you may seek an opportunity to talk through your options in a safe and protected environment. The Leukaemia Foundation has support staff available, free of charge, to help explore your options. This will be your first step in the right direction.
Re-assessing your current role and looking at other employment options

Coming to the realisation that your previous line of employment is not suitable to your level of ability is one of the most difficult hurdles to overcome. Again the Leukaemia Foundation support staff can provide advice and assistance to help you explore what options are available to help you embrace the future. If you are currently in receipt of a benefit through Centrelink and wish to explore what other services Centrelink offer then visit humanservices.gov.au. Centrelink provides a Disability Employment Assistance Service that encompasses a myriad of support and information for the individual regarding job seeking and other services and programs.

There are many other agencies that provide guidance and assistance to help patients return to work. The Leukaemia Foundation Support Services staff can help you research these options further. Please find listed below some helpful links that you can explore:

Disability Employment Services Brisbane (DES)
jobsearch.gov.au

Community Directory
mycommunitydirectory.com.au This community directory provides up-to-date information on disability employment and training services in your local area.

CoAct
coact.org.au
Another avenue some may wish to consider when looking at returning to work is contacting the various private providers in your local area. Employment services can provide individually tailored support for people facing barriers to obtaining or maintaining employment.

Providers like CoAct can assist with:
» re-entering the workforce
» writing CVs
» appropriate workplace training.

Visit the CoAct website at coact.org.au/contact to find your local office.
Volunteering

Sometimes individuals are unaware of their own capabilities. Sometimes the journey has lasted so long that they have had to surrender their position with their employer and are in the position of exploring alternative employment. This can be very confronting. In trying to determine how much time you can offer an employer, you may want to consider volunteering to discover your current abilities and physical stamina.

Volunteering Australia is an excellent place to start: volunteeringaustralia.org.au

Benefits of volunteering:

» improve self worth/self confidence
» create a skill base
» establish friendships and links with community
» create opportunity to explore new options and working environments
» discover your capacity within the working environment
» allow continuation with Centrelink payments while gaining control
» allow awareness of fatigue management.

Retraining

Returning to work can be both exciting and overwhelming. After all that time off, you may no longer feel confident that you can cope with the workplace. If you’re returning to work after a severe or long-term illness, you should do so gradually. Your illness may have made it impossible for you to continue in your former occupation. You may need to set new goals and these may be quite modest when you first start back at work. As your health and confidence improve, you can revise or build on these goals.

Firstly, you need to establish what you want. What are you looking for in a job? Decide if you want:

» full-time or part-time work
» paid employment or work in a voluntary sector
» work in a familiar field or in a new area
» to retrain.
To plan a career, you need to know who you are. You need to have assessed your own values, interests, strengths, weaknesses, accomplishments, personal resources and goals.

**Where can you get help?**

You may only need one person to talk things through with, or you might want to enlist a whole team of people to cheer you on.

Use a professional counsellor, career or guidance officer, mentor, colleague, family member, friend, or any combination of these. Anyone who can give you objective opinions and help you feel positive about job hunting is useful to you.

**Some organisations that you may wish to contact are:**

- Employment Services Information Line 13 62 68
- Employment Plus Line (>45 yrs) 13 61 23
- Other independent employment agencies.

**Further study**

If you wish to pursue further studies you will need to do some research into the areas and institutions that interest you and from there explore what options are available. Initial contact should be made with the Career Guidance Officer at the chosen institution to further explore the entry requirements and application process.

There are scholarships and grants offered through some charity groups that provide opportunities for individuals to pursue further study. If you wish to explore these options please contact:

- Cancer Council ([cancer.org.au](http://cancer.org.au))
- Redkite ([redkite.org.au](http://redkite.org.au))
- Ronald McDonald House Charities. ([rmhc.org.au](http://rmhc.org.au))
The family home

Once you are in a position to review your lifestyle and think about the future it may be appropriate to consider the suitability of your family home.

When you have lived in your home for many years it may become an accepted part of life and something you take for granted. Everyone’s circumstances are different but now could be a good time to think about its suitability for the future.

Depending on individual health considerations and the nature of your home, some questions which may come to mind are:

» If it is a large home with substantial land, will maintenance be a future problem?
» If there is a possibility you may be handicapped, will you need modifications?
» Is the location convenient to medical facilities, family and other amenities?
If you have a large home there may be financial benefits in downsizing and releasing some of the money you have invested.

Financial considerations may also be a negative factor in moving. When you sell a property there are usually agents and legal fees. When buying a new property you have to take into account Stamp Duty, legal fees, moving costs and the cost of fitting out such items as window and floor coverings.

The total cost of selling one property and buying another may well run to tens of thousands of dollars.

If you need modifications to your home as a result of your illness, you should seek advice from your treatment centre or contact My Aged Care on 1800 200 422 to explore in home options.
Legal matters

This chapter applies equally to all members of the community, not just those who have a blood cancer or their carers.

The best time to get your affairs in order is when you are in good health. Here we will consider some of the most common legal documents you should have and where to get help.

Enduring power of attorney

An Enduring Power of Attorney (EPOA) is a legal document giving someone else you nominate the power to sign documents on your behalf or make personal, health and, if you choose, financial decisions on your behalf.

Even when you are in the best of health, there may be times, such as when you are travelling from home, when an important document needs your signature. This is when your attorney may act on your behalf.

There may be circumstances when a person loses the capacity to make decisions for themself and, if there is no one with an appropriate EPOA, the state may appoint the adult guardian to make decisions on the person’s behalf. The guardian has the power to make decisions regarding the person’s care and protection, even if this decision overrides the adult’s wishes.

You have the option of appointing an attorney purely for financial matters and signing documents on your behalf and the same, or a different person, to make decisions on personal or health matters.

You should nominate someone who you can trust as your attorney, a family member, friend or professional adviser. You may also appoint two or more attorneys with the power to make decisions individually or together.

You may nominate the same person or persons to make some decisions on non-health matters on your behalf or have different nominations for this purpose.

We never know what the future holds, so it is important to establish your EPOA while you are in a position to do so.

It is possible to obtain standard forms for this purpose but you are strongly advised to seek legal advice in the preparation of the document as
questions may arise as to whether you may wish to limit the powers of people signing on your behalf or incorporate other special instructions.

An EPOA relating to financial matters comes into effect immediately when it is signed or on a future date you may nominate. In the case of personal/health matters, it only takes effect if you are incapable of making decisions yourself. It ceases to have effect in the event of your death. You also have the power to cancel the EPOA at any time or to draw up a new document to replace the original.

Once the document is completed and signed, it is suggested you make several copies and have these certified as true copies by an appropriate legal person or Justice of the Peace. You can then provide a certified copy to your attorney in case it is ever required.

Wills

It is very important to have specialist legal advice when preparing your Will. There are many questions and options your legal adviser will discuss with you which may not be immediately apparent. This is particularly important when you have dependent family members and you need to determine who will be responsible for them in the event of your death.

If you die without leaving a valid Will, you leave what is known as “intestacy”. Although you may feel your affairs are very simple and your immediate family will receive your assets, this is not necessarily true.

The consequences of dying intestate can be serious for your heirs. At the very least, your estate and beneficiaries will incur greater than normal costs in administering and distributing your estate and they may pay some unnecessary tax. At worst, your estate may be distributed to unintended beneficiaries, or result in a prolonged, bitter and expensive court battle over who gets what.

In any event, dying intestate means that there could be significant delays in the final distribution of your estate. Should you die intestate, distribution of your estate will be determined by a formula set down in legislation. This may mean that your assets do not end up with the person you would have chosen. It also means that you have no control over who distributes your assets as this will be handled by the state.

You will also need to carefully consider who will be your executor as he or she will handle the administration of your estate. Matters such as your
superannuation, responsibility for earlier partners and their children, and whether your Will may be contested, also need to be considered.

These and many other issues can affect whether or not your beneficiaries receive the entitlements you intend for them.

If you already have a Will you need to consider if it is still current. Some questions to consider include:

» Have you married or divorced since your Will was established?
» Is your choice of executor still appropriate?
» Do you want to include any specific gifts?
» Have you appointed a guardian for dependent children?
» Is your Will tax effective?
» Do you have beneficiaries with special needs, such as disabilities?

**Advance Health Directive**

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident.

Although this is a lengthy document, it is simple to complete as it mainly consists of a series of optional questions. There are also sections where you make comments in your own words.

While this form can be completed on your own, you may wish to discuss it with your family and you are also required to have a doctor sign the form to certify that you understand the contents of the document.

Once completed, this form should be kept in a safe place and your family made aware of its location so that it may be produced in the event of your incapacity.

You may also wish to have one or two certified copies made of the document that can be distributed to alternative family members, your GP, friends or associates.
Superannuation beneficiaries

You have the right to nominate the beneficiaries of your superannuation account. If you don’t do so then the balance will usually be transferred to your estate and this may not be the most tax effective option.

You should also be aware that under most circumstances the trustees of a superannuation fund are not bound by your nomination of beneficiaries and may use their own discretion regarding the payment of your benefits.

To overcome this you should lodge a ‘Binding Death Nomination’ form with your fund. This type of nomination must be renewed every three years. If in doubt seek advice from your financial or legal adviser.

Getting help

Help with legal matters is available from several sources including:

» Solicitors
» Trustee companies
» The public/state Trustee in your local state.

Solicitors are usually the first people we turn to for legal matters and you should seek a specialist in estate planning as this is a highly specialised field of legal practice. The solicitor will discuss with you all the possible complications that may arise in your particular circumstances and how to word your documents to achieve your wishes. Usually a Will and Enduring Power of Attorney are prepared at the same time and this may reduce costs.

Many legal practices also provide an estate administration service and can be requested to aid your executors or act as your executors.

Trustee companies also provide a Will and Enduring Power Of Attorney service and specialise in the administration of your affairs, either on death or in the event of incapacity.

If you believe family arguments are likely after your death, it is preferable to appoint a trustee company or legal practice as your executor. A family member or friend may have great difficulty in administering your estate in such circumstances.
Each State Government operates a Public Trustee Office as part of the state justice system. The Public Trustee may prepare a Will for you at no cost but they will usually then become your executor and they will charge normal legal fees for this service.
Appendix

This listing provides contact details of organisations who provide help to patients, carers and their families. The information is correct at time of printing but is subject to frequent changes and you should check the latest details.

The Leukaemia Foundation
leukaemia.org.au or phone 1800 620 420

Australian Government – Money Smart
moneysmart.gov.au

» Money management
» Budget planner
» Superannuation information
» Information on credit, loans and debt
» Helpful financial publications

Australian Government – Department of Human Services

The Department of Human Services is the central organisation for all government financial assistance. It is important to contact the correct department for assistance with your questions.

Centrelink

Information is available on the Department’s website at humanservices.gov.au

For telephone enquiries:

Enquiries about Disability Support Pension, Mobility Allowance, Carer Payment, Carer Allowance, and Sickness Allowance.

Telephone: 13 27 17

Enquiries about Newstart Allowance, Widow Allowance, Farm Help, Exceptional Circumstances Relief Payment, Partner Allowance, Special
Benefit, and Employment Services Providers, including Job Services Australia.

Telephone: 13 28 50

Age Pension, Pensioner Concession Cards, Bereavement Assistance, Widow B Pension, Wife Pension, and Commonwealth Seniors Health Card enquiries.

Telephone: 13 23 00

Disability Employment Assistance

Telephone: 13 27 17

**Medicare**

Information on Medicare is available on the Department of Human Services website at [humanservices.gov.au](http://humanservices.gov.au) or telephone 13 20 11.

**Early release of superannuation**

This information is also available from the Department of Human Services telephone 1300 131 060 or visit their website at [humanservices.gov.au](http://humanservices.gov.au)

**Employment and volunteer organisations**

A variety of organisations provide assistance to patients seeking to return to the workforce in an employed or volunteer capacity.

» JobSearch contains job listings and career information. [jobsearch.gov.au](http://jobsearch.gov.au) or telephone 13 62 68

» Volunteering Australia is the lead agency for volunteers and has a wide range of volunteer positions available around Australia. Visit [volunteeringaustralia.org.au](http://volunteeringaustralia.org.au) or telephone 07 3002 7600

**Financial counselling**

Throughout Australia a counsellor may be contacted through Financial Counselling Australia for assistance with a variety of financial concerns. Contact [financialcounsellingaustralia.org.au](http://financialcounsellingaustralia.org.au) or telephone 1800 007 007.
Banking assistance

The Australian Bankers’ Association provides a website with extensive information on financial literacy, consumer protection, managing your money, budgeting, the Code of Banking Practice and how to resolve problems with your bank. Go to bankers.asn.au or telephone 02 8298 0417.

If you cannot resolve a dispute with your bank, insurance company or other financial institution you may contact the Financial Ombudsman Service at fos.org.au or telephone 1800 367 287.
Contact us

📞 1800 620 420
✉️ GPO Box 9954, Brisbane QLD 4000
✉️ leukaemia.org.au